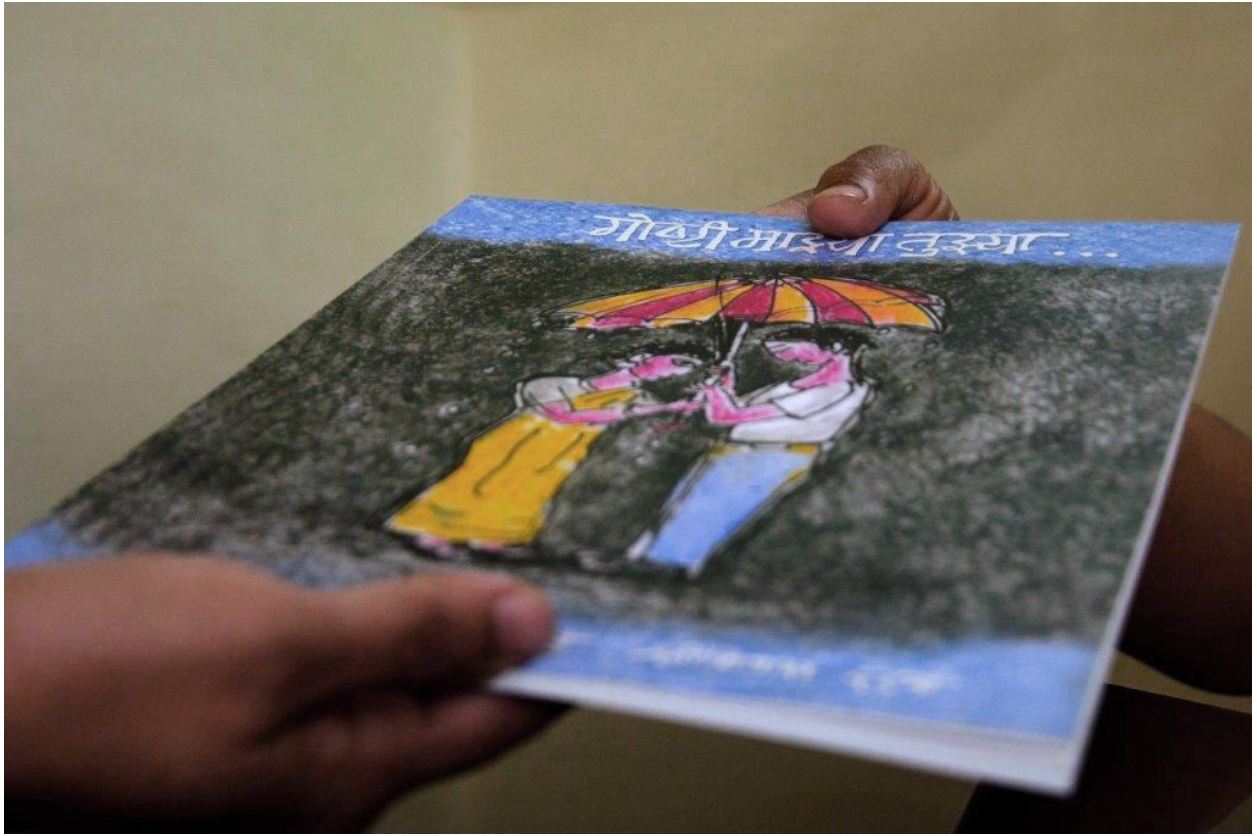


“Let us give you some stories to read.”



*Assessing the readability and usefulness of research based narrative health communication material for sexual and reproductive health of HIV infected women in western Maharashtra, India*

प्रयास  
आरोग्य, ऊर्जा, शिक्षण आणि पालकत्व  
या विषयांतील विशेष प्रयत्न



# *“Let’s Give You Some Stories to Read”*

Assessing the readability and usefulness of research based narrative health communication material for sexual and reproductive health of HIV infected women in western Maharashtra, India

PRAYAS Health Group, Pune

And

Population Research Centre, University  
of Groningen, The Netherlands



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## Abstract

With increasing access to antiretroviral medicine (ART), HIV has become a chronic manageable disease. Reduction in morbidity due to ART and increase in longevity demands focused efforts to ensure good quality of life to HIV infected people. Despite the fact that majority of the people living with HIV (PLHIV) are in their reproductive ages, the issues related to sexual and reproductive health (SRH) of PLHIV are often neglected. High proportion of unwanted pregnancies, induced abortions and lack of informed choice among women living with HIV has been reported across the globe.

From 2008-till 2013, Prayas in collaboration with Population Research Centre, University of Groningen, undertook a research project to study reproductive career of HIV infected women from a life course perspective. This study documented high prevalence of unwanted pregnancies and induced abortions among HIV infected women. It was found in the study that most unwanted pregnancies were due to lack of perceived need to use modern contraceptives along with condoms. The study highlighted the need to provide comprehensive reproductive health services to HIV infected women which probably need to go beyond the emphasis on condom use.

With an objective of reaching with the study findings to the women who participated in the study and to address some of challenges in SRH, Prayas prepared a book titled “Goshti Mazya Tuzya” (Stories-Yours and Mine) in Marathi. The book was based on the previous research regarding impact of HIV on reproductive career of the women. The book contains 7 narratives (stories) related to different SRH issues along with the struggle of men and women to deal with them positively. It also provides information regarding various contraceptive choices for PLHIV and issues to consider while planning a pregnancy. The book adopted a narrative communication approach to highlight some of the challenges mentioned by the women and proposes possible way forward regarding these issues. The aim of the book was not to achieve specific behaviour change among women but to help them understand these issues and motivate them to engage with them.

There is increasing evidence that narrative communication is more effective in impacting social norms and in changing the affective responses, attitudes, beliefs and intentions of the recipients. In contrast to the conventional model of communication, the narrative communication is believed to follow the transportation-imagery model 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. While there is some recent research about usefulness of narratives among cancer and diabetes patients, there is no research on its usefulness among PLHIV.

This exploratory study assesses the readability of the book, the barriers for (not) reading it and explored the perceived usefulness of the book among HIV infected women. It also aimed at

reaching the service providers (mainly counselors) to emphasize the need for better as well as rights based communication on SRH issues with PLHIV.

To assess the readability and usefulness of the book, a mixed methods approach was used. Readability of the book was assessed using readability formula. Women who had received the book were interviewed using structured questionnaires to understand their knowledge and comprehension. In-depth interviews were conducted to understand barriers and usefulness. Women also completed a self-administered tool to evaluate the book.

A total of 258 women who were given the book visited Prayas clinic during May 2015 to November 2015. Of these 190 women were enrolled in the study; 174 for quantitative assessment and 16 for qualitative assessment.

The book was found to be readable for people who have an average 5 years of education [range 2-7 years of education]. Most women had good readability and comprehension except for the words related to male reproductive system which were difficult to read and understand.

Among the 174 women who received the book and were interviewed for this study, 83 (47.7%) had read all the stories in the book, 60 (34.5%) had read a few stories and 31 (17.8%) had either just glanced through the book or had not read it at all. Lower education, lack of reading habit, poor readability and comprehension were identified as the factors associated with not reading the book completely. In the qualitative data, the perception that the book is emotionally disturbing to read, the content of the book are inappropriate for children and the fear of others knowing about their HIV status were also mentioned as barriers for reading the book.

Comparison of knowledge and attitudes of women who read the book with women who did not read it showed statistically significant change in the attitude that avoiding pregnancy is not only women's responsibility (48.3% Vs 25.8%;  $p= 0.037$ ). There was moderate improvement in the knowledge and change in attitudes; particularly the information that male sterilization is simpler procedure than female sterilization, the perceived need to use other contraceptives even when using condoms and the health risks of unsafe abortion.

The qualitative assessment of the usefulness shows that the impact of the book has gone beyond SRH issues and has helped women in improving their self-efficacy, accepting their partners and improved coping by realizing that they are not alone and they are not different from other women.

This study clearly shows the need for health communication which goes beyond aiming at specific behavior change among PLHIV. Based on the findings of the study an empirical model of narrative communication (including its possible negative consequences) is presented in the summary along with the recommendations for further research and practice.

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## Introduction

Despite of remarkable efforts to halt the HIV epidemic, millions of people continue to remain vulnerable for HIV and many lives are affected by the virus. In 2014, 2 million people become newly infected with HIV and there were 36.9 million [34.3 million–41.4 million] people living with HIV (UNAIDS, 2015a). Significant efforts are being made globally to provide antiretroviral treatment to HIV infected people. As of June 2015, 15.8 million people living with HIV were accessing antiretroviral therapy, up from 13.6 million in June 2014 (UNAIDS, 2015a). Building on these progresses, the world has committed to end the AIDS epidemic by 2030 as part of the Sustainable Development Goals (UNAIDS, 2015b). An ambitious 90–90–90 treatment targets by 2020 has been set: 90% of people (children, adolescents and adults) living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing treatment and 90% of people on treatment have suppressed viral loads (UNAIDS, 2015b). Along with the efforts to prevent HIV and provide ART to infected people, more efforts are also needed to reduce vulnerabilities of people for and improve quality of life of HIV infected people.

With these efforts, it can also be expected that more and more people would come to know about their HIV status relatively early in their life trajectory and issues related to providing them the tools to cope with their diagnosis, address their sexual and reproductive health (SRH) needs (as most people infected with HIV globally are in reproductive age group) and address the issues of the quality of life of HIV infected people will become important. While the need to address SRH issues of HIV infected people has been widely acknowledged, it still appears to be neglected in many policies and programs.

Worldwide, among all the pregnancies that occur, the prevalence of unwanted pregnancies and induced abortions (41% and 20%, respectively in 2008) is unacceptably high (Sedgh, Bankole, Singh, & Eilers, 2013; Sedgh et al., 2012), and even higher in low and middle income countries (Singh, Sedgh, & Hussain, 2010). About half of the abortions are estimated to be unsafe (Sedgh et al., 2012), contributing significantly to maternal morbidity and mortality (Dragoman et al., 2014). Moreover, studies from Sub-Saharan Africa, Europe and the United States suggest 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), which could even amount to 55%-65% (Abdala, Kershaw, Krasnoselskikh, & Kozlov, 2011; Decker et al., 2013; Liang, Meyers, Zeng, & Gui, 2013; Loutfy et al., 2012; Schwartz et al., 2012). Prominent determinants of unwanted pregnancies and induced abortion among HIV infected women were the pregnancy being unintended and unplanned (Floridia et al., 2010), higher age of the woman at the time of pregnancy (Barbosa, Pinho, Santos, & Villela, 2012), low CD4 cell counts (Floridia et al., 2010) , having previous children (Liang et al., 2013)

and fear for transmitting HIV to the baby (Maccarthy, Rasanathan, Crawford-Roberts, Dourado, & Gruskin, 2014).

India, which has third largest number of HIV infected people globally, has also made progress in halting the spread of HIV in the country with reduction of 57% in the new infections in last decade (National AIDS Control Organization (NACO), Annual report, 2014-2015 accessed from [[http://www.naco.gov.in/upload/2015%20MSLNS/Annual%20report%20\\_NACO\\_2014-15.pdf](http://www.naco.gov.in/upload/2015%20MSLNS/Annual%20report%20_NACO_2014-15.pdf)] on 2/3/2016) . The HIV epidemic in India is heterogeneous in its spread both geographically as well in the population sub-groups with highest prevalence of HIV among people who inject drugs, men who have sex with men, transgender people and female sex workers (UNAIDS, 2015b). Like the global situation, there are significant gaps in addressing SRH needs of people living with HIV in India. Recent research from India reported high prevalence of unintended pregnancies and induced abortion among HIV infected women due to lack of use of modern methods of contraception other than condoms (Darak, Hutter, Kulkarni, Kulkarni, & Janssen, 2015; Joshi et al., 2015).

Reducing the unmet need for family planning has been challenging. By and large the mass communication strategies to promote contraceptive choices have shown little effect (Lopez, Grey Tw Fau - Chen, Chen M Fau - Hiller, & Hiller, 2014). Further there is little conclusive research evidence regarding the most effective way to deliver contraceptive messages to the women and men in order to improve its uptake and protect the rights of people to choose the method. For example, a recent randomized control trial from Lusaca, Zambia (Wall et al., 2013) which tested the effectiveness of showing videos of contraceptive methods had mixed results. Participants in that trial who did not use any contraception before randomization had no significant change after seeing the video; whereas those who had used any contraception before randomization were found to respond more positively to showing videos.

Among HIV infected women, preventing unwanted pregnancies and induced abortions could be even more challenging due to lack of perceived need to use other (than condom) modern methods of contraception as they are anyway supposed to be advised to use condoms. The low perceived need could also be due to low frequency of sexual contacts among HIV infected people (Darak et al, 2015). Additionally, perceived stigma from health care provider could also discourage people from accessing reproductive health services such as long acting or permanent methods of contraception (Hagey et al., 2015).

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 the most of the interventions are based on cognitive behavior therapy and provided in the form of counseling and psychosocial support.

Studies on role of educational material among HIV infected people to address their SRH needs are limited. Among HIV uninfected people the evidence is in support of providing educational material as it changes the process outcomes (Farmer et al., 2008) for example increase in women's ability to make informed decisions about birth control (Johnson, Edelman, & Jensen, 2003), little research is done on the impact of nature of educational material (format, content, design, style, etc.) on the outcomes. In India the scientific literature on effectiveness of different health communication material is practically unavailable.

In this research we assessed the readability and usefulness of a research based narrative communication material, a book titled "Gosti Mazya Tuzya (Stories Yours and Mine)" regarding the sexual and reproductive health issues of HIV infected women from Western Maharashtra, India. 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.

### **Previous research on which the book is based**

The book that was assessed in this project is based on the PhD research of Dr. Shrinivas Darak, (The life course study of reproductive career among HIV infected women- (LCRC study)) that was carried out from 2008-2013 with Prayas a Non-Governmental Organization (NGO) in Pune, Maharashtra, India in collaboration with Population Research Center, University of Groningen. 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<sup>1</sup>. The research was carried out among 622 HIV infected ever married women attending specialized HIV clinic run by Prayas. The analysis of data revealed important gaps in provision of reproductive health services to HIV infected women. In the LCRC study, the proportion of unwanted pregnancies conceived by women after their knowledge of HIV was observed to be 51% whereas the 50% of all the pregnancies conceived after diagnosis of HIV 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 (Sedgh et al., 2012).

The research study was conducted from a life course perspective taking into account the interaction of timing of HIV diagnosis with timing and sequencing of reproductive events in the lives of HIV infected women from Maharashtra (Darak, Mills, et al., 2015), and by differentially examining the biological (Darak, Janssen, & Hutter, 2011) and behavioural effects of HIV on fertility. The aim was not only to understand the individual reproductive decision-making processes but also to assess its implications for PMTCT and ART programs (Darak et al., 2013).

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<sup>1</sup> The details of the LCRC study are published as a PhD thesis and can be accessed from the website [http://www.rug.nl/research/portal/publications/its-not-only-about-the-baby-understanding-reproductive-career-and-fertility-among-hiv-infected-indian-women-and-its-implications\(e67fe88d-9112-43ca-b912-80dbd0f7cf10\).html](http://www.rug.nl/research/portal/publications/its-not-only-about-the-baby-understanding-reproductive-career-and-fertility-among-hiv-infected-indian-women-and-its-implications(e67fe88d-9112-43ca-b912-80dbd0f7cf10).html)

The LCRC study documented the need to provide comprehensive reproductive health services to HIV infected women which probably need to go beyond the emphasis on condom use. Male condoms are advised to HIV infected people irrespective of the HIV status of the partner to avoid (re) infection with HIV and also avoid pregnancies. However, considering the high rates of unwanted pregnancies, it was felt important to assess women's perceived need to use other contraceptive methods and inconsistent use of condom. The study findings suggested that the change in focus of contraception messages to HIV infected women from 'dual protection' by one method to 'dual method' for effective protection where condoms are promoted as part of a dual method and women are provided with a choice of another appropriate contraceptive method might prove effective.

From the very beginning of the LCRC study, it was planned to take the findings of this research back to the study participants and their significant others. While communicating findings of research to the scientific community through peer reviewed articles is considered an ethical obligation for the researcher, much less attention is given to communicating research findings to the people who have participated in the study, and to people in similar situations to whom the results might be beneficial. There has been increasing recognition recently in the field of clinical research of the importance of communicating findings to participants (Shalowitz & Miller, 2008). However, there are few such examples in behavioural research, and there is also a lack of literature to guide researchers on how to translate their findings for non-specialists.

While communicating these findings to women a narrative format of communication was opted. This format was believed to help the women (irrespective of their marital status) to engage with the issues of sexual and reproductive health and understand their SRH rights and responsibilities. Below is the description of the book, its format and the rationale for choosing the issues covered in the book.

### **About the book 'Gosti Mazya Tuzya'**

We chose to present the findings of our research in the form of stories presented in the form of a book written in Marathi, titled "Gosti Mazya Tuzya" (GMT) which means stories –yours and mine. The seven stories that form the content of the book address different issues derived from the analysis of our data and from the experiences of the women, which were noted by the interviewers and discussed with the author during data collection.

The findings of our previous study were used not only to derive the central themes of the stories but also to describe the protagonists in each story – for example, the timing of their marriage and widowhood, number of children, support from husband and socio-economic status, HIV status of the partner, and so on. However, the stories in the book also go



beyond the results and deal with several other issues which are inherently associated with HIV infection, including disclosure of HIV status within a couple, betrayal in a relationship, and so forth. The stories were also premised on a specific stance we took while preparing the book that is, respect for the reproductive rights of HIV infected women.

The overall themes presented in the stories are:

- 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.
- 2) The importance of knowing about the timing of HIV diagnosis and disease progression and why does it matter when considering becoming pregnant.
- 3) Different contraceptive choices for HIV infected women.
- 4) Right to know the HIV status of one's sexual partner and responsibility for protecting one's sexual partner.
- 5) Dealing with widowhood at a younger age. Widowhood does not deny an HIV infected woman's choices regarding relationships.
- 6) Having a baby in the context of HIV discordance in a couple.
- 7) Women are disadvantaged not only because of their HIV status, but also because they are women.

Each story is unique and remarkable in its own way, and addresses different issues in the reproductive lives of HIV infected women. However, there is a unifying thread across all these stories which also reflect our stance.

- 1) All these stories give 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 that arise due to their HIV infection.
- 2) Each story depicts the extraordinary capabilities with which these women confront the difficult situation regarding their reproductive lives.
- 3) In Indian culture, motherhood is perceived as central to the life of women. Being a mother is often considered synonymous with being a 'woman.' Even in the context of HIV, the most important issues are motherhood of HIV infected women and preventing mother-to-child transmission of HIV. However, based on our findings of the different typologies and trajectories of women's reproductive careers, we have tried, in the stories, to address different issues that HIV infected women and men face regarding their

reproductive lives – issues that go beyond having babies and preventing HIV transmission from the mother to the child.

- 4) During the process of data collection, while examining the unspoken spaces in women's relationships with their partners and significant others, we recognized the superiority of human emotions and love over caste, class, religion and diseases such as HIV. This recognition has trickled through our portrayal of the protagonists of each story, who have different opportunities for education, different socio-economic identity and different levels of support from their partners.
- 5) The illustrations in each of the stories are intended to reflect the ethos of the story rather than being informative.
- 6) Technical information, regarding different contraceptive choices, the effects of unsafe abortions, issues to consider when contemplating pregnancy when the partner is HIV negative, etc. is provided at the end of the story.

### **Narratives for health communication: Theoretical perspective**

Narrative communication is emerging as an effective form of health communication in the research being carried out globally (Shen, Sheer, & Li, 2015). A narrative as defined by Hinyard & Kreuter (2007) is “...*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). In contrast to the traditional model of health communication such as elaboration likelihood model (Withers & Wertheim, 2004) which requires high ability of the message receiver to process the information, the 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 aspect of narrative communication was observed to make it more effective.

Narrative communication has been particularly argued to be more effective in impacting social norms (Moran, Murphy St Fau - Frank, Frank L Fau - Baezconde-Garbanati, & Baezconde-Garbanati, 2013). It has been recommended as one of the evidence based effective strategies for health communication (Kreuter et al., 2014). There are some recent studies assessing 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, the usefulness of narratives for HIV infected people has not been assessed. There are also some efforts to build theoretical arguments regarding why narrative communication would be effective in public health (Lopez et al., 2014). Most commonly applied model for narrative

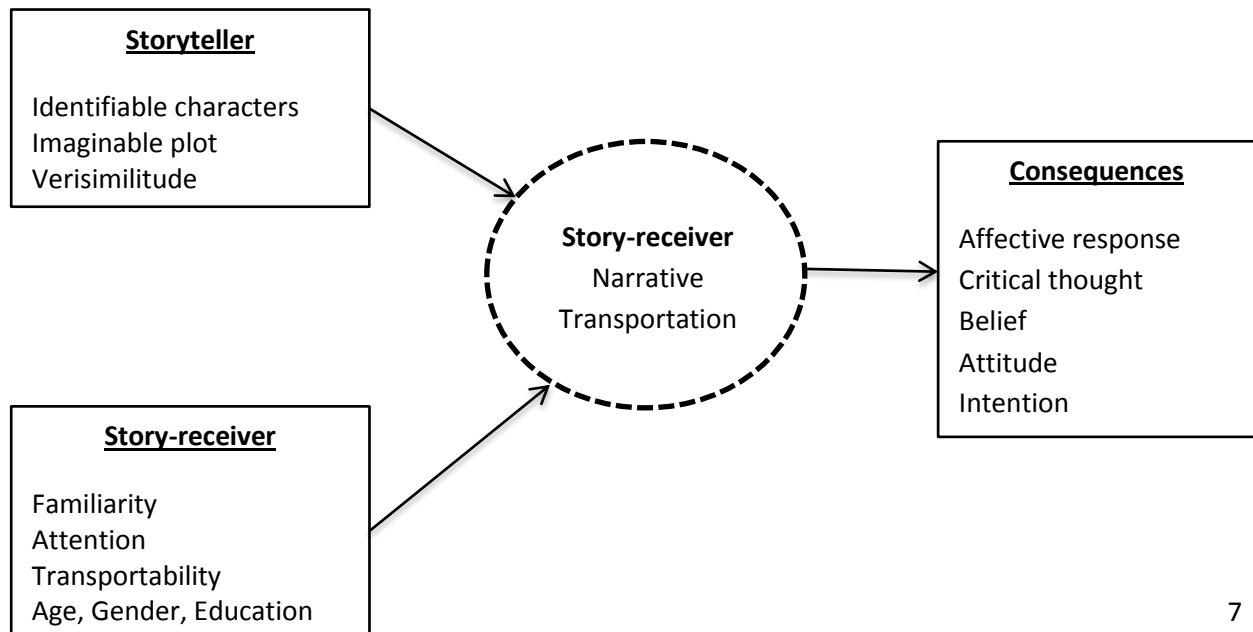
communication is transportation imagery model (Green & Brock, 2000) which has been recently extended by (van Laer, de Ruyter, Visconti, & Wetzels, 2014) and is described below.

***Extended Transportation imagery model of narrative communication***

The extended transportation-imagery model presented below is an evidence based model of which factors can contribute to the process of transportation and what the possible consequences of such narrative transportation are. Based on the meta-analysis of the antecedents and consequences of consumers’ narrative transportation, Van Laer et al (2014) presented the extended transportation imagery model (presented below) to show what factors contribute to transportation and what are the consequences (Wall et al., 2013).

In line with the Transportation- Imagery model the extended model presented by Van Laer et al. provides evidence based list of antecedents of storyteller and story-receiver. For example, storyteller 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 are able to 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* (story receiver’s degree of focused concentration), *Transportability* (story-receiver’s propensity to be transported which functions independent of any particular story and is related to their empathic abilities). Some other demographic antecedents such as *age*, *gender* and *education* have also been identified as factors contributing to the process of transportation. As a consequence of narrative transportation, the story-receiver is believed to have affective and cognitive responses and changes in belief, attitude and intention (Wall et al., 2013).

Figure 1: Extended Transportation-Imagery Model



The book 'Gosti Mazya Tuzya' has several attributes that are described in the model such as identifiable characters, imaginable plot, verisimilitude and familiarity. However the consequences in terms of responses of women after reading the book are not known and will be investigated in this research. Such an exploration among HIV infected people is lacking in general and specific to Indian context. Evaluating the feasibility and effectiveness of health communication material particularly narrative communication among People living with HIV/AIDS (PLHIV) is even more important as engaging in any material on HIV might be a source of stigma and discrimination to people which could be a major barrier for providing health communication material to this population. With narrative communication there could also be issues of remembering the painful past which might deter people from engaging with the health communication material. So the findings from other studies among people not having HIV infection might not be applicable to HIV context.

With this background, this study tries to document the usefulness of providing printed narrative educational material which was based on the findings of previous research in the same population. This exploratory study will focus on understanding the facilitators and barriers for reading the book; assess the knowledge among participants who read the book and who did not read it, evaluate the readability and comprehension among the participant and explore in-depth women's experiences of reading the narratives and its perceived usefulness.

The specific objectives of this research are

1. To assess the readability of the book 'Gosti Mazya Tuzya'
2. To understand the barriers and socio-demographic factors associated with (not) reading the book.
3. To understand the women's perception about the usefulness of the book.
4. Conduct a participatory workshop with counselors to highlight the need for better communication regarding SRH issues of HIV infected people and disseminate the findings on how narrative health communication might be helpful.



## Methodology

### Setting

This study was conducted at Prayas Amrita Clinic, Pune, Maharashtra. Prayas Amrita Clinic is a specialized HIV clinic run by a non-governmental (NGO) not for profit organization. Prayas currently provides care to approximately 3000 PLHIV. Prayas is also implementing a large scale PMTCT (prevention of mother to child transmission of HIV) program in approximately 430 sites through Public Private Partnership (PPP) in Maharashtra.

The current study was conducted among HIV infected women coming to Prayas Amrita Clinic, who had participated in the LCRC study and who were given the book (GMT) to read. Following were the study inclusion and exclusion criteria.

### Participants

#### *Inclusion*

1. HIV infected woman who is aware of her HIV status and is seeking care at Prayas Amrita Clinic
2. Women had participated in the LCRC study of Prayas
3. Women reported that she had been given the book (GMT)

#### *Exclusion*

1. Women not meeting the inclusion criteria
2. Women who reported that they cannot read
3. Women who were not willing to participate for any reason  
Women who were not willing to or unable to provide written consent

This study was an exploratory study which used mix method approach, using both quantitative as well as qualitative research techniques.

### Quantitative data collection

Structured questionnaire was administered to assess:

1. Knowledge about reproductive health issues and choice of contraception in the context of HIV infection
2. Attitude regarding contraception decision making
3. Change in the use of contraception and unwanted pregnancy if any since the last interview in the LCRC study
4. Readability and understanding of the apparently difficult/medical words used in the book
5. Comprehension of a narrative (story)
6. Women's perception about the effectiveness of the book through a self-rated questionnaire

Additionally, data were collected on demographic variables (current age, marital status socioeconomic status, etc.) women's general reading habits, if they had partially or fully read the book, potential barriers for not reading the book and if they shared the book with someone else. The socio-economic status of the women was assessed using Kuppuswamy scale (2014)(Oberoi, 2014).

To determine the readability and comprehension we selected 20 words from different stories that have different level of difficulty. During the quantitative interviews women were given the list of these words and were asked to read the word and explain the meaning of the word. On a separate sheet the interviewer marked if the woman is able to read the word and if the meaning explained by the women is correct. We did not look for exact meaning of the word but more of the functional understanding of what the word means.

#### *Quantitative data analysis*

Data were entered in Epi-info software. The quantitative analysis was done in 'R' [Version 3.2.2] which is open source statistical analysis software. To understand the barriers for reading the book completely, descriptive analysis of socio-demographic variables was done comparing the profile of the women who read the book completely versus women who did not read the book completely (women who did not read the book at all and women who partially read the book). The significance was determined using chi square test. The variables which were significant in the descriptive analysis were tested in multivariate model to determine the significant predictors of reading the book completely. The data on knowledge and attitude were collected in the form of a Likert scale and are summarized with the help of graph.

#### **Qualitative data collection**

The qualitative component of the study was designed to understand the perceptions of women regarding the book, potential barriers and facilitators for reading any health related/HIV related material in general and the given book in particular, the affective responses of the women after reading the book and its usefulness etc. Participants for qualitative study were recruited from the group of women who were enrolled in the previous LCRC study and who had received the book at least a month before the interview. Women were purposively selected for the qualitative study to get maximum variations in the experiences.

Out of 190 women enrolled in the study, 16 women were interviewed by a lady interviewer for in-depth interview. An in-depth interview guide was prepared. Qualitative data collected through in-depth interviews were transcribed. The data were then imported into the 'RQDA' software (R-Qualitative Data Analysis). 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.

## **Ethical Consideration**

The study protocol, consent forms, and data collection tools were reviewed and approved by an Institutional Ethics Committee for Research (IECR) of Prayas. 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.

## **Description of study population**

Out of 622 women enrolled in LCRC study, 363 women received the book. Total 258 women who visited Prayas during May 2015 to Nov 2015 were assessed for eligibility. Out of 237 women who were eligible for study participation, 174 women were enrolled in the study after written informed consent.

### ***Profile of the women who participated in the quantitative study***

The minimum age of the woman was 25 years whereas the maximum age was 50 years. The mean age was 38.4 years and 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 category with upper class, middle class, lower class representing 36.5%, 30.0% and 33.5% respectively. Most women participated in this study were residing in urban area (68.4%).

Almost 50% of the women in this study were not currently married and only 60 women (34.5%) were fecund that is currently married and able to produce children. From their interview in the LCRC study to the current interview, 7 women had a change in their marital status. Of these, 6 were widowed and 1 woman who was a widow in previous interview had got re-married.

From the interview in the LCRC study to the current 4 (6.7%) pregnancies occurred among 4 women who were married and fecund at the time of previous interview (N=60). Of these 4 pregnancies, 2 were planned and 2 unplanned. The details of the 4 women who had pregnancies are provided in a table 10 under the description of usefulness of the book.

### ***Profile of the women who participated in the qualitative study***

For the qualitative component of the study women were recruited to get a range of their experiences regarding the usefulness of the book. Total 16 IDI were conducted. In the table 2, we have described the profile of the women (age of the woman, education, marital status, fecundity, occupation, place of living) and if they have read the book or not.

The age of women participated in IDI ranged from 23 - 45 yrs. The mean age of women was 34.75 yrs. Average years of education in these women were 11.4 years (7 years to 18 years). One participant had completed 18 years of her education and was currently pursuing her PhD. Out of 16 women, 11 were married, one was remarried and 4 women were widowed.

**Table 1: Profile of the women participating in the quantitative study**

Variable	Category	N (%)
<b>Age</b>	25-30	8 (4.6)
	31-35	46 (26.4)
	36-40	67 (38.5)
	>40	53 (30.5)
<b>Education</b>	Primary	38 (21.8)
	Secondary& higher sec	93 (53.5)
	Graduation and above	43 (24.7)
<b>SES</b>	Upper	61 (36.5)
	Middle	50 (30.0)
	Lower	56 (33.5)
<b>Place</b>	Urban	119 (68.4)
	Rural	55 (31.6)
<b>Religion</b>	Hindu	163 (95.9)
	Other	7 (4.1)
<b>Partner HIV</b>	Positive	143 (85.6)
	Negative or Not tested	24 (14.4)
<b>Duration since HIV diagnosis (in yrs)</b>	0-5	8 (4.7)
	6-10	50 (29.4)
	11-15	79 (46.5)
	>15	33 (19.4)
<b>Fecundity</b>	Fecund	60 (34.5)
	Not fecund	114 (65.5)
<b>Occupation</b>	Working	100 (57.5)
	Not working	74 (42.5)
<b>Marital status</b>	Married	88 (50.6)
	Not married	86 (49.4)
<b>Duration since book given</b>	0-6 months	12 (6.9)
	7-12 months	18 (10.3)
	13-18 months	70 (40.2)
	≥19	74 (42.5)
<b>Pregnancy after last interview</b>	No	56 (93.3)
	Yes	4 (6.7)
<b>Was pregnancy planned</b>	Planned	2 (50.0)
	Unplanned	2 (50.0)
<b>Pregnancy after HIV diagnosis</b>	Yes	28 (16.5)
	No	142 (83.5)
<b>Book reading</b>	Read completely	83 (47.7)
	Read some stories	60 (34.5)
	Glanced through the book	15 (8.6)
	Not read at all	16 (9.2)
<b>Read Health related material</b>	Yes	120 (69.0)
	No	54 (31.0)
<b>Frequency of reading in general</b>	Everyday	116 (66.7)
	Occasionally	40 (23.0)
	Rarely or never	18 (10.3)

Five women had undergone sterilization operation and 10 women were fecund at the time of interview. One woman had approached menopause. Nine women were doing some work for their living and 7 women were housewives or not doing any paid work. Out of 16 women 10 were from urban area and 6 were from rural area.

There was only one participant who had not read the book at all. Six participants had read the whole book. One of them read the whole book 2-3 times. Nine participants read only a few stories from the book.

**Table 2: Profile of HIV infected women who were interviewed for in-depth interview**

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

\*Read whole book 2-3 times

\*\* Participant has done M.E and currently pursuing PhD

\*\*\*Read book after introducing about the current study.

# Results

## Section 1 : About Reading the Book

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Assessing the readability of the book using readability formula

Assessing women's readability and comprehension

Assessing the barriers for reading the book

## Assessing the readability of the book using readability formula

Readability of the written text is important in communicating the health messages in written form. Readability can be defined as “the ease of understanding or comprehension due to the style of writing”. The definition of readability may not consider the abilities of the reader and can focus only on the written text (Klare, 1963). Some definitions have also considered the abilities of the reader as well as the factors related to the text (Newbold & Gillam, 2010). There are several readability formulae available for assessing the readability of a written material, for example SMOG readability formula (Simply Measure of Gobbledygook), Fry Formula, Lexile analyzer etc (CDC, 2009).

### Assessing readability of Marathi text

Most of the previous research of readability assessment has been carried out on English language. Clear guidelines for assessing the readability of non-English text written in Indian languages are lacking. Though there are some readability formulae prepared for Indian languages such as Kannada, Malayalam, Tamil, Hindi, Bangla and Marathi, comprehensive research on the topic is lacking.

To assess the readability of text in Marathi language (the language used in the book Stories-Yours and Mine), only one readability formula developed by Sawant G K and Shirke V S in 2003 is available (Shirke & Sawant, 2003). This formula was prepared with the objective of providing the norms of distribution of the readability variables for different grades in school and was developed by conducting primary study among school going children. Readability variables namely average word length (AWL), average sentence length (ASL) and percent difficult words (PDW) were considered for developing this formula. As the school text books are standardized to specific grade level by the editorial board, passages from text books of 1<sup>st</sup> to 8<sup>th</sup> grade were selected to determine the association of above mentioned readability variables to readability of text. Based on the regression equation the derived readability formula for Marathi language is as follows

$$GL_{50} = 2.2519 + 1.9032 \text{ AWL} + 0.0980 \text{ ASL} - 0.278 \text{ PDW}$$

Where

$GL_{50}$  is grade level score of students who could answer one half of the test questions correctly.

AWL- is average word length

ASL is average sentence length

PDW is percent difficult words



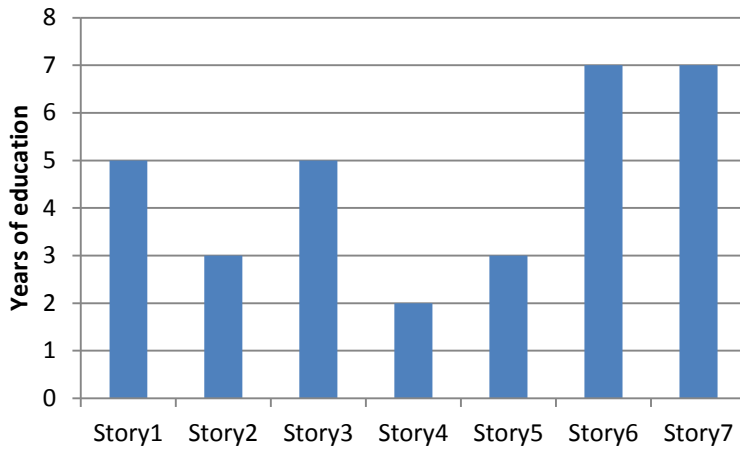
This formula gives grade level scores which can be converted into number of years of education required (for at least 50% of the people) to be able to read the given text.

Due to lack of availability of any other formula for Marathi language we used this formula to assess the readability of all the stories in the book.

**Table 3: Readability of each story in the book according to the readability formula**

Story	AWL	ASL	PDW	GL <sub>50</sub>	Years of education
Story1_Manda-Subhash	3.23	6.05	42.86	7.79	4, 5, 6
Story2_Havva-Hamid	3.00	6.39	36.73	7.57	3
Story3_Sulabha-Suryakant	3.24	5.64	41.13	7.83	4, 5, 6
Story4_Sandhya-Sambhaji	3.01	4.72	33.90	7.50	2
Story5_Jayashree-Dhananjay	2.95	9.33	38.39	7.71	3
Story6_Chittarupa-Sharad	2.99	10.55	29.31	8.16	7
Story7_Two Friends	3.08	8.21	28.70	8.12	7

**Figure 2: Number of years of education needed to read each story**



As can be seen from the table 3 and the figure 2, the minimum years of schooling required to read a story in the book was 2 years and maximum was 7 years which falls within the suggested years of schooling (6-7 years) for preparing health education material.

## Assessing women's readability and comprehension

The readability of the text was assessed by the above readability formula. However it is also important to assess if women were actually able to read the different words in the book and were able to understand the meaning of these words. To determine this we selected 20 words from different stories that have different level of difficulty. During the quantitative interviews women were given the list of these words and were asked to read the word and explain the meaning of the word. On a separate sheet the interviewer marked if the woman was able to read the word and if the meaning explained by the women was correct. We did not look for exact meaning of the word but more of the functional understanding of what the word means.

Among the 20 words given to women, most women were able to read these words (mean 17.19 words). More than 50% of the women were able to read all 20 words

Readability	Definition	N (%)
Good	Able to read all 20 words	86 (50.29)
Average	Read 16-19 words	56 (32.75)
Poor	Read 1-15 words	29 (16.96)

There were a few words which many women found difficult. Below is the list of words that more than 10% of the women were not able to read. Words particularly related to reproductive system (male reproductive organs, reproduction) were found difficult to read by some women.

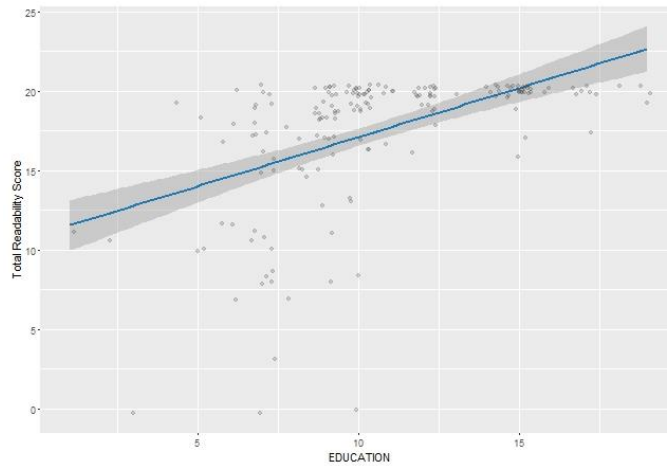
It is also important to note that the words that used in the book regarding the reproductive organs are most common words used in almost all printed material on reproductive health.

**Table 4: Words that more than 10% of the women could not read**

Sr. No	Word in Marathi (English alphabets)	Word in English	Could not read (%)
1	वृषणकोश (Vrushankosh)	Scrotum	27%
2	बिन्दिककतपणे (Bindikkatpane)	Seamlessly	27%
3	कौन्सिलर (counselor)	Counselor	23%
4	नियतकालिक (Niyatkalik)	Periodical	14%
5	वीर्यकोश (Viryakosh)	Testes	14%
6	प्रतारणा (Pratarana)	Betrayal	13%
7	एचआयव्हीच्या प्रजातीचे (HIVchyaPrajatiche)	HIV sub-type	13%
8	जननेंद्रिय (Jananedriy)	Reproductive organ	12%
9	माहवारी (Mahawari)	Menstrual cycle	12%

Further analysis of the correlation of the readability with that of education (Figure 2) shows interesting pattern. There appears a lot of variation among women having up-to the 10 years of education with respect to their ability to read. The variation reduced as the years of education increased. While it is anticipated that education and readability will have a clear linear trend. However, this pattern of lot of variation in readability up-to 10 years of education could have two possible interpretations; 1) the quality of education significantly differs which can lead to this patter 2) There are factors other than education (attending school) for example habit of reading etc. that determine readability

Figure 3: Correlation of education with total readability score



### Comprehension

For the same set of 20 words we assessed if the women knew the meaning of these words. As compared to readability, there were more women who could not understand the meaning of the word they were reading. The mean comprehension score was 12.07 words and the median was 12.00. Except 1 woman, none of the women interviewed could provide the meaning of all the 20 words.

Comprehension	Definition	N (%)
Good	Understand 16-20 words	37 (21.64)
Average	Understand 11-15 words	76 (44.44)
Poor	Understand 1-10 words	58 (33.92)

In general the words that were difficult to read were also difficult to understand except a word बिनदिक्कतपणे (Bindikkatpane) which was difficult to read but easier to understand

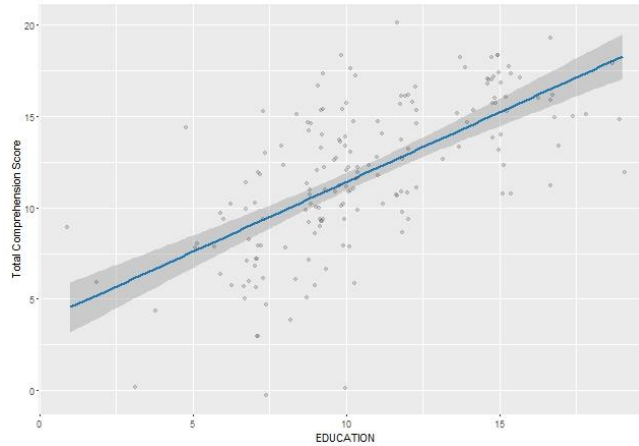
The correlation of education with comprehension was much more linear compared to readability showing increase in comprehension with increase in education. However, unlike readability a lot

of women even after having higher number of years of education were found not to know the meaning of the words (mostly described in the table 5).

**Table 5: The words that more than 50% of the women could not understand**

Sr. No	Word in Marathi (English alphabets)	Word in English	Could not understand (%)
1	वृषणकोश (Vrushankosh)	Scrotum	94%
2	प्रतारणा (Pratarana)	Betrayal	87%
3	एचआयव्हीच्या प्रजातीचे (HIVchyaPrajatiche)	HIV sub-type	82%
4	नियतकालिक (Niyatkalik)	Periodical	75%
5	माहवारी (Mahawari)	Menstrual cycle	70%
6	वीर्यकोश (Viryakosh)	Testes	70%
7	जननेंद्रिय (Jananedriy)	Reproductive organ	57%
8	यकृत (Yakrut)	Liver	54%

**Figure 4: Correlation of education with total comprehension score**



The analysis of comprehension clearly pointed out that education (years of schooling) should not be considered as proxy for comprehension of the text. The analysis also suggests that the readability of a text assessed using the readability formula may not match with the actual readability and comprehension of the text.

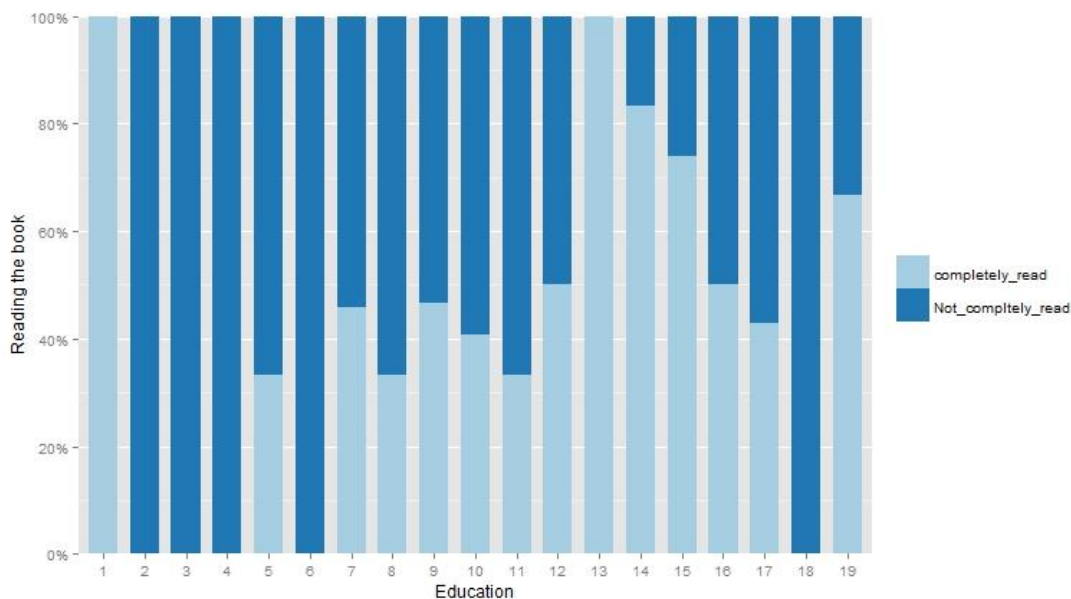
## Assessing the barriers for reading the book

### Barriers identified from quantitative data

Of the 174 women who received the book and were interviewed in the study, 83 (47.7%) women had read all the stories in the book, 60 (34.5%) had read few stories, 15 (8.6%) had glanced through the book and 16 (9.2%) had not read the book at all. For the analysis of profile of the women we combined the women who did not completely read the book (91 (52.3%)) and compared their profile with women who read the book completely.

In univariate analysis, women who had 15 to more years of education (graduation and above) had read the book completely (34.9% Vs 15.4%) whereas larger proportion of women who had education up to 7 years had not read the book completely (26.4% Vs 15.7%).

Figure 5: Education level and reading the book



Women who were used to read something every day (newspaper, novel etc.) read the book completely (77.1% Vs 57.1%) compared to women who occasionally or never read anything. Women who had read other health material previously also were more likely to read the book completely (81.9% Vs 57.1%) compared to women who had not read any health related material before. Women who had better readability scores (62.7% Vs 38.6%) and better comprehension scores (33.7% Vs 10.2%) were more likely to read the book completely.

In a multivariate regression analysis, women who had previously read any health related material were more likely to read the complete book (Odds Ratio (OR) 2.32; Confidence Interval (CI) (1.06-5.24)). Women who had better comprehension were also more likely to read the complete book (OR-3.89; CI-1.07-14.95).

Table 6: Description of factors associated with completely reading the book

	Completely read N=83 (47.7%)	Partial or no reading N=91 (52.3%)	p
<b>Age</b>			0.285
<35	22 (26.5%)	32 (35.2%)	
>35	61 (73.5%)	59 (64.8%)	
<b>Education</b>			<b>0.008</b>
Primary	13 (15.7%)	24 (26.4%)	
Secondary& higher sec	41 (49.4%)	53 (58.2%)	
Graduation and above	29 (34.9%)	14 (15.4%)	
<b>Occupation</b>			0.712
Working	46 (55.4%)	54 (59.3%)	
Not working	37 (44.6%)	37 (40.7%)	
<b>SES</b>			0.669
Upper	27 (34.6%)	34 (38.2%)	
Middle	26 (33.3%)	24 (27.0%)	
Lower	25 (32.1%)	31 (34.8%)	
<b>Place of residence</b>			0.571
Urban	59 (71.1%)	60 (65.9%)	
Rural	24 (28.9%)	31 (34.1%)	
<b>Marital status</b>			1.000
Married	42 (50.6%)	46 (50.5%)	
Currently not married	41 (49.4%)	45 (49.5%)	
<b>Fecundity</b>			0.72
Fecund	27 (32.5%)	33 (36.3%)	
Not fecund	56 (67.5%)	58 (63.7%)	
<b>Duration since HIV diagnosis</b>			0.312
0-10	32 (40.0%)	26 (28.9%)	
11-15	34 (42.5%)	45 (50.0%)	
>15	14 (17.5%)	19 (21.1%)	
<b>Reason for HIV testing</b>			0.465
ANC testing	19 (23.8%)	29 (32.2%)	
Husband positive	31 (38.8%)	30 (33.3%)	
Illness/other	30 (37.5%)	31 (34.4%)	
<b>Partner HIV status</b>			<b>0.077</b>
Positive	72 (90.0%)	71 (78.9%)	
Negative/unknown	8 (10.0%)	19 (21.1%)	
<b>Pregnancy after HIV diagnosis</b>			0.779
Yes	12 (15.0%)	16 (17.8%)	
No	68 (85.0%)	74 (82.2%)	

<b>Frequency of general reading</b>			<b>0.009</b>
Everyday	64 (77.1%)	52 (57.1%)	
Occasionally	19 (22.9%)	39 (42.9%)	
<b>Reading any health material</b>			<b>0.001</b>
Yes	68 (81.9%)	52 (57.1%)	
No	15 (18.1%)	39 (42.9%)	
<b>Readability</b>			<b>0.006</b>
Poor	9 (10.8%)	20 (22.7%)	
Average	22 (26.5%)	34 (38.6%)	
Good	52 (62.7%)	34 (38.6%)	
<b>Comprehension</b>			<b>&lt;0.001</b>
Poor	18 (21.7%)	40 (45.5%)	
Average	37 (44.6%)	39 (44.3%)	
Good	28 (33.7%)	9 (10.2%)	

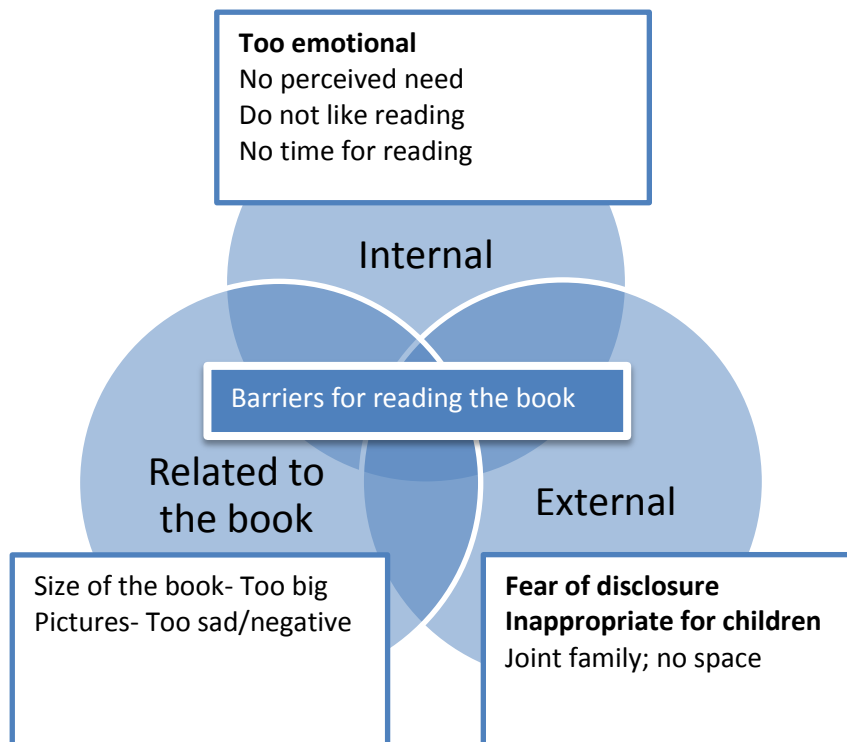
Table 7: Multivariate analysis of factors associated with completed reading the book

Variable	Category	Odds ratio (95% CI)	p value
<b>Education</b>	Primary	<i>Ref</i>	
	Secondary & Higher secondary	0.56 (0.19 – 1.56)	0.269
	Graduate and Post-Graduate	0.79 (0.20 – 3.03)	0.727
<b>Husband's HIV status</b>	Positive	<i>Ref</i>	
	Negative/Unknown	0.43 (0.15 – 1.12)	0.095
<b>General reading</b>	Everyday	<i>Ref</i>	
	Occasionally	0.89 (0.39 – 2.08)	0.787
<b>Read any health material before</b>	No	<i>Ref</i>	
	Yes	2.32 (1.06 – 5.24)	<b>0.038*</b>
<b>Readability</b>	Poor	<i>Ref</i>	
	Average	0.95 (0.32 – 2.86)	0.925
	Good	1.33 (0.40 – 4.57)	0.648
<b>Comprehension</b>	Poor	<i>Ref</i>	
	Average	1.51 (0.59 – 4.02)	0.394
	Good	3.89 (1.07 – 14.95)	<b>0.042*</b>

## Barriers identified through qualitative data

During in-depth interviews women were asked if they faced any difficulty for reading the book. From the barriers mentioned by the women three conceptual categories could be identified under which these barriers can be considered: 1) Internal barriers 2) External barriers 3) Barriers related to the book. The *Internal barriers* are mostly related to the women and her psychological state (for example lack of perceived need, or no inclination to read anything). The *External barriers* are the ones where there is perceived role of others (such as fear of disclosure to others) and The barriers *related to the book* are the characteristics of the book such as size of the book or the pictures in the book that act as a deterrent for reading the book completely. These barriers are linked with each other, for example big size of the book is also associated with fear that others will note that the woman is reading a book about HIV (fear of disclosure).

Figure 6: Barriers for reading the book



Among the internal barrier, most important barrier some women identified was the fact that the content of the book was too emotional and reading the book brought back their painful memories of dealing with HIV. Therefore they avoided reading it.

*I- How did you feel after reading the book?*

*P- Yeah, I read few stories...felt positive but also it was emotionally disturbing (traas zala). I had to make conscious efforts to come out of this feeling. By disturbing I mean somewhere, from inside it was hurting to know that people, that include me as well, 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, 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 line. [36 years, post-graduate, urban, married fecund woman who read only a few stories in the book]*

*P- like me, I knew there were many women who had participated in the study (LCRC study). Each one of them might have had very different [difficult] experience. I felt scared to read about the difficult life situations through which all these women might have gone. When I come here [to this clinic] to take medicine, I can see on the faces of other patients...if I can have so much of difficulties to take medicines, the financial difficulties then how difficult it might be for others as well. So I did not [find courage to] read these stories. [45 years, graduate, urban, married and not fecund woman who did not read the book at all]*

A few women also mentioned that they (in general) do not like to read anything or do not find time to read anything as they are too occupied in the daily activities. Hence they could not read the book.

Among the external barriers, two most important barriers mentioned by almost all women are the fear of disclosure to other and that the content of the book are not appropriate for children.

*I have hidden the book underneath my sarees in my cupboard. I don't want my daughter to see it. She is 16 years old now but she doesn't know that I have HIV. She often asks me why I am taking medicines [ART], what is wrong with me. But I haven't told her anything. She is still young [not mature enough to understand it]. [32 years, 9 years of education, rural, widowed and fecund woman who read a few stories in the book]*

*I have hidden the book. I don't want my children to see it. It's not that I am scared to tell them about my illness [HIV]. Sooner or later I have to tell them. But you know how children are, even a small thing can make a big impact on their mind. So I don't want them to see the book, read it. They might find the images attractive but they will not be able to understand what to take from these images. My elder daughter is 17, she might be able to understand. If she happens to read it then at least she will ask me about it. But two other younger children will not be able to ask me if they feel anything after seeing/reading the book. So I have hidden the book from the children. [37 years, 12 years of education, rural, widowed and fecund woman who read the book completely]*

While most women interviewed, did not find the size of the book or the images in the book inappropriate, some women said that the pages of the book are too big and the images in the book are too sad and negative discouraging its reading. This does not appear to be an important barrier as it was always mentioned along with other barriers such as fear of disclosure and having no time to read.

It is important to note that though these barriers were mentioned by women, many of them had overcome these barriers and had read the book completely. However, for some women it acted as a deterrent for reading the complete book.

## Section 2 – Usefulness of the Book

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Knowledge and attitudes regarding contraceptive methods and reproductive health issues

Comprehension assessment after reading a story

Perceived usefulness and impact of the book

Women's assessment of the book

## Knowledge and attitudes regarding contraceptive methods and reproductive health issues

In the book, 'Gosti Mazya Tuzya', each story was followed by more factual information regarding different contraceptive methods and other relevant reproductive health issues in bulleted points in tables and flow charts. It included information on permanent methods of sterilization, temporary methods of sterilization, specific considerations for HIV infected women and men while opting for some temporary methods of sterilization (such as oral contraceptive pills and intra-uterine devices), issues to consider while planning to have a baby and planning a pregnancy among HIV discordant couples.

Most women had good knowledge about condom use and also about issues related to Antiretroviral Treatment (ART). Almost all women knew (93.1%) that condom is the only device that can prevent sexually transmitted infections as well as pregnancy 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%). However, the knowledge regarding other contraceptive methods was relatively lower compared to 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 them knew about medical abortion (50.6%) and that the medical termination of pregnancy can be done until 20 weeks of pregnancy (53.4%). Very few women (15.5%) knew that oral contraceptive pills are not advised with some specific antiretroviral treatment. While most women (97.7%) said that the decision to use contraception should be taken by the man and the woman together, many of them (59.2%) also said that this decision should only be taken by a doctor indicating the dominant role of health care providers in contraceptive decision making among HIV infected couples. Most women (89.6%) knew that unsafe abortion can lead to sever health problem, at times death of the woman.

The perceived need to use other contraceptive methods in addition to condom was also very low. Majority of the women (74.7%) believed that HIV infected couples need not use other contraceptive methods as they are anyway advised to use condoms. Also a lot of women (70.1%) felt that it is not alright for HIV infected widows to enter into physical relationship even if it is with her consent. However, a segregated analysis of this variable by marital status showed that more women who are widowed (38.4%) feel that it is alright for a HIV infected widow to have physical relations with her consent compared to married women (21.5%) ( $p = 0.024$ ), highlighting the need to discuss the reproductive health issues with HIV infected women who are widowed.

**Table 8: Knowledge regarding contraceptive use and reproductive choices**

	<b>Question</b>	<b>Agree</b>	<b>Disagree</b>
1	Condom is the only device that can prevent STIs and pregnancy	162 (93.1)	12 (6.9)
2	If a couple doesn't want a child in future then a man or a woman can choose for permanent contraceptive method	155 (89.0)	19 (11.0)
3	Vasectomy is simpler than tubectomy	97 (55.7)	77 (44.25)
4	For HIV infected couples, use of condom is essential even when one of the partners is using other contraceptives	163 (93.7)	11 (6.3)
5	For HIV infected people, the decision about appropriate contraceptive method can only be taken by the doctor	103 (59.2)	71 (40.8)
6	As HIV infected couples always need to use condom, there is no need for them to use other contraceptive method	130 (74.7)	44 (25.3)
7	In our country, medical termination of pregnancy can be done up-to 20 <sup>th</sup> week of pregnancy	93 (53.4)	81 (46.6)
8	There are medicines to terminate pregnancy up-to 9 weeks	88 (50.6)	86 (49.4)
9	There is a pill that can be taken after unprotected sex to avoid pregnancy	119 (68.4)	55 (31.6)
10	Un-safe abortion can lead to severe health problems to women, at times death	156 (89.6)	18 (10.4)
11	When woman is taking some specific ARV medicine, oral contraceptive pills are not advised	27 (15.5)	147 (84.5)
12	It is alright for HIV infected widow to enter into physical relationship, with her choice	52 (29.9)	122 (70.1)
13	HIV infected women should not use Cu- T.	42 (24.1)	132 (75.9)
14	It is women's responsibility to avoid getting pregnant	97 (55.7)	77 (44.3)
15	A man and a woman should decide together what type of contraceptives to be used	169 (97.7)	4 (2.3)
16	A women can ask her partner to use condom	162 (93.6)	11 (6.7)
17	If one of the partners is HIV infected and other is not, then the couple cannot have their own child without transmitting HIV to other partner	92 (53.2)	81 (46.8)
18	It is good to disclose your HIV positive status to your sexual partner	173 (100)	0 (0.0)
19	When taken regularly, ART provides long healthy life.	171 (98.3)	3 (1.7)
20	ART minimizes the possibility of mother to child transmission of HIV to a great extent.	146 (83.9)	28 (16.1)

**Table 9: Descriptive comparison of knowledge among women who read the book compared to those who did not read it (selected questions#)**

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

# Questions that are typically stressed in the book are selected for comparison

\*Number shown are for the option disagree (which is the correct option)

There seems to be moderate improvement in knowledge related to some aspects which were emphasized in the book for example male sterilization (vasectomy) is simpler procedure than female sterilization (tubectomy) (58.7% vs 41.9%), perceived need to use other contraceptives even when using condoms (28.0% vs 12.9%), health risks of unsafe abortion (91.6% vs 80.6%). However, statistically significant increase was observed in changing the attitude that avoiding pregnancy is not only women's responsibility (48.3% Vs 25.8%; p= 0.037).

Though the sample size and the study design cannot directly attribute the change in knowledge to reading of the book, the descriptive analysis suggests a role of the book in changing knowledge and attitudes to some extent.

## Comprehension assessment after reading a story

Many women who had participated in the study had not read the book and those who had read it there was a possibility of recall bias while assessing their knowledge. To assess if women

### **Short summary of the story:**

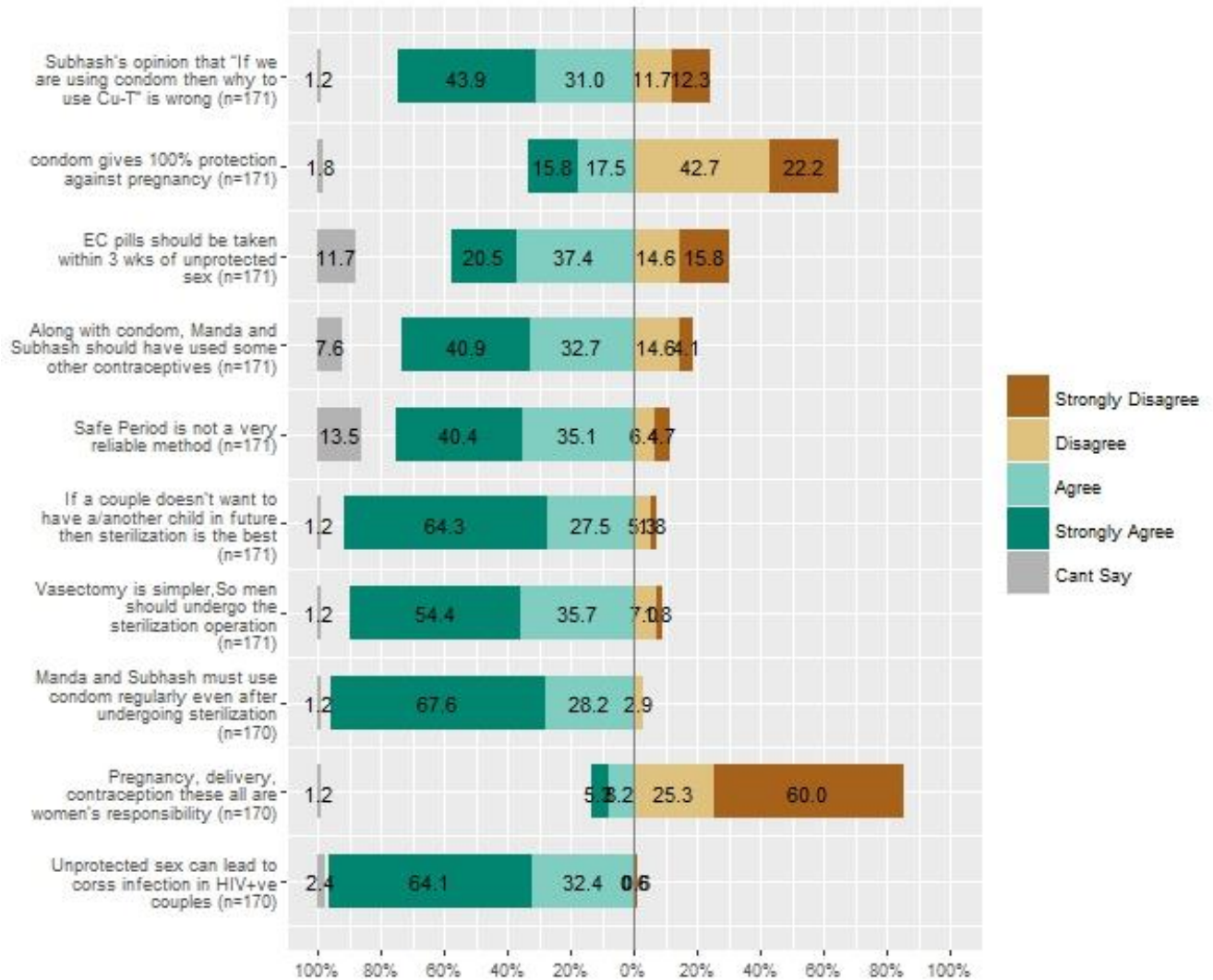
*The story titled 'Manda –Subhash' is a story of a woman named Manda and her husband Subhash. They have two children before they come to know about their HIV positive status. After the birth of her second child (daughter) she opts to use Intra-Uterine Device (Copper –T). If she had not known about her HIV, she had planned to undergo sterilization for family planning after removing Copper-T. But after knowing about their HIV status, she removes the copper-T and both of them feel that since they are advised to use condoms there is no need to undergo sterilization or use any other method of contraception. After the initial struggle of coping with their HIV diagnosis, things start to normalize and Subhash and Manda resume sexual relations. Once in a while Subhash used to have sexual relations without using a condom which eventually results in Manda getting pregnant. Since she had completed her family, she does not want this pregnancy and hence opts to terminate it. After her abortion they see the doctor and the counsellor who are treating them for HIV. The counsellor discusses with them regarding contraception and also suggests them the option of sterilization. He also explains that male sterilization is easier and less invasive than female sterilization and Subhash agrees to go for it. The story depicts the mutual understanding and concern that the couple have for each other.*

understand the stories and are able to get the central message in the story, each woman who participated in the quantitative study was asked to read the first story in the book. After they had completed reading, a small questionnaire (5 point Likert questionnaire) was administered to assess if they have understood the story and what is their opinion about different aspects of the story.

The questions included in the assessment after reading the story included women's opinion about the decision of Manda and Subhash and about the information that is shared to them by the counsellor.

The chart below shows the percentages with respect to five points in the Likert scale

Figure 7: Comprehension assessment after reading the story



It is quite clear from the post-reading comprehension assessment that majority of the women were able to grasp the important points mentioned in the story. Most issues related to condom use, opting of permanent method of contraception etc. were well comprehended by women. However, there seems to be difficulty in grasping the information that is provided in numbers (numeric comprehension). For example many women (58%) could not correctly answer that the emergency contraceptive pills need to be taken within 3 days of unprotected sex. The question was wrongly posed as 3 weeks [almost 12% said that they don't know /can't remember the duration]. The text in the story also explains the concept of safe period which apparently has not been understood by some women as 13.5% of the women did not know if safe period is reliable method of contraception.

However, there seems to be significant change in the attitude of women after reading the story. A simple comparison of the knowledge and attitude related questions (described in the previous sections and completed before the women read the story) show this change. For example, prior to reading the story only 25% of the women (table 9, question 6) said that there was a need to use other contraceptive methods, even when someone was using condoms. After reading the story almost 71% of the women said that the couple should have used other contraceptive method along with condoms. Similarly, in the knowledge assessment 57% of the women had said that vasectomy is simpler than tubectomy but after reading the story 90% of the women agree that vasectomy is simple so men should undergo sterilization. After reading the story 85% of the women disagree with the statement that pregnancy, delivery and childbirth is only women's responsibility compared to 44% women disagreeing to similar statement prior to reading the book.

Though these comparisons are not meant to statistically test the hypothesis of change happening after reading the book, these explorations are helpful to understand the usefulness of the book. The question on sustainability of these changes in the attitude and their role in behaviour change need further exploration.



## Perceived usefulness and impact of the book

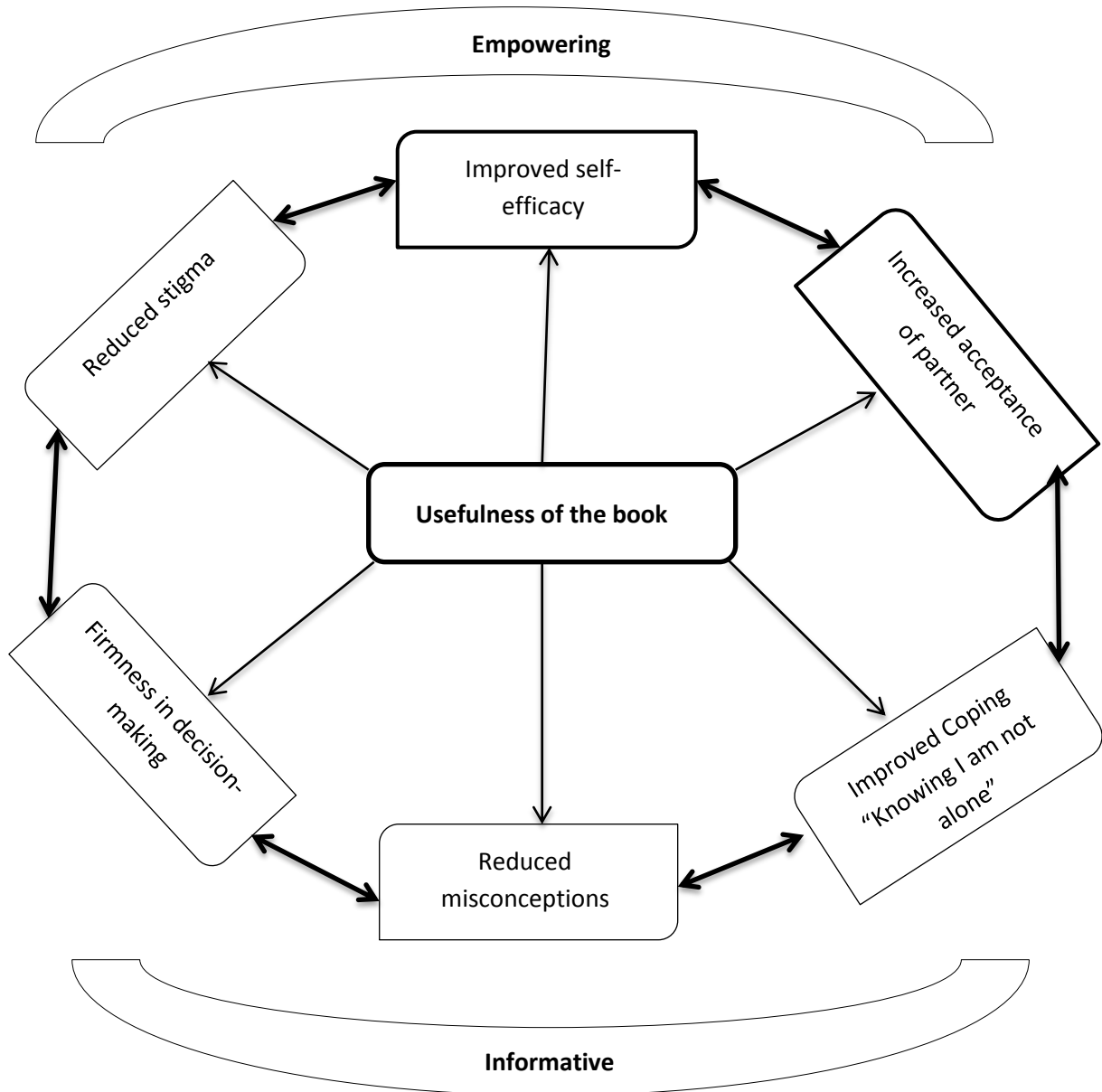
Usefulness of the book and its impact on the lives of women were assessed through in-depth qualitative interviews as the duration for which the women had been given the book and the sample of women who participated in the study was not appropriate to determine the quantitative impact on health outcomes such as occurrence of pregnancies or changes in contraceptive use. From the time of LCRC study till the interview conducted in this study, among the 174 women who participated 4 women had pregnancies. The qualitative description is given in the table below.

**Table 10: Description of pregnancies occurred after LCRC study**

Case 1	Planned pregnancy	Participant was 38 yrs old woman from low socio-economic status and has completed 12 years of education. She had pregnancy in September 2012. It was a planned pregnancy. She has one daughter and wanted to have a son. She continued the pregnancy and has delivered a baby boy.	Her pregnancy is before she was given the book (Apr 2014) and hence no influence of the book can be assumed. She read the whole book
Case 2	Planned pregnancy	43 yrs old woman who has completed 10 yrs of education. She had a planned pregnancy in June 2012. Her 2 daughters had already died, which was the main reason to have the pregnancy. This time it was a boy delivered with caesarean section.	Her pregnancy is before she was given the book (Apr 2014) and hence no influence of the book can be assumed. She read the whole book
Case 3	Unplanned pregnancy	34 yrs woman had completed 10 yrs of education. She had an unplanned pregnancy in January 2015. She wanted to continue that pregnancy but her husband refused for financial reasons so she opted to terminate it. Also her husband is 15 years elder to her and never wanted her to have another child. She has one daughter. After abortion she opted for insertion of an intra-uterine device (Cu-T) and her husband is using condom.	Her pregnancy and use of Cu-T is after the book was given to her (Oct 2013). She read the whole book. Apparently reading the book did not help her prevent unplanned pregnancy but might have helped in choosing Cu-T in addition to condom.
Case 4	Unplanned pregnancy	A 28 yrs old married woman, completed 7 yrs of education. She has 1 daughter and 1 son. She had an unplanned pregnancy in June 2014. She opted to terminate the pregnancy. Currently male condom is used for contraception.	Book was given before (Dec 2013) the last unplanned pregnancy. Had not read the book (only read 1-2 pages). Not a regular reader and even comprehension of words was poor.

In the qualitative interviews women reported the different aspects in which they found the book useful. Many of these aspects on usefulness of the book narrated by the women go beyond not only the reproductive health but also beyond general health and were perceived to be empowering as well as informative. They are summarized in a diagram and described below.

Figure 8: Perceived usefulness of the book



### ***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 and fecund woman who read the complete book]*

Self-efficacy is an individual belief in his or her capabilities to achieve something in a given circumstance. The concept first proposed by Albert Bandura in 1977 is still considered an important aspect in which people deal with their life situation (Bandura, 1977). In the article Bandura mentioned about 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 similar situation as theirs) succeed then that can increase their self-efficacy.

In line with the Bandura's explanation of 'Vicarious Experiences', women reported that reading about how other women in the stories acted in a specific situation seems to have increased their self-efficacy beliefs.

*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]*

The self-efficacy beliefs need not necessarily be related to sexual and reproductive health issues but could also be linked with it. For example at the end of the quantitative interview a 33 year old widow who had 9 years of education and was residing in rural area asked the interviewer a few questions regarding having sexual relationship with a man who has befriended her. She read a similar story in the book which possibly gave her the courage to discuss about it with the interviewer.

There are many women who expressed this feeling that after reading the book "you get the strength to deal with the disease" or "your confidence increases to confront the challenges". This clearly shows that the book has some impact at the level of self-efficacy beliefs of the women. The verisimilitude of these stories, the fact that these stories are based on the real experiences, might be an important contributor towards this impact.

### ***Increased acceptance of partner***

Majority of the married women in India are apparently monogamous and acquire HIV infection through their husbands (Gangakhedkar et al., 1997). This also means that most HIV infected

women, not only have to accept their HIV status but also have to accept the fact that their husbands betrayed them or had sexual relations (in most cases) outside marriage. This often is one of the major stressor expressed by HIV infected women when they come for counselling.

In all the stories in the book, along with women, their partners are also shown to have an important role. There is 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 you both can lead a good life' is also stressed in most of the stories along with the importance of open discussion about sexuality between the couple.

It appeared that many 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 they could not take out these thoughts off their mind before.

*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 like "what has happened in my life, which was so nice before HIV? Who is responsible for it?" Unknowingly I used to blame (tochayache) my husband for that. But after reading this book I had removed such thoughts from my mind. Now I realize that it was not his fault. [37 years, 18 years of education and pursuing her PhD, urban, married and fecund 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 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]*

### ***Improved coping: Knowing I am not alone***

Some women also expressed that after reading the book they realized that there are many women like them and they are not different than other women. This appeared to them as a relief and helped them cope with the situation 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 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 fecund woman who read the complete book]*

*Initially I used to think that I am different from other people. But after reading this book I realized that I am one of them and even I can live a normal life like them. Your sufferings become less when you realize that there are many people like you and you are not alone.* **[38 years, 8 years of education, rural, widowed woman who read the complete book]**

### **Reduced misconceptions**

While some women said that they did not look at the information provided in the book (as they had completed their reproductive career and hence was not relevant for them) but were more interested in reading the experiences of other women, a few women also mentioned that the information provided in the book could be very useful.

*This book will help to clear the misunderstandings people have for example widow infected with HIV should not marry or HIV infected woman should not have a pregnancy, etc. This book 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 wants to have a child.* **[35 years, 15 years of education, urban, married fecund woman who read the complete book]**

### **Firmness in decision-making**

Most of the time health communication material is intended to change the health related practices of people. However, one of the important roles of health communication material could also be to make the choices of people more informed which may or may not include change in their behavior. For example, a woman in this study mentioned that this book has helped her to firmly decide about not having a baby.

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

### **Reduced stigma**

Reduction in stigma though did not come as an important impact of the book, a woman mentioned about it. Reduction in stigma also appears to be related to increased acceptance among couples, at least in the context of what was mentioned by the woman. In her case, her partner had also read the book.

*Since last 8 years my husband used to discriminate against me. He used to sleep on a separate bed. He used to prepare and keep his food separately. He was about to throw me out of the house. But after reading this book, there was a lot of change in him. Now we share same bed. We eat together. The only thing is that we don't have sexual relations [otherwise we do things together]. Even doctor explained him everything about HIV. Previously my mother also used to fear a lot, used to worry about me. But after reading this book her fear has reduced. This book helped to clear the misunderstandings about HIV. [38 years, 12 years of education, urban, married fecund woman who read the complete book]*

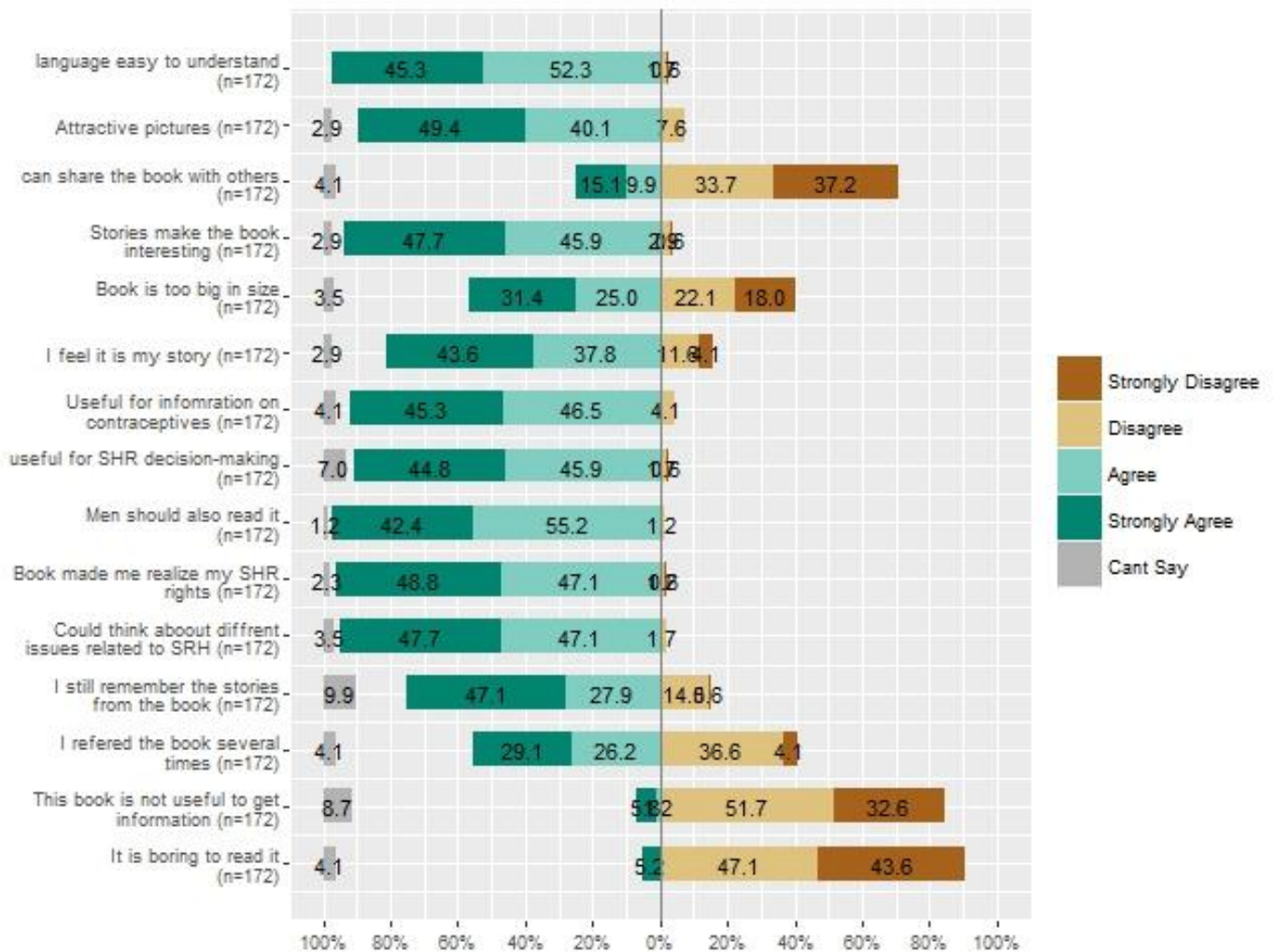
In summary the impact of the book appears to go beyond the issues related to sexual and reproductive health or even health in general. Most women who had read the book perceived it to be empowering, which helped them accept their disease as well as accept their partner and provided them the strength to cope with the situation.

## Women’s assessment of the book

### Using self-administered scale

During the quantitative data collection, women were given a five point Likert scale consisting 15 questions related to different aspects of the book to complete on their own. The questions were selected to reflect the format of the book (language, pictures, size, narrative style etc.), usefulness of the book for gaining information on contraceptives as well as decision making related to sexual and reproductive health (SRH) issues and their recall of the content of the book.

Figure 9: Women’s assessment of the book using self-administered five point Likert scale



The phenomenon of transportation was assessed by asking them if they felt that they are the character in the story. All the women before completing this assessment read one story during the process of the interview so that they knew about the content of the book and hence could rate it.

From the self-administered scale it appears that most women have appreciated the book. Majority feel that the language used in the book is simple to understand and the images used in the book make it more interesting to read. They also find the book useful to get information about different contraceptive methods and also feel that it could be useful in decision making related to different sexual and reproductive health issues. Most women also strongly felt that men should also read this book to make it even more useful.

Almost all women said that format of stories made the book more interesting to read. A high proportion of women (81.4%) felt that they could relate with the character in the story (it felt that it was their story). This can be an indicator that high level of 'transportation' can be achieved by the narrative communication in this format. Many women (75.6%) also mentioned that they could still remember the stories in the book which also indicate that the recall could be better with narrative communication.

In line with the findings from qualitative study described under barriers for reading the book, almost 71% of the women feel that the book cannot be shared with other due to fear of disclosure and stigma attached to the disease. Almost half of the women also feel that the book is too big in size and there should be shorter book with less text into it. This also points to the fact that people who do not have habit of reading might find it difficult to read (in line with the multivariate analysis of barrier for reading the book)

### **From the qualitative data**

Some aspects that are covered in the self-administered scale were also explored in the qualitative data.

#### ***Narrative communication increases the ease of reading and improves comprehension***

Women said that because the information is provided in the form of stories, it increases the interest in reading and also improves 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 fecund and read the complete book]*

Women also felt that some people might not be comfortable talking on 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 woman widow who read few stories in the book]*

***Images are good, but some are bit negative***

There were mixed feelings regarding the images used in the book. While some women felt that the images in the book are in line with the story and by looking at these images you can easily understand what is inside the story. At the same time some felt that some of the images are sad/negative or at times make you feel bit uncomfortable.

*Overall from the stories you feel positive but somewhere, from the images you feel that 'negative border'. As I said, it is always there in back of your mind that you have this [in curable disease] ... [36 years, post-graduate, urban, married fecund woman who read few stories in the book]*

Overall women appreciated the book especially that it is written in the form of stories. Because the book is about HIV a lot of women have the fear of disclosure of their HIV status to others and hence feel that the book cannot be shared with others.

## Summary of findings

This exploratory study documented the readability, assessed the barriers for reading the book and explored the perceived usefulness of the book ‘Gosti Mazya Tuzya’ among HIV infected women. The book, which was prepared by taking the insights from the previous study among ever married, HIV infected women attending a HIV clinic in western Maharashtra, India was given to the same women who had participated in the previous study. It contains stories regarding different issues confronted by HIV infected women and men with respect to their sexual and reproductive life.

The assessment of the readability of the book using existing readability formula developed for Marathi language showed that the book is readable for people who have an average 5 years of education (range 2-7 years). The existing formula for Marathi language considers average word length, average sentence length and percent difficult words for estimating the minimum years of education needed to read the text. The formula was designed for assessing the text written for school book and was based on the primary study among school children.

Assessment of readability and comprehension among women showed that 83% of the women had average or good readability and 66% of the women had average or good comprehension. Overall the words that appeared unfamiliar were difficult to read and understand. There were also words related to the reproductive system (of mostly male reproductive system) that were difficult to understand for many women. Most of the written materials on the topic of reproductive health typically have these words mentioned. Our findings suggest that there is need to find simpler and easily understandable words regarding the organs of male reproductive system. It also appears that more than the education, the habit of regular reading might determine readability and comprehension among women.

Among the 174 women who received the book and were interviewed for this study, 83 (47.7%) had read all the stories in the book, 60 (34.5%) had read few stories and 31 (17.8%) had either just glanced through the book or had not read it at all. Considering the fact that majority of the women were above the age of 35 (and probably completed their reproductive career) and almost 50% were not currently married (majority were widow and were unlikely to get married again), it appeared that many women read the book or made the attempt to read it. While assessing the socio-demographic profile of the women who read the book compared to those who did not read it (or read few stories) interestingly education and marital status does not appear to be significantly related to the reading of the book. It suggests that the book is perceived relevant by women irrespective of their marital status. Only two variables appeared as significant predictors of reading the complete book; women who have read any health material previously were 2.32 times and women who had good comprehension were 3.89 times more likely to read the complete book. This highlights the importance of habit of reading health material in determining if written health material would be read or not.

From the qualitative study, several other barriers were identified that can be considered as internal (related to women and their psychological state), external (related to other people) and related to the book itself. The internal barriers included the perception that the book is too emotionally disturbing to read, and reading about the sufferings of other women made the reliving their own past and reminded them of the issues they have decided not to think about. This was an important barrier reported by some women. This particular aspect of the book (of being able to connect with the women emotionally through narratives) is both the strength of the book as well as its weakness as there were also many women who derived strength from these narratives. This possible negative aspect of narratives, which mostly reflects women's coping with the disease have not be reported in previous studies on usefulness of narrative communication. The other internal barriers reported by some women were lack of perceived need to read anything related to sexual and reproductive health (as they have completed their family size), lack of time for reading and lack of desire for reading.

Among the external factors, fear of disclosure of their HIV status to others and fear that their children might see the book were reported by many women. Most women irrespective of the fact that they read the book or not mentioned that they could not read the book in front of others because they fear that others will ask them why they were reading the book on HIV. They had to hide the book and read it when no one was around. There was also concern for women who were widowed to read the book on sexual and reproductive health. Because the images in the book explicitly showed different aspects of relationship between husband and wife (and also some images about abortion and delivery), most women also felt that it is not appropriate for children to see the book which also acted as a barrier to read the book especially for women who were staying in joint families and did not have enough privacy for reading.

Though this was not the feeling shared by most women, some women felt that the size of the book is too big (not a standard size) so it is difficult to carry it in their purse or put it along with other books without getting noticed. They also felt that some of the images in the book were too negative and sad which discouraged them from reading the book.

Comparison of knowledge and attitudes of women who read the book with women who did not read it showed moderate improvement in the knowledge and change in attitudes related to some aspects which were emphasized in the book for example male sterilization (vasectomy) is simpler procedure than female sterilization (tubectomy) (58.7% vs 41.9%), perceived need to use other contraceptives even when using condoms (28.0% Vs 12.9%), health risks of unsafe abortion (91.6% Vs 80.6%). However, statistically significant increase was observed in changing the attitude that avoiding pregnancy is not only women's responsibility (48.3% Vs 25.8%;  $p=0.037$ ). Though the sample size and the study design cannot directly attribute the change in knowledge to reading of the book, the descriptive analysis suggests some role of the book in changing knowledge and attitude to some extent.

The assessment of comprehension among women immediately after reading a story suggested that most women could understand the important concepts mentioned in the story. Numeric comprehension (understanding and recollecting information presented in numbers) appeared difficult as many women could not recollect the maximum period for taking emergency contraceptive pills mentioned in the story. It also appeared that reading the story brought some changes in the knowledge and attitude of women when compared to their answers prior to reading the story.

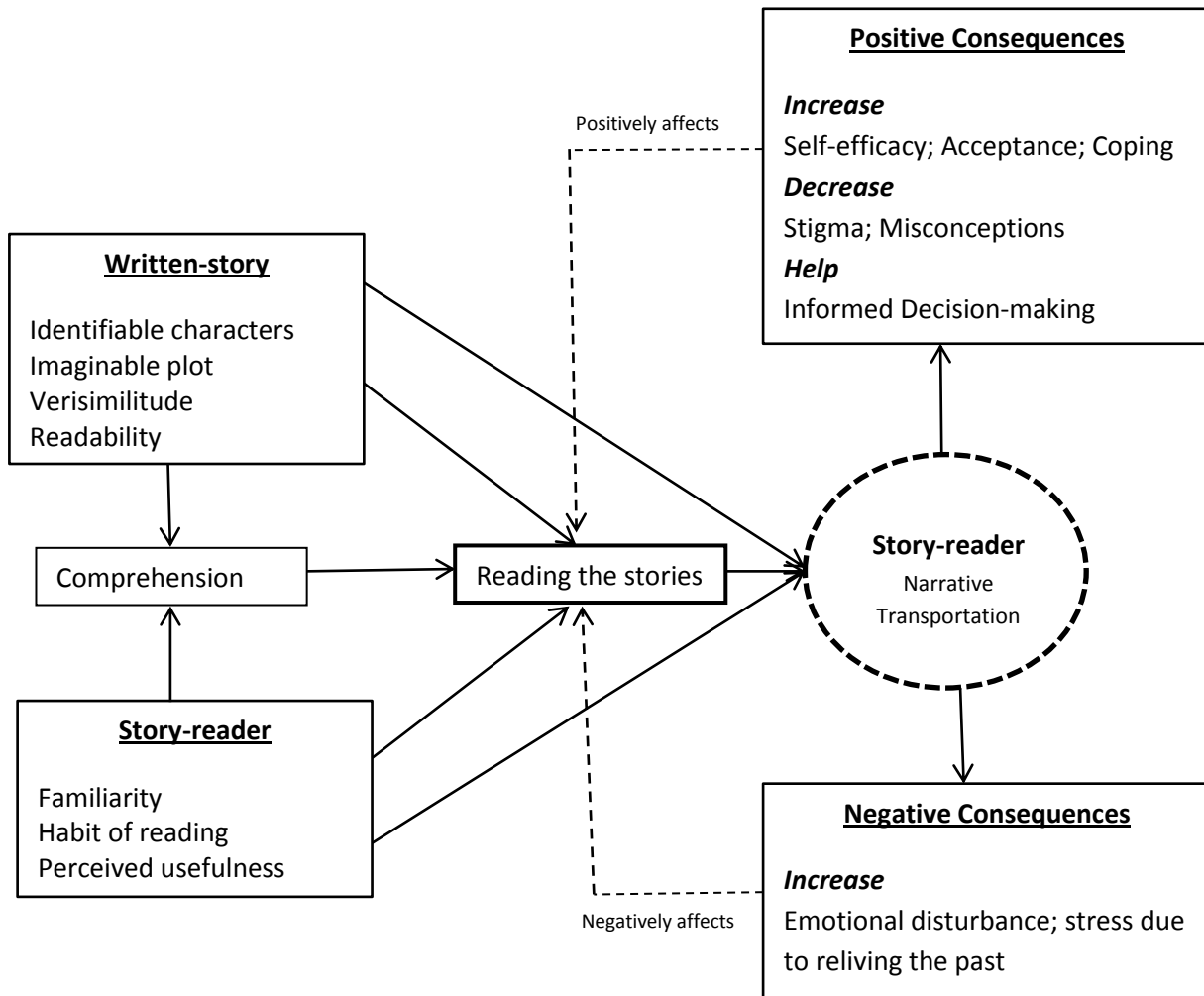
Based on the qualitative assessment of the usefulness of the book it appears that the impact of the book had gone beyond SRH issues and even beyond general health issues. Improved self-efficacy and confidence, renewed hope, better acceptance of the partner and better coping by knowing that they are not different were most frequently mentioned aspect of the impact the book had on these women. Reduction in misconceptions, reduced stigma (mainly from the partner) and making their decision firm were also mentioned by some as the ways in which the book had helped them. However, the sustainability of these changes in attitudes and its relation with behavior change need further studies.

Based on the self-administered tool, it appears that majority of the women appreciated the narrative style of the book. Many of them also felt that the story they read in the book felt as if it was their story (transportation). Stigma and fear of disclosure also appeared as a significant aspect of the book as most felt that it cannot be shared with others (especially those who do not know about their HIV status). Among those who had read the book, almost half of them had shared the book with others who knew about their HIV status such as husband or other family member.

Based on the findings of this exploratory study on usefulness of narratives among HIV infected women, we present the empirical model of narrative communication (Figure 10) and its usefulness for this population.

Overall, narrative communication appears as a promising way to provide health messages to HIV infected people. HIV infection does not only have impact on the health but it affects many interpersonal, psychological and social dimensions of life. There is often lack of space for many HIV infected people to talk about these issues. In such situations having a well written narrative book that can address these issues and motivate people to cope with their stressors could be a valuable tool to improve their quality of life.

Figure 10: Empirical model of narrative communication and its usefulness for HIV infected women



## Way forward

### ***Creating tools to assess readability of Marathi text intended for adult population***

While there are several readability formulae available for assessing the text written in English language, only one such formula was available for Marathi language. This formula was developed for accessing the readability of school books by collecting primary data from school children to derive the equation. Our research identified that lack of availability of readability assessment tools for Marathi text intended for adult audience. Due to considerable linguistic difference between English and Marathi, using readability formulae developed for English might not be beneficial in understanding the readability of Marathi text. Therefore creating a tool specific to Marathi and specific to adult population is a necessity. Making such tool available will not only enable others to assess the readability of the written text but can also strengthen the drive towards making simple and readable health information accessible. Also such formula should not only consider the difficulties of reading from the linguistic point of view but should also consider comprehension of the text.

### ***Assessing short term and long term impact of narrative health communication for HIV infected people***

Health communication, most of the times is 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 behavior change communication and also that such efforts can have impact beyond health. However, the short term and long term impact of such interventions and their generalizability needs further research.

### ***Creating guidelines for preparing narrative health communication for HIV and other significant public health issues***

Based on previous research on readability and comprehension (mostly of English language) there are several guidelines regarding preparing health material in general (for example *Simply Put: Guidelines for preparing easy-to-understand health material prepared by the Center for Disease Control and prevention (CDC), USA*). However, specific guidelines regarding preparation of narrative are lacking in general and specific to Indian context. Though there are some recent efforts in this direction (for example a recent paper by Thompson and Kreuter (2014) that outlines some aspects using narrative in public health practices) more efforts are needed to guide people to create effective narratives for addressing different public health issues.

### ***Supplementing one-to-one counseling with written narratives***

Providing individual counseling is an integral part of providing HIV treatment and care services. 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 important and also feel inappropriate to discuss during counseling. Also, through one to one counseling, people might not learn about the experiences of others and how others have coped with some of the similar challenges. Therefore, a book like ‘Gosti Mazya Tuzya’ could be used to supplement the counseling process. Counselors could motivate people to read the book and can discuss about their feelings and issues in the next counseling session. The way people react to these narratives might also provide better insights to the counselor regarding the way they are coping with their disease and the specific stressors.

## Annexure

### Dissemination through A Collaborative Workshop for Counsellors on Sexual and Reproductive Health of HIV Infected People

Prayas Health Group (PHG) and Pune district AIDS Prevention Control Unit (DAPCU) organized a workshop for counsellors working under the National program at Integrated HIV Counselling and Testing centres (ICTCs) and ART centres on 29/12/2015 at Pune.



#### Background:

Sexual and reproductive health of HIV infected, though acknowledge as an important part of the prevention of mother to child transmission (PMTCT) program has been largely neglected. The recent research studies across the globe and from India have shown that there is high proportion of unintended pregnancies and induced abortions in HIV infected women. To sensitize counsellors regarding these issues, Prayas and Pune DAPCU organized one day workshop for the counsellors to discuss SRH issues of HIV infected people and the need for better communication on these issues with infected people.

Prayas in collaboration with DAPCU is implementing Prevention of Mother to Child Transmission (PMTCT) Program in 6 districts of Maharashtra state in more than 430 private



hospitals under the public private partnership (PPP) initiative. Hence to organize this workshop, Prayas approached DAPCU, and realizing the need to have detailed discussion on this topic with the counsellors, DAPCU supported the idea of having one day workshop for counsellors on SRH issues.

### **About DAPCU:**

Under National AIDS Control Program-III (NACP- III), the management of HIV prevention and control program has been decentralized to district level. Across the State of Maharashtra the District AIDS Prevention Control Units (DAPCUs) are established in 30 districts which are considered to have higher HIV prevalence (more than 1% ANC prevalence in district in any of the sites in the last 3 years). DAPCUs play important role in monitoring and coordination of service delivery from the different facilities in the district. Efforts are made for effective HIV awareness campaigns, strengthening of referral linkages, and provision of care and treatment to all the HIV positive people in the district. DAPCUs are also expected to play a key role in integration of NACP with National Rural Health Mission (NRHM) and work closely with other departments in government setup to mainstream the HIV/AIDS Programs.

### **Participants:**

The participants for this workshop were mostly counsellors working in the Integrated Counselling and Testing Centres (ICTCs) and Anti-Retroviral Treatment (ART) centres from Pune district. Forty one counsellors working in ICTCs and ART centers in Pune district attended the workshop. Additionally two counsellors from Prayas, two district supervisors and a district Program Officer from DAPCU, Pune also attended the workshop.

### **Objective of the workshop:**

The specific objectives of the workshop were

- 1) To highlight and discuss about the need to address SRH issues of HIV infected people including prevention of unwanted pregnancies and unsafe abortions among HIV infected women
- 2) To discuss and advocate the right based approach in the existing counselling practices about the various Sexual and Reproductive Health (SRH) issues in HIV infected people
- 3) To discuss about effective communication strategies, including use of narrative written communication such as the book Stories Yours and Mine.

To achieve these objectives the workshop was conducted in 4 main sessions.

1. Overview and discussion on various SRH issues of HIV Infected women
2. Group discussion with 4 case studies about different SRH issues and what can be done about it as a counsellor
3. Family planning methods for HIV infected people- a technical overview
4. Communication on SRH issues

The workshop started with welcome speech and introduction of the Prayas Team.

### **Session wise overview and summary of the discussion**

#### **Various issues related to SRH of HIV infected people**

The discussion on various SRH issues of HIV infected women started by asking the participant to do free listing of all the issues they think are related to the sexual and reproductive health of HIV infected people.

##### **Issues mentioned**

ANC testing

Family planning methods

Prevention of Mother to Child Transmission (PMTCT),

Antiretroviral treatment

Medical Termination of Pregnancy (MTP)

Nutrition in pregnancy

Hygiene

Breast feeding

Sexually Transmitted Infections

The issues mentioned by the participants are given in the adjacent box. Most of the issues listed by the participants were related to the medical aspects of sexual and reproductive health. None of the participants mentioned about issues such as marriage, beginning of sexual relationship, consent, sexual and reproductive rights etc. This made it clear that more comprehensive discussion on the concept of sexual and reproductive health was needed. This exercise was also helpful to clarify with the participants that we would not be discussing all the issues that are linked with SRH of HIV infected people but would rather focus our discussion on how to identify these issues and take appropriate actions mainly related to unintended pregnancies in HIV infected women, safe abortion and

family planning methods for HIV infected people. During this session the counsellors were also asked to verbalize the questions they face regarding SRH while dealing with their clients. Many

questions were related to different options for pregnancy among HIV discordant couples, why HIV is not transmitted even after unprotected sex among some couples, artificial insemination, safe/unsafe abortion, co-relation of fertility and addiction, etc. Some of these questions were discussed and clarified in this session.

In order to clearly define the need to discuss SRH issues and also the issue of unwanted pregnancies and unsafe abortions among HIV infected women, presentation of recent research findings from Maharashtra (based on the research conducted at Prayas and published in peer-reviewed articles) was done. The book ‘Gosti Mazya Tuzya’ was also distributed to all the participants at the time of registration. The stories mentioned in the books were used for designing the session on group discussion.

#### **Group discussion with 4 case studies from the book ‘Gosti Mazya Tuzya’**



In this session participants were divided into 8 groups and 4 cases from the book distributed to the groups (1 case for 2 groups). Participants were asked to discuss the case among their group members. Two specific questions were given for discussion for each group. First question was to discuss on the issues that are related to SRH in that case and the second question was to create a communication plan on the identified issues.



Representatives from the groups that discussed the same case were asked to present about the discussion in the group and about the communication plan they decided for that case. After their presentations other participants were given the opportunity to ask questions to the presenting group. This also was an opportunity for facilitators to discuss about other relevant issues related to that topic. For example in one of the cases, a woman who had little control over her husband's inconsistent condom use and who had two unwanted pregnancies and induced abortions, there was a good discussion on the need to use other contraceptive method along with male condom to prevent unwanted pregnancies. Some counsellors were of the opinion that if HIV infected people are advised to use other methods of contraception such as sterilization or copper T then they would not use condom very consistently which might lead to cross infection among couples. However, a good debate was generated on this issue and it was argued by other counsellors that in situations when there is high possibility of inconsistent condom use then it might be essential for women to also use other method of contraception to prevent unwanted pregnancy while emphasizing on consistent condom use.

The group discussions went very well for all four cases and all the participants were very enthusiastic during the discussion. It was an interactive session and everyone participated in the discussion.

## Family planning methods for HIV infected people

Advising a particular method of family planning (other than condom) is typically done by medical care provider. However, basic knowledge about different contraceptive methods available for HIV infected people and some considerations for HIV infected people with specific



contraceptive methods (for example drug interaction of oral contraceptive pills with antiretroviral treatment) is essential for counsellor to effectively communicate about it with the client. In this session, various family planning methods with their advantages and disadvantages were discussed. Special

emphasis was given on the difference in choosing methods for HIV infected and non-infected people. Irrespective of the use of other methods of family planning, the importance of consistent use of condom for HIV infected couples was emphasized in this session.

## Communication regarding SRH:

Effective communication is a key to successful counselling. All the counsellors were well aware about the principals of good communication including the importance of verbal and non-verbal communication. In this session we had an open discussion on some of the concerns which counsellors had regarding communicating specific things, for example how to communicate different options for HIV discordant couples to have pregnancies while reducing the risk of HIV transmission to the partner. Most counsellors mentioned that as a counsellor, their role is to give options to people and the ultimate choice/decision has to be taken by the client. However, there was a good discussion on the issue and it was discussed how giving choice is not a neutral phenomenon. The way things are communicated, the verbal and non-verbal communication significantly shapes the interpretation of people regarding what is being communicated. In this session, the various methods used for communicating information during counselling patients/clients such as using flip charts, videos, films, pictures, printed material, books, storytelling, role play, etc. were explained. It was also suggested that using more than one method help the client to understand the information better. One of the important aspects discussed was that only giving information is often not enough to influence behaviour change among client. Therefore, the educational material for e.g. 'Gosti Mazya Tuzya' that can also emotionally connect with people could be helpful.

## Stories for Better Health: Consultative meeting to understand creative writers' perspective

### **Introduction:**

The research done at Prayas on the usefulness of the book 'Stories yours and mine' also shows the usefulness of narratives for women to cope with their illness and feel empowered by reading the stories of other women in similar situation. With this emerging evidence as well as the findings of our research in mind, a consultative meeting was planned with people who are engaged in developing written health communication material.

### **Objectives of the Meeting:**

Though narratives are effective in health communication, it is not the widely used method of health communication, mainly due to the lack of expertise in constructing effective stories. There are limited guidelines available to help others to develop narratives. Considering the growing evidence on the effectiveness of narratives, there have been some recent efforts in describing how to collect, develop and disseminate the stories regarding health communication (Zwald M et al 2013, Thompson T et al, 2014). However, none of these were from India.

There might be many public health practitioners in India who might feel intuitively the need to use narrative communication to best address the issue they are engaged with. However, lack of guidance on different issues that a person has to consider while writing an effective narrative may discourage people from using this approach. Lack of knowledge that stories could be effective tools for communication might also lead to many people putting efforts and resources on less effective communication techniques. Therefore, with the objective of increasing the discourse on use of narratives in public health in India and sharing the study findings, we planned a meeting with people having different capacities related to development of health communication such as public health practitioners, creative writers, health professionals etc.

The specific objectives of the meeting were:

1. To share findings of the study 'Assessing the readability and usefulness of research based narrative health communication material for sexual and reproductive health of HIV infected women in western Maharashtra, India'
2. To start a discussion on overall role of written narrative health communication material in public health in Indian context
3. To discuss situations/health conditions where narrative health communication might be more effective
4. To discuss about what can be done to increase the use of this form of health communication

## Profile of the participants

We invited experts from different fields such as public health, communication, linguistics, creative writing.

1. **Dr. Arun Gadre:** Coordinator SATHI Cehat, Pune based Non-Governmental Organization, a well-known writer and a Gynecologist. He has basic training in Counseling, communication, BCC and prepared few text books and other health communication material.
2. **Dr. Sanjeevani Kulkarni:** Trustee and Coordinator, Prayas Health Group, Pune. She is working in the field of HIV/AIDS and sexuality since last 30 years. She has prepared a range of health communication material using various forms such as booklets, books, narratives, informational, slide show, films, etc. She has been working in the field of education and parenting for more than 25 years. She is the Founder trustee and editor of 'Palakneeti Parivar' which publishes a magazine called 'Palakneeti' which brings the issues related to parenting in mainstream discourse. She is the first author of the book 'stories yours and mine'.
3. **Dr. Mohan Deshpande:** Graduate in Medicine. Involved for more than two decades in School Health Education and Training of Village Health Workers, grass root activists especially on Health-Communication. Founder of a group called Aarogya Bhan (*Aabha*), a health communication activist group. He is the second author of the book 'Stories Yours and Mine'
4. **Mr. Vilas Deshpande:** Journalist and Ex. Deputy Director of State Information, Education and Communication department for Maharashtra.
5. **Dr. Vinay Kulkarni:** Trustee and Coordinator, Prayas health Group, Pune. A well-known HIV physician and Dermatologist working in the field since last 3 decades. He has prepared a range of health communication material such as booklets, books, text books, slide show, films, etc. He had conducted many awareness and training programs on HIV/AIDS for different sections of the community including health care professionals.
6. **Ms. Madhuri Purandare:** A well-known writer and artist. She has written many books for children as well as adults. She has also illustrated and translated a number of them.
7. **Dr. Kapila Bharucha:** A well- Known Gynecologist, Professor at International College of Education, also Professor at The Institute for Health Management, Pune, the Centre which was set up to develop low cost audio-visual and training materials for the NGO & Government sectors; and for addressing urban health issues in slums.
8. **Dr. Ritu Parchure:** A public health researcher associated with Prayas who have experience of working in public health program as well as conducting research
9. **Dr. Trupti Darak:** Researcher associated with Prayas and has worked on this research project.

## **Summary of the discussion**

The meeting started with a round of introduction of all the participants of the meeting. Then Dr. Shrinivas Darak explained the objective of this meeting along with a brief presentation on the findings of the study '**Assessing the readability and usefulness of research based narrative health communication material for sexual and reproductive health of HIV infected women in western Maharashtra, India**'. The findings indicated that the narrative health communication was effective in coping with HIV disease. Dr. Shrinivas Darak gave an overview about narrative health communication, theory behind how it works and current evidence on using this form of health communication in various health conditions in public health.

To facilitate the discussion, the issues which should be considered while writing a narrative were enlisted and then the group discussed these issues in details.

## **Narratives in public health**

### ***When to use narratives?***

Most of the time health communication material is prepared with objective of changing unhealthy behaviors and motivating people to adopt healthier behaviors. The participants discussed this issue of the purpose of health communication in general and specific to narrative way of communication. In general there was consensus that health communication material should not only focus on changing the behavior but also on empowering people to take informed decisions.

Merely providing information will not be enough in many situations to achieve informed decision making and in these situations narrative communication might be a better approach. However, a narrative is not appropriate in each and every situation. There are situations where only information will be sufficient for e.g. a person undergoing surgery for hernia will require an informational material on hernia. But the situations where there are complex issues such as dealing with stigma, discrimination in HIV/AIDS, cancer prevention, prevention of non-communicable diseases, etc., narrative will be more effective. Also from the above mentioned study it was evident that narrative helps in coping while living with HIV. When the personal and social dimensions are evident and strongly intertwined with the acquiring the disease, experience it and/or accessing treatment for it then some of these socio-cultural dimensions can be addressed through narrative. A narrative can be more effective in situations where there is resistance to messages due to various reasons. These barriers and their solutions can be highlighted in the narratives so that reader can try to resolve those barriers and take positive actions for better health.

### ***What makes narratives effective?***

It was discussed that an interpersonal communication cannot be substituted by any health communication material and multiple forms of health communication material are useful in



different conditions. Participants were of the opinion that for narratives to be more effective there should be deep concern about the health condition, urgent need of solutions, and excitement for the information. There are certain specific aspects of the narratives that were believed to be related to its effectiveness.

### ***Who has written the narratives- Source Credibility?***

Previous literature suggested that the credibility of the person/organization writing the narrative is important for making the narrative more effective. However, the participants did not agree with this view. It was discussed that the effectiveness of narratives will depend on how well versed the writer is with the whole situation. If the writer's purpose of writing is clear and it is not in the form of command or preaching and if the reader finds it identifiable and emotionally appealing then it doesn't matter who wrote the narrative.

### ***Plot of narrative- similarity with the lived reality***

Literature of narrative communication often points out that narratives are effective because of the process of 'transportation' in which the reader is transported into the narrative world. For this to happen, it is suggested that the plot used in the narratives should reflect the lived realities of the people. All participants were in agreement with this point. However, it was also discussed that it is not possible to cover all the plots in a single story and it is not needed. It should be identifiable on broader level. A narrative should be able to show the reality of that situation. A narrative helps a person to come out from his own situation and take a next step. People have power to imagine and hence some aspects of the narratives, even when they are not identical to the lived realities of the people but are imaginable and convey the emotions that people can relate to then that can also help the reader to transport into narrative world.

### ***Resolution of Conflict***

An important issue on whether there should be resolution of conflict in narratives was discussed in detail. It was suggested that it would be unethical and unartistic to provide a direct resolution of any conflict because then writer will be imposing his/her thoughts on the reader. A narrative should not be prescriptive. Instead of giving direct resolution a writer can give multiple alternatives and give the freedom to the reader to choose the solution from those alternatives.

It was discussed that for reader to take positive actions it is important to take into consideration the social, cultural, familial, economical and life style factors which act as barriers. It will be more effective if all these factors are considered while writing a narrative and various alternatives are provided to overcome these factors. The alternatives can be in the form of experiential expressions (for e.g. the various ways the family members will react to the situation).

### *Illustrations*

There was a discussion on how illustrations should be used in narrative. It was suggested that illustrations should be clear and expressive. It should aim at creating a mental image that the person might have while reading the text. It should represent the essence of the story and not the content of the story. It should not subdue the effect of writing. Illustrator should think about what is essential to show and should be well versed with the context and subject. As illustrations attract the reader to read the material they should be used to show the complex concept. It was also discussed that whether illustrations should be positive or negative. While talking with women who participated in the above mentioned study, they shared that due to negative pictures in the book they avoided to read those stories due to fear of emotional disturbance. It was suggested by the experts that the purpose of using the illustration should be clear and there should not be any adjustment for making it more effective.

### *Language*

It was discussed that language used while writing the narratives should be simple. Length of the sentence should be short. Language should be appropriate for the audience. A writer should keep in mind that without decreasing the depth and seriousness of the message how language can be made appropriate for the audience. The writer should go into the role of the reader to understand how the reader will appreciate the message. Sometimes it can lose the essence of the story in making language more simplified. To save losing words from a language, instead of giving simple alternative words, explanation of that word can be given. While using scientific term, explanation of the term or illustrations explaining that term can be given along with that term. It was suggested that while writing on any subject, a list of the words related to that subject should be prepared which will be helpful while actual writing on that particular subject.

### *Assessment of a narrative*

It was discussed that there are lot of readability formulas to see the readability score of text in English language. These readability scores mostly give general idea of how hard a document will be to read by providing the minimum years of schooling (Grade) required for reading the text. But these formulas do not measure person's level of comprehension. However, most participants were of the view that such formulae will be of little use as there is no linear relationship between grade of education and the reading ability of a person. Readability depends on multiple factors such as quality of education, age, reading habit, etc. So it will not be useful to prepare any such formula.

It was suggested by the experts that there should be a checklist of the essential things a writer should consider while writing any health communication material.

## Summary

This consultative meeting provided the writers perspective on narratives as health communication. The important points that come out of the discussion are summarized below.

- Health communication material should not only focus on changing the behavior but also on empowering people to take informed decisions
- Narrative communication is better suited when the conflicting personal and social dimensions are evidence and intertwined with the acquiring the disease, experience it and/or accessing treatment for it
- For narratives to be more effective there should be deep concern about the health condition, urgent need of solutions, and excitement for the information.
- The credibility of the source (individual or institution) that is producing the narrative may not be important making it more effective. A well written narrative will be effective irrespective of the credibility of the source
- The plot of the narrative should be imaginable. It need not reflect most aspects of the lived realities of people.
- The narrative need not provide direct resolution of the conflict but can provide multiple alternatives so that the readers have the freedom to choose from them.
- Illustrations should reflect the essence of the writing and not the content. It should depict the mental image created while reading the narrative.
- Simple language with words used in daily life should be used. However, to save losing words from the language, instead of giving simple alternative words, meaning and explanation of apparently difficult words should be given.
- Assessment of written material based on a formula is difficult and understanding the grade level is less informative as there is no liner relationship between education and reading-comprehension.
- All the health communication material should be pretested before disseminating them in targeted population.

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