### Story Sharing for Sexual Health:

# Piloting Culturally-Relevant Intervention with South Asian Immigrant Women in Canada

Roula Kteily-Hawa, PhD, MSc, MPH, BEd, OCT Vijaya Chikermane, V., MA, Lori A.Chambers, PhD, Mandana Vahabi, PhD Jaspreet Soor, MBChB Praney Anand, MA Josephine P.H. Wong, PhD

<sup>1</sup>Kteily-Hawa, Roula, Family Studies and Human Development, Faculty of Health Sciences, Western University. ORCID ID: <a href="https://orcid.org/0000-0001-5581-0017">https://orcid.org/0000-0001-5581-0017</a>

<sup>4</sup>Vahabi, Mandana, Daphne Cockwell School of Nursing, Faculty of Community Services, Toronto Metropolitan University

<sup>4</sup>Wong, Josephine, Daphne Cockwell School of Nursing, Faculty of Community Services, Toronto Metropolitan University

#### **Corresponding Author:**

Roula Kteily-Hawa, PhD, MSc, MPH, BEd, OCT Associate Professor & Undergraduate Program Chair Family Studies and Human Development, Faculty of Health Sciences Western University

<sup>&</sup>lt;sup>2</sup>Chikermane, Vijaya, 7.10 Stories

<sup>&</sup>lt;sup>3</sup>Chambers, Lori, School of Social Work, Faculty of Social Services, McMaster University

<sup>&</sup>lt;sup>5</sup>Soor, Jaspreet, Alliance for South Asian AIDS Prevention

<sup>&</sup>lt;sup>5</sup>Anand, Praney, Alliance for South Asian AIDS Prevention

1285 Western Road London, ON N6G 1H2 Canada Email: roula.hawa@uwo.ca

**Acknowledgements:** We are grateful to all the women who participated in this research. We would like to acknowledge our eight women peer leaders, Abeera Khan, Anjum Sultana, Hadia Akhtar, Mahnoor Shahid, Nora Dikho, Ratna Chaudhary, Roopali Rokade, and Sreya Banerjea, for their important contributions in the successful implementation of this research.

**Funding:** This work was supported by Women's Xchange Programme of Women's College Hospital. The funders of this study did not play a role in implementing the research, evaluating outcomes or manuscript preparation.

Conflict of Interest: The study authors declare no potential conflict of interest, real or perceived.

Submitted 1 August 2023, revised 7 March 2024, accepted 10 April 2024.

#### **ABSTRACT:**

Objective: There is a scarcity of research on sexual health education among women in South Asian diasporic communities in Canada, resulting in a need for designing culturally relevant approaches to teach about sexual health and HIV prevention, seen as taboo topics. This community-based research study was designed to determine the effectiveness of using culturally relevant stories as a model for sexual health education for South Asian immigrant women (Toronto, Canada).

Design: South Asian women participants were randomly allocated to either a fact-based intervention (n=40) or a story-based intervention (n=38). Focus group data from fact-based and story-based educational workshops were thematically analyzed and interpreted using the parasocial contact hypothesis.

Findings: Although participants found the fact sheets to be informative, they were not culturally relevant. The educational sessions using stories were judged to better meet this criterion with many participants feeling the information was relevant to their community, useful for friends and families, and relatable to their lives. Participants assigned considerable value to the family as an important site for sexual health education. Finally, study participants, particularly those who had the storytelling intervention talked about the importance of having a safe space to discuss taboo topics like sexual health.

Conclusion: Learning about sexual health through stories is deeper relative to static fact sheets. Both play a role in helping South Asian women learn about sexual health and HIV prevention; however, story sharing was seen as a culturally relevant approach that emphasized the role of the family in sexual health conversations. Family life educators and other health practitioners need to draw on cultural competence as they design culturally relevant material and interventions for sexual health education.

**KEYWORDS:** Community health partnerships, Community health research, Community-Based Participatory Research, Health disparities, HIV/AIDS, Canada, Women's health, Health outcomes

### Introduction

Story Sharing for Sexual Health (SSSH) is a Community-Based Research study designed to determine the effectiveness of using stories as a model for sexual health education. The study was led by the Alliance for South Asian AIDS Prevention (ASAAP), an AIDS service organization based in Toronto (Ontario, Canada).

The term "South Asian" refers to an extremely diverse group of people whose origins can be traced to the region of South Asia, which includes the principal countries of Bangladesh, Bhutan, India, Maldives, Myanmar, Nepal, Pakistan, and Sri Lanka. It also refers to people who identify themselves as South Asian although their country of last permanent residence is not in South Asia. This includes South Asians from places such as Africa (especially East and South Africa), Caribbean (Guyana, Trinidad, and Jamaica), South America, and Pacific (Fiji) and European countries who trace their origin to the Indian subcontinent and continue to describe themselves as South Asians.

Targeting South Asian women in the Greater Toronto Area (GTA) as a sample population, the SSSH study used mixed methods to assess story-based tools developed for ASAAP's HIV prevention programs. The objectives of the study were to (a) explore the role that stories can play in sexual health learning and education, (b) determine how participants respond to and retain information from stories as compared to fact sheets and (c) mark how stories may affect attitudes and perceptions with regards to sexual health and people living with HIV.

Story sharing tradition has been used by communities for centuries to express needs, pass on traditions, preserve history and as an effective learning tool<sup>1</sup>. With this understanding, the SSSH team aspired to use story sharing to discuss the highly taboo topics of sexual health and HIV prevention within the South Asian community<sup>2</sup>.

### **Developing the Partnership**

ASAAP has an extensive experience with engaging peer leaders in programming and adopting models of storytelling to strengthen community outreach, laying a strong foundation for the research study. ASAAP's use of peer-led, story-sharing blogs and forums has been an effective approach to breaking community silence and promoting open conversations around sexual health and the need to resist systemic marginalization<sup>3</sup>.

ASAAP has been a leader in community-based HIV prevention interventions for over a decade, starting with the Brownkiss program, a peer-led program run through ASAAP in 2013. The program which focuses on using peers from targeted communities and providing tailored sexual health education, opened the door for ASAAP to partner with the academic community to support their work on the ground through evidence-based research.

To undertake this study, ASAAP mobilized long-standing partnerships with community members and local researchers, including co-authors on this manuscript RKH, JW, LC, and MV, and all of whom are racialized women who had collaborated on previous community-based participatory research (CBPR) projects in sexual health and who were skilled in sexual health using a gender equity lens, and storytelling epistemologies. The Executive Director of ASAAP, community leader and co-author VC, applied and received funding from the Women's Xchange program at the Women's College Hospital, University of Toronto, with the support of the academic team. Academic researchers were invited by ASAAP to support the project by offering research expertise.

Given the community-based participatory research approach in the study, the 'research team' was comprised of both community and academic researchers who are entirely women of colour, sharing project responsibilities in an equitable manner. Community team included the

executive director of ASAAP, the research coordinator, ASAAP research staff, and the trained peer leaders. Academic researchers included a senior team of researchers from Toronto Metropolitan University (formerly Ryerson University) and other early career researchers. There were many meetings that took place, starting with grant application, ethics review, peer leader training, thematic analysis, and knowledge translation through community forums. As such, this community—university partnership arose authentically through organic connections formed between racialized women who are invested in the collective empowerment of our communities.

Because ASAAP itself is embedded in South Asian sexual health education networks <sup>3</sup> the CBPR context of this partnership arose in a community-led format whereby community knowledge strongly informed the research framework, including grant-writing, peer leader recruitment and training, and participant recruitment. This research study was initiated by, led by, and rooted in the lived experience as well as sexual health expertise of racialized women who exist in multiple settings. The SSSH Study ensured an equitable framework, and shared visioning, of how to engage community members in sexual health capacity building and emphasized building the collective capacity of racialized women to meaningfully lead research. Continuing the CBPR focus in research capacity building, members of this team are authors of this article, including ASAAP staff members.

### **Story-Based Learning**

Story-based learning is well-recognized as an effective strategy for adult health education <sup>4,5</sup> However, there is a scarcity of research on story-based health education among adult women in South Asian diasporic communities <sup>6</sup>. To address this gap, the SSSH pilot study reported herein was designed to explore the role of mindful storytelling<sup>7</sup> in popular education (i.e., story

sharing with facts and personal experience catered to the audience) as a model for sexual health education involving South Asian women in the GTA.

The term *storytelling* refers to the social, cultural and educational activity of *story sharing* <sup>8</sup>. In South Asian communities, storytelling is a well-established means of cultural learning and empowerment<sup>1</sup>. Culturally relevant stories, especially stories shared by people or peers with whom participants can identify, can strengthen the effects of this popular education approach because peers share information in a non-threatening and relatable manner <sup>9, 10</sup>.

According to Remer <sup>7</sup> practitioners often rely on evidence-based fact sheets to provide health education. Remer, however, opined that there is added value in sharing others' experiences when providing health education. This approach adds others' practical experiences to the evidence. Of special importance is mindful storytelling so that trauma is not introduced when presenting stories as part of education and support <sup>7</sup>.

The potential for trauma is real when using story sharing around sexual health, in particular HIV, as stories may trigger intense emotions in the audience and practitioners, and researchers may or may not be aware of individuals' health status or situations relating to sexual assault. Mindful practice and research protocol ensure that constructed interventions remain authentic to the experiences of both the story tellers as well as the listeners and participants <sup>7</sup> Greenhalgh, Campbell-Richards, and Vijayaraghavan <sup>11</sup> reported that story sharing was effective in managing chronic illnesses (in their case, diabetes) because people were able to personally connect to both the experiences (stories) and facts presented.

Drama-based and interactive theatre-based storytelling have also proven to be effective, especially among multicultural youth <sup>12</sup>. While not included as methods in this study, the art of storytelling and interactive interventions align well, with all four strategies engaging participants

emotionally to impart culturally relevant information in a safe environment, increasing participation and enhancing deeper learning.

### **Conceptual Perspectives**

Parasocial Contact Hypothesis

This study drew on the parasocial contact hypothesis. The concept of parasocial was originally conceived to explore how media personalities (e.g., television or movie) can help reduce prejudice and stereotyping <sup>13</sup>. Studies show that vicarious contact through media, and textual representations, including peer educators, decreases stigma among populations receiving educational and informational materials <sup>14, 15</sup>. In this study, parasocial contact was initiated through a peer leader model, whereby peers who facilitated the interventions shared stories written by South Asian women living with HIV, thus improving social connection and leading to deeper learning of sexual health.

Cultural Relevance vs. Cultural Competence

This study used story sharing to communicate *culturally relevant* sexual health education. As a caveat, *cultural competence* and cultural relevance are often conflated and used interchangeably but they are distinct constructs. Individuals who are *culturally competent*, "acknowledge the influence that culture plays in communication and action, recognize the dynamics within cross-cultural relations, enhance their cultural competence through the acquisition of additional knowledge, and amend and adapt existing knowledge and practice with accompanying shifts in cultural competence" <sup>16</sup>. Whereas, *cultural relevance*, takes into account people's cultural backgrounds, interests and lived experiences potentially improving their engagement and academic achievement. This goes far beyond simply changing imagery to

represent the target population such as translating documents or designing materials that have recognizable prints or designs <sup>17</sup>.

Cultural competence refers to being able to work across cultures because one is aware of one's own identity and cultural biases and has learned to value and adapt to diversity and practice accordingly <sup>16, 18</sup>. It demands a "critical understanding of the underlying socio-political and economic processes of power, privilege, and institutional racism that create, support and maintain existing health disparities" <sup>19, p. 158</sup>. It goes without saying that educators and researchers must be aware of their own power and privilege when they design and deliver information and adapt to participants' needs else wise the educational experience may not be culturally relevant <sup>17,20</sup>.

#### **Research Design**

### Peer Leader Training

The study received ethics approval from Toronto Metropolitan University (formerly Ryerson University). A project coordinator and eight (8) peer leaders (women from South Asian backgrounds) were hired and trained to engage in recruitment and data collection. These peer leaders worked in a team of three (3) members and were trained in a community-based format in principles of community-based research, research design, data collection, HIV/AIDS 101, STIs and healthy relationships, social determinants of health, focus group facilitation and recruitment, consent and confidentiality, referrals and participant support, navigating difficult conversations, and social determinants of health<sup>6</sup>.

The hiring process for peer leaders also took into consideration candidates' involvement in South Asian women's contexts, knowledge of local community centers and networks of South Asian women, and their propensity for leadership and ability to act as popular opinion leaders.

Peers were hired through a committee made up of two program staff, one of whom was eventually selected as the research coordinator for the project, as well as the executive director of ASAAP. These existing strong ties to community at all levels of the project allowed peers to create community connections effectively; a strength of the study was the team's ability to activate existing community connections of trust between focus group participants, ASAAP, and peer leaders which allowed the project to reach a diverse population of South Asian women across the GTA.

The peer leaders held important roles in participant outreach, data collection, focus group facilitation and knowledge translation and exchange, all of which are a critical component of the research design. The peer leaders took on the role of either a Lead Facilitator, Support Facilitator, or Note Taker in each focus group intervention session and rotated through those roles throughout the interventions. A peer-leader training manual was designed by the research team to make sure all practices for recruitment, intervention and data collection were consistently followed across community sites <sup>21</sup>.

#### **Participants**

A convenience sample of 78 South Asian women, ages 22-64 were recruited. We used a combined method of convenience sampling and a multi-site approach. Participation inclusion criteria were: 18 years of age and over, self-identifying as South Asian, being able to read and speak English fluently, and living in the GTA.

Participants were recruited through partnerships with community agencies and community health centres in the GTA neighbourhoods where large populations of South Asians reside. To engage women, posters and e-flyers were distributed to community partners and networks serving South Asian women and communities. Snowball sampling and word-of-mouth

approaches were also used to engage women. The project coordinator and the eight peer leaders also engaged in recruitment and data collection. Given the participation inclusion criteria and our limited resources, convenience sampling was deemed appropriate.

#### Intervention

The study design entailed two peer-facilitated intervention models. The first intervention was a conventional factual information model that used Toronto Public Health's fact sheets on HIV, HPV, and Chlamydia. The second intervention used culturally-relevant stories addressing biomedical information comparable to Toronto Public Health's fact sheet, including information regarding risks, transmission, and treatment. Stories, by their nature, provide a social and culturally relevant context for information delivery; furthermore, two of the stories were produced by South Asian women living with HIV as part of an anthology thereby providing vicarious contact with people living with HIV, and three others were developed through the Women's Sexual Health platform at ASAAP (see Appendix I for a sample story).

South Asian women participants were randomly allocated to either a fact-based intervention (n=40) or a story-based intervention (n=38). All peer leaders delivered both interventions at various sites and rotated between roles. Each session began with a comprehensive review of consent and confidentiality followed by the administration of a preintervention survey which included sociodemographic questions and questions about (a) knowledge of basic concepts of sexual health and safer sex and (b) attitudes and perceptions of HIV/AIDS and sexual health. Next, the peer leaders delivered a 45-minute intervention (fact-based or story-based). This included handing out either fact sheets about HIV and STI prevention developed by local public health authorities or tailored stories developed by South Asian women

living with HIV and/or ASAAP staff. Once participants were able to sufficiently read, review and engage with the materials, the same sexual health survey was administered post-intervention.

After completing the survey, the peer-leaders facilitated an audio-recorded focus group discussion to gain an in-depth view of the participants' experiences post-intervention. In more detail, after each intervention workshop, a facilitated focus group discussion covered three areas:

(a) What did the participants learn and what new information was gained, (b) Did the material provide culturally relevant information and (c) What recommendations or changes to the material provided would they make? Because peer leaders delivered a group intervention (story vs fact sheets), it made sense that the discussion pertaining to the intervention was a group discussion. Focus group discussions helped further explore participants' perceptions, understandings, and engagement with the intervention material (fact sheets or stories).

At the end of the focus groups, each participant was given a resource list of community agencies that provide health services and social support. The total intervention lasted approximately 3 hours. All participants received an honorarium to compensate them for their time.

### Data Analysis

Post-focus group reflection data collected from the women peer leaders were used in triangulation to gain a better understanding of the use of fact-based and story-based approaches to engage South Asian women in HIV/STI prevention and sexual health education.

The focus of this paper is on the rich qualitative data gathered through focus groups. The audio-recorded focus group transcripts were transcribed (pseudonyms assigned) and reviewed to gain familiarity and a more comprehensive understanding of the data. The pseudonyms were grouped by session type; either factsheets or stories and a set of codes were developed using

NVIVO, identifying common themes. Line-by-line coding was performed on the common themes based on specific questions, indigenous concepts expressed by the participants and adult learning concepts. The coding was checked by at least two research team members to ensure agreement on interpretation and then the themes identified from both sessions (factsheets and stories) were also compared to offer a more nuanced analytical discussion.

### **Findings and Discussion**

A total of 78 women who self-identified as South Asian, were aged 18–60 and living in the GTA, took part in 11 focus group sessions. Among the participants, 73 (94%) were born outside of Canada, 60 participants (88%) self-identified as heterosexual, 8 (12%) as lesbian/bisexual and 11 (14%) did not answer. Fifty-five (70.5%) of the women had completed university degrees. Nearly half of the participants (n = 38) took part in the story-based sessions, and the remainder (n = 40) took part in the fact-based sessions. For a detailed sociodemographic profile for the participants see Table 1.

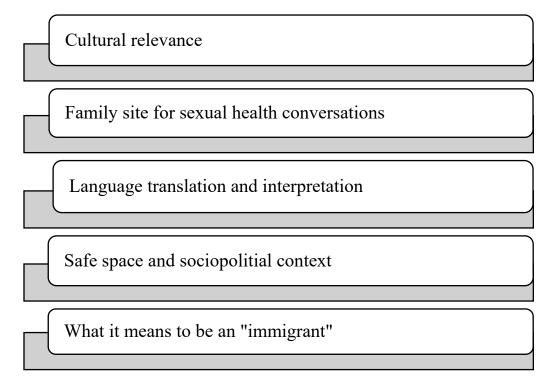
Table 1: Participant Demographics

Variable	Total (N=78)	Missing Data
Age, mean (SD)	38.15 (4.44)	
Age, range	22-64	
Born in Canada		1 (1.3)
Yes	N=5 (6.4%)	
No	N=73 (93.6%)	
Time Living in Canada, mean (SD)	6.15 (2.51)	
Highest Level of Education.	N=78 (98.7%).	1 (1.3)
High school diploma or less or equivalent	N=23 (29.4%)	
With undergraduate/graduate degree	N=55 (70.5%)	
Employment Status	N=76 (96.2%).	3 (3.8)
Non-full-time employed	N=38 (50.0%)	
Full-time employed (includes full-time home makers)	N=29 (38.2%)	
Retired and others	N=9 (11.8%)	
Sexual Orientation	N=68 (86.1%)	11 (13.9)
Heterosexual/Straight	N=60 (88.2%)	
Non-heterosexual/Bisexual	N=8 (11.8%)	

Our findings contribute significantly to the dearth of literature on storytelling and South Asian women and HIV prevention <sup>6,14,21</sup>. In this section, findings from thematic analysis of the transcribed focus groups are presented by examining cultural relevance of both modes of delivery. Overall, our findings indicate that storytelling is an effective strategy for adult sexual health education <sup>4,5</sup>. In particular, our results affirm that culturally competent curriculum planners are able to ensure culturally relevant material <sup>16,17,18</sup> as evident from the sessions in which participants identified the stories as more culturally relevant than the fact sheets.

Also, the parasocial contact hypothesis proved to be a useful approach because findings support its assertion that vicarious contact with peer educators (leaders) improves the dissemination and internalization of educational materials pursuant to sexual health <sup>13, 15, 19</sup>. And the women participants who are the story listeners bonded with the stories and their characters (i.e., nonthreatening learning) leading to deeper sexual health learning <sup>9,10</sup>. Specific key findings are now presented with attendant discussion. See Fig. 1

Fig1: Themes common and unique to intervention



Themes Pursuant to Cultural Relevance of Fact Sheets

Although participants agreed that the sexual health information contained in the fact sheets was useful for the South Asian community, the general consensus was that the communication approach of the fact sheets was more detached and did not allow the women to culturally relate to it even though it may have provided information. Participants felt that the storytelling format was easier to follow and relate to.

I think for me it was very good, pictures would definitely help . . . But I think just as it is . . . it was very good for me. FS4

I think also if some examples are given to certain information like if you're talking about this entire information... if one example is given then sometimes people would be able to relate and understand a bit better, I feel like. FS3

Another concern was difficulty with accessing the information. Many participants considered the specific language and terminology used in the fact sheets to be inaccessible and not culturally relevant. This finding even held for English terms with the English-speaking audience. Participants also recommended changing the fact sheets so that they accommodated native South Asian languages.

I just felt like it was just like this big wall of info and like I feel like if I didn't know anything beforehand it would just be totally alienating. FS2.

Having it in, you know, the various languages would also help to reach out to larger populations. FS4

I agree with all my group mates it is more good for everyone if it's being translated in other languages too so that everybody should know about this in detail right, some there are scientific terms and . . . terminologies there so we don't know that in-depth but if that is translated in different languages that is more easy for us to understand. FS11

Many participants commented on the lack of sociocultural context of the fact sheets. Specifically, participants discussed the shortcoming of providing information without addressing the stigma and shame associated with HIV or sexual transmitted infections in the South Asian community. They felt that they could use more culturally relevant information to offset denials or inadvertently shaming others. While these topics were taboo for them, they also recognized the need to address them for health reasons<sup>2</sup>.

I think handing a community of women that don't ever talk about sexual health a fact sheet isn't necessarily the best strategy. They may not understand a lot of the information that's in there and they might be too embarrassed to take the piece of paper home and read it. FS2

Improvements and Recommendations: Fact Sheets

When asked about ways for improving the fact sheet materials, the participants suggested the following improvements:

Language and Translation. Stemming from the discussions on access, language and interpretation, a major recommendation was to translate the materials in native South Asian languages and provide an interpreter for future sessions

Visuals and Videos. A common recommendation offered across the sessions was to add visuals and potential video accompaniments to the fact sheets provided.

Additional Data. Suggestions were also made to include examples of how STIs affect people and to include data on how South Asian women are particularly affected

I think it would have been more appropriate to have a video presentation with this group, more like a video...yeah, audio and visual together. FS4

Themes Pursuant to Cultural Relevance of Storytelling

Overall, participants deemed the storytelling approach to be relevant to their community, useful for friends and families, and relatable to their lives. The stories seemed particularly effective in enabling participants to emotionally connect with people living with HIV and relate to sexual health issues for a chronic disease -- similar to Greenhalgh et al.'s <sup>11</sup> findings.

We want to share with our kids and family, my other members, it's easy, and it's like a disease not a shameful anything. S6

My mind is changed about those persons. They are not a different kind of people; they are like us, all of us. Anyone can go through this phase so just respect all of them. Even I feel we should not discourage or we should not be shameful of other people when you get to know that he or she is having an HIV. S4

Like so many people who have these STIs, they don't like to speak about this to anyone but they, they showed the courage and they spoke to us, they wrote it and then they give the message to us, that's really, really helpful to us. S3

Many participants felt the stories were culturally relatable and appropriate. Moreover, the use of storytelling engaged women in critical reflection and analyses of facts presented. In some cases, the actions of the characters in the stories led to a discussion of culture itself and what this means in a cross-cultural and or intergenerational context. Women referenced particular aspects of the stories or characters in subsequent discussions suggesting their retention of details and the need and/or want to know more about the topic <sup>11</sup>. The following comments illustrate this finding of cultural relevance.

It's very good. When I was reading the story, I think that 'this is, is this condition with me what can I do that time.' This [story approach] was very good. S4

In some situation, if we put ourselves in that criteria . . . maybe we think that if we, we are in the same situation [as in the story] what will we do, so that's a better thing to learn. S1

While most participants appreciated the hope that was engendered through the story approach (see quote below), some participants felt that the stories were at times "too positive" in that the outcomes ultimately involved acceptance and support from families or self. They felt that this may not be reflective of reality. Those who have had more difficult experiences of family isolation or abandonment may feel further isolated in thinking that "others have made it and I haven't." In the future, the stories may have to reflect this possibility because unmindful interventions that do not take into account trauma during learning can be counterproductive and harmful <sup>7,11</sup>.

The stories and the conclusions and all you know it gave us a motivation that life doesn't end - we can still live happily and lead a very healthy life. S4

When it comes as a story we really feel like, the person means these things can happen to anyone . . . we are healthy today and tomorrow who knows . . . they were living life like us but one day happened like they had to face something. S3

Improvements and Recommendations: Storytelling

When asked about ways for improving the story sharing intervention, the participants offered the following suggestions:

Some Factual Complement. There was general agreement that each story can include a short list of facts at the end to ensure the reader is clear about the information and has a link of where to go for potential supports.

Translation. Suggestions were made to translate the stories in South Asian languages

Note on confidentiality. Suggestions included that a note of confidentiality be included

with the stories that specify that they are fictional or that describe the context.

The thing is like everything was good it's like there is any possibility by the end of the – we should give a summary sort of thing like precautions and we need to highlight those things, like that would be easy to remember. S1

From the stories there was brief information about brief statements about like STIs and the Chlamydia and little bit about AIDS and HIV and the vaccination thing, I would like to have a little more detail about all those to simply have more clarity. S2

Common Themes

When the fact sheet focus group discussions were compared with those of the stories, two themes emerged that were common across the board.

Family site for sexual health conversations. Participants in both the fact sheet and story sessions assigned considerable value to the family as an important site for sexual health education, similar to Driessnack's <sup>22</sup> assertion. Many expressed a clear desire to want to facilitate an open and supportive environment for their children, grandchildren or both who were looking for guidance related to their sexual health. The major barrier to this strategy identified was their 'shyness' and the stigma associated with the topic. A number of women expressed the need for tools and the right language that could support them in talking with their families about sexual health evidenced in the following quotes. Because storytelling is a well-established means of cultural learning <sup>1</sup> this support should be forthcoming.

Like what do you actually say when you have to talk to your partner about it or talk to your kids about it or talk to your family or talk to your doctor. How do you bring that up? Cause I don't think it's that easy sometimes to just say well tell them or go get tested. S2

"I would love if my grandmother had this conversation with me as awkward as it would be but I would know that I have that comfort level within my family because that's supposed to be your safe zone." FS1

One thing is talking about sex. I'm shy and how to talk my, any family member and my kids, I don't know so I always against it, sex education is not good but now I am happy here. Really, sex education is good for our kids because when I not talk to her, him, but in the school they talk and they know everything. S2

Language translation and interpretation. There were considerably more suggestions for translation and interpretation in the fact sheet sessions than in the story sessions despite the

spread of participants who spoke English as a Second Language (ESL) being fairly consistent among both groups. This finding is supportive of the idea that cultural appropriateness and relevance of sexual health education material is far more nuanced than language translation alone<sup>17</sup>. The storytelling approach, comprising narratives developed by South Asian women living with HIV or people in organizations working with them, seemed to make the sensitive, tabooed information more accessible. Remer <sup>7</sup> agreed that there is value in sharing others' stories when providing education about health.

I thought [the story was] an interesting way to present the information because it personalizes it in a way that you know if somebody just presented you a list of these facts it doesn't, it doesn't sort of stay with you, but now you have this picture of, you know, a woman [of the same culture] and her story and her kids and how it affected her life and how she felt and all those things make you know the effect of having HIV much more real and personal for people I think. S2

### Additional Findings

Two additional findings emerged from iterative readings of the data set - in particular the role of the study context and how participants perceived the concept of immigrant.

Role of study context. When provided with a safe space to have taboo discussions – a place that offered autonomy – study participants, particularly those who had the storytelling intervention, were able to share their true thoughts about sex education, which might not have been possible for their South Asian counterparts in the public arena and media milieu (per <sup>12</sup> Roberts et al.). In the future, researchers should remain cognizant and vigilant of contextual policy changes and perhaps turn to an emergent research design that can change on the fly as the situation changes. Indeed, being culturally competent requires awareness of social-political processes that impact health <sup>19</sup>.

Perceptions of what constitutes immigrant. Although a majority of the study participants were born outside of Canada (meaning they are immigrants to Canada), they still believed immigrant to refer to a group different from themselves. One participant commented that "immigrants need to know about sexual health." Participants routinely made generalizations about the nature of the South Asian community and believed themselves to be the exception to the rule (or stereotype) being discussed.

This finding suggests that future researchers need to be cognizant of this possible change in self-identity over time and bear it in mind during the research design process by including questions that focus on length of stay and acculturation. It might have powerful implications on any efforts to ensure culturally relevant sexual health education. "How and why people choose particular identity categories for self-definition or for the description of others" is an emerging topic of interest in immigrant-related research <sup>23, p. 3</sup>. "Ethnic identities are socially constructed and amenable to change" <sup>23, p. 2</sup>. meaning it is quite possible that the study participants had experienced an identity shift from immigrant to Canadian.

### Study Limitations

Due to budget limitation, we could not afford language interpretation during the focus groups. As previously indicated, participants in this study were fluent in English, however accommodating South Asian languages and materials is the next relevant step in reaching women not fluent in English. A related issue is the need for longer time for some interventions due to participants' comfort and reading speed with English, possibly resulting in participant fatigue. Although this does not take away from the trustworthiness of the data collected and our study findings, accommodating South Asian languages may be needed in future research design to offset this limitation.

Finally, the study was rooted in building community capacity and employed peer leaders to facilitate the sessions, which is one of the key strengths of this study. Although all 8 peer leaders received standardized 4-day-training as peer research associates, have varying styles of facilitation can be a limitation. Thus, although the questions and structure of the sessions were the same, differences in probing and group guiding were possible. This can present a challenge for this particular aspect of the research design. Nevertheless, given the significant role that peer leaders play in facilitating culturally relevant sexual health material as well as reducing stigma associated with HIV in the South Asian community, parasocial contact initiated through a peer leader model remains to be the most fitting study design.

#### **Implications for Practice**

The following recommendations are based on the combined findings of fact sheet and story session groupings as well as the comparative discussion and provide a well-developed and compelling description of how the findings inform practice. This information is useful for researchers, practitioners and family life educators.

Story Packages

The stories present as a more effective tool for sexual health education, are culturally relevant, and do more to challenge HIV stigma. To move forward with the stories as a holistic education tool, it is recommended that the stories come in the form of sexual health packages of sorts. In the package, each story would include a short list of the key facts related to the health condition highlighted. The package would also include a visual accompaniment and a list of health-related contact information.

The development of these story packages can be a next step in testing this model of programming and are well aligned with the stated recommendations or areas of improvement made by research participants.

### Language and Translation

Based on discussions of access, language and interpretation, it is recommended that the stories continue to use simple, clear language and that as/when possible materials are translated in South Asian languages.

#### Videos and Animation

It is recommended that videos to animate the stories and sexual health information in general be developed if and when resources allow. Strategies may be research and incorporated that support a model of visual communication that could negate the need for entire translations. This could be a graduated research study to test culturally appropriate videos as an educational tool and the potential for non-verbal video/visual messaging, although alternative tools will need to be present for people with visual impairment.

### Addressing Gender and Cultural Norms

Due to cultural and gender norms around sexuality, sexual health is not usually openly discussed or perceived as a need by community members for themselves, though they may identify it as a need in general for other members in their communities. This detachment was observed to occur much more frequently in focus group sessions with fact sheets. Participants across both sexual health education models identified a significant gap in resources to be able to successfully navigate sexual health in their own lives; while stigma and gender norms around

shyness prevented easy discussion of these topics in the family, they did identify family was an important site of sexual health conversations for which they wanted more tools and support. This presents a valuable opportunity for practitioners and family life educators working with South Asian communities

Centering Additional Populations and Communities

It is strongly recommended that story-sharing and storytelling models of sexual health education be designed and offered to communities of men and those representing other racialized populations. Men's engagement and role in sexual health was discussed in the focus groups and some women felt that men would considerably benefit from this form of dialogue and education.

In general, multiple strategies and approaches towards storytelling are possible to strengthen community knowledge of sexual health and to counter the stigma placed on sex and on people seeking support.

Stories represent one of the most basic and ancient human forms of learning. Their potential for social justice work is immense and requires both exploration and action. Health educators and other practitioners working with immigrant communities need to draw on cultural competence as they design culturally relevant educational material and interventions, particularly in the area of sexual health and HIV prevention. The results of this study also paved the way for future research focusing on other immigrant populations.

#### References

- 1. Davis CV. Talking tools, suffering servants, and defecating men: the power of storytelling in Maithil women's tales. Journal of American folklore. 2009 Jul 1;122(485):267-96.
- 2. Luhar, M. "Nonprofit groups battle sexual health stigma in South Asian community." NBC News Online, 2017, May 18. Retrieved from <a href="https://www.nbcnews.com/news/asian-america/community-groups-battle-sexual-health-stigma-south-asian-community-n759491">https://www.nbcnews.com/news/asian-america/community-groups-battle-sexual-health-stigma-south-asian-community-n759491</a>
- 3. The Alliance for South AIDS Prevention: ASAAP's Capacity Building Services. https://www.asaap.ca/capacitybuilding
- 4. Lee H, Fawcett J, DeMarco R. Storytelling/narrative theory to address health communication with minority populations. Applied nursing research. 2016 May 1;30:58-60.
- 5. Robillard AG, Reed C, Larkey L, Kohler C, Ingram LA, Lewis K, Julious C. In their own words: Stories from HIV-positive African American women. Health Education Journal. 2017 Oct;76(6):741-52.
- 6. Kteily-Hawa R, Hari S, Wong JP, Chikermane V, Chambers LA. Development and implementation of peer leader training for community-based participatory sexual health research. Progress in Community Health Partnerships: Research, Education, and Action. 2019;13(3):303-19.
- 7. Remer M. The value of sharing story. Midwifery Today with International Midwife. 2011 Jan 1(99):28-66.
- 8. Chaitin J. Narratives and Story-Telling Beyond Intractability. Conflict information consortium. Boulder: University of Colorado. 2003.
- 9. Bandura A. Social cognitive theory in cultural context. Applied psychology. 2002 Apr;51(2):269-90.
- 10. Singhal A, Cody MJ, Rogers EM, Sabido M, editors. Entertainment-education and social change: History, research, and practice. Routledge; 2003 Dec 8.
- 11. Greenhalgh T, Campbell-Richards D, Vijayaraghavan S, Collard A, Malik F, Griffin M, Morris J, Claydon A, Macfarlane F. New models of self-management education for minority ethnic groups: pilot randomized trial of a story-sharing intervention. Journal of Health Services Research & Policy. 2011 Jan;16(1):28-36.

- 12. Roberts M, Lobo R, Sorenson A. Evaluating the sharing stories youth theatre program: an interactive theatre and drama-based strategy for sexual health promotion among multicultural youth. Health Promotion Journal of Australia. 2017 Apr;28(1):30-6.
- 13. Perse EM, Rubin RB. Attribution in social and parasocial relationships. Communication research. 1989 Feb;16(1):59-77.
- 14. Kteily-Hawa R, Hari S, Soor JK, Wong JP, Chikermane V, Chambers LA, Vahabi M. Paradigm shifts in sexual health: Quantitative analysis of story and fact-based health education interventions. The Canadian Journal of Human Sexuality. 2020 Apr 1;29(1):45-56.
- 15. Schiappa E, Gregg PB, Hewes DE. The parasocial contact hypothesis. Communication monographs. 2005 Mar 1;72(1):92-115.
- 16. Bowman, S. "Cultural competence." Barton-Bellessa SM, editor. Encyclopedia of community corrections. Sage Publications; 2012 Apr 17, pages 101-103.
- 17. Ladson-Billings G. Toward a theory of culturally relevant pedagogy. American educational research journal. 1995 Sep;32(3):465-91.
- 18. Dana RH, Allen J, editors. Cultural competency training in a global society. Springer Science & Business Media; 2008 Nov 13.
- 19. Jernigan VB, Hearod JB, Tran K, Norris KC, Buchwald D. An examination of cultural competence training in US medical education guided by the tool for assessing cultural competence training. Journal of health disparities research and practice. 2016;9(3):150.
- **20.** Sagar PL. Transcultural nursing theory and models: Application in nursing education, practice, and administration. Springer Publishing Company; 2011.
- 21. Kteily-Hawa R. Designing A Peer Leader Training Manual for Community-Based Sexual Health Research: Action-Oriented Implications for Adult Education. Canadian Journal for the Study of Adult Education. 2021 Mar 2;33(1).
- 22. Driessnack M. "Who are you from?": the importance of family stories. Journal of family nursing. 2017 Nov; 23(4):434-49.
- 23. Foner N, Deaux K, Donato KM. Introduction: Immigration and changing identities. RSF: The Russell Sage Foundation Journal of the Social Sciences. 2018 Aug 1;4(5):1-25.

#### Appendix I

Chlamydia—Getting Tested and Treated

I'm sitting in a sterile, uncomfortable room in my hospital gown waiting impatiently for the nurse to return. I wish I was anywhere else; I know that this exam is necessary but that doesn't make it any less uncomfortable.

My name is Saba. I came in for my routine checkup about three weeks ago. I try and do this every time I have a new partner. We'd been dating a few months and I was in some serious honeymoon phase. The first few times we were really good about condoms and I'm on the pill too so I wasn't worried. But the last time we got so caught up in the moment and he insisted he would pull out. Yes, the withdrawal method of safe sex- HA! Not a method to be trusted.

During the routine check-up, I had a simple swipe test and I got my results that same day. I felt so angry and upset that I had an STI—a sexually transmitted infection: chlamydia. I felt like it was stupid of me and I should have known better, but really I know that's not the case. I started thinking about whether Imran knew all along and just didn't tell me or whether he didn't know at all.

I knew I had to tell him and that he should get tested too. I'd heard that sometimes you would feel a burning sensation when urinating but I hadn't had any symptoms and I knew there was a real chance that he hadn't had any either. Having an STI and not having any symptoms—what's that about? How are we supposed to know to go to the clinic or get tested? I guess it's just about knowing if you're at risk—and having a little fun without a condom put me at risk.

They gave me a single dose of Azithromycin and I had to make sure I didn't have sex for a week, so the antibiotic had a chance to clear the infection completely. I'm here today to make sure the medication worked and the chlamydia has been completely cleared out of my system. I know that this course of treatment has been successful for many in the past so I'm hopeful that it'll work.

Practising safer sex or always being careful is so much harder than it sounds. Imran and I aren't even together anymore, he was not happy about my news. In fact, he insisted that I'd been with other guys and put him at risk, he even called me names that I don't want to remember. Needless to say, I was not impressed.