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Exploring Storytelling Approach with Service Design to Create Empathetic Experiences for Adolescents Living with HIV: A Case Study

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Abstract

In India, a significant number of children live with HIV. Due to a lack of awareness and social stigma, they do not make timely and responsible life decisions around intimacy and HIV status disclosure. In this paper, we share our experience of collaborating with Prayas Health Group (PHG), a prominent Non-Government Organization in Maharashtra (India) that is dedicated to enriching the lives of HIV patients. We used Service Design methods to create a solution that disseminates essential information and enables Adolescents Living with HIV (ALHIV) to make informed life decisions. The solution is an interactive story media where adolescents make decisions around in-design encounters that parallel with possible real-life encounters. As a result, they learn more about the subject and its implications, leading to improved real-life decision-making. This paper demonstrates the orchestration of human and technology touchpoints through multiple dynamic and choice-based scenarios.

Keywords: Social impact, Service Design, HIV, Storytelling

Introduction

An estimated 1.75 million adolescents globally are living with HIV as of 2020 (UNICEF, 2021). Most adolescents and youth with HIV live in developing countries, acquiring it from their mothers through mother-to-child transmission. There is an estimated 2.32 million People Living with HIV (PLHIV) in India in 2020 (National AIDS Control Organization, 2020). The state of Maharashtra in India, where the current

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design intervention is being evaluated, has the highest number of PLHIV at 0.39 million (approximately).

Since the increase in access to Antiretroviral Treatment (ART), the survival rates of PLHIV, including children, have improved. These children are now in their adolescence and young adulthood (Mkumba, Nassali, Benner, & Ritchwood, 2021). However, there is limited attention to the changing needs of these youths while they transition to adulthood (Bhana, et al., 2020) (Baryamutuma & Baingana, 2011). A qualitative study from southern India among Adolescents Living with HIV (ALHIV) documented a range of concerns in romantic relationships such as confusion about whether to marry a HIV-positive or HIV-negative partner, and safety concerns in childbearing (Vranda, Subbakrishna, Ramakrishna, & Veena, 2018).

Disclosure of HIV status to an intimate partner is an important stressor for ALHIV (Toska, Cluver, Hodes, & Kidia, 2015). The fear of rejection, stigma, and public exposure after disclosure influences a range of important decisions that can directly or indirectly affect these young adults' physical, mental, and social health. Therefore, we recognized providing ALHIV support and guidance as a critical intervention to help in decision-making while disclosing HIV status to partners.

Overall, there is limited evidence on the prevalence and consequences of disclosure of HIV status to ALHIV's sexual partners, and how to support them in this process. Studies from South Africa (Kidman & Violari, 2020), Thailand (Boon-Yasidhi, et al., 2021), and anecdotal evidence from India (Vranda, Subbakrishna, Ramakrishna, & Veena, 2018) (Pune, 2010) suggest that ALHIV find it difficult to disclose their HIV status to their partners mainly due to the fear of rejection.

Based on the need for timely and responsible disclosure of HIV status and helping ALHIV make informed decisions on choices related to sexuality and disclosure, we have prototyped a service design intervention that incorporates interactive digital storytelling and design methods to make the solution more engaging to the end user. The solution focuses on promoting "learning through exploration", where users can explore various scenarios in a safe environment and make informed decisions when they encounter similar situations in real life. This is a "social" service that can be provided by NGOs and government organizations. The role of the service design team in this study was to enable these bodies. Through this journey, we reflect on how service design can provide a unique way to approach such sensitive issues and provide an innovative solution.

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Service Design in the Modern Age

After its emergence in the nineties (Mager, 2009), the subject of service design has been gradually established as a part of holistic and innovative design education. Progressively, it has displayed its value in numerous projects across industrial, private, and public sectors. With increasing demands for holistic and user-centric experiences, companies are beginning to understand the significance of service design. Several companies including telecommunication providers, insurance companies, banks, hospitals, transportation, and hospitality industries have started dedicating their resources to research in-service experiences and service design. To name a few examples, Virgin Atlantic, McDonald's, and Volkswagen are investing heavily in service design research to improvise their service experiences (Mager, 2009). Service design has helped add value to businesses and promote organizational change to improvise internal efficiencies and experiences (Joly, Grenha Teixeira, Patrício, & Sangiorgi, 2018).

Service Design—Then and Now

In the recent past, service design was primarily a method of designing and developing services and service businesses (Miettinen, 2013). As increased number of service designers, researchers, and practitioners began to address wicked problems through the service design approach, it became evident that we need to step beyond its traditional interactions. We need to focus on seamlessly integrating cultural, social, and personal interactions across many stakeholders to provide a meaningful service experience (Simo, Satu, Essi, & Antti, 2012). Services must be dynamic in nature to satisfy the growing needs of the users. Service design methods can play a key role in creating empathetic solutions for social issues. With it, one can think of creative ways of addressing large-scale socio-cultural issues. In the current context, service design can help us understand the complexities of cultural and social constructs that impact ALHIV. Designers can employ existing methods of service design to understand the user needs better. For example, in this study, we use methods of tacit knowledge extraction to find insights that the study participants did not share previously (Mahamuni, et al., 2018). We also used another service design tool called "empathy square" that enabled us to empathize with the needs and wants of all constituent elements of the service, that is, users, stakeholders, the environment, and the servicescape (Mahamuni, Meroni, Khambete, & Mokashi, 2019). Empathy square (Figure 1) plays a crucial role in enabling designers to make sustainable services aimed towards creating a social impact.

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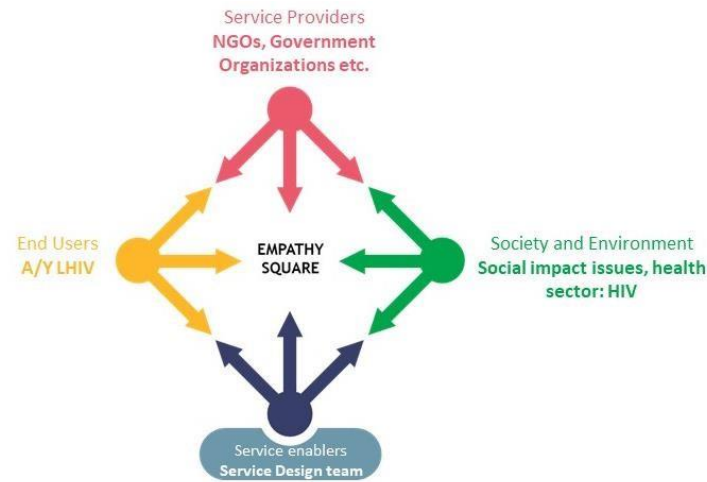DAD | PUC-Rio Pontifícia Universidade Católica Do Rio De Janeiro
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Figure 1. Empathy Square

With the help of service design, organizations can deliver enriched service experiences that are inclusive of all stakeholders' needs. This is done by understanding a problem from multiple perspectives of the involved actors and using design thinking to co-create innovative solutions.

Problem Areas Addressed in the Study

ALHIV in India are significantly affected by the social stigma around HIV and its impact on social interactions. The taboo around the subject discourages them to have an open discussion, leading to a lack of awareness of important steps necessary for recovery and safety. Two key issues that our study revealed were disclosure and sexuality. Primarily among adolescents, uncertainty, stigma, and lack of awareness about these issues generate significant stress in the process of decision-making. Additionally, a higher possibility of unfavorable outcomes can have a significant impact on their physical and mental health. Hence, it is important to assist them in making more informed choices.

Through service design, we anticipated a solution that would help ALHIV prepare for scenarios that they might encounter in real life. We started by understanding user needs, followed by creative ideation, conducting workshops for idea generation and refinement, and finally rapid prototyping a solution. The prototype is an interactive story-based UI where the users are exposed to a range of available choices at each encounter, and experience the consequences of their decisions in a safe space. Through it, the users get an exploratory outlook on the problem. The choices are not enforced on the user. Rather, it lets users explore what their choices may lead to.

Another benefit of this approach is that it makes the solution useful for two types of users: 1) users about to indulge in intimate relationships for the first time, and 2) users who have already indulged and experienced some level of consequence.

The study focuses on young adults (ages 21-26). This age group might experience sexual encounters soon, if they are already not sexually active. And they have several questions about it. It is necessary to clarify their questions to enable them to make more informed life decisions. In this study, we took a story-based approach to design various sub-services that would address the prominent problems creatively.

While understanding the needs of the user group, we noted down their entire life journey during the research (Figure 2). This helped us create a more holistic understanding of user needs. This approach played a crucial role in producing robust interventions that do not become irrelevant beyond the age of adolescence. This analysis was a result of several one-on-one interviews with users. The interview insights were then translated into a persona and subsequently, a user journey for that persona. The journey was extrapolated to the entire life journey and major problem areas were identified. The graph in Figure 2 depicts how the generalized intensity of these problem areas varies across the lifespan of an ALHIV.
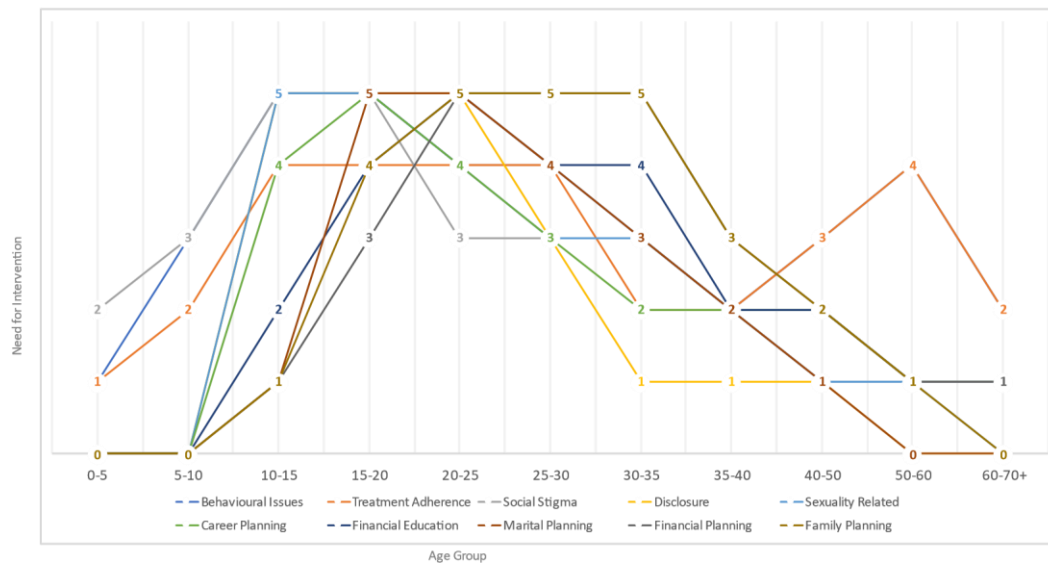

Figure 2. Problem areas identified during user research and their progression over users' lifespan

We analyzed ten major aspects (as shown in the graph) which are as follows:

1. Behavioral issues
2. Treatment Adherence

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3. Social Stigma
4. Disclosure
5. Sexuality related
6. Career planning
7. Financial Education
8. Marital Planning
9. Financial Planning
10. Family Planning

The above graph shows how each of these aspects varies across the lives of HIVpositive individuals. We can see that sexuality and disclosure prevail, having the highest intensities in the journey. These two factors further lead to issues in other areas such as marital affairs.

Design Intervention

A story-based approach to orchestrate sub-services and create an empathetic service response

The novelty of this project was to explore storytelling and use it as the central point to create a solution that resonated with the end user. Participating NGO (Prayas Health Group) conducted workshops where twenty-one adolescents were interviewed. Their stories showed how social factors played a key role in creating taboos around HIV which led to poor awareness of serious issues. Especially at the age when children transition to adulthood and have many questions about life in general, they are not provided the necessary information on how to deal with their condition. These problems span across social circles and families, increasing the problem exponentially.

After understanding the problems, we ideated ways to solve them. We created an interactive story-based mobile service (mobile service is more accessible to the users given their financial and social background) that let users go through experiences that they might face in real life. By allowing them to explore it in this safe environment, they were better prepared to make an appropriate decision when they face a similar scenario in real life.

To develop the story, we also studied various aspects of storytelling and its progression across time in drama structures by Aristotle and Freytag to create an engaging narrative (Freytag, 1872; Hoffe, 2009). This is because drama structures by Aristotle and Freytag include elements of exposition, rising action, falling action, and

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finally, resolution. In both structures, the initial half of the storyline sees a gradual increase in action (rising action) until it reaches a climax. Following the climax, the storyline gradually progresses to a slow retardation of action, until it reaches the conclusion (ending).

We created a story that utilized similar aspects to make it more engaging. We will learn more about it in the following section. In the prototype, the users can choose the protagonist's gender and HIV status to be more relatable. This helps customize the story according to the relevant context that users face in their real life, making the story more helpful. The story focuses on engagingly raising awareness and provides help and support in terms of:

1. Education
2. Sexual choices
3. Disclosure of HIV status
4. Marriage
5. Family planning
6. Employment: HIV-safe workplaces, health insurance, employment contract, work culture

This holistic problem-solving technique helped us solve user problems more realistically. This, combined with the ability to customize the story as per user choice made it suitable for individual needs. This helped us produce a story that uniquely resonated with each user's life experiences.

In the following section, we will look at the intervention in further detail.

Overview of the Concept

The service titled 'My Choices' has been prototyped in the regional language of Marathi, spoken in the state of Maharashtra, India. The Marathi implementation of the design is called 'Majha Paryay' which translates to 'My Choices'. We chose the language as per the linguistic comfort of the target audience. For the convenience of the readers of this paper, we have translated parts of the User Interface into English.

The narrative is about a romantic relationship between a HIV-positive and a non-HIVpositive character. The design allows users to choose between experiencing the story from a HIV-affected female or male perspective. This is because the narrative requires the users to make decisions around physical intimacy and sexual choices. The story takes the user through the journey of the chosen protagonist and requires the users to make choices on their behalf. At different intervals of the story, the user is posed with a set of options to choose from that dictates the progression of the

story. At the end of a story trail, user can start over again and choose a different option to experience the alternate narrative.

Objective

The design intends to provide users with an opportunity to explore situations that an ALHIV might encounter in a romantic relationship. The design enables users to realize the benefits of early disclosure and responsible physical intimacy to avoid complications that might result from hiding essential facts about their HIV status. The design does not intend to draw a strict line between right and wrong choices as reallife situations are complex and such distinction might not provide practical insights to users. Therefore, the choices provided in the design allow the users to explore all options irrespective of their correctness and analyze the impact. This holistic perspective gives users an outlook that is otherwise risky if explored in real-life situations.

Plot

We have implemented the female perspective of the narrative as a prototype version. The names used in the story are fictitious and have been used for representational purposes only, without any intended correlation to a person. The design narrative focuses on the journey of a protagonist named Vijaya (female) and her partner Sachin (male). Vijaya must make some tough decisions (when their relationship gets intimate) regarding her HIV status. The user needs to help Vijaya choose whether she should opt for responsible disclosure, safe sexual contact, protect herself from societal judgments, or give in to the fear of rejection.

Methodology

The design narrative was written by researchers and the HIV program manager at Prayas Health Group, Pune, India. The design and research implementation collaboration was conducted with researchers and designers from Tata Consultancy Services Ltd., Pune, India. The initial story exchanges between these two stakeholders were made using Microsoft Word and Microsoft Excel. This was later shifted to the online visual collaboration tool, Mural as the story branching grew more intricate.

From the beginning of the project, we adopted a collaborative approach of continuous feedback, and created wireframes using Adobe XD for feedback and discussion. This quick step of prototyping a clickable version of the design proved valuable in refining the narrative and navigating between the options. Some of these options were identified as redundant early on and replaced promptly.

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We analyzed storytelling aspects to create a resonating scenario for the end users. We first tried to understand the intent of each interaction in the service and how it should make the user feel. Based on the understanding, we noted the narratological aspects that the story must address to be engaging and collaborated with the participating NGO (Prayas Health Group) to develop the final storyline. The collaborative nature of the project helped us leverage the NGO's expert understanding of the issue.

As the wireframes were being refined, in parallel we finalized the story's flow. We used Mural's online visual collaboration platform for this purpose. Mural provides a bigger canvas that helped create branching and long story trails. The wireframes were translated into a mid-fidelity prototype, that is, a Minimum Viable Product (MVP) that could be used for testing. We explored an impersonal illustration style and created context-suitable illustrations using Adobe Photoshop. The user interface of the prototype was also further refined for a clean look using Adobe XD. Figure 3 shows a snippet of the refined prototype of the design. The design prototype was assessed with 35 HIV-affected adults.
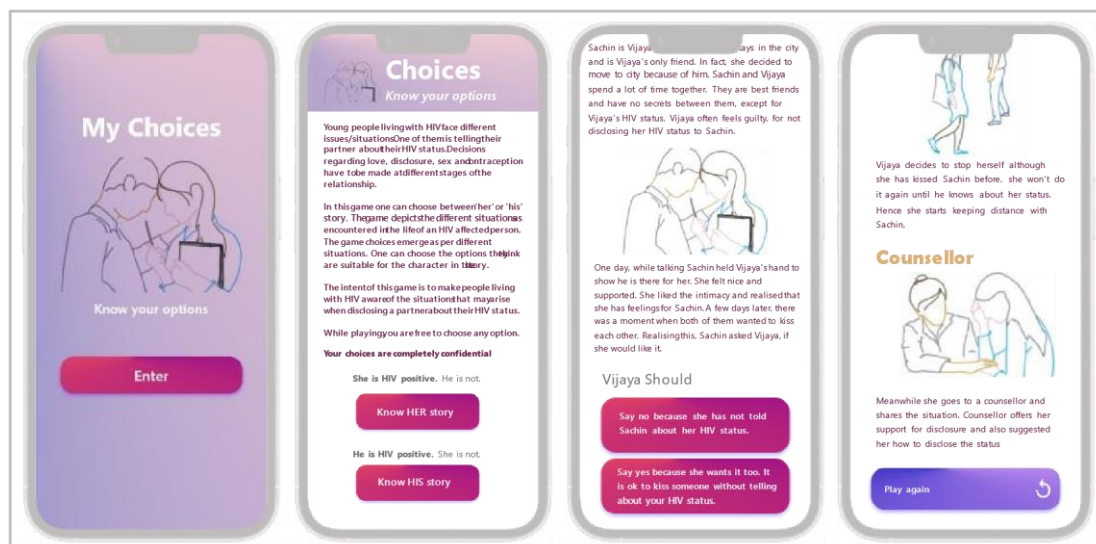

Figure 3. Refined design prototype used for testing

Validation

The solution was assessed with 35 A/YLHIV (Adolescents/Youth Living with HIV). The group comprised both male and female participants. These participants were chosen as per their availability. All participants are HIV positive. These participants were previously part of in-person workshops conducted by the participating NGO (Prayas Health Group) and had adequate exposure and education about HIV.

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We shared the URL to the platform application with the study participants, which they explored at their convenience on their devices. Later, we sent out an online questionnaire. Each participant individually went through the design before filling out the questionnaire. The following day, they were invited for a group discussion where the participants were prompted to share their thoughts. The evaluation aimed at assessing the following points:

1. Overall experience with the design
2. If the storyline resonated with users' real lives
3. If users learned anything new while using the design
4. If the Interface was easy to navigate and visually ergonomic
5. If the language, options, and images in the story were easy to understand

All the participants felt that the structure of the design and its presentation, including the language and associated images, were easy to understand. All of them could navigate easily and connect with the available choices to understand the different story trails in the design. They mentioned that it generates curiosity regarding "what happens next?" in the story and the available options.

Emotional Connect and Resonance

Ninety-one percent of the participants felt an emotional connection to the story. One girl reported that she was unable to comprehend the protagonist's situation of having HIV since birth. This directs us to the need for creating a more open narrative for youth who might have acquired HIV at later stages and not necessarily at birth. Several components of the story such as the intimacy between partners, the emotional state of the protagonist, or the decision complexity and uncertainty invoked visible emotional reactions among the participants.

Fifty-five percent of the participants shared that they felt a high level of emotional connectedness as if they were reading their own stories. This segment of participants took a significant amount of time at each decision point of the design. They explained that at some points, it became stressful and emotionally overwhelming due to the high relatability of the story with their own lives. This points towards the need of having an emotion regulation mechanism, as such issues might lead to users feeling discouraged in exploring all the choices.

New Information and Learnings from the Design

Participants felt the design could have elaborated more on "methods of disclosure". Participants expressed the need for details on practical aspects of sexual relationships. For example, "how a pregnancy test is conducted?", or "how to use various types of contraceptives?". They were aware of the importance of disclosure

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and pointed out how it is subjective to individual situations in one's life. During the discussion session, participants showed conflicting views over varying decision points which helped the counselors to understand them better and have a fruitful discussion on the topic. The enthusiastic discussion we had with the participants was due to the high level of engagement that the story provided. It was also pointed out that the design currently focuses mostly on partner communication. However, there is a need to address aspects that have a relatively larger probability of occurrence in the Indian context such as "arranged marriage" or "marital life".

Navigability and Visual Ergonomics of the Interface

None of the participants faced any issues in the story navigation. The participants found it extremely interesting to navigate between various story trails and experience the narration from multiple angles.

Ease of Language and Visuals

The visuals in the story kept the users engaged and immersed in the design. The language used in the design was Marathi. Hence, the users were able to comprehend the text with relevant emotions as Marathi is their native language and therefore, did not require language translation.

A Story-based Approach to Address Service Interventions: Discussion

The story addresses scenarios that a HIV-affected user might encounter in their life, such as moving to a different city for a job or studies, loneliness, and need for support, romantic involvement, fear of rejection, fear of intimacy, and disclosure of their HIV status. The narrative reflects upon crucial decision points in the life of an ALHIV. Cultural influences form the basis of problems around HIV and so, it is important to address these aspects. Lack of understanding of culture has been a major failure point in past efforts of spreading awareness about HIV (Duveskog & Sutinen, 2013). There is a potential of improving the story narrative by using the drama structures of Aristotle and Freytag (Freytag, 1872) (Hoffe, 2009). We have incorporated a few of these techniques revolving around time, environment, perspective, and character archetypes that make storytelling in interactive media more engaging (Kampa, Haake, & Burelli, 2016). We mapped various service design elements used in the story to different configurations and scenarios in the story (Figure 4). As shown in Figure 4, we can see how we can map these elements to service design elements.

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1. **Setting**: This corresponds to the problem space for which we are solving, and the narrative derived from it, based on user research.
2. **Characters**: These are customizable personas that users can configure. In the current story, this can be either Sachin or Vijaya, and service stakeholders.
3. **Plot**: This can be mapped to the customer journey map which was derived after extensive user research (Figure 2).
4. **Conflict**: The conflicts represent concerns and constraints that users and stakeholders of the service face.
5. **Theme**: This is representative of the entire design direction of the narrative.
6. **Narrative arc**: This represents interventions, prototypes, and prototype narration scripts.

With the help of this intervention, we were able to create an appropriate solution for the users that were more engaging and resonated with the real-life scenarios that they face. At the same time, the solution allowed users to explore their options without pushing for a right or wrong solution. Taking a storytelling approach helped us create an engaging solution. At the same time, it helped us understand the needs and wants of the end user better. Our holistic approach helped users understand all the scenarios that they might have to face in their lives, related to disclosure and sexual health. Using the power of storytelling, in conjunction with service design thinking, we produced a novel way of tackling the issue.
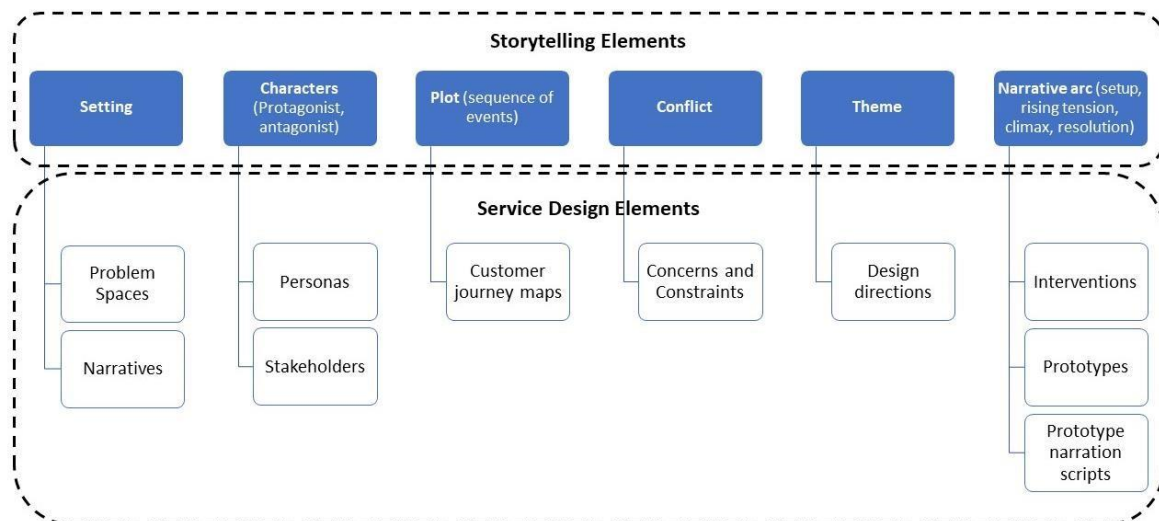

Figure 4. Mapping of storytelling elements across service design elements

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Through this case study, we realize how storytelling in combination with service design can be used to create more empathetic experiences for other problems as well, in a systemic way.

Conclusion and Future Steps

The study requires validation across a larger user group. The future step is to primarily focus on that. There is also a need to create other story branches that do not necessarily focus on sexually-contracted HIV or romantic relationships. This is to cover more diverse aspects that might resonate with a larger audience. There is also a need to make storylines from the perspective of all present genders and sexual orientations, to create a more inclusive solution. We also need to identify other areas that can benefit from such an approach. Overall, the study helps us understand how the service design approach, in this case, the use of storytelling, can help address a large-scale social issue. Also, how we can add this method to a diverse set of strategies used in service design for others' benefit.

The study, at the current stage, has shown promising results. It forms a meaningful way of understanding problems in modern-era service design that can also help make large-scale technologies more empathetic.

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