



Nurturing empathy for social cohesion

Participatory, community-based
communication design research with
gay youth living with HIV in Lebanon

by Bahaa Harmouche

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Design in Visual Communication Design

Department of Art & Design
University of Alberta, 2017

To see the videos for research purposes only, please send request at harmouch@ualberta.ca to grant digital access.

Abstract

1.0 Introduction: my story	9
2.0 Literature review	10
2.1 Design practice	10
2.2 Relevant theories of communication	11
2.2.1 Semiotic theory	12
2.2.2 Communication theories and models	14
2.3 Design thinking and processes	17
2.3.1 Human-centered design	17
2.3.2 Social design	19
2.4 Interdisciplinary theories used in design	22
2.4.1 Theories of social cohesion and integration	22
2.4.2 Theory of the oppressed	28
2.5 Overview of the Lebanese social situation	30
2.5.1 The gay community: current social and judicial issues	31
3.0 Research method	35
3.1 Discovering and investigating the problem	37
3.1.1 Background from the medical field	44
3.1.2 Media influence and representation of HIV and gay characters	47
3.1.3 Perspectives of gay youth living with HIV	54
3.2 Defining and developing the approach: co-design workshop	58
3.2.1 Recruitment of participants in Lebanon	59
3.2.1.1 Relationship with Proud Lebanon	60
3.2.1.2 Preserving the anonymity of participants	61
3.2.2 Workshop structure	63
3.2.2.1 Narrative: writing the messages	63
3.2.2.2 Storyboarding: visualizing the messages	66
3.2.2.3 Voice recording: audio and music	67
3.2.2.4 Image recording: photo and video	68
3.2.2.5 Editing: shaping the stories	70
3.2.2.6 Screening the visual communications (videos)	70
4.0 Results and data analysis	75
4.1 Reading participants' narratives (biographical documentary videos)	75

4.2 Facilitator observations	88
4.3 Pros and cons of the method	90
5.0 Evaluating the impact of the videos	94
5.1 Screening of participants' videos to gay youth	94
5.2 Screening of the participants' videos to the public	106
5.2.1 Participants' observations and feedback	108
5.2.2 Public and stakeholder reaction	109
6.0 Future research	112
7.0 Conclusions	113
8.0 References	115
9.0 Bibliography	
10.0 Appendices	123

Dedicated to my husband—
Darren Andrychuk—for empowering me,
for believing in my capabilities and
for being my soul mate and supporting
me in my journey.

To my six heroes—who shared your
stories and allowed me to experience
your journeys—you changed my life and
I am forever grateful for your trust.

Acknowledgements

My journey through the Master of Design program would not have been possible without the guidance and the support of the Department of Art & Design at the University of Alberta, especially my one-of-a-kind supervisor Professor Susan Colberg. Thank you for letting me pursue my passion and follow my dream. Thank you Sue for your constant encouragement and moral support. Your leadership, mentoring, wisdom and design aesthetic made me the designer I am today. Your human kindness filled me with hope and pushed me to believe that the world is a great place.

In the first year, I was taken under the wings of Professor Bonnie Sadler Takach. I would like to thank her for believing in me and my teaching skills. Her pedagogy and ethics shaped my way of teaching.

Furthermore, I would like to send my gratitude to the faculty, staff and students of the Department of Art & Design. For my first-year professors, Aidan Rowe, Robert Lederer and Gavin Renwick, thank you all for sharing your wisdom and advice. Graduate Student Advisor Dawn McLean, thank you for listening to me and giving me advice for two wonderful years. Blair Brennan, thank you for guiding and taking care of every student.

For my teaching assistant educators, I am blessed and honored to have been given the chance to be in your classroom. Gillian Harvey and Justin Pritchard, your passion for design and design education was contagious. Thank you both for your knowledge and support. My fellow grad student Mischa Patel, thank you for sharing the long hours in the office with me. I cherish your friendship.

Finally I would like to thank my families all around Canada and the world. My first family, Rowan Haigh, thank you for your time and constant help. Without you, this paper would not have seen the light of day.

My Edmonton family, Michel Lévesque, Josh Clendenin, Bruce Gross, Rob Marchak and Dubhe Boloix, thank-you for your genuine support, advice and above all your friendship through my journey.

My Regina family, Hillberg & Berk, thank you for your support and your trust in me. Dwight Matusko thank you for your friendship and support.

Finally, for my Lebanese family, Bshara Attalah, Liliane Hanbali, Nevine el Hibri, Julian Kerboghossian and Hiba Mahmoud, thank you for your support

during my stay in Beirut while conducting my research. I am eternally grateful for your friendship, kindness and support. Special thanks to Proud Lebanon and Bertho Makso for trusting me and my workshop and allowing me to be part of your small family. Thank you to Helem, AFE, M-Coalition and Marsa for being kind enough to provide me with all the material needed and facilitating the flow of my research, in particular, George Azzi, Eli Ballan, Jaques Mokhbat, Diana Abou Abbas and Glenn Wagner who provided fantastic support. Thank you for Nathalie Fallaha and her Vit-e team for welcoming us in their design firm.

My six workshop participants, you are the true definition of resilience, empowerment and love.

Mum, thank you for always being there for me.

Abstract

The marginalization of gay youth living with HIV (GYLWH) in Lebanese society is well documented. The topic of gay youth living with HIV in a deeply conservative and homophobic society has not been studied in any great depth. The story of gay youth in Lebanon is one of the stigmatization of minorities within and by other minorities. The question of how to break down 'walls' built on foundations of ignorance, intolerance, and self-loathing is yet to be examined. Using participatory, community-based communication design methods, this thesis project presents a model that uses visual communication design, in the form of digital storytelling (the making of videos), to help build trust among GYLWH in Beirut, Lebanon in order to remove barriers between groups and individuals and reduce stigma.

The research project tested a design thinking process, for social designers dealing with marginalized groups, in the form of a workshop procedure that was implemented within/by a support group.

This research was concerned with bridging the gap between GYLWH and their community, using visual communication design as a means of initiating a dialogue between the two groups. The research shed light on the lives and experiences of gay youth living with the virus. This process had a dual effect. It helped GYLWH to build confidence by allowing them to speak up and express themselves through sharing their stories with their community, and it nurtured empathy in gay youth (GY) by exposing them to the realities of living with HIV and by opening a discourse that resulted in their personal growth.

1.0 Introduction: my story

During my stay in Egypt from 2004 until 2013, I witnessed various levels of stigmatization connected with HIV/AIDS and gay issues. I remember one day I was in a cinema watching a movie called *The Yacoubian Building* based on a book written by Alaa Aswani. The film represents modern Egypt after the coup d'état of 1952 and is set in *The Yacoubian Building* (a once-grand edifice in Cairo) and tells the story of its inhabitants. One character, *Hatim Rasheed*, was an educated gay editor for a French newspaper. This was a gay character, portrayed for the first time, on-screen, without any stereotypical effeminate characteristics. *Hatim* was killed by a thief he picked up on the street for a sexual encounter. The shocking thing for me was the reaction of the audience in the movie theater immediately after the death scene—they clapped when the gay man was killed. In the 21st century, this reaction speaks volumes about the stigma still associated with gay life in the Middle East.

This experience was the driving force behind this research. Silenced voices go unheard in a judgmental, conservative world and this is where the role of social designer comes in play in this thesis research project. Through a participatory, community-based communication design process, helping gay youth living with HIV (GYLWH) in Lebanon, to tell their stories through designing digital videos, can help explain the lives and/or experiences of these marginalized minorities to their communities in an attempt to create awareness and empathy in order to help reduce the stigma of living with HIV.

In this project, 6 gay youths living with HIV designed and shared their stories (as digital videos) to try to break down the walls of ignorance and help further understanding about what it is like to live with HIV. Through design thinking, the research addresses the questions of “what”, “why” and “how” social integration and cohesion should be fostered between two minority groups, GYLWH and gay youth in Lebanon.

2.0 Literature review

Different epistemological theories from many fields help to enrich analytical thinking when dealing with important social issues, like the marginalization of a minority group, such as gay youth living with HIV within a larger gay community. Before delving into the main issue, theories from the field of visual communication design are discussed, followed by theories from the fields of communication, sociology, and education.

2.1 Design practice

Historically, the field of visual communication design was widely considered as part of art, and then became a field in its own right. In his book, *Communication Design: Principles, Methods, and Practice*, design educator Jorge Frascara endeavoured to 'map the terrain' of the design field, and was one of the few authors to define visual communication.

Visual communication design, as we know it today, developed its essential components in the 1920s. It changed in the 1950s when new developments in psychology, sociology, linguistics, and marketing attracted the attention of designers, leading them to change their objective from artistic creation to effective communication. We are now witnessing a third stage, primarily based on developments in technology, which have resulted in increased attention paid to notions of interaction between the public and information (Frascara, 2004, p.35).

Frascara and other design educators, like Alain Findeli (2001), have discussed the evolution of the design field, starting from mainly aesthetic concerns to become primarily concerned with functional minimalism.

Frascara used 'visual communication design' whenever he focused on the field generally, and he reserved the word 'design' to embody the process of 'conceiving, planning, projecting, coordinating, selecting, and organizing elements' to create visual communication (Frascara, 2004).

By defining 'design' this way, we can see that Frascara describes visual communication as a part of the communication field as a whole, and focuses on the process that takes place when building a 'visual' and a 'communication.'

Visual communication design, seen as an *activity*, is the action of conceiving, programming, projecting, and realizing visual communications that are usually produced through industrial means

and are aimed at broadcasting specific *messages* to *specific sectors of the public*. This is done with a view toward *having an impact* on the *public's knowledge, attitudes, or behavior* in an intended direction (Frascara, 2004, p.2).

In his definition, Frascara highlights many points that are needed to explain the trajectory of any design thinking process or project. Looking at the italicised words in the definition above, we see different points that Frascara wants us to realize. There is the activity that refers to the 'process' or 'design thinking' that a designer goes through when addressing any design problem. There is the message that, in this context, refers to the communication theories that are needed to build messages for a specific target audience. Finally, there is the interdisciplinary aspect of design as it uses theories from other fields to explain phenomena and to appropriate different tools and methods to help address a problem.

Relevant theories were chosen for the current study upon reflection of the above points addressed by Frascara. From the communication field, elaborate theories helped when choosing the appropriate channel needed to broadcast messages across to society. From the field of sociology, theories addressing the dynamic of a society were applied especially when dealing with social integration between society and minority groups.

2.2 Relevant theories of communication

Communication is sending and receiving messages, sharing information, interacting with others face to face or via any number of old and newly emerging technologies (Krcmar, Roskos-Ewoldsen, & Koerner, 2016, p.18).

The definition above illustrates the connection between the fields of communication and visual communication design. Communication *per se* can be verbal and non-verbal. Communication involves different models of message *transfer* while communication design focuses on message *creation* through the visual. Frascara points out that visual communication is about creating visuals that are 'aimed to broadcast specific messages' to a targeted public (Frascara, 2004, p.2). So, visual communication design is more specific in the sense that it is targeting and aiming a defined context.

Debates are ongoing about whether Communication Theory constitutes an independent field or not. Robert T. Craig — a communication theorist at the University of Colorado — examined this question thoroughly in his essay ‘Communication theory as field’ where he expressed that the strength of the communication theory lies in its interdisciplinary nature, using methods from other fields (Craig, 1999). He argued that the best results in communication research occur when theory and practice blend together to attain ‘dialogical-dialectical coherence’ (p.129). Frascara and Craig echoed each other when thinking about the connection of both visual communication and communication to other fields, and highlighting their interdisciplinary nature.

Craig presented a typology of the theories of the communication field by dividing them into seven categories (rhetorical, semiotic, phenomenological, cybernetic, sociopsychological, sociocultural and critical) demonstrating that the field of communication is ‘metadiscursive’ (Craig, 1999, p.129). This echoes Stuart Hall’s main discussion of the similarities and differences between a semiotic approach and a discursive one. Hall pointed out that a semiotic approach deals with ‘how culture and representation work’, while the discursive approach deals with the ‘effects and consequences of representation’ to the political and economical level (Hall, 2013a). Both approaches (semiotic and discursive) influence each other, which goes back to Craig’s ‘dialogical-dialectical’ phenomenon where the most impactful communication is the one that not only states the fact, but also goes beyond to reveal political and economical agendas.

Theories that are relevant to this research project are showcased below, followed by an overview of the different models of communication that are useful in this context. The models of communication highlight the importance of feedback in the process of communication.

2.2.1 Semiotic theory

When discussing representation, the main source of influence and theory comes from semiotic theory. ‘Semiotic’ is one of Robert T. Craig’s seven categories of communication theories mentioned in his paper. Craig explained that communication through the theory of semiotics consists of ‘intersubjective mediation by signs’ (Craig, 1999, p.136) .

The ‘father of modern linguistics’ Ferdinand de Saussure was a leader of the semiotic movement. His way of thinking about language had a great influence

on developing representation and cultural analysis to aid in understanding the process of creating and analyzing meaning. Saussure believed that 'language is system of signs' and analyzed signs through signifier (form) and signified (idea). That is, when we say any word, the process of representation concerns both recalling the form and getting the idea (or interpretation) of it. Charles Sanders Peirce adopted Saussure's semiotic theory and added to it.

[He] ... paid greater attention to the relationship between signifiers/signifieds and what he called their *referents*. What Saussure called signification really involves *both* meaning and reference (Hall, 2013b, p.19).

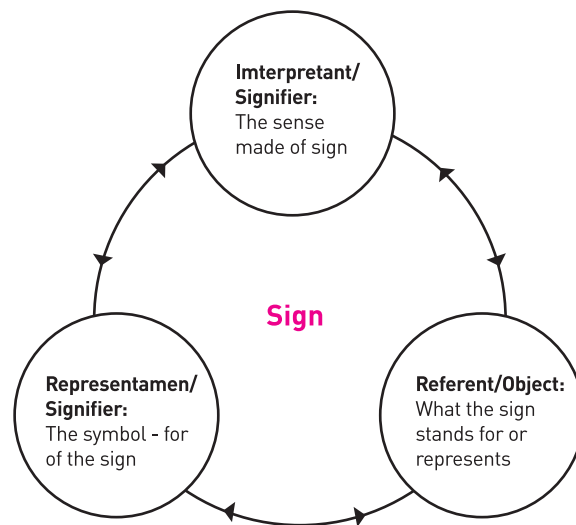


Figure 1.1 Semiotic model of Charles Sanders Peirce [Everaert-Desmedt, 2011]

Roland Barthes then took the concept and applied it to reading visuals. Barthes went through the processes of determining denotation and connotation in the creation of meaning. Denotation is the first level of reading codes, which involves a descriptive basic level of the activity. Connotation is the act of decoding conventional meaning to search for new, broader 'semantics field of the culture'. (Hall, 2013b)

Sociologist and cultural theorist Stuart Hall went on to explain that all meanings we decode are relevant to social context and specific to certain cultures. Those meanings differ from one culture to another, which makes the meanings or the interpretations dependent on the culture context (Hall, 2013b, p.19). Therefore, when the media representations of gay culture and people living with HIV are analyzed, it is necessary to focus on a specific culture. This thesis adopts the Lebanese culture in particular and the Middle

Eastern and North Africa cultures in general.

Hall highlighted the connection between semiotic theory and the analysis of visual representations, but he was more concerned about their differences.

One important difference is that the semiotic approach is concerned with the how of representation, with how language produces meaning—what has been called its 'poetics' whereas the discursive approach is more concerned with the effects and consequences of representation—its 'politics' (Hall, 2013a, p. xxii).

2.2.2 Communication theories and models

There have been many studies and models created to showcase the transformation of communication. Models of communication are classified as either linear or non-linear. The linear models of communication can be tracked to the time of Aristotle when communication was considered to occur between a sender and a receiver. The sender sends a message that is received by a person or an audience.

Following the same path of linear communication, political scientist Harold Lasswell was more interested in the effect of the message rather the message itself relative to the political field (Schulz, P., & Cobley, 2013, p.18). His model (in 1947) used the following question: "Who says what to whom in what channel and with what effect?" Those are questions that designers use while they are in the process of researching a design project. The main goal of Lasswell's model (Figure 1.2) was the use of persuasion based on the propaganda effect used during World War I for communications in the army (p.356).



Figure 1.2. Harold Lasswell linear communication model (Mishra, 2017b)

With the invention of the telephone, Claude Shannon (1948) added 'noise' into Aristotle's equation to highlight the interruptions that can occur while transmitting a message to a receiver (Baecker, 2013, p.88). This model was a mathematical one that provided an approach of how to send maximum information in a given channel and Warren Weather experimented and

studied with different type of channels (Figure 1.3) in 1949 (Craig, 1999, p.122; Schulz & Cobley, 2013).

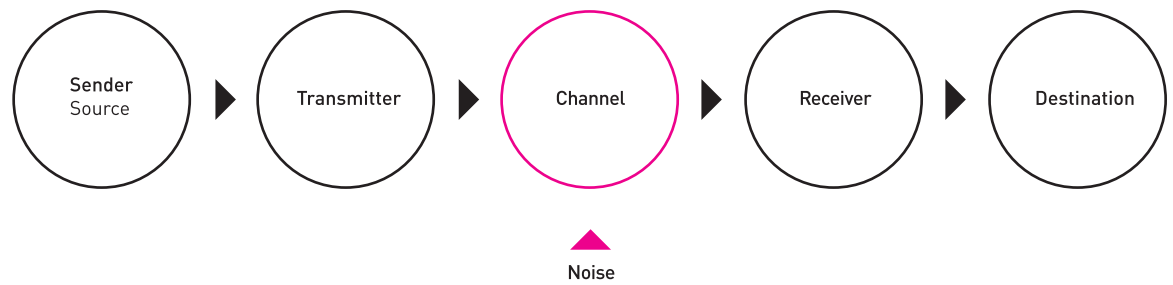


Figure 1.3 Shannon and Weaver communication model (Baecker, 2013, p.85)

In summary, the messages are encoded by a source and sent through a channel. The messages sent will be decoded by a receiver, and sent back to the source as a feedback.

Wilbur Schramm, founder of the field of communication studies, defined communication as 'sharing information, idea or attitude', which is based on the person's experiences. He endorsed three elements of communication: source, message and destination (Figure 1.4). As well, he emphasized the encoding and decoding of messages and suggested that communication is circular, where both the sender and the receiver participate in encoding and become equal partners in the exchange. (Schulz, P., & Cobley, 2013, p.401)

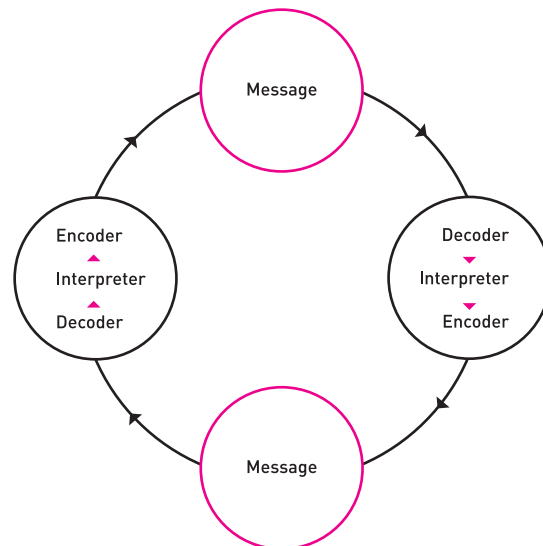


Figure 1.4 Wilbur Schramm communication model (Mishra, 2017a)

It was not until Melvin Lawrence De Fleur's 1954 model that we get into the more refined circular module of communication (Figure 1.5). De Fleur, a social psychologist and educator, refined the Shannon Weaver model by combining

the “two-way communication” and the “linear feedback” models of communication from Westley and Maclean. De Fleur expanded the Shannon Weaver model by adding mass media and “feedback” devices. The importance of this model is that the communication is circular and allows for two-way feedback. The feedback device helps to analyze the target audience. The receivers are not considered members of the target audience; the target audience will send feedback using the feedback device, which will produce a more specific analysis. In the literature, De Fleur’s model is not mentioned as often as that of Berlo and Schramm, even though this model was the first to talk about the two-way feedback and the target audience. The importance of presenting the De Fleur model is to highlight the importance of feedback and circular type communication because they are essential points in human-centered design thinking and process. Feedback is always taken in consideration to refine any piece of communication design aimed at a specific target audience, as demonstrated in the following section.

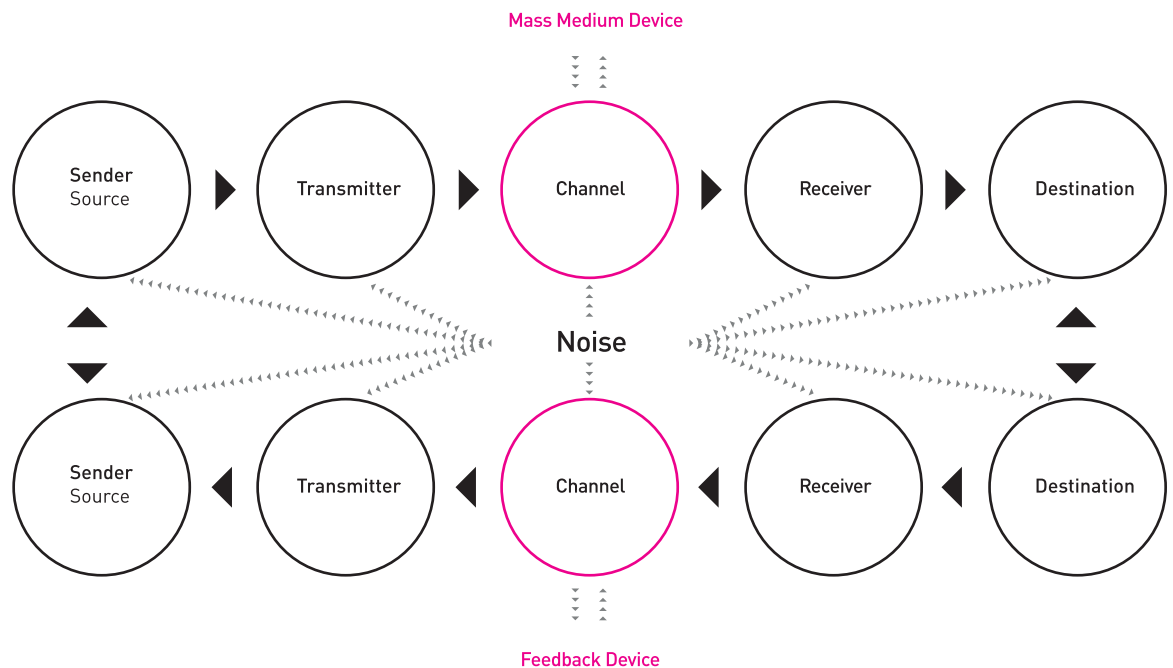


Figure 1.5 Melvin Lawrence De Fleur's 1954 communication model [De Fleur Model of Communication, 2012]

2.3 Design thinking and processes

Design thinking relies on our ability to be intuitive, to recognize patterns, to construct ideas that have emotional meaning as well as being functional, and to express ourselves in media other than words or symbol (Brown & Wyatt, 2010, p.33).

Tim Brown is CEO of IDEO a global design firm that uses human-centered design-based approaches to help “organizations in the public and private sectors innovate and grow”(IDEO, 2014). IDEO thinks of the design process as a system of “overlapping spaces”: inspiration, ideation, and implementation. The process of design thinking in this research was inspired by IDEO design thinking as well as by the Design Council’s Double Diamond design process that entails four stages: Discover, Define, Develop, and Deliver. In the Double Diamond design process, there is a divergence in the research stage and a convergence while choosing the best design solution for the problem (*Figure 1.6*).

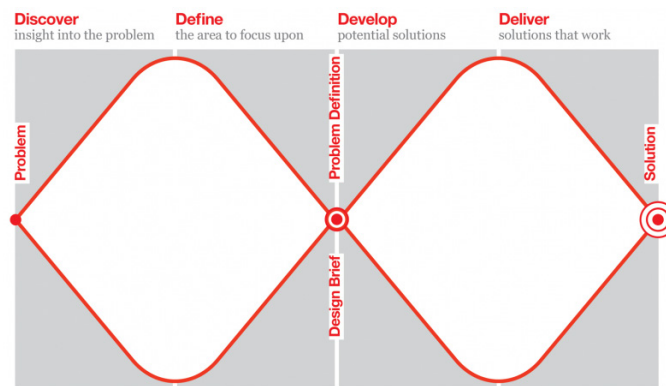


Figure 1.6 Design Council's Double Diamond design process (Design Council, 2015)

The design process used for this thesis research project consists of six stages: Discover, Investigate, Define, Develop, Evaluate, and Deliver. The first two stages, an assessment of the problem, will be conducted and results will be collected. In the second pair (Define and the Develop) analysis and co-design will take place (detailed context and scheme discussed in Section 3). In the final pair (Deliver and Evaluate), the design will be presented and the influence of the design will be studied. This section will showcase the evolution of design thinking and social design.

2.3.1 Human-centered design

In this section, the evolution and development of design thinking is described and mapped. The purpose of compiling such documentation is to observe the

evolution/progression of placement by users/individuals in design practice and research (Figure 1.7).

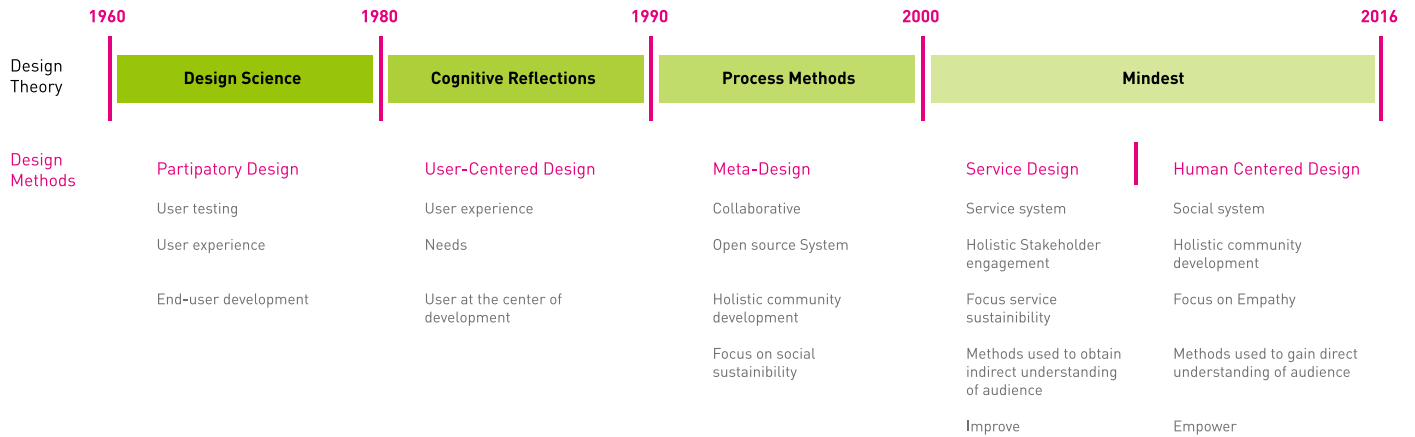


Figure 1.7 Evolution of design theory and methods

Over time, design thinking placed the user at the end of the process, that is, they became involved only at the prototype testing stage. The user's presence was to test the efficacy of the product already designed. This trend started in Scandinavia in the 1960s. At the time, it was known as "participatory design" (not to be confused with the co-creation or co-design method which became dominant in 2007) (Sanders & Stappers, 2008).

The progression of the participatory phase in research ideology moved to a more user-centered phase where testing was less about usability and more about user interests and needs, placing the user at the center of the development process (product or system).

After the millennium, there was a shift to the service-design method, which focused on understanding the use, interaction, and journey of the product/service (labeling it a service unit) rather than the experience of the user. This phase saw the blending of service and product as creative thinking and became a service aiming at adding value to a product (Kimbell, 2009, p.4). Stakeholders and individuals interacting with the service system replaced users.

It was this product/service thinking that brought the holistic mindset that leading design thinker Ezio Manzini addressed through his multidisciplinary research in service marketing and meta-design. His method was a collaborative one that focused on social sustainability instead of service sustainability (Buchanan, 1992).

Currently, human-centered design is re-emerging in design practice methodologies. Designers recognized clusters of products, and their effect of the environment, which led them to focus on a social system rather than a service system. This mindset attempts to gain direct understanding of audiences using an empathic method and aims for holistic community development (Fuad-Luke, 2008). This is the method most relevant to this thesis research project.

Interestingly, the transformation in design research from a user-centred to human-centered approach meant that participants became individuals. The value of designing was now related to beneficial values of the individual in question and the altruistic attempt to better society.

At this point, design as a discipline was trying to reinforce responsible behavior in connection to what is happening in the world. New methods of design and design thinking are promoting the value of the individual as part of an environmental and socio-cultural system (Fuad-Luke, 2008, p.19).

Designers need to be alerted to and aligned with what is happening to the world in which they live. And it is incumbent upon educators to inject those discourses to academic curricula in order to influence the next generation to become more aware and socially responsible.

2.3.2 Social Design

More recently, many educators and designers (e.g., Jorge Frascara, Victor Papanek, Alastair Fuad-Luke, Victor Margolin, and Sylvia Margolin) called for design in the service of social agendas. They all facilitated the movement toward social design.

In graphic design, the designers' work is to "*organize communication in society*" (Frascara, 1998, p.20). In this procedure, Frascara highlighted the perceptual and the behavioral abilities needed by designers. In this context, the responsibility of the designer does not stop at applying design principles while designing (in the service of aesthetics), but requires designers to be aware of the impact of visual communication design on social, individual, and environmental parameters. This requires that designers become analytical, sensitive, and "in touch" with respect to the environment and their clients.

Design Educator Richard Buchanan articulated the notion of usability and the need for human compassion through design practice (Buchanan, 2001, p.37). He defined human-centered design and highlighted the ethical responsibility of design practice. Buchanan crafted a reflective article in response to the opening speech by the Minister of Culture at the Design Education Forum of Southern Africa, “Reshaping South Africa by Design,” held in Cape Town in June 2000, in which he stated:

It is true that usability plays an important role in human-centered design, but the principles that guide our work are not exhausted when we have finished our ergonomic, psychological, sociological and anthropological studies of what fits the human body and mind. Human-centered design is fundamentally an affirmation of human dignity. It is an ongoing search for what can be done to support and strengthen the dignity of human beings as they act out their lives in varied social, economic, political, and cultural circumstances (Buchanan, 2001, p.37).

Such a sense of responsibility can only be attained through the education of design students with projects involving real social issues. Many scholars encouraged this notion at the time:

Design skills cut across all situations, but skills in relating to vulnerable or marginalized populations rather than to a brief from a manufacturer need to be developed by future social designers. Students of social design will have to learn more about social needs and how they are currently addressed by helping professionals. They might do an internship with a clinical team in a psychiatric hospital, a community agency, or a residential facility for the elderly. They would also need a stronger background in sociology, psychology, and public policy. (Margolin & Margolin, 2002, p.29)

To avoid irresponsible errors in design, designers had to learn about and understand a given social issue and play the role of protector rather than critic. Usually, the involvement of the designer with a social issue is through the creation of a campaign for fundraising or awareness. Fundraising provides a tangible result while fostering awareness gives an intangible result, which targets behavioral changes or influence. However, most of the projects aimed towards social issues provide both benefits because design and social awareness are intertwined (Papanek, 2007, p.112).

The Margolins were the first to call for a 'social design' model that is drawn from the literature of social workers' practice for helping marginalized people in society (Margolin & Margolin, 2002, p.25). They went on to describe the principles of social workers' practice:

...six-step problem-solving process that includes engagement, assessment, planning, implementation, evaluation, and termination. (Margolin & Margolin, 2002, p.26)

In their paper "A 'Social Model' of Design: Issues of Practice and Research" Margolin & Margolin (2002) did ask for a broader research agenda for social design and the need to document all that research to demonstrate the contribution of the design field to the well-being of humanity in communities. This thesis aims to make a contribution to the field of social design and to address some of the many questions asked by Margolin & Margolin (2002).

What role can a designer play in a collaborative process of social intervention? What is currently being done in this regard and what might be done? How might the public's perception of designers be changed in order to present an image of a socially responsible designer? How can agencies that fund social welfare projects and research gain a stronger perception of design as a socially responsible activity? What kinds of products meet the needs of vulnerable populations? (Margolin & Margolin, 2002, p.29).

The Margolins initiated the call for social design, which has now led to designers and authors who talk about social design to define it as an altruistic act. Social design educator Nynke Tromp defined social design as 'How products and services can help us act in ways that benefit society'. In their paper "Introduction: Design Innovation for Society", Tromp and Bijl-Brouwer suggested that "the focus on underlying needs and concerns of stakeholders fosters open dialogue, and thereby the space to not only improve the outcome of design, the service, but equally so the provision of the service: its governance". They went on to clarify that design is not only about providing ideas to make services better, but also should go deeper to the core of improving the 'organization and the governance of services' (Tromp & Bijl-Brouwer, 2016, p. 2145).

2.4 Interdisciplinary theories used in design

Interdisciplinary research is a mode of research by teams or individuals that integrates information, data, techniques, tools, perspectives, concepts, and/or theories from two or more disciplines or bodies of specialized knowledge to advance fundamental understanding or to solve problems whose solutions are beyond the scope of a single discipline or area of research practice (National Academies of Science, Engineering, & Medicine, 2005, pp. 32-33).

Participatory research, by its nature, employs interdisciplinary inquiry. That is, it calls for human-centered research where the researcher will be studying human behaviour and collaborate with different stakeholders and professionals from different fields. Consequently, the researcher will be exposed to knowledge and theories from different fields during his inquiry. Frascara mentioned the interdisciplinary nature of visual design process:

Design is a problem-oriented, interdisciplinary activity. There is a need to identify important problems and develop interdisciplinary strategies to deal with.... It is necessary to consider the discovery and definition of physical and cultural problems as an essential part of design. The nature of each problem might suggest the spectrum of disciplines required to confront it (Frascara, 1998, p.35).

This research project employs an interdisciplinary approach, reflecting the nature of the design process as per Frascara's explanation above. The following section showcases the different theories used in the research process.

2.4.1 Theories of social cohesion and integration

Frascara was keen to mention the importance of using the knowledge of other fields in design research. He talked about the field of sociology, especially, when trying to understand 'social phenomena' embedded within a community.

Sociology is important because there is a need to contextualize the conception of the activity of the graphic designer in a frame of reference that overflows the specific bounds of the professional field and becomes grounded in the broader dimension of society. The

importance of the notion of audience in the process of communication calls for a better understanding of social phenomena. The methods of enquiry used in sociology can provide graphic designers with useful instruments for the investigation of communicational problems (Frascara, 1997, p.7).

Social cohesion has been of interest to sociologists and psychologists, and was influenced by the rapid social change from the 19th century until postmodern times –the social capital society. The attempt to theorize social cohesion created a lot of confusion and made it hard to look at it in one perspective.

The French sociologist, Émile Durkheim, both a social psychologist and a master of social cohesion, theorized that social cohesion “results from interdependence, shared loyalties and solidarities.” His break-through study of suicide in 1897, where he highlighted that different rates of suicide reflect differences in social integration, demonstrated that categories of people with *strong social* ties had low suicide rates, whereas categories of individuals without them had high suicide rates (Bruhn, 2009).

Sociologist Talcott Parson succeeded Durkheim and expressed his fear of liberal theory by supporting the functionalist approach, treating society as a system of interdependent subsystems, not individuals. This approach was criticized as being fearful of change and diversity, focusing completely on the society as a whole.

Liberal theory then succeeded classical thinking by focusing on individual behaviors. Liberal sociologists thought that social order results from ‘private behaviour in private institutions such as markets, families and social networks’ (Jenson, 1998, p.12).

In his report *Mapping Social Cohesion: The State of Canadian Research*, Jenson (1998) criticised the literature of social cohesion for focusing on the whole of society rather than on structure and institutions, while the studies focusing on the local community were often concerned with individuals’ well-being and inclusion only.

In his book *The Group Effect: Social Cohesion and Health Outcomes*, John Bruhn explained the concept of social cohesion by classifying it into three

categories: empirical, experimental, and social network analysis. Bruhn explained the difference between the empirical and experimental as that the former theorists (Émile Durkheim, Sigmund Freud, Gustave Le Bon, etc.) ‘interpreted their social data as they observed’ without creating a method to check and extend their observations (Bruhn, 2009, p.35).

The definitional confusion in the social cohesion literature is symptomatic of the complexity involved in reciprocally linked individual-level and group-level phenomena (Friedkin, 2004, p.410).

So, what is social cohesion and can it be attained?

The term “social cohesion” is used to describe a process more than a condition or end state, while it is seen as involving a sense of commitment, and desire or capacity to live together in some harmony (Jenson, 1998, p.5).

Social cohesion appears as a concern when the social ties and solidarity of a society are at stake. Usually, this happens when social structure changes quickly due to fast changes in life generally.

In his paper, *Mapping System Integration and Social Integration*, Nils Mortensen focused on the contemporary sociologist who provided a great deal of explanation on the social cohesion in “Meta-theoretical mapping”. He realized that the contemporary theories were developed through three meta-theoretical dimensions: micro vs. macro, structure vs. actor, and objectivist vs. non-objectivist. He explained each dimension as follows: (i) macro is a phenomenon ‘where the number of actors or individual is too large to allow face to face contact’ as compared with micro (ii) structure vs. actors refers to model that ‘sees social phenomena through relations between elements versus actions done by actors’ (individuals or collective groups); and (iii) ‘objectivistic approach’ refers to the possibility of attributing qualities or values to a society from the outside vs. the inside (*Figure 1.8*) (Mortensen, 1999, p.14).

Two of the major contributors to a definition and conceptualization of social cohesion, in postmodern society, are sociologists David Lockwood and Anthony Giddens.

		Micro level, face-to face relations dominant		Macro level, indirect relations dominant	
		Objectivistic approach, observation	Non-Objectivistic approach, participation	Objectivistic approach, observation	Non-Objectivistic approach, participation
Actor Model		01 Rational or strategic individual action, operant conditioned behaviour	02 Meaning – using actors, knowledgeable agents	03 Rational or strategic collective action	04 Subcultures, expressively oriented movements
Structure Model		05 Prisoner's dilemma situations, exchange relations	06 Communication and normativity in groups	07 Economic and bureaucratic systems, positive law, culture as system	08 Gemeinschaft, solidarity, culture as lifeworld, democratic public system

Figure 1.8 Three meta-theoretical dimensions and examples of their combinations in sociological theorizing borrowed (Mortensen, 1999, p.16)

Lockwood's point of departure was his distinction between macro (civic integration referring to the universal rules and rights of economic institutions) and micro (social cohesion), and his comprehension of the interdependence of one and another. Social cohesion (the city, the neighborhood, the local community) consists of the primary (family and networks of relatives and friends) and secondary (associations and networks, bonds of trust between them) relationships that hold the local community together (Lockwood, 1999, p. 83).

...social cohesion may be thought also to be a function of the strength or weakness of primary social relationships, of which those of kin, friends and neighbours are the most important. Beyond this, the extent of a more general 'altruism', that is, trust in, and willingness to help, those beyond these primary networks, might also be considered as an aspect of social cohesion (Lockwood, 1999, p.69) .

Through the lens of Lockwood, the focus of this thesis is on the target at the micro level, 'gay Lebanese youth living with HIV', and their relation to the larger Lebanese gay community at the macro level. On a secondary level, this thesis research explores the influence and the ripple effect of the micro level on the macro level, examining the reaction and feedback from the community.

In March 1995, the World Summit for Social Development met in Copenhagen and focused on social integration along with poverty eradication and

employment creation as part of their action plan. The aim of social integration was explained in chapter 4 of report article 66 as follows:

The aim of social *integration* is to create 'a society for all', in which every individual, each with rights and responsibilities, has an active role to play. Such an inclusive society must be based on respect for all human rights and fundamental freedoms, cultural and religious diversity, social justice and the special needs of vulnerable and disadvantaged groups, democratic participation and the rule of law. The pluralistic nature of most societies has at times resulted in problems for the different groups to achieve and maintain harmony and cooperation, and to have equal access to all resources in society. Full recognition of each individual's rights in the context of the rule of law has not always been fully guaranteed. Since the founding of the United Nations, this quest for humane, stable, safe, tolerant and just societies has shown a mixed record at best. (United nation, 1996)

Based on this declaration, the Division for Social Policy and Development of the Department of Economic and Social Affairs (UNDESA) went on 'exploring the role of multi-stakeholder dialogue in the process of building more integrated and peaceful social relations'.

UNDESA defined social integration as a process and not an end result, as it should bring groups together by choice and not by force. As a process, there is the potential for it to work or not, but the UNDESA described, in the report, successful social integration and suggested a process plan:

Successful social integration processes encourage "coming together" while respecting differences. Participants acknowledged the difficulties in articulating unity and diversity within the context of social justice. Unity refers to coherent interconnection of diverse people living in a society (UNDESA, 2005, p.16).

In this study, Ms. Brigid Donelan and Dr. Patricia O'Hagan presented a model framework to examine and strengthen social relations (*Figure 1.9*). This model showcased the stages and trajectory of a disintegrated society (fragmentation, exclusion, polarization, coexistence, collaboration and cohesion) and proposed the model to attain social cohesion. The model is not to be generalized to every social issue, but can be interpreted, constructed,

and reconstructed to fit the case in study. The stages provided a tool for stakeholders to help them identify the stage they are at and what is required to move them to the next and better stage. The stages in this model represent the different steps of social relation, and in each of these stages Donelan and O'Hagan defined the need and the intention, with the appropriate dialogue procedure for each stage.

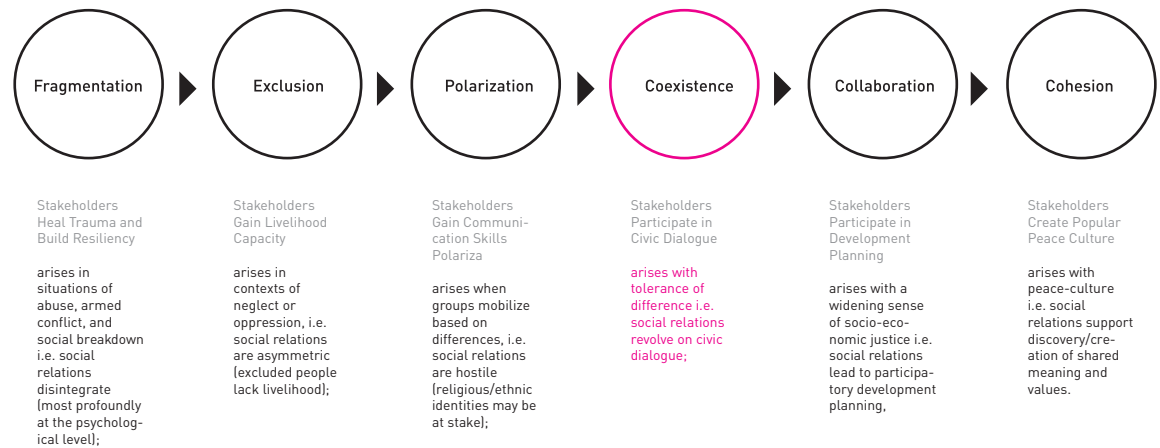


Figure 1.9 Stages to social integration (UNDESA, 2005, p.16)

Three formative stages of social relations are addressed in D-SIP as follows:

- (i) Fragmentation - arises in situations of abuse, armed conflict, and social breakdown i.e. social relations disintegrate (most profoundly at the psychological level);
- (ii) Exclusion - arises in contexts of neglect or oppression, i.e. social relations are asymmetric (excluded people lack livelihood); and
- (iii) Polarization - arises when groups mobilize based on differences, i.e. social relations are hostile (religious/ethnic identities may be at stake).

Three expansive stages of social relations are included as follows:

- (i) Coexistence - arises with tolerance of difference i.e. social relations revolve on civic dialogue;
- (ii) Collaboration - arises with a widening sense of socio-economic justice i.e. social relations lead to participatory development planning; and
- (iii) Cohesion - arises with peace-culture i.e. social relations support discovery/creation of shared meaning and values.

The stages proposed in Figure 1.9 are used in this study as tools to help identify the stages of disintegration and to be able to work towards the next, better stage as indicated above.

It is critical to highlight the importance of dialogue as mentioned in the UNDESA report:

Dialogue is an evolving field of practice ... It facilitates transformation through building relationships of trust, clarifying underlying issues behind debates/disputes, and accepting responsibility for change. Dialogue facilitates mutual understanding among people from diverse backgrounds, provides opportunities for healing and reconciliation, and creates a safe space for crafting a common vision/aspiration for a community/society to be built (UNDESA, 2005, p.8).

The importance of dialogue recalls Nils Mortensen's definition of micro phenomena that are based on face-to-face contact between and/or among actors.

Micro-phenomena are phenomena where actors are in face-to-face-contact with each other, whether such contacts are permanent or sporadic. The notion of face-to-face interaction is, however, becoming increasingly unsatisfying in (post)modern societies where different media such as the telephone, telefax and international networks of e-mail make direct contacts possible without a co-presence in space (Mortensen, 1999, p.14).

It is clear that face-to-face meeting or contact is essential in the process of creating social integration and is a key to understanding the type of relationship between parties to create a place for interaction. Mortensen also hinted at the evolution of new media in postmodern society and their potential influence on interactions during the process.

Finally, the importance of space has been mentioned in these studies. Creating a space for interaction needs to be taken into consideration and pre-planned for the interactions to be effective.

2.4.2 Theory of the oppressed

Brazilian educator and philosopher Paulo Friere was the leading pioneer for critical pedagogy. In his book, the *Pedagogy of the Oppressed*, Friere described the essence of his pedagogy based on inclusiveness, humbleness, and love in a 'liberatory pedagogy', reiterating that 'love' is the key to liberation.

Dialogue cannot exist... in the absence of a profound love for the world and for men. The naming of the world, which is an act of creation and re-creation, is not possible if it is not infused with love. Love is at the

same time the foundation of dialogue and dialogue itself...Because love is an act of courage, not of fear, love is commitment to other men. No matter where the oppressed are found, the act of love is commitment to their cause—the cause of liberation... Only by abolishing the situation of: oppression is it possible to restore the love which that situation made impossible. If I do not love the world—if I do not love life—if I do not love men—I cannot enter into dialogue (Donald L. Finkel & Ar, 1995, p.104).

Friere, like other communication theorists, highlighted the importance of dialogue. For Friere, dialogue is the key for learning and understanding any situation, but will never happen if it is not imbued with love and an open mind from the educator as per the above quote. Those attributes are valuable, especially in the field while researching and connecting to people (Donald L. Finkel & Ar, 1995, p.109).

Friere talked about "conscientization" and "problematization". The phenomenon of "conscientization" is the ability of the person to be aware (conscious) of one's own situation and the ability to detach from it for the sake of remaking it. Therefore, the method of problematizing the situation will allow the detachment from submerging in life and highlight and reflect on the issues with a new perspective, enabling the student to work on his/her situation for the better. The reflecting stage is the space where the critical thinking starts. This reminds us of Dewey's process of reflecting on one's experience that will build the intellectual development (Donald L. Finkel & Ar, 1995).

For Friere, educators and 'educatees' should go through the process of 're-birth' by erasing their oppressor/oppressed personas to become a more liberated and receptive member of society. This pedagogy is liberating for both (educator and educatee), as through the experience of teaching and learning, both parties will learn from each other's experiences, and truth will liberate them to become critical thinkers.

The whole process of this pedagogy aims to create collaborations with the marginalized/oppressed groups, to let them take control of their own lives through knowledge and education. This research was built upon the same pedagogical objectives. Friere's pedagogy is adopted in this study because it has had a major influence on participatory research in communities, especially when it comes to the different roles that a researcher must play

during the research process: facilitator, mediator, researcher, and design engineer.

The final objective of every communication design is some kind of behavioral change in a target population that occurs after the communication has taken place (Frascara, 1998, p.26).

2.5 Overview of the Lebanese social situation

Lebanon is a Middle Eastern country that has experienced a lot of political and internal conflict. Being Lebanese and having lived in the country for almost 30 years, I witnessed a lot of conflict from war, both national and international. Lebanon went through a major civil war from 1975 to 1990. The civil war was based on conflicts between different groups, mainly sectarian, with strong religious and political ideologies. In November 1989, there was the summit of Taif in Saudi Arabia that was held to stop the civil war and proclaim Lebanon as a 'sovereign, free, and independent country and a final homeland for all its citizens' (Taif, 1989). After the Taif, Lebanon had to plunge into the aftermath of war and rebuild its infrastructure and revamp business to regain tourism and economic status in the region.

Lebanon is known for its multi-sectarian society. The people are both Muslim and Christian, and each main religion is divided into factions. That is why in the Taif agreement there was a rearrangement of the deputy seats to equally represent all the religions. Therefore, the Taif agreement allocated 64 seats for each religion. (Krayem, 1997) (Taif, 1989)

Christians:	64 Seats	Muslim:	64 Seats
Maronite catholic	34	Sunni	27
Greek Orthodox	14	Shia	27
Greek Catholic	08	Druse	08
Gregorian Armenian	05	Alawite	02
Catholic Armenian	01		
Protestant	01		
Christian Minorities	01		

After the Taif, Lebanon experienced some reconciliation and peace. The country was doing well from 1990 until 2005, trying hard to regain its reputation (as a peaceful nation) and become an economic, intellectual, commercial, and tourist capital of the Middle East. In 2005, the assassination of the Prime Minister Rafiq el Hariri led to a lot of disturbance in the country

due to many public demonstrations and a series of political assassinations over the period of a couple of years. In 2006, Lebanon witnessed an Israeli attack on the capital, Beirut, caused by the conflict between Israel and Hezbollah that lasted 34 days. More internal political conflict happened when ministers of a party resigned and a reformation of the new government took place. Then in 2013, a parliamentary election was postponed because of the civil war in Syria and one million Syrian refugees entered Lebanon. Lebanon was without a president from 2013 until 2016. This research project was conducted in Lebanon after president Michel Aoun was elected in November 2016.



Figure 1.10 The Middle Eastern and North African (MENA) region with member countries (MENA, 2017)

2.5.1 The gay community in Lebanon: current social and judicial issues

Looking at the brief political and constitutional situation in Lebanon will help explain the situation of the gay community in the region and specifically in Lebanon. In the Middle East and North Africa (MENA, *Figure 1.10*) region, same-sex relations and sex workers are still condemned by 'religious doctrines, social norm and often the law'.

A worldwide review shows that same-sex conduct is illegal in 76 countries, 19 of which are in MENA. The region includes five of the seven countries worldwide where consenting homosexual acts are subject to the death penalty, at least on paper: Iran, Saudi Arabia, some parts of Somalia, Sudan, and Yemen (Setayesh, Roudi-Fahimi, El Feki, & Ashford, 2014, p.4).

‘Lebanon has a small but active gay scene, and the country has been promoted as a gay travel destination’ (F.V.T., 2014). Even though Lebanon is considered the most liberal of the Arab countries, same-sex relations are still penalized through a penal code.

Lebanese Penal Code 534: “All sexual intercourses contradicting to nature are punished from 3 months up to 1 year, additionally to a penalty between 200 and 1,000,000 Lebanese Liras” (Nammour, 2016, p.2).

Article 534—that was retained from the time of French colonization—has been the fight of the Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) non-governmental organizations (NGO). These NGOs are registered as human rights organizations and are trying solely to provide medical and judicial help to the LGBTQ community. The first LGBTQ NGO was registered in 2004, the first LGBTQ NGO in the region. This article threatens the privacy and personal freedom of the general population but specifically the LGBTQ community.

Even though the Republic of Lebanon was one of the countries to sign and approve the International Convention on Civil and Political Rights, Article 534 breaches many of the convention rights; Joe Hammoud (member of the Youth Coalition for Sexual and Reproductive Rights in Canada) elaborated on the effect of Article 534 on youth in his report “Report to The United Nations Human Rights Council for The Universal Periodic Review of The Republic of Lebanon”. Hammoud mentioned each and every article ‘invaded’ by the Lebanese penal code 534:

Article 534 falls in contrast with the International Convention on Civil and Political Rights, which protects the right of safe life from discrimination (articles 2 and 26), freedom of expression (article 19) and bans the interventions in an individuals’ private life and their right of existence and thoughts (article 18)... Articles 2, 17, 18, 19 and 26 are violated; in terms of non-discrimination policies on gender, class, ethnicity, language, social status, and religion and/or political ideology (Nammour, 2016, p.5).

Afterwards, the NGOs worked hard to stop the use of the ‘anal probe’, which is an egg shape product inserted into the rectum to check for traces of sperm. The police were abusing the use of this probe to humiliate gays, especially youth, when arrested or suspected of being homosexual. In 2013, the

Lebanese Order of Physicians banned the use of this test, as it is considered a method of torture. After the doctors banned its use, the Ministry of Justice pushed the prosecutor to condemn the use of the test generally, citing its use as invasive and abusive to humanity (Massena, 2012).

Recently, the country went through a major judicial case fiasco where a gay youth went from being a witness to his friend's death to being convicted himself because he confessed his sexual orientation in court. The young man was interrogated as a witness, first because he dined with his friend before the latter's death, and then the court convicted him and four others for a misdemeanor based on the prejudice of Article 534 (Nammour, 2016, p.5).

The gay community in Lebanon is barely represented in the academic literature. The subject is always grouped under the name Men Sleeping with Men (MSM) because there are a lot of men sleeping with other men who never consider themselves gay, again mirroring a religious society that reconfigures reality for its own purposes. Therefore, the gay community exists, but not legitimately because it is still controlled by authority.

To summarize the attitude of the region towards homosexuality, a recent survey conducted by Pew Research Center to determine the acceptance of homosexuality in the world showed that the countries that are least accepting to homosexuality are the countries that are highly influenced by religion. Lebanon has an 18% acceptance rate, the highest in the Arab world, while Egypt and Tunisia scored 5–6% (Kohut et al., 2013). Even in Jordan where the practice is legal, 97% rejected homosexuality. The research elaborated on the fact that African and Muslim countries are leading in the rejection of homosexuality, a fact that will continue to slow down the cohesion process for the whole society. This is the reason that the current thesis research focuses on trying to integrate Gay Youth Living with HIV (GYLWH) into the Gay Youth (GY) community and not the society at large. With all this rejection, one would think that the major support for any gay subgroups would come from the larger gay group.

The last point that will connect to the following section is the effect of Article 534, as per the report of Nammour, in putting the Most At Risk Populations (MARPs) at even higher risk concerning health and safety. This group (MARPs) and especially the MSM...

... tend to oppress their need of access to comprehensive and non-judgmental sexual and reproductive health services and clinical care, as a mean not to be stigmatized or reported to authorities, or become well known via word of mouth; leading to further consequences like persecution, marginalization, and violations of their social and economical rights supported by the absence of legal protection (Nammour, 2016, p.4).

The above comment is one of the major reasons for the recent rise of the HIV cases in Lebanon, as the lack of judicial support leads men to refrain from medical testing, which contributes to the risk of all sexually transmitted diseases (STDs), especially HIV.

Through all the epistemological reviews of diverse fields, the crucial need for 'dialogue' to attain any sort of community integration or cohesion became apparent. The micro level of the issues had to be examined and understood in order to link them to the macro level of social effects. This is one of the main pillars of this research: to discover how to bring GYLWH into a face-to-face dialogue with members of the Gay Youth (GY) community without disclosing HIV status. These concerns were highlighted when using the De Fleur model that focused on the medium (channel) and the feedback from the target, two critical points in a participatory design research. The choice of the channel in this study is connected to the anonymity of the GYLWH participants, and the communication process is dependent on the feedback from the GY community.

3.0 Research method

Community-based participatory research (CBPR) design has been applied as the research method in this thesis project. In their book, *Participatory Visual and Digital Research in Action*, Aline Gubrium and Krista Harper used “Participatory Action Research” (PAR) as an umbrella term to represent other terminologies such as CBPR and collaborative anthropology (Gubrium & Harper, 2013a, p.13); however, this thesis research project will use CBPR as a term. Aline Gubrium, who is an Associate Professor and Program Head of Community Health Education at the University of Massachusetts, Amherst, published a myriad of articles and books on the use of visual and digital research in community and health studies.

Participatory design as a method is essential to this study, as the design process is led by the participants who share their experiences. The researcher/designer facilitates this process by guiding the participants, or members of the community, to design and express whatever they need to convey in a visual way. Participants become producers by accepting visual methods to initiate “veritable” social research (Gubrium & Harper, 2013a, p.13). Terms like “co-design”, “co-create” or “collaborative design” are used in the literature to imply participatory design, but they all mean the same thing. The term “co-design” is used in this thesis research project.

After identifying the relevant literature, the next step was to define the problem. Aline Gubrium quoted Claudia Mitchell, a professor and pioneer in visual and digital research at McGill University, about the way participatory research should focus on data analysis and how researchers should try to organize “the mountain of data” and select the information that it is needed for the study.

Claudia Mitchell (2011) cites Fiske and Neuman's (1987) work, which speaks of three types of texts in participatory videomaking: “primary texts”, “producer texts”, and the “audience texts”. These three types of texts each provide distinctive sites for visual data analysis (Rose, 2007) that map onto characteristic questions (Gubrium & Harper, 2013, p.185).

Mitchell defined each text on its own to answer the “what”, “how”, and “why” research questions using a triangulation method that is often employed when there are mixed methods in a research process. Because the research herein is qualitative, and uses multiple methods to “visualize” the “truthiness” of the

study's subject (Gubrium, Harper, & Otañez, 2015, p.123), the “what” research question attempts to define and assess the problem, i.e., the marginalization of Gay Youth Living with HIV (GYLWH).

Mitchell's triangulation method of analysis was paired with the six design process stages mentioned in section 1 that was influenced by the double-diamond process of divergence and convergence in design thinking, created by the British Design Council to map the phenomenological qualitative study in hand (Figure 3.1).

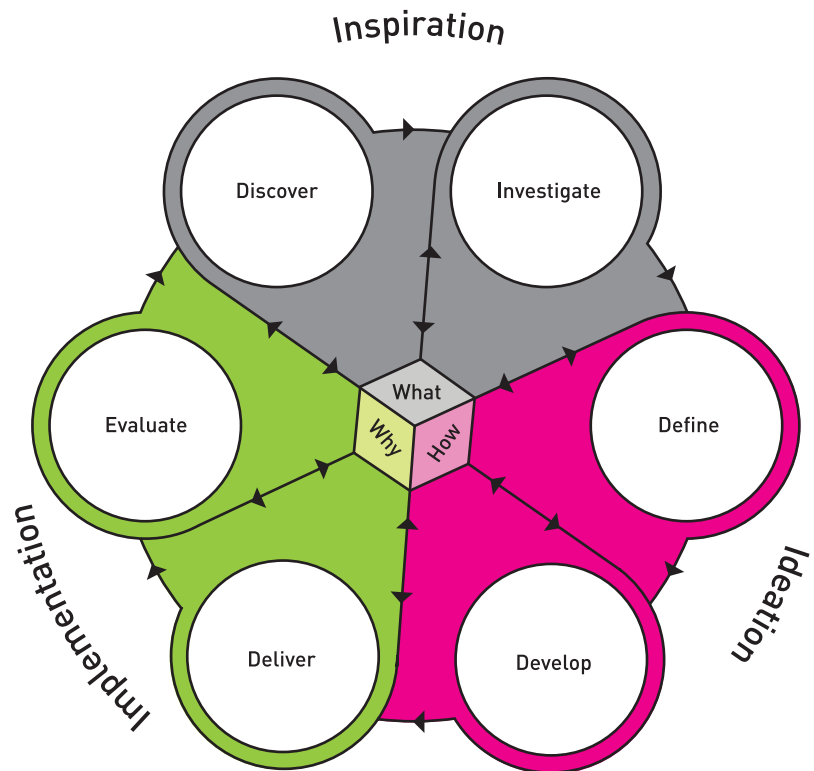


Figure 3.1 Research design thinking process

The “what” research question explores the primary text, which describes the assessment and definition of the problem as indicated in the design-thinking model (Discover and Investigate stages). In this context, it helps us to understand the cause and consequences of the social marginalization of GYLWH by the larger gay community in Lebanon. In order to accomplish this, three semi-structured interviews were conducted with experts. Two professional activists and an infectious disease specialist gave their professional opinions about the marginalization of GYLWH phenomena. Adding to that, a study of media representation of gay characters and people

living with HIV was conducted through two “musalsalat” (“TV series” in Arabic) entitled “Ishk el Nissa” and “Samra”. This provided information from a “popular” perspective.

The “how” research question was approached through a co-design workshop with GYLWH in Lebanon who worked on producing six digital narratives of their experience dealing with HIV over a period of six weeks (Define and Develop stages).

Finally, the “why” research question entailed the study of the reaction of the Lebanese gay community towards the six digital movies through the use of an online survey method (Deliver and Evaluate stages). Two screenings of the digital stories were held in Lebanon, and two after-screening discussions were also held. Screening discussions provided the most valuable data at this stage, as they represented the interaction between the study subjects and the community.

3.1 Discovering and investigating the problem

Three semi-structured interviews were conducted in Beirut, Lebanon with two gay activists (George Azzi and Elie Ballan) working with NGOs (Helem and M-coalition) and a medical doctor (Jacques Mokhbat) working on sexually transmitted diseases (STDs) to understand the causes and consequences of the marginalization of the GYLWH by the gay community there.

The interviewees identified the Lebanese culture and its portrayal of the gay community as being the main cause of marginalization. Due to the lack of research focusing on gay youth living with HIV in Lebanon, western literature was used to examine studies tackling the relationship between gays living with HIV and their communities.

In a paper entitled “HIV-related stigma within communities of gay men: a literature review”, Smit et al. gathered all the reviews and studies that had been done on HIV stigma in gay communities and compiled the causes and consequences of this behaviour (Smit et al., 2012). Smit et al. quoted Michael R. Botnick, a scholar and research program manager at the BC Center for Disease Control, who published many studies concerning the gay community dealing with the HIV/AIDS pandemic. Botnick observed a division between HIV negative gay men and HIV positive ones and he observed how HIV-positive gay men have an

increased tendency to withdraw from both their usual social scenes and wider society (Smit et al., 2012, p.405).

Of the four causes of discrimination that the literature review uncovered in the article, two were obviously applicable to Lebanese society. Smit et al mentioned the presence of “discrimination and rejection by non-HIV infected gay men” and “self-stigma”. The former (discrimination) dealt with blame by the gay community of a promiscuous lifestyle for spreading the disease by infected gay members. This highlights the *internal* stigma and self-blaming of people living with HIV, which is the outcome of an *external* stigma that sometimes leads to “internalized homophobia”. This social stigma and pressure can lead to suicidal reactions, especially in the gay community and with GYLWH.

In addition to the perceived stigma from external sources, “internal stigma” or “self-stigma” is a confounding issue among HIV-positive gay men and can be the result of ongoing external stigma (Smit et al., 2012, p.407).

When dealing with Lebanese society, causes that are particular to this culture need to be considered. Lebanese society is a culture controlled by religion that looks at any sexual act beyond the religious frame as taboo. It is not surprising that Lebanese society condemns gay behaviour and considers the gay lifestyle to violate religion’s dictates. Religious context is one of the major causes of fear and guilt affecting gay community members, which creates internal shame and an inner homophobia that disrupts their well-being. The interviewees repeatedly pointed to this ill attitude of Lebanese gay men, making it the dominant cause of stigma in the community. Ballan gay activist living with HIV explains:

I know a lot of youth who, because of stigma, they lost their spark, they lost their will, they are scared all the time and all of them, they wanted to be with people who are HIV positive. And not because it makes everything easier or not, just because they will feel less judged, they will be with someone who completely understands them and they will not give them the same bullshit as the other people... (E. Ballan, interview, October 28, 2016).

The religious environment influences the way that society looks at HIV.

From the social perspective, HIV is related to sex and sex is a taboo subject, therefore the possibility of discussing HIV is doomed to failure. Azzi (gay activist) mentioned how people are not comfortable talking about anything related to sex; to do so shames them, which creates psychological problems that may lead to suicidal actions.

Firstly, from the religious comes the historical western inheritance that shaped the stigma towards HIV in the 1980's. The slogan "HIV equals death" was stamped in the minds of the broader community. HIV/AIDS was considered a "gay disease" at the time. The aftermath of this still shapes the image of the gay community today in that whenever there is talk about HIV, it is always related to the gay community. Secondly, the reference to death is problematic. Unlike the Mexican culture which celebrates death, the Lebanese culture sometimes thinks of death as a punishment from God; death has a very negative connotation. This is how religion creates taboos like sex and "non-natural" behaviour (gay acts): by inducing fear through religious "myths" and sermons.

In addition to the societal-religious aspect, there is the role of education. Three interviewees mentioned that the lack of education concerning the virus creates fear and induces a negative attitude. This is a very common phenomenon, the fear of the unknown. Dr. Mokhbat (infectious disease specialist) mentioned in his interview how throughout history, marginalization was employed by the church during pandemic crises. The church controlled people by exploiting the fear of the spread of disease (especially STDs like syphilis), often with fatal consequences, primarily due to ignorance and a general discomfort talking about STDs. Religious leaders would discriminate against people with such diseases and sometimes burn them.

So, HIV suffered as a virus, and as a medical entity, suffered from the discriminations against gays and all wells good thinking people, looked at gays, looked at sex in general, in a very condemning way, as if they never have done sex. So because of that, and in any sexual transmitted diseases, and we know from history that syphilis, herpes, have always suffered from discrimination by the good thinking, right thinking, righteous catholic, the key issue is what we need is to trivialize, de-exceptionalize HIV, I think we have to fight for it (J.Mokhbat, interview, October 26, 2016).

As mentioned previously, medical advances in recent years have developed HIV medication and improved patient health status. As per Mokhbat's elucidation, even if scientists do not find a cure for HIV, there are pill combinations that prolong the lives of people living with HIV, allowing infected people to experience a normal life with a manageable disease. Additionally, there is now a Pre-Exposure Prophylaxis (PrEP) pill, an anti-HIV medication that helps to protect HIV-negative people from becoming infected. PrEP provides a solution for people who are sexually active and wish to maintain a promiscuous lifestyle; PrEP is a good preventive medication. Also, people who are not taking PrEP and participate in unsafe sex can take an anti-HIV medication within 48 hours after unprotected sexual encounters, which can prevent the virus from infecting the immune system.

Unfortunately, Lebanese society has a low tolerance for reading and distributing information/news that can make a difference. Rather, it is a culture that embraces gossip, and gossip perpetuates negative messages quickly (not information that has positive value or impact). Therefore, the recommendations from activists and doctors about awareness and education have to be repeated continuously because one of the main sources of discrimination is the *lack* of education and the creation of judgments based on myths and old medical news.

I personally believe that we need a very strong education, very very strong education, from a very young age, in schools, in universities, in clubs, in places where the young people are sitting, that's where we have to target, and very aggressively, and very very seriously, and be open, God damn it, sex is occurring, so why not give them condoms, why not make condoms available, why not talk about condoms, why not distribute condoms, and then be open about it, making stupid laws and regulations etc. is totally nonsense (J. Mokhbat, interview, October 26, 2016).

Ballan expressed his belief in embracing the old way (pamphlets and diverse print materials) of dealing with HIV education, as he is convinced that people are still in the "old ages" ruled by ignorance when dealing with the virus.

...but we are way back in the dark ages, we need to start by the simplest of messages, shaking hands does not transmits HIV, hugging someone does not transmit HIV, HIV is not AIDS, AIDS is different, AIDS is a case HIV is a virus, it has to be back at this, the point is awareness and no

matter how much you try to work on awareness still there are certain parties that will fight you back... (E. Ballan, interview, October 26, 2016).

Another predominant condition is the gay community's tendency towards self-destruction, caused by a propensity to gossip. Along with a "gossipy" character and a lack of education about HIV, this community tends to transfer inaccurate and out-dated news and shows little empathy with or social support for people living with HIV. This cultural norm is tackled and discussed in many local movies and TV advertisements, where we see a Lebanese character always gossiping with neighbors or friends. Dr. Mokhbat hinted that because Lebanon is a small country, with a small gay community, gossiping becomes a habit.

...since [the gay community] it's a small community, close community, and people know each other, especially in Lebanon a lot of people know each other I think people become the victims of gossip and discrimination because of that... (J.Mokhbat, interview, October 26, 2016).

...we live in a culture of gossip, a culture of people they talk about each other, about blaming, shaming, shading and humiliating each other, sometimes it is just for fun, but although we all do it for fun, we need to know the thin line between hurting someone and just laughing together about it... (E. Ballan, interview, October 26, 2016).

While meeting and collaborating with many LGBTQ+ and NGOs, many expressed their concern about the lack of knowledge toward HIV issues, especially given the diverse HIV campaigns to educate and raise awareness in the public and, more importantly, within minority groups. The ignorance stems directly from the lack of discourse about sex and/or the nonchalant attitude of youth towards HIV, apparent from a 2016 statistic online report posted about people living with HIV in Lebanon (Avert, 2016).

The causes outlined above have major consequences for GYLWH. This group experiences double discrimination—from Lebanese society on a macro level and from the Lebanese gay community on the micro level. Ballan, an "out" gay man living with HIV in the country and working to spread awareness through an NGO called M-coalition, summarized the impact of discrimination on GYLWH. He points out that GYLWH alienate themselves socially as a reaction to the social segregation imposed by the gay community and by

society in general. This social alienation reduces their confidence and weakens their spark to live life to the fullest.

...it attacks a very personal space in them, their confidence their courage, their stamina and stepping out and being who they really are, and being who they want to be and aspire of who they want to be. I know a lot of youth who, because of stigma, they have lost their spark, they lost their will, they are scared all the time and all of them they wanted to be with people who are HIV positive (E. Ballan, interview, October 26, 2016).

This can lead to many mental and emotional disturbances that affect their well-being. Youth living with HIV get to hold the burden of society in one hand while holding their medical condition and the virus in the other. The amount of stress that they face in daily life, such as losing a job if they disclose their HIV status, may lead to major high-risk behavior.

Confidentiality is a major concern for people considering HIV testing. Unauthorized disclosure of HIV status to family members, employers, and other health workers is a frequent abuse that can lead to severe consequences, including physical violence, for people living with HIV (Setayesh, Roudi-Fahimi, El Feki, & Ashford, 2014, p.16).

The article “HIV-related stigma within communities of gay men: A literature review” (Smit et al., 2012, p.408) outlined many irrational behaviours as a consequence of bearing this burden and facing discrimination. Some GYLWH, especially those facing significant discrimination, turn to alcohol and drug abuse, using mood-altering substances to reduce their inner pain of being lonely and miserable (Smit et al., 2012, p.409).

Another complication arises when GYLWH want to start dating. The lack of education in the gay community concerning the HIV virus means that GYLWH experience a lot of rejection when pursuing relationships.

The harm this caused to their self-esteem and self-confidence was often serious and long-lasting. Some men reported subsequently developing significant social and sexual distance from other men with HIV, whom they frequently characterized as morally inferior (Smit et al., 2012, p.408).

This form of alienation fosters internal blame and shaming, leading to inner homophobia and, consequently, fatal circumstances that the community cannot foresee. This is what Ballan meant when he said that sometimes the community talks and judges for fun, but when society does this type of bullying, its members never think about the circumstances. Ballan described this careless use of criticism as throwing knives that leave invisible scars in the survivors.

This is the role of the rest of the community... these people are “throwing the knives”, sometimes without even knowing that their friend is positive, but these thrown knives are leaving scars and scars that even though they are healed, but they still leave scars (E. Ballan, interview, October 26, 2016).

This type of passive bullying leads to social disconnection and alienation from the surrounding community members.

Adding to this, Azzi describes how GYLWH stop seeking help from specialized private services as those...

... community based services are also becoming challenging because the problem is that they will probably meet other gays there, even collecting the medication their treatment from the ministry of health is a form of exposure, so I think that people are less prompt to seek help, assistance and medical support, when they are HIV positive which has, of course, lots of consequences on their lives (G. Azzi, interview, October 26, 2016).

This fear of becoming the target for judgment regarding their positive status pushes GYLWH to remain incognito but, at the same time, pushes them to abstain from taking their medication—their only hope for survival—or getting their regular blood tests. This overwhelming stigma highlights the harsh effects on the lives of GYLWH and the despicable discrimination by society in general and the gay community in particular. That a person would refrain from seeking out necessary medical help to create the illusion of a shameless life, free from taboos, reflects sadly on the cost of dignity and pride.

This social pressure creates a psychological burden for GYLWH. Gay youth already have enough pressure dealing with their sexual orientation while

facing religious and cultural norms of society, but those with HIV face the additional burden of judgments from within their own gay community, the community where they should feel the safest, the community that GYLWH thought would protect them for belonging to it.

Interestingly, many of the reports and research articles reviewed for this study concentrated solely on women living with HIV in the MENA region. The lack of studies of gay men, despite the gay community being the most affected by HIV, speaks volumes about the “invisibility” of this community in the MENA region. One has to wonder if GYLWH, who experience discrimination socially, are also discriminated against as academic subjects or as the target of research studies, receiving less funding in the region. It is important to highlight that a lot of research has been conducted on women studies and people living with HIV in general, but little research has dealt with LGBTQ+ communities dealing with HIV.

Through the analysis of interviews with professional, gay youth living with HIV are marginalized by the society as well as their own community. Strict religious influence, ignorance and lack of protective policies contribute to alienating GYLWH. This marginalization affects them psychologically and socially, leaving them vulnerable, alienated, and totally disconnected from their society and community.

3.1.1 Background from the medical field

On World AIDS Day, December 1st 2016, the Ministry of Public Health (MOPH) with the World Health Organization (WHO) held a conference in Beirut (that I attended) to share their statistics and plan for the 2017 year. By the end of 2016, Lebanon had 108 new cases. 32.7% of them were HIV, 20.2% AIDS cases, 93.5% were male, 47.7% were homosexual (almost half of the cases), and 38.3% were not specified. As per the end of 2016, the cumulative number of cases of men living with HIV is 2,001.

Field work in Lebanon concerning the action and control of the HIV/AIDS epidemic was organized and planned as follows:

In 1989, as a follow-up to the Lebanese government's declaration that HIV is a serious public health threat, the National AIDS Program (NAP) was founded. Currently, the NAP operates through a joint project between the Ministry of Public Health and the World Health Organization.

It is responsible for every aspect of the HIV epidemic in Lebanon, including prevention of HIV, education about the disease, raising awareness, fighting stigma and discrimination, epidemiological surveillance and research, as well as M & E (UNAIDS, 2014, p.3).

Throughout the years, Lebanon has maintained a stable spectrum of cases, but in the past two years, with its neighbor country Syria experiencing civil war, Lebanon has welcomed 2 million refugees. With this unprecedented phenomenon, the risk of STDs has increased, which has led the NAP and the NGOs to create more programs to increase the numbers of medical tests, to educate, and to protect refugees.

The WHO regional director, Dr. Ala Alwan, pushed for the plan of 2017 to focus on discrimination in medical health. The MOPH, in collaboration with the NAP and WHO, and following the 2011 Political Declaration on HIV/AIDS calling for the “zero new HIV infections, zero discrimination, and zero AIDS-related deaths”, the focus was on stopping discrimination in the medical health system in Lebanon and on encouraging citizens to trust the medical system, thereby protecting and encouraging the most at risk population (MARP) to test. The slogan of the campaign was “dignity above all”, which was one of the 10 targets during that meeting.

Eliminate stigma and discrimination against people living with and affected by HIV through laws and policies that ensure the full realization of human rights and fundamental freedoms (Hamidreza Setayesh et al., 2014, p.7).

The WHO, MOPH and NAP created a declaration flyer for medical institutions to stock and distribute to everyone. Shared complaint forms could be accessed through the MOPH website and NGOs. The declaration, which looked like an oath, stated the following:

We do not discriminate based on age, gender, nationality, race, sexual orientation, HIV status, behaviors, illness, disability, religion, political affiliation or social or economic status.

We commit to:

- 1. Always treat you with respect and compassion*
- 2. Always respect your independence & control over your health care choices*

3. *Always seek your informed consent before providing health services*
4. *Always observe your right to privacy and confidentiality*
5. *Always make sure that our actions do not harm your health or social wellbeing*
6. *Always act in your best interest*
7. *Always take your comments & complains seriously and respond to them*

In the paper “Quality of life in people living with HIV/AIDS in Lebanon”, Dr. Jacques Mokhbat—head of the STD department in Rizk Hospital and an activist and protector of patients’ rights—investigated ‘why’ and ‘how’ people living with HIV (PLWH) live. It was the first study of its kind to be conducted in Lebanon. When studying quality of life, ‘the physical health; psychological health; social health; and the environmental factors’ were examined, all of which contribute to defining the well-being of PLWH.

In Lebanon, studies on the knowledge and attitudes of the general population toward AIDS showed lack of knowledge and fear of the disease (National AIDS Control Programme in Lebanon, 2004). In addition, the Lebanese culture is a conservative one that gives high importance to traditions, social norms, religion, and family values (Abboud, Nouredine, Abu-Saad Huijer, DeJong, & Mokhbat, 2010, p.688).

The above explanation makes it clear why PLWH remain anonymous and are cautious in sharing their status with anyone (p.692). The study showed that PLWH, described by Dr. Mokhbat, are well cared for by their families. As mentioned previously, this attitude of caution is likely due to PLWH avoiding discriminatory reaction from society. PLWH are protecting themselves by not exposing their status to avoid social judgment and tend to choose wisely with whom they share their status. Additionally, some PLWH only confide in certain members of their family, which is related to the family-bonding culture Lebanon that still retains. Some youths live with their parents or depend on their parents in domestic life. What was interesting in the report was identifying the lack of research and documentation on the quality of life of PLWH in Lebanon and the MENA region, and the effect of stigma and discrimination on PLWH.

Stigma and accompanying discrimination reduce one’s social interactions, leading to possible job loss (reported in 24.3% of cases), among others. This conclusion is supported by the significant correlations between the mean MQoL- HIV, and the stigma items

related to people avoiding the HIV-infected person upon learning of his/her status, blaming him/her, and depriving him/her of good health care (p.693).

There is a lack of documentation on the study of quality of life of PLWH in general; no studies exist for GYLWH. Even though data reported from diverse studies by the WHO or NAP pointed to the fact that youth and homosexuals, or men having sex with men (MSM) generally, constituted the majority of the most at risk population (MARF), no documentation elaborated on their quality of life because it is not easy to reach these groups. In the book report, “Characterizing the HIV/AIDS Epidemic in the Middle East and North Africa” researchers pointed out the increase in discrimination towards the higher risk group:

Men who have sex with men form the most hidden and stigmatized risk group of all HIV risk groups in MENA. They are often subjected to harassment and even brutality (Abu-Raddad et al., 2010, p.31).

In summary, Lebanon lacks in-depth studies concerning the quality of life of PLWH and specifically GYLWH. According to the United Nations program on HIV/AIDS (UNAIDS), Lebanon has 2,400 PLWH. It is important for a country with a population of 4 million to focus on them. Because there is a lack of literature concerning the cause and consequences of the stigma of GYWH from the gay community in Lebanon, western studies that explored strategies recommended by researchers on how to plan for an HIV/AIDS research were consulted. An extensive ethics protocol was devised and submitted, especially concerning international HIV/AIDS research (Canadian Association for HIV/AIDS Research, 2008) see Appendix D.

For these reasons, this thesis research focuses solely on the lives of GYLWH, their stories and quality of life.

3.1.2 Media influence and representation of HIV and gay characters

Television series/soap operas or *muslasalat* are very popular in the Arab region. These series reflect the region's socio-political realities. With almost “152 specialized satellites channels’ television series are still dominant since the 1960’s” (Buccianti, 2016, p.53). Gay characters/ personas have long been represented in Arab movies and series. The representation of gay characters was split between the flamboyant and the oppressed dramatic. The former

is used for comic relief and sarcasm highlighting the representation of the “other” as opposed to the social code of hetero-normativity, while the latter is represented in melodramatic stories dealing with social oppression (Jaber, 2016, p.213).

As for characters with HIV their presence was limited until the release of the Egyptian movie entitled *Asmaa* in 2011. The movie was about a woman named Asmaa who died because of medical neglect; she was trying to get an operation, but doctors refused to perform the procedure unless she disclosed how she became infected with HIV. Trying to cover up her husband’s adultery while he was working abroad, Asmaa refused to confess the reason. The movie remapped the importance of the HIV issue in the Arab media and marked a shift in the attitude of how people look at people living with HIV in the region (Setayesh et al., 2014, p.20).

Unfortunately, recent *musalsalat* do not include gay characters living with HIV; therefore this “media representation” section will focus on the latest two series produced in Lebanon (both in 2014) and aired on Lebanese and satellite channels — *Ishk el Nisaa* on the Lebanese Broadcast Channel International (LBCI) and *Samra* on the AlNahar Drama channel.

Contextualizing the representations in these series provides insight into the social attitude towards queerness and people living with HIV in Lebanon. As mentioned in the first section, the use of Stuart Hall’s reading of the visual will help reveal socio-political and cultural insights about the country.

In *Ishak el Nisaa*, Nadeem is an upper-class doctor living in both Paris and Lebanon. Nadeem, who is an educated, masculine-acting, and well-built man in his late twenties, tries to come out to his family by first getting the help of a family friend. In Episode 34 we see Nadeem approaching this family friend by saying that he wants to talk about something that he himself doesn’t consider wrong or shameful, but that society does. Nadeem adds that he was trying to hide his sexual orientation all his life by dating girls, but it was all a deviation and distraction from his reality. Nadeem’s main concern is the approval of his mother. Yet when he tells his mother, she is horrified and disowns him while criticizing his homosexuality as deviant and wrong. He tries to regain his mother’s approval, and that of society, by dating an ex-girlfriend again, but this leads to more drama. His failure to have sexual intimacy with his girlfriend pushes him to a dark place and he attempts suicide. By the end of episode 45,

Nadeem goes to the kitchen cupboard and, while the voice of his mother in the background blames and dishonors him, he picks up rat poison and drinks it (Figures 3.2 and 3.3). After Nadeem is saved by his American boyfriend, he faces his mother again and she tells him that she was tough in order to protect him from what he would have had to face in Lebanese society if he were to come out of the closet. Nadeem decides to stay and live in Paris instead.



Figures 3.2 & 3.3 Nadeem suicidal scenes in "Ishk el Nisaa" Lebanese soap opera (Online Production, 2016)

Through Nadeem's character, we can see a lot of societal context and identify many clichéd scenarios. For a start, there is the social refusal to acknowledge the concept of queerness/homosexuality in general. This becomes obvious through his mother's response after Nadeem comes out to her. She describes queer behavior as "Shawez" which translates to "deviance" in Arabic languages. This word summarizes the social rejection of anything different than hetero-normalcy and gender binary. The social norm in Arabic culture is based on reproduction that is achieved between a male and a female, which enforces binary thinking and acting. Judith Butler, philosopher and gender theorist, talked about binary and gender performativity in her article where she explains that:

... gender is made to comply with a model of truth and falsity, which not only contradicts its own performative fluidity, but serves as a social policy of gender regulation and control. Performing one's gender wrong initiates a set of punishments both obvious and indirect, and performing it well provides the reassurance that there is an essentialism of gender identity after all. That this reassurance is so easily displaced by anxiety, that culture so readily punishes or marginalizes those who fail to perform the illusion of gender essentialism should be sign enough that on some level there is social knowledge that the truth or falsity of gender is only socially compelled and in no sense ontologically necessitated (performance: pt1.Identity and the self, p.107).

The fact that Nadeem tries to please his mother and immerse himself in a heterosexual relationship shows that he was trying to conform to Lebanese social codes. He tried to perform and abide by the social construction of male gender. He was submitting to the political beliefs of the social hegemony's around hetero-normalcy.

On the darker side, the suicidal act that Nadeem commits is wholly expected, according to the activists, because Nadeem is facing the suppression of self (interior) and oppression by society (exterior). This stereotypical act represents reality in conservative societies, which is the consequence of enforced socio-political pressure.

Another point highlighted by this gay character is the privilege experienced by higher-income classes comparing to the lower ones. Throughout the TV series, Nadeem dealt with his private life by traveling from Beirut to Paris. Not all social classes can exercise this privilege; it is only possible for members of the higher-income classes. This makes sexual freedom impossible for most gay people and even the privileged can only exercise this freedom elsewhere. This privilege is one way to separate public and private life and reflects the socio-political construction of the country that is ruled by oppressive political dominance. Many political groups have oppressed Lebanese society throughout history, including the French colonization from 1923 to 1946 and the Syrian occupation from 1976 to 2005. Currently, Lebanon is governed by civil war militia leaders, who exercise their political agendas, forcing social segregation through classes and diverse religious sects so that the militias can stay in power and control the country. The strategy of politics of segregation represent, as per Friere, the control of the 'oppressor' over the 'oppressed'.

In his article, "The Myth of the Queer Arab Life", Saleem Haddad mentions the dichotomy between public and private life. On this issue, the Arab world is incongruous. Haddad gives examples concerning this dichotomy, one of which is the raid that the police conducted on a cinema in the Tripoli area in 2012. This cinema provided a hook-up place for gays, and during the raid 36 gay men were arrested. The cinema was exposed on one of the Lebanese television channels through a program called "inta hurr" (translated as "you are free"). The host of the program was outed by LGBTQ+ NGOs showing a picture of him in a gay club in Mikonos. The host refused to apologize, saying

that “the breach of public morality is one thing, and sexual freedom is something else”. Haddad ended his discussion of the cinema by concluding that gay life is for those who have power and money, who can afford to fly abroad and practice their sexual life. For those without the means, pursuing sexual freedom is a hit or miss proposition, which can lead the less privileged into prison (Haddad, 2016).

Haddad is an Arab writer who talks about why he left his country as a gay man seeking kinship in the western world (Haddad, 2016). Haddad’s article highlights the decision Nadeem and many other capable or lucky Lebanese gay youth think about or achieve. This raises the question, is leaving your own country for “betterness” a personal failure or simply a refusal to accept the cultural pressure imposed by the socio-political, hetero-normative, binary hegemony? Heather Jaber, a Lebanese scholar with whom I co-chaired a panel at the American University of Beirut conference against social harassment in 2017, wrote an article called “Crossing the Border: Rethinking Failure and Exile in Lebanese Musalsalat”. Jaber argued that exile and failure in TV series should be seen as a triumphant move, where gay characters are socially aware and critically analytical of their situation. Therefore, the act of leaving an oppressive system is a courageous move towards the better. Paolo Friere called those decisions “conscientization”, which is the realization by the subject [oppressed] of his surroundings and the development of critical and analytical thinking where the subject reacts to an oppressive system instead of remaining silent.

Two main insights were deduced from the reading of Nadeem’s character in the Lebanese television series *Ishk el Nisaa*. Being gay in Lebanon is a privilege available to a specific class that can afford to pursue their “private” life away from a “public” one to express their sexuality. Gay life is a struggle because it breaks all the hetero-normative binary cultural pressures and can lead to suicide or exile.

As mentioned previously, the lack of gay characters living with HIV in recent Lebanese TV series necessitated a search for a series that included heterosexual characters living with HIV. “Samra”, a 2014 Lebanese series, is the most recent one to revive the importance of talking about HIV. An analysis of this series helped to gather insights on society’s attitude towards people living with the virus and the community of which they are part.

The setting for the series is a “gajar” (gypsy) community. Members of this community do not have identity cards, as they are considered illegal, and cannot cross any borders. They are stuck in a slum camp where they build a small community and practice their life, alienated from society. The lack of legal papers or registration with the government means that they cannot get temporary jobs, let alone permanent ones. Consequently, the way they generate money for a living varies. Some depend on their skills such as crafting gold, dancing, butchering, dealing with drugs and weapons, while some of the women work as helpers or prostitutes.

Although the series revolves around a beautiful gypsy dancer named Samra, the analysis here focuses on two characters, Reem (female) and Wael (male). This heterosexual couple has a very distinct relationship: they sleep with each other but Wael doesn’t confide his love for Reem as he feels that he is not good enough for her. Wael’s mother, whom he has never met, left him to be raised by everyone in the camp and never declared him as her son.

Reem accepts work as a prostitute to help supply drugs for Wael’s addiction. Wael’s boss, the brother of the tribe leader and a drug dealer, will not provide drugs to Wael unless he convinces other women in the tribe to work for him.

Wael escorts Reem to clients and waits for her until she finishes to split the money and take her back to the camp. In episode 11, Reem notices skin lesions on her arm. Volunteer doctors, who visit the camp to provide medical help, see the lesions and decide to take Reem and Wael for blood testing in a hospital. The doctors discover that both are HIV positive and have a very compromised immune system. The doctors order them to start treatment on the spot.

Many themes surfaced after the news of being HIV positive and a behavioral pattern emerged in the two. Immediately after their medical examination and orientation, Reem and Wael go through a self-protective mode. Their first reaction is how to keep their medical status secret for fear of being marginalized and thrown out of the camp. This self-protection leads to social alienation (Abboud et al., 2010, p.693); Reem and Wael try to remain out of their tribe’s sight, only discussing their status with close friends and with each other. Both characters build self-blame. Reem blames herself for the possibility that she might have transmitted the virus to Wael, while the latter blames himself for pushing Reem to sleep with other men for money.

Eventually, this alienation and self-blame leads to self-destruction. Reem ends up hating her body while Wael turns to drug and alcohol abuse.

In their gypsy community, the fear of the unknown leads to punishment. After a member of the tribe hears Reem and Wael discussing their medical fear, the tribe decides to throw them out of the camp and burns their houses and belongings, leaving them with no shelter (*Figures 3.4 and 3.5*). This image recalls Dr. Mokhbat's interview where he talked about medieval times, during the syphilis epidemic, when patients were burned for fear of spreading disease. Ignorance leads to marginalization. Fear of the unknown, similar to Butler's clarification about the lack of gender performativity, causes marginalization. This fear is compounded by the fear of death. The death theme that was discussed in the previous section connotes punishment. Even on the personal level, Reem mentioned on many occasions that she doesn't want to die. Viewers of *Samra* receive these negative affirmations, especially the association of HIV to death, an old stigma that emerged in the 1980s.



Figure 3.4 and 3.5 Wael & Reem's evacuation scene in "*Samra*" Lebanese soap opera (AlNaharDrama, 2016)

In the series, we see the couple triumph over the fear of sickness with the help of the primary character, Samra, and the tribe's fortuneteller. The couple work on their love. Wael tries to work on himself to get out of substance abuse, while Reem uses her love of children to open a small nursery. But, as in all soap operas, the drama must go on and Reem is put into an attempted rape situation. A neighbor, who is a government employee, has his eyes on her. He brings his kids to Reem for babysitting and at some point tries to rape her. Now Reem is put into a situation where she has to reveal her HIV status to stop him from raping her. Once more, Reem and Wael flee the area before they are ejected out of the neighborhood. The series reflects the prejudice of the community in that exposing Reem's medical status means that the nursery will be shut down. From a medical standpoint, she will likely never transfer the virus to the children, but parents will not understand this.

The analyses of the two series above highlight a few generalities in Lebanese society. First, the media represents gay men as lost individuals with inner homophobia, trying to make amends with their families and communities, but always granted failure or exile. Second, people living with HIV are blamed and punished by their own community. Both themes portray weak and passive personas, surrendering to their faith or life choices. Therefore, a gay person living with HIV experiences double marginalization. Youth living with HIV are marginalized by mainstream society on a macro level and by their own community on a micro level, leaving them silent and vulnerable in their own world of isolation. This is how media in the MENA region portray gays and people living with HIV. How do GYLWH see this world? What levels of discrimination do they experience and which levels affect them the most?

3.1.3 Perspectives of gay youth living with HIV

After contextualizing the representation of gay culture in Lebanese society, as well as looking at the reaction of society to people living with HIV, this study explores the point of view of gay youth living with HIV.

In her book, *Participatory visual and digital research in action*, Aline Grubium explains how the “Photovoice Method” is used in community-based participatory research (CBPR). This method, first used by researcher Carolyn Wang in the public health field, is a method of inquiry performed in three stages. It requires “generating photography, eliciting narrative and hearing participant’s voice” (Gubrium & Harper, 2013b, p.71–72). The “Photovoice” method was used in this study as an icebreaker to encourage participants to express their thoughts and feelings visually through the lens of a camera. Participants (Nassib, Walid, Samer, Houssam, Ihab and Hamid) were handed a folder containing a disposable camera, a notebook and four questions. All participants had mobile phones and they preferred using their mobile phone cameras in the process. The exercise called for participants to answer the following questions visually (by taking photographs):

- 1 What is “stigma” for you?
- 2 What is your favourite place or “sanctuary”?
- 3 What is your “unpleasant place”?
- 4 Who do you confide in (can be a person or a thing)?

It was interesting to discover what GYLWH think about their gay community specifically and the larger society in general. The exercise provided an

opportunity to gather anthropological and ethnographic background on the participants, and sharing narratives in the group session provided important group-bonding time. Participants were allowed to use images from the Internet if the object needed for the photography was unattainable. Like for example one of the participant's favourite places was Canada, so we allowed him to use a representative image from the Internet (Figure 3.6).

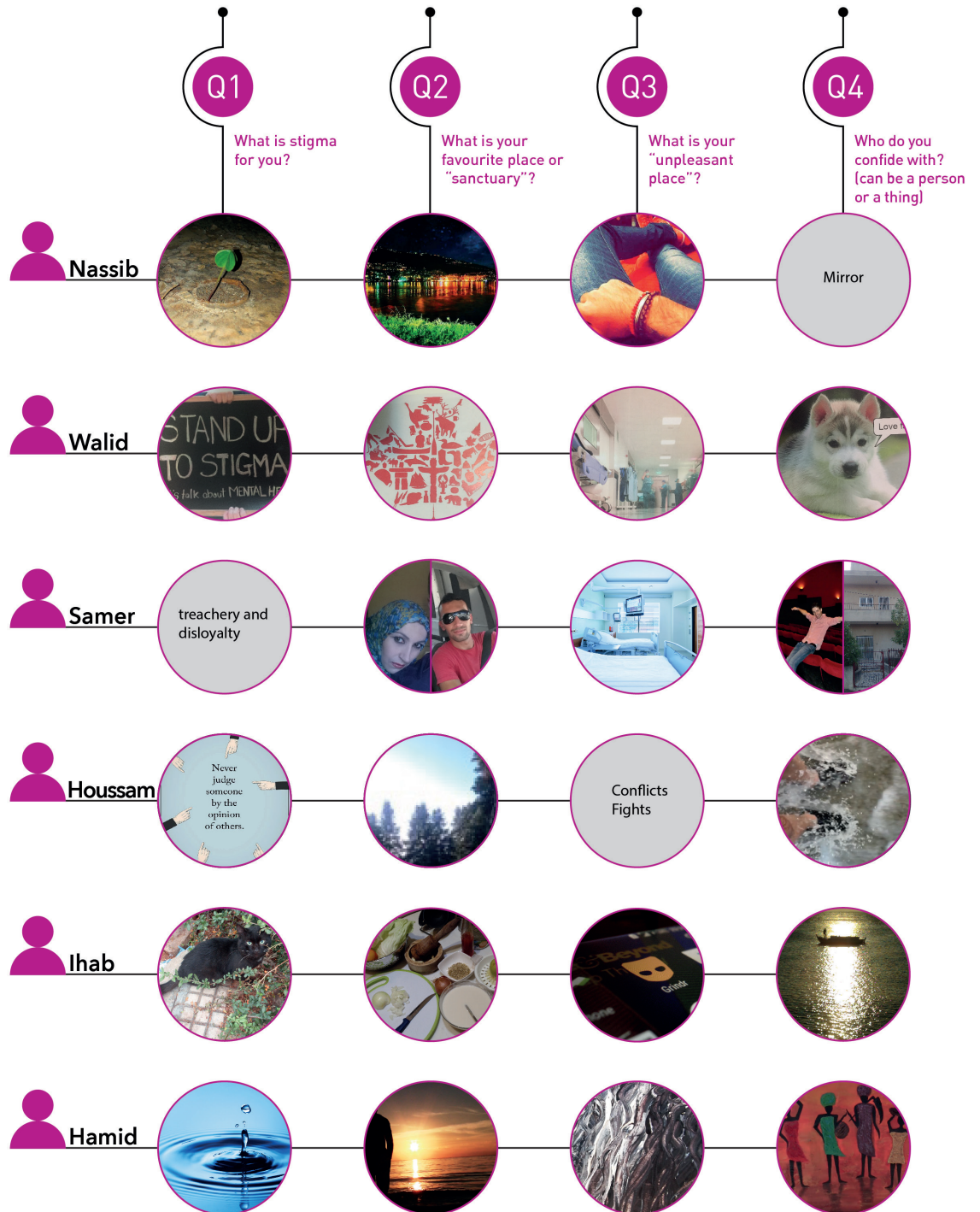


Figure 3.6 "Photovoice": Participant's visual answer

The choices and the narratives elicited from the photographs were very powerful and informative. For example, Ihab chose a black cat to represent discrimination (stigma). Everyone avoids black cats because they represent bad luck in Lebanese culture. The black cat is punished for being different, by having a black colour purely from genetic circumstances beyond its control. This cat connotes the attitude of society towards anything that is out of the normative scope. It represents marginalization perfectly.

For Houssam, discrimination is built on ignorance, his photo represented an accumulation of repetitive false information, describing the gossipy behavior of the community. Walid and Hamid also described the effect of gossiping, but through images of ripples caused by a drop of water on a larger body of water, denoting the way society amplifies stories for the sake of gossip and dramatization.

Finally, Nassib visualized the effect of discrimination an image of a single plant, in the middle of nowhere, portraying the alienation that people living with HIV feel. According to Samer, they also feel “treachery and disloyalty”. This sense of betrayal that GYLWH feel towards their own community recalls the Smit et al. paper on the causes and consequences of marginalization of GYLWH by the gay community.

Moving to the second question about their “sanctuary”, most of the images were devoid of humans. Most of the participants found sanctuary in nature. The sea appeared in images on many occasions. Some participants highlighted the concept of calm, a place of refuge away from the eyes of society. One participant found sanctuary in his house, a place where he feels grounded and secured. For Walid, sanctuary was in another country on another continent. Looking for sanctuary in an unattainable place is akin to dreaming of utopia. Interestingly, the sea can provide a path to utopia, to places that promise “betterness” and kinship. The hope for “a better place” (escape) is a common theme for marginalized groups, but at the same time, it could represent the helpless state of mind that participants experience.

Fear of hospitals predominated when visualizing “unpleasant spaces”. The narratives derived from the hospital imagery were intriguing. For Walid, the fear of hospitals stemmed from his concern of contaminating a place with his own blood. He mentioned that he was scared to be in a situation where he was unconscious and bloody, such as after an accident, and having to

be taken to a hospital. His primary fear was the transmission of the virus to another person. This fear highlights the lack of knowledge about the HIV virus. The virus cannot live long outside the body (CDC, Atlanta GA) and health care workers always take the necessary precautions. However, the fear of Walid represents his guilt about hosting the virus in his blood. Societal pressure in this scenario creates internal phobia and self-blame as mentioned earlier. In the group discussion, we explained to this particular participant that hospitals are responsible for sterilizing clinical spaces and that he should never feel responsible for other people's laziness.

Still on the topic of hospitals, there was the fear of health discrimination. Being in a hospital means that one's status might be disclosed without their consent. Medical health discrimination was mentioned in the interview with activist Ballan. He said that some hospitals had breached the anonymity of numerous patients living with HIV and exposed patients' status to the public. This is definitely a concern knowing society's attitude towards HIV.

"Loneliness" and "darkness" were brought up as well while describing "unpleasant places". Nassib feared being alone and Hamid feared darkness. These two ideas are correlated because loneliness can lead to psychological darkness, especially when we are dealing with people living with HIV. Sadness and loneliness can induce negative thoughts and may cause risky behavior. Finally, Ihab pointed to Grindr (a gay dating app) as his unpleasant place to be. Pointing to this app, which is a place where gays express their sexuality openly, is very significant. This app represents a large segment of the gay community, especially for young people; therefore fearing gay "mecca" means fearing judgment and mistreatment in what supposed to be a safe place.

The final question dealt with the place or the person that participants "confide in". In the paper "Quality of life in people living with HIV/AIDS in Lebanon" Abboud et al. pointed out how people living with HIV choose carefully to whom they disclose their status. The answers by the participants were shocking in that they chose places, and even animals, over humans. Walid confided to his dog only. When asked about the reason for his choice, he told a story of how a very close friend of his stopped talking to him after disclosing his HIV status, which made him resistant to share his medical status with anybody else afterwards.

Two other participants recalled the sea and water. Again, they are dreaming of an underwater utopian world, for a nonjudgmental and accepting place to

be safe in. Only two of the six participants talked about a family member and for them “the mother” was always a key player. Whether Mother Nature or their biological mother, the participants adopted a very deep emotional tone in their voice. Hamid highlighted his special bonding with the opposite gender. He explained how women understand him the way he understands them. This connection refers to bonding over oppression. Women in Lebanese culture are still fighting for their rights and for equality with men. Lebanon is a country that values tradition, and the mothers, as mentioned in the first section, are seen as very holy and sacred because they are portrayed as caregivers.

In summary, Lebanese GYLWH live in a society that is highly influenced by religious values, immersed in hetero-normative beliefs based on the gender binary, and divided between private and public personas. The gay community in Lebanon lacks current education on topics related to HIV. Additionally, the community is absorbed with gossip and adopts a judgmental attitude towards anyone identified as “other”. These circumstances place GYLWH in a vulnerable position, alienated, fearful of exposure and discrimination, scared to ask for help, immersed in silence and neutrality. As a result, GYLWH are deliberately alienating themselves, in the hope of finding of a utopian place.

3.2 Defining and developing the approach: co-design workshop

Along with language, dancing, marching, and singing are uniquely human ways to install a sense of hope and courage (Van der Kolk, 2014, p.334–335).

In his book, Dr. Bessel Van der Kolk describes his 30 years of experience working with people dealing with trauma. Van der Kolk expresses how diverse creative expressions (drama, art) help in regaining control over the self, especially when people face life-threatening experiences. In such circumstances, people lose their verbal expression and cannot describe what they are passing through. Subsequently, any creative activity helps people who have experienced trauma because they learn to express themselves in unique ways by pushing beyond their comfort zones.

Using the concept of dialogue as focal point, the “How question” was addressed through designing a workshop for gay youth living with HIV (GYLWH) where they could open up by doing creative exercises in order

to design their own messages for their own community. The workshop was designed to be the communication tool for GYLWH to express what is happening to them internally, in a creative and inspiring way.

The first step was to search for a non-governmental organization (NGO) involved with GYLWH. Proud Lebanon was the only NGO in Beirut that held a support group for GYLWH. The first step was to contact the CEO and founder of the Proud Lebanon, Bertho Makso, and build a relationship of trust with Proud Lebanon by highlighting the importance of the research as a potential benefit to participants and to the NGO.

The proposed research passed the research ethics requirements of the University of Alberta (see Appendix A). The research plan was divided into three stages: recruiting participants, conducting the workshop, and showing the resulting visual communications.

Gayle Restal and Miriam Gonzalaz from University of Manitoba published a policy brief on strategies to address HIV related stigma (Restal & Gonzalaz, 2014). A forum was held in 2012 in Manitoba to build recommended strategies for dealing with HIV stigma. Four strategies were recommended based on six categories of HIV/AIDS reduction strategies. The six reduction strategies are: I. Information Based II. Skills-building intervention III. Counseling intervention, IV. Contact with stigmatized groups V. Structural interventions and VI. Biomedical interventions. Each reduction strategy aims at specific criteria.

The recommended strategies of dealing with HIV stigma were combinations between one or two reduction strategies that seems to work best. The one that best fit the research in hand was “Information in combination with contact with affected group has been shown to increase tolerance toward people living with HIV/AIDS and reduce stigmatizing attitudes” (Restal & Gonzalaz, 2014, p.3). This strategy involves people living with HIV to contact individuals or groups face-to-face or by video testimonial backed with educational information and discussions. Based on Restal and Gonzalaz recommendation the workshop was designed upon.

3.2.1 Recruitment of participants in Lebanon

Targeting gay youth living with HIV as research participants is a very sensitive and difficult business as we — the researcher and NGO members — could

not advertise it openly. As discussed in the previous section, HIV is a sensitive subject to Lebanese society that leads to discrimination. The negative attitude of society towards the gay community on the one hand, and the subject of HIV on the other, made it difficult to have an open and organic recruitment process. Proud Lebanon suggested using the registered members who had attended a previous support group to begin with. They also suggested encouraging the members of the previous support group to advertise the upcoming workshop to their friends by word of mouth. At this point, we were recruiting young, gay males living with HIV, who had resided in Lebanon for at least the past year. Sample blurbs about what to expect were formulated and sent to Bertho to post on social media platforms like WhatsApp and Facebook, the two primary platforms he uses for Proud Lebanon to connect to GY and GYLWH in general.

3.2.1.1 Establishing a relationship with Proud Lebanon

Creating a relationship with an NGO, especially the first contact, was somewhat intimidating, especially as living in another country, we had not yet had a face-to-face meeting. Initially we used Facetime and Skype for communication. Clarity and transparency in communication was key in building this relationship. Designing the steps of the research workshop was important in getting Proud Lebanon on board with the research stages. We were always clear in explaining all the steps of the workshop and the expectations from it.

During the preparation and design process, the focus was, above all, on the safety and well-being of the participants. Participants would be digging into deep emotions of their experiences dealing with HIV, and this might cause some discomfort during the workshop. Being prepared for the worst was always the strategy to deal with any unfortunate events. Therefore, the decision to have a therapist on call during the process was very important.

The support group was usually held on the premises of Proud Lebanon because it was a location that some members trusted and felt comfortable visiting. As well, Proud Lebanon is a registered NGO so the location provided a legal place to practice a support group and would not become a targeted location for unusual activities or investigation by the police. The government was keen to investigate any “suspicious gathering” if identified by members of the public, especially after the Syrian crisis and the presence of many Syrian refugees in Lebanon. The Lebanese government was being overly cautious for fear of any terrorist planned attacks.

3.2.1.2 Preserving the anonymity of participants

The advantage that we had was framing the workshop as a support group. In a way, it is an assurance to the participants that they will benefit from it and that it is not a waste of their time. The hope of everyone involved in the workshop, was for positive outcomes but that could not be guaranteed. The whole team was motivated to focus on supporting every participant technically (in the design process) and/or emotionally (alleviating self-doubt concerning their work). Some of the participants were worried about the feedback and reactions that they might get from the public towards their stories. These concerns were shared by all participants.

Communicating their experiences openly to the gay community made them feel vulnerable and sharing their design videos made them feel anxious. As an example, one of the participants (Hamid) reached the final stage of the process, watched his video, and said that he felt uncomfortable showing his work to the community. Even though Hamid's video had no visual cue revealing his identity, he was keen to inform us about his trepidation. We reassured him that the video would not be shown to anybody until he was feeling entirely comfortable about it. In the end, his workshop friends expressed how powerful his work was and lauded his message design. He regained his confidence and gave us the "go ahead" to screen his powerful video.

During the design process, we kept reminding the participants, and ourselves, about the need to maintain and secure the anonymity of the participants. Preserving their anonymity was for their own protection because the videos would be aired to the gay community and we wanted to make sure that the participants' medical status would remain private. This would ensure that they would not be stigmatized after the screening by any member of the gay community who happened to recognize any of the participants. To preserve anonymity, we had to oversee and revise thoroughly every stage in the process, from the writing of the narrative to the editing of the video.

In the narrative stage, we made sure that the participants did not reveal any personal information that could reveal their identities. One example a participant decided to name his village in south Lebanon in his narrative, a village with only 200 people. If, by chance, one of the village residents heard about the story of the video from anyone, people would start investigating

and talking about the issue until they discovered his identity. The fact that the village was far away and secluded, made it even more likely that the participant's identity might be revealed.

During the visualization stage, we ensured that the characters would be filmed in a very discreet way without revealing facial or body traits that could be recognisable to people they knew. All participants were active in the community and met other gay or straight friends daily. So for example, having a specific tattoo on the arm provided an easy visual cue for others to recognize them. One of the participants realized that his tattoo was clearly visible in one of the scenes, so we edited the frames using iMovie software to zoom in and crop the tattoo out of the frame(s).

Another example of telling visual cues was identified by NGO counselors when they were shown a video sample to gain permission to screen the videos on their premises. The counselors pointed to the medicine bottle a participant used in his video. The medication was a very specific brand with a unique gradient of blue to yellow on the label, and was the only one that the Ministry of Health provided to all HIV patients. The counselor highlighted the risk of revealing the name, shape and colour of the bottle, as it would become a recognizable sign of HIV treatment. Anyone seen using this medication would automatically be connected to HIV and consequently stigmatized.

In the same video that featured the medicine bottle, the participant filmed his test report. On the report, the name of the hospital was visible, and this hospital was one of two major medical organizations in Lebanon providing detailed HIV testing. By revealing the name of the hospital, the participant would become a target of a curious and nosy society. In this case, any patient seen or heard mentioning that hospital's name would be linked to HIV. Therefore, we had to return to the editing phase and pixelate (add a filter to mask the object) these two items (the medication bottle and medical test result) to avoid any risk of revealing an identity in the future or showing material that could create stigma.

Participants had the choice to be actors in their own films or to use an actor to represent them. One out of the six participants decided to remain behind the camera directing and filming, using the researcher as an actor. It was easier to use someone from the group rather than getting someone from the outside as, by this stage in the workshop, trust had been built and it was the

most efficient and safe solution.

During the voice recording of the narrative, participants decided to either use filters to disguise their voices or chose someone from the group as a surrogate voice. Voice is a very recognizable trait and can specifically identify a person if the listener knows them, especially close friends and family members.

These precautions proved to be key in the design process. Participants felt more confident, and worked openly when they realized how keen we were to preserve their anonymity. Participants confided in us, trusted us, and trusted the process when they realized that we put their wellbeing and comfort first. Building relations and creating confidence with participants are very important aspects in participatory research. Once participants trust the process and the researcher, real insights are revealed and momentum is created.

3.2.2 Workshop structure

The workshop was designed to contain six sessions — narrative writing, storyboarding, voice recording, video recording, editing and screening. Because the support group was scheduled to meet once a week, the workshop needed to fit into participants' schedules, as they all had commitments during the week like work and/or studies. To this end, we met every Saturday for three hours from 3:00 to 6:00 p.m.

The six sessions represented the stages of building a video narrative starting with the writing stage of the video's script till the showing of it. The advantage of weekly meetings was that it gave all participants time (one week) to think about and work on their material. Because they all had jobs and day-to-day activities or family engagements, one week gave them the right amount of time to produce material and stay on schedule. Staying on schedule was important in order to complete their videos, as each stage of the video process has new skills and benefits, therefore missing or mixing stages might be overwhelming for participants.

3.2.2.1 Narrative: writing the messages

The narrative stage involved two actions: the writing and the editing of the script. In the writing process, participants were asked to “unload” everything they felt or wished to communicate to the gay community about their experience living with HIV. In the second stage, participants had refined or edited their written texts to fit the length of a 4 to 5 minute video. This involved careful timing while reading their text.

“Digital stories often start with the pictures. Our easiest direction to anyone thinking about making a digital story is to look around his or her house and find images that provoke memories and stories that are meaningful” (Lambert, 2013, p.27).

Following Lambert’s ethnographic thinking with the concept of triggering memory through the visual to open up feeling and emotions was the first step before moving to writing. After the first session, and the “photovoice” discussed in the previous session, participants felt comfortable enough to open up and write, as we had already covered the topic of discrimination and discussed it in the introductory stage. That prepared the participants psychologically and smoothed their transition into the writing process, as it set them up to pursue what they wanted to say in their scripts. As mentioned according to communication theory (sec.2.2.2, p.13), the narrative becomes the message that participants pass to the community, which makes this stage a very sensitive and emotional one.

Because Lebanon is a trilingual country (Arabic, French, English), the participants were given the choice to write in the language that they felt they could be most expressive in and confident using. Four out of six participants decided to write in English and the remaining used a Lebanese dialect of Arabic and classical Arabic. The Lebanese dialect is the day-to-day language used only in Lebanon while classical Arabic is the form used in literature that is taught in schools in all Middle Eastern countries such as Egypt, Jordan and Syria.

In Arabic language, when we hear a conversation between two people without seeing them, we can tell the gender of the person the talk is addressed to. The language is built on male/female genders, so the listener will hear “he” or “she”. During one of the workshop sessions, participants were talking to each other in the feminine form. We assumed at this point that some of the participants identify with the feminine gender and that they wanted to be addressed using she/her. Usually when someone gay is addressed in the feminine, they are considered to be the bottom/receiver in a gay sexual act. In the workshop, addressing the other person in feminine was a choice where the participants had prior knowledge about the other participants’ gender identification and on how they liked to be addressed. But at one point, a friend of one of the participants visited during a workshop session and in a

conversation, he addressed one of the participants in feminine as a tactic to try to dominate the situation or the argument that they were having. Through this observation, we realized that addressing someone as feminine can be used to oppress the other. This action is a reflection of Lebanese society where women are considered to have less value than men and are treated as second best. The female gender is considered to be passive and is expected to be submissive towards the male gender (Dabbous-Sensenig, 2002).

It was an interesting situation when this was brought up in a discussion in the workshop, and it was intriguing to try to understand this phenomenon. We highlighted that the “other” should never address a gay man in feminine form if there was no consent to do so. We asked participants if they ever gave consent to be addressed as female and if they liked to be addressed as such. Most participants didn’t like the fact that they get addressed as female, a few didn’t mind, but to our surprise they never gave consent to others to do so. When pointed out that they had been addressed as female to oppress them and treat them as less, then they felt offended after thinking of it.

This phenomenon was not a surprise to them as they were all raised in the same culture where women are dominated by men and represented as passive and weak. Therefore, the bottom/passive/receiver in the gay community is considered weak and has no choice but to be dominated by the top/active/giver/alpha/masculine. Hetero-normative social customs are reflected in the gay community where this dichotomy of male versus female, powerful versus passive, renders anything between the two extremes as odd, with no place in society’s perception. The combination of a gay bottom/receiver living with HIV is doomed. Not only is he looked down on for being gay, but he is also considered weak for being passive and discriminated against for living with HIV. The feeling of being “less than” others and being treated badly for this set of circumstances affects all GYLWH negatively. They are being traumatized for life from mental stress to internalized homophobia and social alienation.

During the narrative writing stage, the researcher made sure that the participants were inspired enough to express their emotions and thoughts easily. Often participants got frustrated or experienced writer’s block. The role of the researcher here was to help participants overcome these obstacles by asking questions like “what do you want to say?”, “what did you feel at this moment?”, or “what does this treatment do to you?” The

researcher needs to assess the situation and what the participant is writing about, then without influencing him, help him break through the silence so that the participant can express himself fully.

Concerning the written text, the researcher read the scripts and gave advice on English grammar, sentence structure, and reducing repetitive ideas. Fine-tuning and supervising the flow of the story building were the main concerns for the researcher at this stage. Participants generally did not know what the end results would look like, therefore some guidance and support in this regard was necessary.

3.2.2.2 Storyboarding: visualizing the messages

At the beginning of the workshop, we distributed a storyboard sheet (*Figure 3.3 & 3.4*), which was intended to help participants organize the visuals in their narrative. This tool helped them to be as creative as possible in expressing visually what they wanted the viewers to see and feel when watching and listening to their video creation. A storyboard helps visualize the flow of the video in a two dimensional way, where participants get the chance to check the relationship between visual and textual elements and to brainstorm a myriad of visual solutions that might be possible (Lambert, 2013, p.17).

The storyboard sheet is a template for organizing video content. It consists of two identical rows. Each row has four rectangular boxes for images. To the left of the first row, there are labels for 'Title', 'Image', 'Effects', 'Transition', 'Voice Over', and 'Soundtrack'. The second row has the same labels, but the 'Title' label is missing. The 'Image' label is positioned to the left of the first image box in each row.



On the right figure 3.3 Storyboard sheet and on the left figure 3.4 First day giveaway work folder

Some participants used the storyboard as a starting point to get acquainted with the exercise in laying down their thoughts or at least to build a skeleton of the vision for their video. At later stages, some decided to veer away from the storyboard's rigid format and be more creative and experimental with their visuals during the editing stage.

In principle, the storyboard is a time-saver to help organize the timing and the flow of the visuals the creator is hoping to achieve. One of its purposes is

to allow participants to add a “shot list”, which is a list of visuals they intend to take. This helps designers to be prepared by having identified in advance all the pictures or videos they intend to make during their video/photo shoot. However, in this type of project, documenting personal stories or narratives, words can open up many visual possibilities that can be substituted or amended in later stages of the design process.

3.2.2.3 Voice recording: audio and music

In this stage of the workshop, participants recorded their narratives to be used as voice-overs. The voice over, in this type of video making, determines the length of the video piece. It was difficult to book a sound recording studio due to budget and time constraints. Every participant had different schedules, and gathering them all during the week for a studio recording session was impossible. Therefore, we asked participants to record the voice over on their mobile devices using any voice recording application. For those who did not have a good recording device, we shared our smartphones during the workshop session and sent the recording files to participants by email to use in the editing stage. On the Apple iPhone, the Memos application is a good recording application and the files can be easily uploaded to Google Drive or sent by email.

Prior to the recording, we asked every participant to go through their narratives one more time, to rehearse them well, and decide on the tone and mood they wished to convey through their video. While the narratives were personal, connecting with the words they wrote was not difficult, but during the recording participants tended to focus on technical issues instead of delivery. They were reminded to forget about the technicalities and focus on the content of their narratives. The trick with voice over recording is to stay true to one’s feeling and follow the words written. The more genuine and truthful the delivery, the better a message is conveyed and received. The participants were reminded to keep in mind what they wanted the viewer to feel while watching their videos. By doing so, the tone of voice will enhance the delivery.

Some participants used this session to rehearse, preferring to record the message in their own environment on their own devices, and shared the results with us at a later stage. They all wanted privacy during message recording. This stage proved to be a turning point, with emotions and vulnerability fluctuating wildly as they became cognizant of the authenticity of their project.

Concerning anonymity and identity protection, we gave participants the choice of filtering their sound recording to disguise their voices. Masking or filtering the quality of the sound is an easy task during the editing stage. The other option was to use someone from the team (researcher, assistant or Proud CEO) to record their narrative. Two out of six decided to use other people, while the rest decided to filter their voice recording to make them unidentifiable.

For background music, the group was provided with links to collections of royalty-free music to use in their video edit, if they wished. By this stage, after writing the narrative and brainstorming visuals for the storyboard stage, participants had a good sense for the mood and pace of their video creation. The group was encouraged to listen to a variety of music tracks to determine if any pieces represented the mood of their story. We demonstrated how important music is for inducing emotions and for highlighting certain visuals in their video (Lambert, 2013, p.17). After giving examples, and listening to the pace and rhythm of select soundtracks, participants began searching for the right music for their videos.

During the music session, it was interesting to observe all participants with their earphones on, trying to connect to the right music. All we could hear was: “this track doesn’t represent me” or “this track is so me”. Afterwards, we continued to discuss interesting topics and personalities in music, including some famous Lebanese musicians.

3.2.2.4 Image recording: photo and video

After the participants felt comfortable enough with their stories, and were ready with the video shoot list, they organized their time to be able to finish what they needed to do in the week to come, primarily filming and gathering as much visual material as possible for the next stage: editing. Participants were divided into groups of two. Each chose the person they felt most comfortable working with. One group experienced conflicts in time management, but pulled through after lots of encouragement. We were keen to help participants who wanted to experience video recording with the video camera borrowed from the University of Alberta instead of using only their mobile devices. Those participants were also concerned that family members or friends would go through their mobile devices and find the video footage of their projects. We resolved the issue by leaving the digital video footage on the

professional camera, which remained with the researcher until editing time. We helped any participant who used the professional camera during their shooting days to ensure that everything ran smoothly. One participant asked me to be the cameraman on the day of his video shoot, as his teammate was unavailable during the chosen recording day. Another participant asked me to be the actor in his video for the same reason. One of the common themes in participatory research is to always expect the unexpected and be ready for improvisation and adaptation, “it needs flexibility” (Gubrium & Harper, 2013b, p.123).

During the shooting day, it was fascinating to watch participants completely control the situation, giving specific directions on what they envisioned and wanted to shoot. They directed the actors and their movements on camera like professionals. During that day, everyone forgot that it was a research project we were working on as we concentrated on making the videos, and the participants were very excited by the process. We witnessed their serious side, focused on the tasks that were very empowering to them. Suddenly they became directors of their own video and they were able to control whatever was happening on that day. Using the language of therapy, they became masters of their own selves. It was evident in their complete involvement on that day, and in their care in choosing the right angle and the right place or background elements. Participants that day took ownership of the situation and felt pride in what they were doing.

One participant decided to use only still photographs, as he wanted to express his state of mind towards the city of Beirut. He scheduled a week of photographic shooting with his professional camera, roaming the streets and depicting elements of the city that reflected his story.

The beauty of this stage is that all participants took a camera or a mobile device and documented images that reflected what they were feeling, capturing their unique visions and stories in a serious and sincere way. Their “visions” of living with HIV came alive and were documented, through their devices, for posterity. At some point, participants truly embraced the project as they discovered the freedom to express themselves without social judgment or constraint. They were all determined to finish what they had started and say what they wanted to say. For the first time, they were present “in the moment”, observing and discovering things about themselves and expressing their emotions about living with HIV. We saw

them at their most vulnerable.

3.2.2.5 Editing: shaping the stories

Editing is the stage where everything is folded into a creative design project. The relationship between images that are put side by side to create a narrative is fascinating to observe in the context of visual association. Although the process can be time-consuming, and the art of editing can take many years to learn, gathering videos and images and compiling them into a coherent story can be an amazing and empowering experience.

Most of the participants were deeply involved in the editing process at this stage. After introducing them to the iMovie application, which comes with any Apple computer product, and training them in how to use it, the participants continued experimenting with the application and immersed themselves into the editing process. As participants attempted to build video scenes from their storyboards, we were there to help with technical issues. Enthusiasm and excitement was high at this stage. Participants observed what they had recorded and tried to organize the pieces to convey their messages effectively in their small video projects.

Editing was one of their favorite stages. It was the stage where: "... things that we worked on are seeing the light. The things that we were saying are indeed happening not staying on paper..." As Houssam (one of the participants) expressed in his interview.

For Nassib (another participant) it was the stage when "we expressed what we have inside in a different way". The participants reported that this stage truly revealed what they had worked on for the past five weeks and represented everything they had wanted and aimed for. Fulfillment at this stage was an expected outcome and according to all participants it was their favorite stage.

3.2.2.6 Screening the visual communications

For some participatory exercises, the video making ends after the editing stage, but in this research study, the process of social influence (the effect of the videos on the audience) was just beginning. We had two types of screenings: an internal private one and a public one. The internal screening occurred soon after all participants had finished their videos. The internal screening was equally important as the external one. It was imperative (Gubrium & Harper, 2013a, p.128; Mitchell & De Lange, 2012, p.2–3) that each participant celebrated his impressive work by showing it to his peers and to

the research team as a milestone of achievement.

The screening stage is the most effective one for collecting research results, as we get perspectives from within the group (internal); the benefits of the work performed by the participants; and from outside the group (external); the reaction of the community and discussion about the issues in the videos (Mitchell, 2011, p.79). The screening stage is essential for many purposes. It will reflect the community that it is designed for and it becomes an educational tool for outreach that might be used to influence policy makers (Gubrium & Harper, 2013, p.96). On the internal side, participants learn more about themselves by focusing on questions they previously did not have the time for. This is reminiscent of the principles of the slow design movement in which Alastair Fuad-Luke and Carolyn F. Strauss spoke about slowing the person to allow “emotional space for reflection and transformation” (Strauss & Fuad-Luke, 2008, p.4). Some participants mentioned the change and development that they experienced after the workshop, as it gave them time to reflect on what had happened to them. On the external side, the video provided a way to influence and educate a community that has been ignoring the problem of discrimination towards GYLWH.

After we had collected and screened the short narrative videos, there was a celebration of what the participants had achieved in the workshop. The main objective of the research, at this stage, was to observe the impact and effect of the workshop on the participants. Up until this point, all participants had poured their hearts and souls into the project. They had challenged themselves, improved their skills and produced something that represented them.

Through interviews and discussion with the participants after the internal screening, we learned a great deal about the impact of the workshop on the participants. Psychologically, the creative process of making the videos allowed the participants to traverse their trauma using a medium that allowed them to express what was happening inside them. According to Dr. Bessel Van der Kolk, any creative exercise provides a great tool for people that have faced trauma to express themselves, as culturally we are forced to overcome all adversity and keep going. But if we don’t understand what we are feeling, how can we overcome it?

Love and hate, aggression and surrender, loyalty and betrayal are the stuff of theater and the stuff of trauma. As a culture we are trained to cut ourselves off from the truth of what we’re feeling. In the words

of Tina Packer, the charismatic founder of Shakespeare & Company: “Training actors involves training people to go against that tendency— not only to feel deeply, but to convey that feeling at every moment to the audience, so the audience will get it— (Van der Kolk, 2014, p.337).

One of the participants, Nassib, mentioned in his interview how the process made him think of “where he was seven months ago and where he is now psychologically”. It allowed him to think about what he had experienced and to re-evaluate his life now that he was dealing with living with HIV. Nassib’s story is a testament to the need for reflection and time to understand what he was going through. He had also experienced war trauma in Syria. At the time, he was a young photojournalist (only 19 years old) who was documenting visuals from the war against the Syrian regime. Unfortunately, an extremist Muslim religious party detained him. He did not understand why he was being detained, and was beaten, tortured and poorly fed. Things would have been far worse if he had mentioned his homosexuality. After a while, they promised to release him, as they could not find anything to hold against him. Physically he was very weak, so they gave him vitamin injections so that he could regain his health. He was unaware that they had also given him the HIV virus on purpose. Sadly, Nassib’s story was not yet over. He came to Lebanon as a journalism student in Beirut, where his health worsened. A trip to the hospital for blood tests revealed that he was infected with the HIV virus. From the burden of war and a family scattered between Syria and Lebanon, the HIV news sent Nassib into a deep depression over so much loss. Luckily, he received some help from different LGBTQ+ NGOs, and the government put him on medication. After seven months of dealing with trauma by showing persistent resilience, Nassib needed time to slow down and think, which is exactly what the workshop provided for him.

Two of the participants, Houssam and Hamid, were members of the first support group organized by Proud Lebanon that occurred prior to the one we led. It was interesting to listen to their description of our workshop compared to the one before. They were very critical of the heavy medical material that bombarded them in the first workshop. Hamid mentioned that he became bored and sleepy, especially because the support group convened on Saturday afternoons, and that material was too dry.

Another difference between the two workshops was that ours used active

engagement in a creative process. The two felt that the design skills they acquired were useful and very interesting, especially because our workshop was creatively challenging and intriguing at the same time.

Hamid mentioned that in this workshop he was thinking like a regular human being, not like a person living with HIV, which allowed him to express thoughts more creatively. The fact that he had to represent his narrative visually made him dig deeper. In his words, it was a “newer way of thinking”. Houssam, on the other hand, highlighted walking in the city and taking pictures, which made him feel connected to the city in ways he had never experienced before.

Hamid approached the writing phase differently than did the others. He mentioned that he did not want to over-think things, so he wrote the narrative in 10 minutes and then put it away. During the shoot, and editing afterwards, he said that he felt happy and content for the first time in a long time. He told his counsellor that he did not want to re-connect to the old feelings of the time when he contracted the virus. All these changes in attitude pointed to a conscious effort to live in the present. When he watched his movie, he cried a little.

During the group discussion, participants noted two consequences of the shared video screening: it was educational and they got to know their fellow participants in a way that would not have been possible before the screening. Every participant was surprised by the stories of the others, by what they had experienced dealing with HIV.

Last but not least there was the story of Ihab, perhaps the most interesting of all. Starting the workshop, we met this quiet person who did not like any physical contact. Ihab came from a verbally abusive relationship that made him dislike his body intensely. When anyone tried to hug him, during the first few sessions, he recoiled from physical contact. Through the workshop process, Ihab opened up a little and shared some of his stories while writing his narrative. In our post-workshop interview, Ihab was very open about what he had learned. He credited the workshop with helping him to start talking about his inner feelings and to express himself better. Initially, he was blocking out thoughts of HIV and did not want to deal with his story, but in his words, “there was something bugging me inside and I had the chance to dig in it by working on the video and showing it to the world, it was something

really good”. By the end stages of the workshop, Ihab became too driven and too confident in his own skin and wanted to reveal his face at the end of his movie. Of course, we could not let him do this as we had promised to protect his identity, but it brought us happiness to see how a small creative exercise had built such tremendous confidence in him.

Through activities, such as story circles, script revising, digital media construction, and semiprivate and public airings of their stories, participants often gain a sense of ownership of their experiences (Gubrium, 2009, p.190).

This quote captures exactly what happened to the participants in the workshop. They all traveled into their experiences to own their personal struggles and gain empowerment through their own bravery, resilience and desire to live life. The study demonstrated that participants needed confidence and a safe place to express themselves and open up. The workshop and its creative exercises facilitated this process. It stimulated all their senses, brought meaning to what they had experienced as gay youth living with HIV, and made them compassionate viewers of their own and others stories. They cried, supported each other and, perhaps for the first time, celebrated their own lives. Their stories influenced them internally as much as they influenced the broader community. It was the first drop that created a ripple effect outward, as demonstrated in the following section.

4.0 Results and data analysis

In this stage of the research, analysis of the participants' work will answer the "how" question. At this stage, there is an attempt to understand the life of GYLWH and the to assess what they lack in order to provide them with the appropriate help. This is very important for the NGOs as they will know where to invest their efforts and research to be able to highlight the findings in the coming stage.

4.1 Reading participants' narratives: biographical documentary videos

Sarah Pink and Gillian Rose each wrote books about visual methodology, and talked about the many ways of reading contextual and intertextual materials (Pink, 2012, p.154; Rose, 2007, p.12). Studying a compilation of images requires a systematic way of analysing the compilation. Rose called it "discourse analysis", referring to Michel Foucault's analysis to reach the regime of truth. Discourse analysis provides a way to go beyond the psychoanalytical method to reach sociological knowledge (Rose, 2007, p.141–143) , which is exactly the focus of this study.

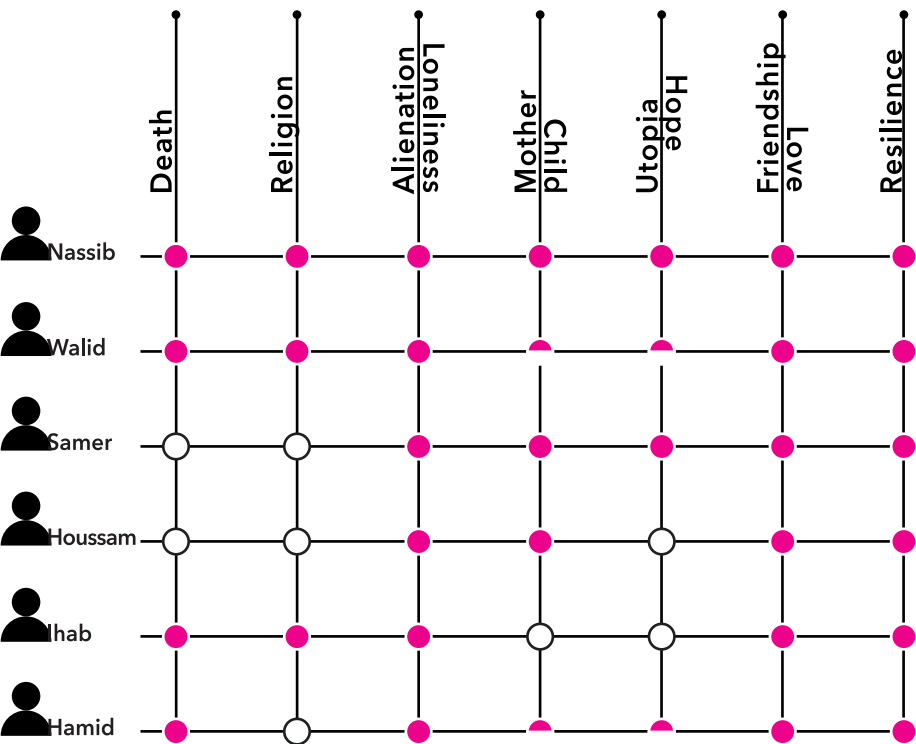


Table 4.0 Participant's pseudonyms and their themes

Analyzing the short videos by the participants, dominant themes emerged (Table 4.0). Keeping in mind the literature review done by Smit et al—discussed in section 2 concerning the causes and consequences of marginalization of gay males living with HIV by the gay community—

the findings from this video analysis helped in understanding the dual phenomena of stigmatization and marginalization that occurs in Lebanese society between GYLWH and the gay community.

4.1.1 Death theme

Very powerful words and images were used in the videos to highlight the theme of death, which is not surprising as death has long been a factor in discussions of HIV-related matters. As mentioned in the previous section, the stigma of the 1980s slogan “AIDS = Death” came from the high number of casualties, worldwide, resulting from the AIDS epidemic.

In the videos, the theme of death appears in two different ways. There is the immediate thought of physical death that most participants felt when they first learned about the HIV virus detected in their blood. Then there is the symbolic or social death that they felt while going about their day-to-day lives.

The lack of information in Lebanese society concerning HIV can induce thoughts of death as the participants face this ‘vacuum’ that facilitates extreme and negative interpretations. In three of the videos, it is evident how little information participants had about the HIV virus prior to their infection, and how their minds and thoughts propelled them straight to the idea of death. Even more shocking, however, was the participants’ representation of social death as being far more dramatic than dealing with the health issues of contracting the HIV virus.

Nassib’s video was all about that moment when he learned that he was HIV positive. He showcases the feeling of loss, and the moral death caused by social judgement, brilliantly. The combination of dramatic music and slow-motion visual effects leaves us breathless, drowning with him in his despair and loss. When he shows the heart-shaped red candle splashing wax on his white hospital viral test, he addresses the community through his voice over: “Don’t fight me. Fight the disease. I am not the enemy”. It portrays people living with HIV and their fear of social stigma as being more powerful than the fear for their own health or even their own lives. The heart-shaped candle directly represents Nassib’s broken heart. The plea, in his narrative, to society asks them not to blame him for something they know nothing about, and reflects on his prison history as well as dealing with the virus (*Figure 4.1*). Another powerful scene in Nassib’s video shows him walking down a hospital hallway when the camera pans to a sign on the wall that gives directions to

the morgue. The filming in slow-motion, represents the feeling of being lost, not knowing where to turn or to whom. It represents the psychological state of mind that the person goes through after receiving bad news, of feeling lost, afraid and helpless (Figure 4.2).



Figure 4.1



Figure 4.2

In Walid's video, the same social concern was portrayed by using an even more powerful image. In his narrative he is asked if he will die and what will happen to him now. Walid shows us an ugly trash bag on the stairs, portraying a shocking image of how society treats people living with HIV...like trash (Figure 4.3).

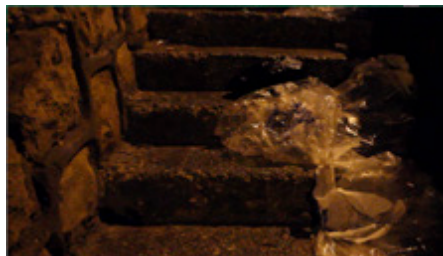


Figure 4.3



Figure 4.4

Ihab proved to be very vocal about the healthcare system and the way it treats HIV patients. When he was dealing with his first viral load test, which checks the patient's immune system and the stages of infection in the body, the nurse looked at his test results as if he had "looked at a rotten body". Using these words, Ihab shows us a horrifying visual of a skeleton crawling with maggots, connoting the social death that he experienced as a result of his treatment by people working in the medical care field (Figure 4.4).

It is frightening how a patient, who needs medical care and reassurance, has to deal with the stigma that is surrounding him even before beginning treatment. The burden of suddenly becoming 'nobody', silenced before knowing the medical options, is scary. When reading research about the quality of life of people living with HIV, not a single study mentioned these

moments. This inability to acknowledge patients' feelings, no matter how mundane, can leave patients feeling heartbroken or even suicidal.

4.1.2 Religion theme

The second most prominent theme in the videos involved religious influence. As discussed in the previous chapter, the Lebanese community, comprised of approximately 35 religious sects, is awash with religious influence. This religious influence comes through strongly in the videos and the interpretation of it was very interesting. Ethnographically, it is a testament to the immersive religious influence of Lebanese society, but how each participant dealt with religion was unique. Some expressed their beliefs visually while others used only text. For example, Walid's movie ended in a fateful way, surrendering to God's will. His voice at the end of the video floats over a wide-angle night shot of Luna Park, telling the community to let him live his life "as God intended it".

In Nassib's video two churches make an appearance. At the beginning, one church depicts a waiting scene for the HIV test results, and the shot is moving and shaking as if to capture his mood (*Figure 4.5*). He shows us his state of mind, his questioning of religion and his doubt about life. At the end of his video, Nassib is walking at night towards a church, thanking his friend for standing by him (*Figure 4.6*).



Figure 4.5

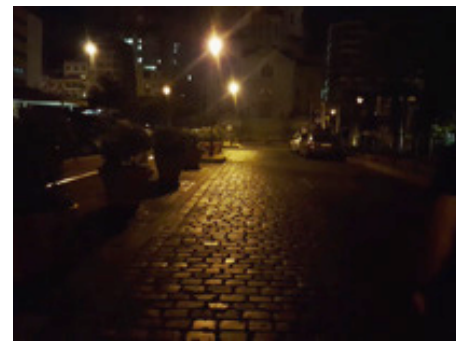


Figure 4.6

Nassib presents a powerful and emotional state in this scene, exuding serenity and peace. The scene represents acceptance and love, but it also reveals his feeling of loss, something he depicts at the beginning of the video. If a religious person were to interpret this scene, s/he would likely behold the awakening of a connection to God's path. From a psychoanalytical perspective, the scene depicts the acceptance of HIV and a reconciliation between him and the virus.

Ihab shows us the influence of religion when he talks about miracles. He redid the HIV test hoping for a miracle — that he had read about in books — hoping that the test, this time, would come back negative. Visually, he shows candles to symbolize the miracle which, in most religions, connote hope. In Ihab's narrative, we see the desire for deception in the face of science, a chance for miracles to refute science. The struggle between science and religion has a long history. For a culture immersed in religious beliefs, facing the harsh reality of scientifically-based news is hard to accept. This struggle is showcased in Ihab's narrative as he deals with social deception and religion. The doctor's gaze was full of blame as he looked at Ihab, as if he had seen the "devil". (Figure 4.7 and 4.8)



Figure 4.7



Figure 4.8

Religion, in a medical context, only seemed to add to the pain that the participants were experiencing. Religion added uncertainty and feelings of loss by re-enforcing self-blame. Of all the characters in the study, Ihab had experienced this pressure most acutely. To be cast as a devil by an influential member of society sent a strong signal to Ihab that he had done something wrong. In this society, HIV is related to sex, and sex outside marriage is considered sinful. The religious seed was planted long ago by the beliefs of this society. Firmly rooted, it will add nothing but pain and will continue to foster homophobia. For GYLWH, this means living with guilt as society reminds them that contracting HIV is God's punishment for being sinful (Tolino, 2014, p.81–82).

4.1.3 The mother theme

The next most prominent theme that appears in the videos is that of the "mother". As discussed in the media analysis of Lebanese soap operas, the character of the mother is a very important figure in the life of gay males in the Middle East. The "mother" is very sacred in this culture and she represents purity. She is the caregiver and offers unconditional love.

There is a saying in Lebanese culture that summarizes this relationship: “*rida allah wa rida al waledein*” (the satisfaction of God, then those of your parents). This saying is influenced by different religions. In the Koran, verse (17:23) in *sūrat l-isrā* translates to:

“And your Lord has decreed that you not worship except Him, and to parents, good treatment. Whether one or both of them reach old age [while] with you, say not to them [so much as], “uff,” and do not repel them but speak to them a noble word.” (Dukes, 2010)

In the bible, Exodus 20:12 it says:

“Honor your father and your mother, that your days may be long in the land that the Lord your God is giving you” (Version, 2013).

Therefore, social and religious pressure is felt by children to obey, respect and never mistreat their parents, no matter what the circumstances. For gay males, there is guilt about not providing the parents with grandchildren. They are accused of being selfish, especially by religions like Islam that forbid adoption (Tolino, 2014).

Though it seems like a cloying cliché to say so, it is hard to imagine anything more soothing than a mother’s love, particularly for a group of people who experience stigma and at times feel like outcasts. Closeness between mothers and their gay sons is a stereotype and like all stereotypes, sometimes they ring true (LaSala, 2011).

Dr. Michael C. LaSala, an associate professor at the School of Social Work at Rutgers University and author of *Coming Out, Coming Home: Helping Families Adjust to a Gay or Lesbian Child*, wrote an online article “Gay Men and Their Mothers: Is There a Special Closeness?” (LaSala, 2011). He explains that any mother-gay son connection is due to “sharing interests and a certain sensitivity”. LaSala also mentions that these mothers have feelings of guilt because they believe that they are responsible for their sons’ sexual orientation; therefore, they are extra attentive and work on connecting with their gay sons. Conversely, the feelings of guilt also occur in the gay sons. LaSala suggests that if mother and son form such a connection out of guilt, it can be a powerful and interesting union.

Whatever its cause, this feeling of commonality and connection to mothers is a unique (and fortunate!) aspect of the parent-child relationship in some gay families (LaSala, 2011).

The narratives tell us which participants have close connections with their mothers. In Samer's script, this was obvious and predominant in the way he showcases this relationship using powerful emotions. When Samer told his mother about his HIV status, his mother responded by offering to pour her own blood into his if would make him feel better. Visually, the video shows a medium shot of his mother trying to cut herself while he pushes the knife away. This powerful symbolic scene expresses the connection between mother and son. The mother is portrayed as a protector and caregiver to her beloved son.

Samer brought his mother to meet the group one day, after asking for everyone's consent. It was empowering to see this wonderful, simple, veiled woman supporting her son in life or death. She was there to educate herself and stand by her son, who had just learned about his HIV status and was dealing with strong emotions. The relationship with his mother, though, helped to balance him and made him feel better able to deal with HIV.

In his narrative, Samer talked about how he confides in his mother and brother. They are his two 'pillars' that he can depend on. There was also a relationship with his father that contradicted the one with his mother. The video shows a close-up shot of tears on the actor's cheeks, representing the reaction of the main character while looking at the father and wondering if he should disclose his status to him. In this shot, Samer is grieving his damaged relationship with his father. Samer blames his father for neglecting Samer's medical attention as he had a severe gum inflammation. Samer declared many times in the workshop how he never had intercourse with anyone but that he had contracted HIV from oral sex. Samer thinks that if had received the right medical attention (early on for his gum inflation) it would have prevented him from contracting HIV.

Nassib talked emotionally about his mother, saying that she was very holy and powerful. He recalled her words when she used to tell him that he deserves life and that he should embrace it. When narrating these words, his visual shows a night shot of an amusement park, which signifies/symbolizes childhood (*Figure*

4.9). This simple image represents Nassib's yearning for his mother's presence and protective warmth. Nassib is also lamenting the childhood that he has lost once the virus starts to reside in him. This is accentuated by a choking, raspy voice full of pain. Nassib misses his parents physically, as he had left them in Syria and had not received any news of their fate.

Walid did not mention his mother, but he ended his movie with a plea to the world to let him be so that he could live his life peacefully. On those words, we see a shoulder shot of Walid pointing to another amusement park (*Figure 4.10*). He too misses his childhood that he feels has been lost. This final scene is very emotional and powerful. It denotes how special and valuable his relationship with his mother must have been to him. During the second session of the workshop, Walid had decided to disclose his status to his mother and he brought her along, asking the founder of the Proud Lebanon and myself to be present during the disclosure. The reunion was tough yet very educational to the Walid's mother. Even though the mother was a veiled religious woman, with very limited educational background, she wanted to support her son. She mentioned that, at the end of the day, he is her son and her job as a mother is to protect her son. Torn between religious duty and a mother duty, Walid's mother wished nothing but happiness and safety for her son, but asked him to keep his lifestyle secret.

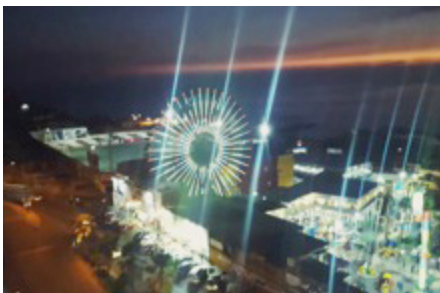


Figure 4.9

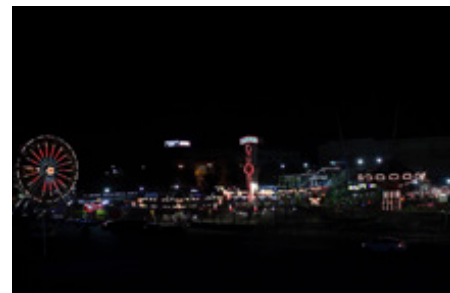


Figure 4.10

Unfortunately, not all participants had this moment of family reconnection. In contrast, Houssam harboured feelings of guilt towards his mother. In his narrative, he mentions how he was scared that she would find out about his status. He did not want to disappoint her. When talking about her at the beginning of the video, he uses a sparkling street light at night, the image out of focus, representing his hesitant feelings. And when he says "so I lied to her then", he uses a wall of graffiti representing a plant with leaves with one of the leaves drawn as an eye (*Figure 4.11*). This eye could represent his

mother's protective eye or the fact that she is watching him. He knows that deep down, his mother is worried about him. But as the eldest, Houssam has a social role born of religious pressure. And that pressure creates a wall between his mother and himself. In the Middle East the eye symbolizes a protector against the evil eye, usually an eye on a hand called "hamsa hand". It is a superstitious symbol that the Greeks, Jewish and Turks use as well. The eye is always a female eye, a reflection of how women symbolize luck, protection, care and happiness (Afshar & Ahmadi, 2013).



Figure 4.11

Later in his video narrative, Houssam expands on his relationship with his mother. He shows us his guilt in a heartbreaking way. From guilt, Houssam feels that he has disappointed his mother. She "never accepted" his sexual orientation and wanted him "to change". Additionally, he has "dishonoured" her by not providing progeny, breaking his social and religious obligation. Asking a gay man to change is firmly rooted in religious thinking, and in some religions, homosexuality is depicted as an illness (Tolino, 2014, p.81).



Figure 4.12



Figure 4.13

Houssam chose fluorescent nightlights with red and orange colours when he was describing the quarrels with his mother (Figure 4.12 and 13). The shapes and colours of the images represent his anger, his pain, and the suffering that he feels. Then he switches to more wall graffiti, this time a cartoon character drawn with plus symbols on the eyes. The whole narrative gives us an extremely powerful story. It expresses his eagerness and the yearning he feels to return to his childhood and to his mother's warm hugs.

An intriguing paradox is that mothers are portrayed as pure and powerful, yet women in Lebanon are still considered to be passive. The contradiction is a puzzling feature of Lebanese society. But what is more mystifying is the fact that members of the gay male community consciously and unconsciously adopt a similar practice by talking to each other in the feminine without the consent of the person being addressed. As mentioned previously, this is intended to show a lack of respect. This lack of respect is damaging because members are categorizing themselves and each other as passive and weak.

Sexually transmitted diseases, and especially AIDS/HIV, are also frequently mentioned and are considered as divine punishments for non-Islamic sexual behaviours. According to one author for example AIDS isn't even a disease, but a punishment (Muntaşir Mażhar 2006, p.186), the "divine punishment for homosexuality" (Ibid. p.191), "God's answer to the violation of divine law" (Ibid. p.190). (Tolino, 2014, p.81)

If religiously and socially the culture condemns homosexuality and thinks that sexually transmitted diseases are punishment from the divine, it is not a surprise that GYLWH will feel alienated and immerse themselves in dreams of utopia.

4.1.4 Alienation and escape theme

Most of the participants portrayed their feelings of alienation and loneliness in the videos. In almost all videos, slow-motion scenes depict characters walking in a pitch-dark street (*Figure 4.14*) or sitting alone reflecting. The participants in their narratives talk about their experiences with their friends rejecting them when their status was revealed. Some participants even talked about the mistreatment they experienced. Therefore, it is not surprising that they stopped disclosing their status to others. Feelings of abandonment and loneliness are key factors leading to social alienation, self-stigma, high-risk behavior, mental and emotional impairment, and rejection in relationships (Smit et al., 2012, p.407–408) .

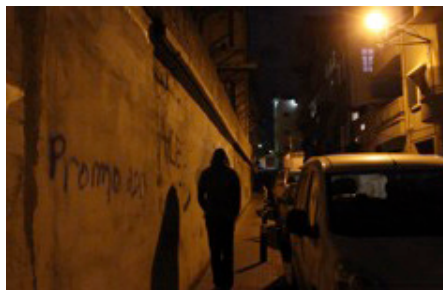


Figure 4.14



Figure 4.15

Another image shows Walid with his back to the camera, looking at a group of young people playing. He appears to envy the others their freedom and yearns for childhood (*Figure 4.15*). This wistful representation suggests that Walid, like many others, is feeling like an outsider in his own community. His marginalization by a marginalized group is ironic and highlights the hypocrisy of a supposedly tolerant community.

Another visual portrayal of alienation occurs in Samer's video when he shows an empty movie theatre with red chairs and himself. Samer indicates that he spends most of his time now in such theatres to get away from everything. He substitutes movies for his missing relationship with humanity. He alienates himself from everyone to be in a place where he feels the least judged (*Figure 4.16*).

While movies are Samer's salvation, cooking provides a refuge for Ihab (*Figure 4.17*). In his narrative, Ihab talks about cooking as a way to release stress and to be away from people. In a black and white image, he expresses how soothing it is to lose himself in the smell of spices while cooking. Both Ihab and Samer are retreating into a safe place that is familiar and away from the gaze and judgment of others.

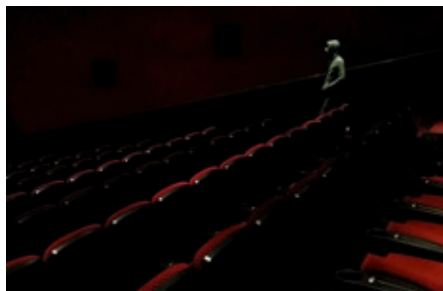


Figure 4.16



Figure 4.17

4.1.5 Friendship and love

As a consequence of their alienation/loneliness, some participants were left longing for friendship or love. Looking for love is a universal theme, but is especially prevalent in Middle Eastern literature. Joseph Massad mentioned in his book *Desiring Arabs* of the poets like Abu Nuwas who were “infatuated by youthful boys” and seeking forbidden love (Massad, 2007, p.260).

In their narratives, most participants avoided blaming friends for rejecting them after confiding and disclosing their status. Some participants wrote to thank the friends who did support and help them. Either way, it shows the

sensitivity of the participants towards friendship. It is important to mention that the Lebanese culture values closeness among family members. When this closeness is broken, for fear of confiding in family members about their health status, people often search for friends or relatives to confide in. The culture is not particularly keen on seeking help from psychiatrists or counselors. This was evident during our workshop when we encouraged participants to talk with NGO counselors and the participants were very resistant to the idea. There is a belief that psychiatrist and counselors are for people with mental health issues only.

Most participants mentioned the rejection by friends and the disappointment that they felt afterwards. Walid addressed the community by asking them not to be scared: “we won’t hurt you, on the contrary we are here for you, we don’t wish to hurt anyone”. This line made us think of inner pain and the longing to be with someone. These words in Walid’s narrative accompany the image of him looking at a group of young men playing. Hearing from a person living with HIV that he is more concerned about the wellbeing of the others than with his own health is very moving. Society strips people living with HIV of their humanity and compassion, and considers people living with HIV as nonchalant and irresponsible, which society believes makes them untrustworthy.

Hamid, on the other hand, did talk about the community and the blame they threw on him. He showed his alienation by using glasses of white wine to represent the community and red wine to represent himself. With jump cuts techniques in editing, giving us the sense of jumping forwards in time, he showed us how the community left him alone to deal with the HIV virus instead of standing by him. Hamid said in the narrative, which was a letter to the HIV virus, that the community “feared you [the HIV virus], they didn’t understand you”. This scene provides a powerful message about how people fear the unknown. Also in his narrative, Hamid blamed the virus for him losing “friends and lovers”. When he talks about this loss, he draws a heart in the sand and then a wave wipes the heart away. Hamid is longing to have the freedom to find love again and, in a way, is weeping inside for loves lost.

Unlike Hamid, three other participants (Ihab, Samer and Nassib) celebrate their friends. Ihab thanks the straight community that helped and embraced him. In his video, the visuals change from black and white to colour when talking about his friends and family. Even the music transforms into a happier mood. His video reinforces the notion that people living with HIV need love and care.

In Nassib's video, called "be my friend", the same upbeat feeling prevails when he thanks his friend for helping him and for being the 'rock' that he needed in his darkest moments. The change to upbeat music enhances this feeling of gratitude, projecting contentment and hope. One scene shows him desperate and lost, slumped over a table at home. Then we see the hand of his friend, holding his hand and giving him his medication. This image (*Figures 4.18 and 4.19*) connotes 'the saviour'. Nassib was helped by a gay activist who connected him with the right doctors and registered him with the Ministry of Health for medical assistance. In his video, we experience the gratitude and humility that he feels towards this person, and Lebanon, for embracing him.

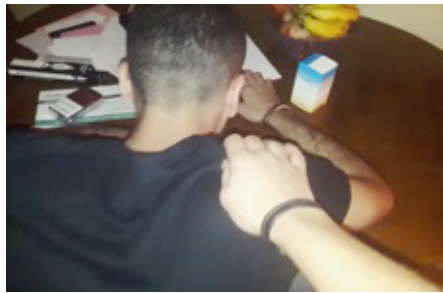


Figure 4.18

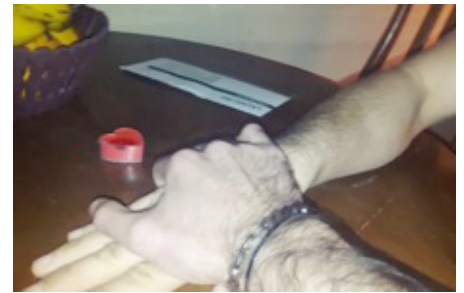


Figure 4.19

4.1.6 Resilience theme

All these stories are linked/connected by the resilience of the participants. In every video, there is a courage and maturity that is moulded by resilience. Most of the participants felt the pain of being an outsider not once but twice. In his narrative, Samer states that he is a person holding three masks: the acting straight one, the gay one, and now his HIV one. He illustrates this by wearing three physical masks and removing them one after the other. In this scene, we feel his burden and see the resilience through coping and facing the world. Houssam similarly shows this struggle by standing in a river and facing the current (*Figures 4.20 and 4.21*).



Figure 4.20

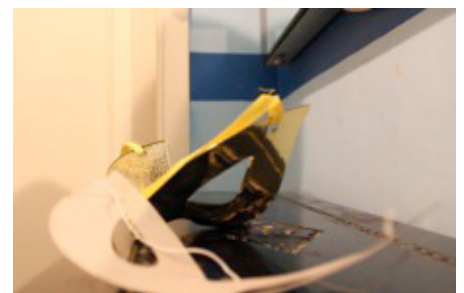


Figure 4.21

This is the resilience that André P. Grace — author and professor at the University of Alberta Faculty of Education — writes about in his book *Growing into Resilience: Sexual and Gender Minority in Canada*. The first part of the book entitled “steeling life in the face of adversity”, Grace explains how some sexual and gender minorities build the steel effect when facing negative experiences, which helps them reduce vulnerability during future adversity. That is, they become resilient to future “cultural, social, economical or political” problems. This effect arms youth with a problem-solving mindset when facing trouble (Grace, 2015, p.3–5). Those “steeling life” can hope for and dream of utopia. Most of the participants in this study dealt with their dreams of a better place in the videos. As in Section 2, which analyzed the Lebanese soap operas and discussed utopia, Samer and Walid talked about emigrating to another place for kinship in their videos (Figure 4.22). The last scene of Samer’s video shows him online, checking the Canadian immigration website (Figure 4.23).

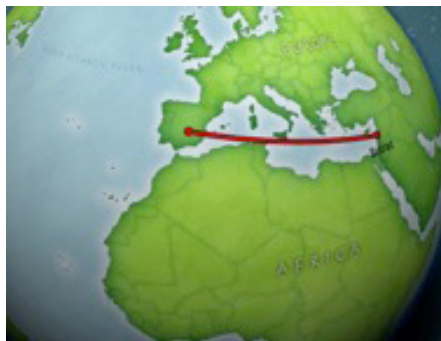


Figure 4.22

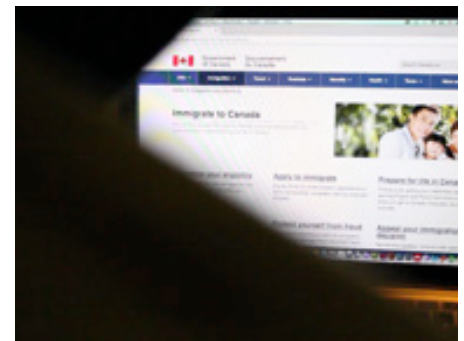


Figure 4.23

Throughout the video analysis, the frustration of these young men was obvious. They live with much internal pain, are afraid to discuss their status with anyone, and plead for acceptance of who they are. These participants are devalued by their own community for not being “clean”—clean is a code word used in gay dating applications to communicate that a person is HIV negative.

4.2 Facilitator observations

Opening up to a researcher can be intimidating and frightening. We were amazed by how the six participants allowed us (researcher and assistant) into their lives and how they opened up to share their important and critical moments and feelings. The design videos proved how providing a non-judgmental space, filled with empathic feeling, can elicit positive and healing experiences, where participants feel creatively driven to express themselves

freely. This space, unlike the utopic space, is achievable. It is a space that French philosopher and social theorist Michel Foucault identified as “heterotopia” or “other spaces”. In his book *Insult and the Making of the Gay Self*, Didier Eribon, a French philosopher who wrote and analysed Foucault’s work in many books, explained the concept of heterotopia:

Foucault’s “gay politics” is mapped out in this double movement, in the double gestures of resistance and of “heterotopia”: the invention, perhaps within urban geographies, perhaps within individual or collective consciousnesses, of new possibilities existing outside established systems (Eribon, 2004, p.334).

The space of the workshop comes out of a mixture of the ideas of Foucault and Friere. It is a space where ideas and emotions can be expressed freely. It is that space “existing outside established systems and function in non-hegemonic conditions” (Eribon, 2004, p.334–335). A space filled with Frierian love and empathy, where people are encouraged to “come together” for social change, as per the UNSAD definition of integration.

It reminds us that mundane experiences, which Alain Findeli mentioned in his paper “Searching for Design Research Questions: Some Conceptual Clarification” need to be addressed by social designers before solving more complicated social-issue problems.

But this apparent banality of daily human experience conceals a rich complexity, well known by designers who are working in experience, service, or social design. Indeed, every daily human activity (work, going to school, taking a vacation, being at the hospital, going shopping, being retired, etc.) is an entanglement of various interrelated dimensions and values (economic, social, psychological, cultural, geographical, historical, technological, semiotic, etc.), with each dimension being due a systematic inquiry and interpretation (Findeli, 2010, p.297).

In the workshop space provided, participants were able to act in a more relaxed way, allowing them to become immersed in the design process. The more they became involved, the more easily they could express their feelings. This was evident by comparing the first session, in which most participants

displayed a firm posture and reserved attitude, to the last session when everyone appeared relaxed and participated fully and vocally.

In the previous section, Ihab was presented as a very reserved person, rejecting any physical contact. He was transformed into an open and engaged person, recounting his struggle with physical abuse in his last relationship. After the workshop, Ihab agreed to be interviewed on World AIDS Day for television (protecting his identity by changing his voice and blurring his face during the interview), which showed his remarkable personal growth.

Participants' empowerment came from within. The act of revisiting their past traumas and visualizing the stories made each participant realize how courageous he had been. The journey also made them realize that they had successfully navigated choppy waters to arrive at a safer place. This moment provided a turning point where they could re-evaluate what they had been through and consider how they might move forward.

4.3 Pros and cons of the method

Reiterating Van der Kolk's assertion that changes need to happen to people after going through traumatic conditions, "the body needs to learn that the danger has passed and to live in the reality of the present" (Van der Kolk, 2014, p.22–23). As demonstrated by this workshop, a creative exercise can definitely help in this situation. Not only did the participants discuss their experiences and gradually open up, but they also had the chance to think creatively about their stories and deal with the trauma in a focused, mature and thoughtful way.

Three participants (Nassib, Houssam, and Ihab) were interviewed after completing the workshop to determine if and how they had benefited from the creative exercises. All three spoke positively about the experience. For Nassib, it provided an opportunity to re-evaluate the events he had experienced. Like any person going through trauma, he didn't feel that he had the time to step back from his situation and view it from a different angle. The digital narrative allowed him to do this. In his words, he could "see where Nassib was 7 months ago, and where he is now" (Nassib, personal communication, November 22, 2016). Houssam talked about confidence and how the workshop helped him to feel comfortable "talking about what he is passing through". He highlighted that he is a private person who does not like to talk about what he is feeling, but with the creative exercises he found a way to

express himself differently (Houssam, personal communication, November 23, 2016). Ihab made it clear that, at the beginning of the creative exercise, he had no faith in the process and was very skeptical. During the interview, he mentioned how he was neither ready to rethink about his HIV nor deal with it and that it was a chapter that he closed a long time ago (Ihab, personal communication, November 24, 2016).

Ihab represented a typical case that Van der Kolk mentioned in his book. People who pass through trauma think they have dealt with their issues, but pushing the feelings aside only suppresses them. In his interview, Ihab said that by “bringing it [the HIV experience] back and starting to work on it through the sessions, it became something I am talking about with others.” Ihab also mentioned that after the workshop, the negative feeling connecting him to his HIV experience was almost wiped away. Ihab went through a wonderful transformation that everyone witnessed and they commended him for it.

Another important comment that the participants made in their interviews was the fact that the narratives were not just creative expressions that helped them articulate freely and creatively, but also vehicles to communicate to third parties. This added dimension gave the exercise a stronger value to them. Nassib said that he was happy that “we send messages to the world to see”.

The main concept behind the workshop was to provide a way for GYLWH to verbalize their feelings and to express themselves. Participants dealt with issues they did not want to talk about or had never had the chance to talk about. The workshop gave the participants a creative tool to help them learn to accept living with HIV. The confidence that the participants built during the workshop was a positive by-product of normalizing life with HIV. The virus was discussed like any other topic. The participants were treated with care and respect. The focus was on the small and mundane things that the Lebanese culture takes for granted like the respect of personal space, personal choices and decisions, and everyone felt listened to as each participant related his story.

The workshop communicated to GYLWH that acceptance of the situation is the first step to beating stigma. The reinforcement of this idea, during the six sessions, made participants feel confident enough to show their previously disguised faces on camera. This is a testament of how the “odd/fearful”

become “ordinary”, that is how living with HIV can become accepted and ordinary. Talking routinely about HIV to people living with HIV (as well as those who are not) will get them accustomed to the idea of the virus, to “banalize” it, in the words of Dr. Jacques Mokhbat (J. Mokhbat, interview, October 26, 2016). Given the development of HIV medicine and the ongoing research into HIV transmission, risk of transmission is minimal (even for unsafe sex) between an undetectable HIV+ partner on anti-retroviral treatment (ART) and an HIV- partner (Rodger et al, 2014; Cairns, 2014). Even though studies are ongoing, the transmission rate between partners is almost zero, which should help alleviate some of the stigma towards HIV. (Rodger et al., 2014)

In general, the workshop has received positive comments and appreciation from the participants and the collaborating NGO, Pride Lebanon. Working and connecting with people who just need a voice (and receiving their appreciation) were the most fulfilling parts of the workshop. Building the trust between participants and the NGO was the most difficult task in the whole process and it seemed overwhelming at the time. The idea of having to earn people’s trust and not let them down was daunting, and yet, in the end, it was also highly fulfilling.

The whole process was unpredictable, which is a feature of participatory research, and the flow of the process depended on the circumstances. Two technical incidents happened during the workshop that required quick fixes to save the day. The first one occurred on the day of the editing when one of the computers failed. Unfortunately, the editing stage required this additional computer. As a ‘work around’, the participants were encouraged to view their video recordings on the camera screen and choose the takes that they liked best by writing the registered digital numbers on paper until the next available (functional) computer was free. Fortunately, participants had access to a third computer that they could share. The lesson learned: always have an extra (back-up) computer on location. The second technical incident occurred when the software iMovie stopped working and we didn’t have an Internet connection to re-install it. The group used one of the participant’s computers to run the demo for all participants to watch. Lesson learned: in places with no access to internet, have an installation disc copy of the software available, if possible. Both Mitchell and Gubrium warn of unexpected things that might happen during workshops and the importance of being able to improvise (Gubrium, Harper, & Otañez, 2015, p.27) .

The digital video aspect of the workshops was very attractive to the young participants as it encouraged them to learn new skills using computers and software. The exercises built their confidence in using computers and increased their productive drive (Gubrium & Harper, 2013, p.39). In the end, the workshop made participants feel good about themselves and encouraged them to get involved in the process of how to engage the community through communication via digital narrative.

5.0 Evaluating the impact of the videos

After getting some answers from the “why” through the digital and the internal discussion from the previous section, the implementation stage starts. Participants had messages to share with their community that needs to be “delivered” and “evaluated”. The videos will attempt to produce “dialogical” phenomena that will feed the “why” question.

5.1 Screening of participants’ videos to gay youth

Fortunately, our efforts in collaborating and planning with a myriad of NGOs and friends from the LGBTQ+ community afforded us the opportunity of screening the videos twice to the members of the gay community.

Helem, the first LGBTQ+ NGO in Lebanon, hosted the first screening of participants’ videos for a small group of gay youths. Helem posted a video trailer, on their Facebook page, that we had edited to entice people to attend-the screenings. Helem framed the screening under their AIDS Week calendar, which is the first week of December (*Figure 5.1*). We did not advertise the location of the screening, just the name of the organization, as the NGO had just moved to a new address and they were trying to keep this location private for security reasons. Helem had been attacked by certain members of the public at their previous location, so keeping their new address quiet was important.

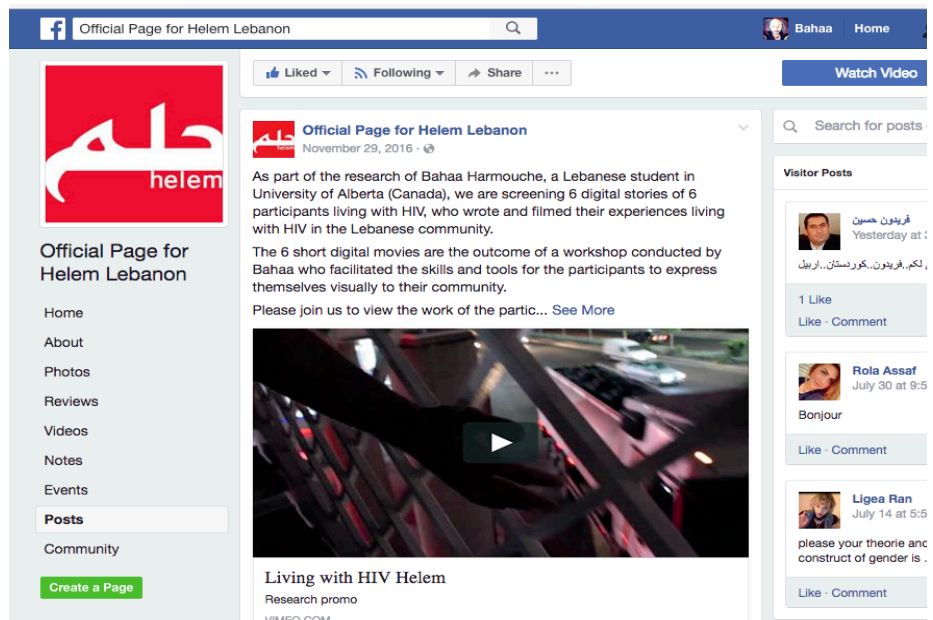


Figure 5.1 Facebook marketing the first screening at Helem NGO

Usually video producers attend their screenings and conduct a discussion afterwards. In our situation, participants did not attend for the protection of

our participants' identities. We prepared an online survey where viewers will share their opinion on the effect of the videos after seeing them, and then held an open discussion after the completion of the survey.

Typical for November, it was raining heavily on the day of the first screening and Beirut streets were flooded. This made transportation a bit challenging. Nevertheless, we hosted ten gay youths who made the time and effort to attend and watch the short movies. Beforehand, we presented consent information and explained the process before distributing an online link where the participants could take the survey. After the surveys had been filled out, we held a discussion with all the attendees. According to Mitchell and Gubrium (Mitchell, 2011, p.85–86;) (Gubrium & Harper, 2013a) discussions, like these are critical and bring up a multitude of community concerns that might help uncover some of the reasons behind the marginalization of HIV gay youth.

As mentioned, the targeted video viewers (GY) received a link to the online survey at the beginning of the screening session. The online survey was to be filled out after the screening and before the discussion session. The objective was to get a sense of how the short digital videos were received.

Of the thirteen gay youths who attended, eight did not have any friends living with HIV so the whole experience was new for them. On the whole, feedback about the video was overwhelmingly positive. The viewers expressed their appreciation for the work that was presented and noted that the diverse messages came across as clear and understandable (see survey results Appendix B).

Interestingly, all of the viewers answered in the affirmative when it came to the question about whether they would hug a person living with HIV and treat them like any other person, with a bit of additional empathy.

We observed, from the reaction of the viewers, that they were immersed in the narratives and interested in the topics. We realized how viewers were taken by the stories, they asked to repeat a video and raise the volume as they needed to get the full story well. Unlike the west, few videos are made by the gay community in Beirut or tackle real representations about the life of GY or GYLWH, so these efforts made a significant contribution to spread real stories of what GYLWH are passing through in Lebanon, and to raise the curiosity of the viewers to watch.

Despite all the initial “positivity”, viewers reported through the survey that they had mixed feelings after seeing the videos. The predominant feelings expressed were sadness and empathy. The sadness arose from the narratives that GYLWH presented, as they depicted very unfortunate situations. The sad feelings induced empathy and sympathy towards the characters. Only one viewer expressed indifference (see survey results Appendix B).

The discussion with the gay youths (GY) who had watched the videos was very interesting and brought up many topics such as healthcare and social stigma. At the beginning of the discussion, the GY chose their preferred and least preferred videos. They mentioned how Walid’s video *Khalass Jahel* (Arabic for Enough Ignorance) was a bit repetitive in the narrative and came across as overly dramatic. The most talked about movies were *HIVampire* (Samer’s video) and *Stigma* (Ihab’s video). The group acknowledged and respected the fact that the movies were created by GYLWH highlighting their experiences and featuring their narratives and that this made the movies interesting to watch.

Concerning the topics of the videos, it was clear that the viewers realized the different perspectives and approaches that GYLWH had used. Viewers highlighted the social and personal experiences of GYLWH as noteworthy, issues that GY (viewers in this scenario) had no experience with. The ideas of being rejected by family members and friends and being fired from work were shocking to some GY viewers. GY discussed the lack of information about the aftermath of being diagnosed with HIV. The viewers admitted that they never knew that some people could be fired from their work— a topic Ihab raised when he lost his first job after telling his boss.

At this point in the discussion, we (researcher, assistant and Helem head of activity) raised the topic of medical insurance testing protocols. We told the viewers how some insurance companies in Lebanon ask for an HIV test, especially when joining a new company. Insurance companies can reject coverage for any new employee who shows HIV infection in their blood test. Even more damaging, as a result of the bloodtest, the whole country will know about the new employee living with HIV, as discussed in previous sections. Lebanon is a very small country and the chances of the lab nurse or technician knowing someone in the patient’s family is relatively high. This is why many blood tests use a code number system, which hides the patient’s identity so s/he can remain registered in the hospital system and in insurance records without prejudice (J. Mokhbat, personal communication, October 26, 2016).

Insurance companies prefer not to cover cases related to HIV complications, as these are less profitable and higher risk. However, the Ministry of Health does provide free medication to all HIV patients. The disqualification of insurance coverage for people with HIV raised a lot of sympathy for those affected, but it also highlighted how disconnected the gay community was from the reality of what is happening to other members of the gay community. This “disconnection” was puzzling for us to witness, as sexually transmitted diseases, especially HIV, have higher rates of transmission in the gay community than in other communities, and gay youth are one of the most vulnerable groups with respect to HIV infection. The viewers were GY and registered members who visit this NGO regularly for other activities (e.g., book discussions, film screenings), so it was very concerning how ill-informed they were about HIV issues.

That brings us to an observation about NGOs. When we were searching for resources and information (see Section 2), we contacted diverse NGOs that dealt with HIV matters. We visited Marsa, which works solely in the areas of health awareness and sexual transmitted diseases and offers a 24/7 clinic for free HIV testing. We also contacted Living Positive and Mena Rosa, which both work on social awareness and educational campaigns about living with HIV in regions between Lebanon and Egypt. Their latest work was the campaign entitled Speak Up, targeting health care mistreatment of patients, especially those agencies which disclose patients’ medical status without their consent. This campaign featured two stars from the TV series Samra, both of whom played struggling HIV+ characters (Section 2). We learned that these NGOs are funded by different western countries, through their embassies. Each NGO has its own programs, agendas and plans. Each targets different groups. Mena Rosa focuses on women living with HIV in the Middle East whereas Proud Lebanon works with the larger gay community, especially GYLWH. Helem helps LGBTQ+ communities with various issues (legal rights, awareness and social help). There appeared to be good intentions to help those who need assistance, yet all this energy was a bit dispersed when it came to GYLWH. The focus of these agencies seemed to be solely on political and social issues rather than addressing the pleas of GYLWH for empathy and support as they went through these difficult experiences. It saddened us that a large problem, especially for the gay community, which represents the most at-risk group for HIV infection in Lebanon (40% of new HIV cases), was ignored while the NGOs worried about their political agendas and funds. In many ways, the NGOs were imitating the politically divided country that they

were operating in instead of joining forces to care for the people they had pledged to help.

During the discussion session with the target viewers, many stories emerged that made the session extremely informative for everyone in attendance concerning the gay community in Lebanon.

One gay youth, who we will call 'X' here, told two stories about incidents that happened to him, and through these stories we gained some insight into the attitudes of the gay community towards people living with HIV. The first incident happened when he was with his friend in a gay-friendly bar in Beirut. During the evening, a gay man approached X and started gossiping about a person who happened to be X's friend. The gay man did not know that it was X's friend, but warned X to be careful as X's friend had HIV. It was a common scenario that occurs in gay nightlife, one that Hamid mentioned in his video using the wine glass metaphor. A stranger disclosed X's friend's medical status with no thought to discretion. X said in the discussion that he had never confronted his friend about his status, but kept it a secret until his friend was ready to confide in him. Concerning the gay man who "outed" his friend, X asked him not to disclose anyone's status ever again.

This story is typical, as people love to gossip and feel that it is acceptable to "out" people if it concerns their sexuality or medical status. People living with HIV might be more at ease and ready to reveal their status if society did not see this as an issue for public consumption.

The second incident also involved X's HIV-positive friend, mentioned above. Both happened to be in a gathering with other gay friends. Someone in the group mentioned that he had met someone, using a dating application, who happened to be living with HIV. Another member of the group asked this person to disclose the HIV+ person's identity on the application on the pretext that he wanted to avoid chatting and connecting with an HIV+ person. The first man refused to disclose the identity of the HIV+ person by saying that it was not ethical. In both scenarios, there were unfortunate incidents that viewers were sympathetic to during the discussion.

Regarding the first incident involving X's HIV+ friend, all the GY viewers wondered what that HIV+ person must have felt. This situation happens often where members of the community talk about a taboo topic, disregarding the

probability that someone in the group is affected by the topic. An equivalent situation occurs when a straight group bashes gay life while a closeted gay person is sitting in that group. However, in this situation the bashing occurs in a gay group.

The second incident, where the gay man insisted to know the identity of the HIV+ person so that he can avoid chatting with him online, is a common problem in the gay community when relationships are based on sexual encounters only. The mentality that everything is about sex detaches people from human kindness and causes them to treat others like objects. People become objectified, viewed as merchandise on a shelf. We cannot strip people of their emotions and dignity because they are ill or live with a medical/genetic condition.

Based on the post-screening discussion, the videos humanized people living with HIV; GY could empathize with GYLWH. During the discussion, the GY group identified two scenes that resonated with them and enhanced the discussion further. The group spoke about the scene with three masks that Samer included in his video. They could immediately identify with it because every gay person in Lebanon passes through the closeted stage where he has to hide his sexual identity. This common experience means that all gay people know what oppression feels like. The viewers also identified a similar scene in Ihab's video that resonated with them (they all asked about the maker). In the final scene, Ihab says "enough" and takes his mask off. This act captures the feeling that all the GY share: the oppression that hinders them from being free to live and express themselves without fear.

The discussion was informative. It allowed people to sit and think for a while about this social issue, an issue that is not discussed by society for cultural and political reasons. At one stage, we asked members of the group if they would date someone living with HIV and how would they handle it. The group stumbled and there was silence in the room. One of the viewers said that he was very unsure about dating an HIV+ person, but that he would respect the person. Another person mentioned that he would talk to a doctor to check the circumstances. What was interesting about this interaction is that GY thought about the situation at all, as they have likely never done so before. In a way, it prepared them to think about what they might do if they were ever faced with this experience.

Even more eye opening was the fact that they created a slogan for how someone should react on a date when the other opens up and discloses his status. They all agreed that they should respect the person because, by disclosing his HIV status, he shows respect and caring for you. This led to the slogan that everyone should “be a gentleman and not a jerk” when being around someone living with HIV.

In this first round of discussions, GY continued to take the lead on determining the topics for discourse. After we had asked a few major questions (above), the GY started talking about the gay community in Lebanon and how judgmental it is, especially once it had become dominated by dating applications driven by sexual desire.

Joseph Massad, who is considered to be the successor of Edward Said on post-colonialism and orientalism studies, and who wrote the book *Desiring Arabs*, proclaimed that the “gay” identity in the Arab world did not exist before the pre-modern West. Massad called it “male to male sexuality”, which existed long before the West created the “gay international movement”, and claimed that gayness is a product of the West.

Further, Massad claimed that the gay movement was based on the creation of “the International Lesbian and Gay Association (ILGA) and the International Gay and Lesbian Human Rights Commission (IGLHRC)” whose agenda was to fight for the liberation and protection of LGBTQ+ rights. But in his own book, he mentioned how Abu Nuwas, a very renowned medieval poet, used to like young boys and women. Massad backed the idea that Nuwas was a “narcissist” and not “homosexual” for being attracted to young boys and women (Massad, 2007a, p.89). While this dichotomy of being attracted to both genders, which existed throughout history and goes by terms like “men sleeping with men (MSM)” after being called “male–male sexuality” in the Middle East, Massad’s claim seems hypocritical, as do other justifications coming out of the Middle Eastern world. If the Middle East region would, for any reason, approve of homosexuality (Massad, 2007b, p.166) we would like to find out the how many MSM candidate would remain. As we know through fact and many studies (Abu-Raddad et al., 2010, p.32) that many men do not identify as gay – through social and religious pressure, as it is not accepted (Tohme & Ghanem, 2015). They try to live a heterosexual lifestyle, and sleep with other men in secret.

The term 'MSM' comes from the religious doctrine that there are only two genders, male and female, which exist for the purposes of reproduction. Any relationship that does not pursue reproduction is therefore not recognized. But using the term 'MSM' tarnishes the female persona, in that men are implicitly granted the right to have relations with both genders while women are expected to remain passive and accept that they can never explore this option. So Massad's debate about global western influence and refusing to use the words "gay" or "homosexuality", preferring the term "male-male sexuality", is more about the dichotomy between the sexes and the 'superiority' of the male to the female. Massad's writings are based on notions of gender binary and male superiority, completely overlooking the rights of women.

In the GY discussion, this led to debates on the use of the feminine dialect in the gay community. Even though the discussion was heated at the beginning, with some members objecting to the idea of censoring their expressions or identifying with fixed genders, the idea was communicated that GY rights are preserved and respected when the consent is mutual between two men. That is, there is no restriction in expressing gender preferences if the user hears/ knows that the other has given consent. This idea was introduced in Section 2. There is a difference between approaching someone using the pronoun that they choose and forcing the female pronoun on a gay male. This language of oppression is usually based on the expression of masculinity towards the effeminate or in sexual roles such as active or passive (giver or taker). It also reinforces the idea that women are passive and dominated in the "Arab" world.

To a large extent, both in theory and in practice, human rights are not the same for men and women in the Arab world... which can be largely attributed to government decisions, traditional values, and dominant patriarchal interpretations of Islam... (Dabbous-Sensenig, 2002, p.1).

After reading Chapter 3 of *Desiring Arab* by Joseph Massad, which discusses the influence of the West in the formation of the gay movement in the Middle Eastern world, I felt extremely agitated. Massad talks about the West's inconsistent expectations in that the West "attacked medieval Islam's alleged sexual licentiousness, the modern West attacks its alleged repression of sexual freedoms in the present", both of which were executed at the expense of "gay Arabs" (a term reinforcing the existence of gays in the Arab world). Not to dismiss Massad's influence on the political and economical side, but concerning the gay debate, it was misrepresented and treated

through Massad political agenda. Massad mentioned that most documents about homosexuality, in the Middle Eastern region, were written by Western people and that linguistic misinterpretation was a problem. His argument is poignant as words, in Arabic language, have different meaning depending on the context, and those interpretations needs someone who is an expert in the language or belongs to the same culture. Massad book concept was all directed to the wrong judgment of the West to the Arab culture as the latter looked at Arab culture through colonialist point of view. The same argument is directed to Massad especially when discussing the gay culture in the region. Massad analysed homosexuality in the Arab world through a conservative heterosexual point of view, which makes it unfair and misrepresented. His biased point of view (to heterosexuality) was clear when he discussed the Queen boat invasion in Egypt and the prosecution of 23 gay men for being at a gay party on a boat on the Nile River. Massad argued the trial and the raid by the police on the boat as an acceptable act ignoring and dismissing the victims from their human rights and freedom. Massad argument was based on political agenda. Massad investigated some of the names of the letter sent by Amnesty international and International Gay and Lesbian Human Rights Commission, to condemn the arrest and pressure the Egyptian government to release the arrested men. For Massad the Western pressure is political as the names were pro-Israelis and anti-Palestinian members, accusing them of applying Western political agenda through the gay movement (Massad, 2007b, p.183). In his debate Massad forgot the gay detainee, as he believes that human rights are a Western influence that has no place in the Arab culture.

Following this argument this will represent the Middle Eastern cultures as one "Muslim world" ruled by the "Islamic Sharia" which is not the case for Lebanon. Lebanon is considered "the most Westernized of all Arab countries and the one (theoretically) best placed to reflect some gender sensitivity" (Dabbous-Sensenig, 2002, p.2). This representation of the Middle East showcased a region that adopts a relaxed approach towards anything influential from the West and implies that all the region's gay people were represented by "minority rich informants" (Massad, 2007b, p.166) whereas the poorer gay demographic was largely invisible.

This lack of visibility is largely why we worked with gay youth who identify themselves as gay. They came from diverse backgrounds, but all wanted to share their own stories about their struggles being gay and living with HIV. Few stories about gay life are depicted by gay Arab writers. The exceptions

include the autobiographical experiences of Sofian Merabet (professor at University of Texas Austin) in *Queer Beirut* and depictions of gay life in Morocco by the Moroccan-born writers Rachid O. and Abdellah Taïa, who both now live in France. That is to say more studies and stories from the Arab gay community and especially the GYLWH are needed to contribute to literature as well as to expose true stories to concerned societies (Badin, 2016).

The second screening of the videos took place in a gay-friendly coffee shop to which we asked the participants (the video makers) to invite friends. Members of the public who happened to be at the coffee shop at screening time (mostly from the gay community) were also welcomed. Keeping the identity of the video-makers protected and safe, it was fulfilling for them to hear what people were saying about their work and messages. This screening was to publicly celebrate the effort and time that the GLWHIV video makers had invested in their projects.

We borrowed a pull-down screen and used Proud Lebanon's projector and speakers to create an informal and friendly ambience. As well, we gave online links to some of the familiar gay youth people that Proud Lebanon invited, asking them to fill out the online survey when they had the opportunity. That same day, out of 14 viewers, we received feedback from four GY who had completed the online survey using their mobile devices. We provided an introduction of the project before the screenings and explained the reason behind the videos. Coincidentally, this screening coincided with World AIDS Day, which occurs on December 1st each year.

One of the general public attendees was a schoolteacher and she brought to our attention a very valuable point during the discussion. She mentioned how the educational system in Lebanon lacks gender sensitivity and sexual education (Dabbous-Sensenig, 2002) and suggested that short movies like these could be shown to students and used for components of sex education, especially as the visuals contained no inappropriate or overt representations. Further, she extended her interest by suggesting to project the movies in her class. As enticing as it is, our research is aimed at gay youth at this stage, so we renounced the offer. It was gratifying to hear this feedback, as these videos could induce empathy in a younger demographic (16 to 18 years of age) and start to instill flexible attitudes based on knowledge in the younger generations (McLaren & Leonard, 1993, p.122).

Another attendee was an medical doctor, a general practitioner from Syria who happened to be invited by one of the participants (Walid). This doctor was extremely interested in the videos and he complimented the schoolteacher by reiterating the need for youth sexual education, which is mostly absent or guided by instinct in Middle Eastern communities. Education is a very crucial and valuable point when trying to protect young people from sexually transmitted diseases (STDs) in general and HIV in particular. The idea that people can see the aftermath of living with HIV, including the socio-cultural complications, would likely resonate with viewers and be more effective than hammering youth with safe sex messages, as per the statistic shared by the ministry of health and UNAIDS during their annual conference on World AIDS Day in Lebanon that had an alarming number of 44.7% of 150 new cases belonging to the gay community.

The discussion after the screening provided a powerful experience for the gay community because it exposed them to real stories about an issue that has largely been ignored: the quality of life of gay youth living with HIV (GYLWH). Using participatory research, GYLWH can express their thoughts and show us their feelings. This process contrasts with that used by Massad who based his research on literature, historical events and a political agenda that ignored the human side of the issues. The discussion space was heterotrophic (as unusual and different from any public spaces) and provided a safe, non-judgmental space where every member of the community could express his/her thoughts and feelings about the marginalization of GYLWH. Watching stories that are created, shot and edited by GYLWH in Lebanon provides the viewer with a story as close to their truth as possible. It embodies the idea of "cinema verité", short videos produced by the people represented. In the process, GYLWH were only directed to bring all their elements together and organize them into a coherent message. GYLWH had full control over what to film and how to film it, using their intuition. Granting GYLWH the freedom to do whatever they wanted fostered their creative expression and it provided a sense of empowerment to take control of how they wanted their stories to come across. We can argue that their interpretation might not contain the total truth as it is a one-time record of in a moment of time, but we can also argue that it represents their emotions and their honest feelings as they navigate living with HIV and coping with the prejudices of the gay community. Mitchel, Gubrium, and Pink were keen to voice, for educational and knowledge purposes, the social, anthropological and ethnographical

knowledge about communities, especially the ones that are difficult to (Gubrium & Harper, 2013, p.92; Pink, 2012, p.157).

Working with video production as a group process... offers participants access to a type of socially constructed knowledge that is particularly significant to addressing themes and issues such as gender violence, which are in and of themselves difficult to express through single (and fixed) images (Mitchell, 2011, p.89–90).

When GY were asked (in the survey) to express what they had learned from the designed videos, one of them said that he had “never met anyone with HIV, but the designed products encouraged” him “to meet all of them [people living with HIV] and show them support”. Indeed Pink mentioned the benefit to every party in participatory research, including the producer and the viewer, is that the outcome can “inform, educate, remind, challenge and empower both” (Pink, 2012, p.157).

Eleven out of 13 of audience members used many positive expressions in the survey. They were united on the concept of “accepting”, “supporting”, “loving”, and “caring” about each other in this small community. The GY audience was open to receiving these stories and to being influenced by them. This is based on the Frierean concept of “conscientization”, which is the act of becoming conscious of an issue that needs to be highlighted. Friere’s way of highlighting the “problematization” of a social issue by influencing decision makers and audiences to become more conscious of the problem by highlighting its political effect. Students –in our case participants and viewers – will hopefully detach themselves from the social epitomes and stigma connected to HIV/AIDS issues and build new models of critical thinking to help us understand and connect to real stories that will explain their sentiments and reasoning to marginalized groups (Finkel & Ar, 1995, p.96). This is the dialogue, that has been orchestrated through visual methodology and participatory inquiry, a democratic dialogue that Friere praised in his book *Pedagogy of the Oppressed*, where every member of the society is given the chance to understand and tell his or her own truth through dialogue, in this research it was the audiences that learned from those stories (Heron & Reason, 1997, p.283; McLaren & Leonard, 1993).

5.2 Screening of the participants' videos to the public

[Humans] are not built in silence but in word, in work, in action-reflection.... If it is in speaking their word that humans transform the world by naming it, dialogue imposes itself as the way in which [humans] achieve significance as [humans]. Dialogue is thus an existential necessity (Friere, 1972, p.60–1).

From the social, educational, and communication pedagogies, dialogue along the lines of the kind described above by Friere would be inevitable, and silence would be banished. In the pursuit of a larger impact, Proud Lebanon had planned to organize a large public event before the weekend preceding World AIDS Day, specifically on Saturday, November 26, 2016. *Celebrating Life* was the title of the event and many influential people attended. Writers, theater directors, actors, medical doctors, singers, cultural counselors from embassies such as those for Canada and The Netherlands, activists, media journalists, volunteers, and GYLWH attended this event.

The theme of the event, celebrating the life of people living with HIV was developed by a friend, renowned actor Bshara Attalah, who acted in my 1996 graduate play entitled *What are Tuesdays like?* which dealt with stories of people living with HIV in the 1980s. Attalah envisioned a campaign for the 2016 World AIDS Day and collaborated with Proud Lebanon, the GYLWH workshop participants, and Lebanese celebrities to film the campaign (Atallah, 2016 a,b). The campaign message was to stop stigma in healthcare mirroring the Ministry of Health 2017 plan. Attalah and Proud Lebanon decided that the *Celebrating Life* event would be the right time to launch the campaign and invite speakers from the medical field and activists from various other fields.

Little did we know, at the time when we were wrapping up the workshop, that Proud Lebanon and Attalah would ask us to be part of the *Celebrating Life* event. As part of creating this work, there was an ethical trust established between the NGO and the participants, which needed to be addressed before participating. However, all members concerned agreed that it would be a perfect opportunity to promote the research workshop and the messages created by participants (GYLWH).

Proud Lebanon suggested that I represent the GYLWH participants by talking about the workshop (that we had just finished in Beirut) in specific

terms and the research in general. We all came to a consensus—Proud Lebanon, Attalah and I—to create a trailer showcasing all participants' movies and promoting the second screening date, which was aimed at the public in general and the gay youth audience in particular (see previous section). Additionally, it was agreed to screen one of the short movies produced by participants. The purpose of the single screening was to influence stakeholders and policymakers when budgeting or creating policies concerning people living with HIV in general and GYLWH specifically. The inclusion of stakeholders and/or policymakers is essential in participatory and community-based research, as it encourages them to implement beneficial long-term changes.

In a meeting of all members organizing the event (research participants, the NGO, Attalah and researcher) we chose Nassib's short movie as it was in Arabic and best fit the theme of the event "celebrating life". The selection was agreed to by all members, especially by the research participants, as we did not want anybody to feel less represented on the day. The members thought that it would be best if I said a few words to the public to explain the work of the participants, the workshop process and research objectives, impressing on stakeholders the importance of funding such creative work and the benefits to GYLWH.

Addressing the public about the importance of breaking the stigma of HIV and providing empathy and love to youth in general, and the GYLWH in particular, was the most difficult yet most fulfilling thing I had ever done. Showcasing the work of GYLWH was an effective way to explain the role of social design and its influence on the community.

Two main TV channels (LBCI and Hayat) covered the event. They explained the objective of the event and showed the activities that were offered by NGOs to people living with HIV. The two channels interviewed us and we explained the process of the workshop and presented the effect on GYLWH. They also interviewed Ihab, who talked about his story (as it was in the participants' videos, Ihab's face was pixelated on TV and his voice recording was distorted to maintain his anonymity). In the interview, we highlighted the importance of providing a space where the voices of the silenced can be amplified so that the community can hear them. In communication theory, the TV provides a channel/platform—as in De Fleur's communication model in Section 1—to project the stories, induce empathy, and build a dialogue for discourse

(Schulz, P. & Cobley, 2013, p.384). This circular mode of communication allows feedback from every party and facilitates the best process of analysis to arrive at elaborate, refined, and effective results. The communication channels provide an educational-dimension by showing the lives of people living with HIV to a society that has turned away from them.

Through participatory research, people are exposed to real stories that they have never heard or did not want to hear. Stories that are narrated by real people with real social issues are hard to ignore (Gubrium & Harper, 2013, pp.113, 123) . This strategy differs from that of Massad, who decided to write about “homosexuality” from the sexual desire side. His point of discussion switched the focus from the social struggle of people adapting to their reality, to a judgmental political approach. To our surprise, GYLWH never mentioned sexual behavior or desire in their videos, although one participant showed a very brief scene showing four feet and a close up of lips kissing. All participants preferred to talk about love and acceptance.

5.2.1 Participants’ observations and feedback

Inclusion has three results: 1) the needs of the voiceless are heard; 2) the voiceless learn that they can speak and be heard and acknowledged and respected in a peaceful way; and 3) institutions make more common the inclusion of the voiceless. In people-driven/ bottom up approaches, the voiceless can express their needs and concerns, as well as engage in building their future at local and community level (UNDESA, 2005, p.4).

During the public screening of the *Celebrating Life* event, participants were part of the audience, blending in with other audience members in the theater auditorium. We treated participants like guests, but presented their work on stage without pointing to or looking directly at them, in order to protect their identities. There is something extremely rewarding about watching the participants see the effect of their work through the reactions of and discussion with the audience. In the previous section, the benefit of feedback from participants in the workshop was discussed. Both Nassib and Ihab, in their interviews, were vocal about the gratifying experience of creating a message, to “put it out there for everybody to hear it” (Ihab, personal communication, November 24, 2016). 4 out of 6 participants

mentioned how they had “benefited from the messages that they sent to the world” (Nassib, personal communication, November 22, 2016).

The most empowering moment of the *Celebrating Life* event was looking at Nassib’s face in the audience as he filmed me introducing his work and speaking about the research. Nassib shed tears of joy that his message, his voice was out there in the world, watched and listened to by the masses. It was also humbling to see him present his work at the second event, as participants were not allowed (for security reasons) at the first private screening to the gay youth at Helem. While on stage talking about this social issue and representing participants, we (researcher/designer and assistant) realized that our roles had changed/evolved from designers to social designers. That we could facilitate a workshop, with marginalized minorities, to design short movies to influence change, even for one person in the audience, felt like a triumph.

Participants took part in the dialogue that happened that day. They felt included in the fight to reduce stigma. They felt that their stories were more important than being only creative processes to help them talk about their trauma. They could “walk the walk” with their passage through their trauma. Their stories became communications to initiate an important conversation.

As a researcher, designer, and facilitator, standing on stage and speaking about GYLWH, I became a storyteller showcasing video designs created by others, talking about lives that matter, and helping people living with HIV to become activists to their cause and to speak up in creative way. In our interview with Nassib after the workshop, he expressed that he would like to be trained to become a facilitator to help others who have gone through experiences like his (Nassib, personal communication, November 22, 2016). His words expressed how marginalized and stigmatized people can become empowered by becoming activists who may empower others and influence social change.

5.2.2 Public and stakeholder reaction

Dialogue further requires an intense faith in [humanity], faith in their power to make and remake, to create and recreate, faith in their vocation to be more fully human (which is not a privilege of an élite,

but the birthright of all).... Founding itself upon love, humility and faith, dialogue is a horizontal relationship of which mutual trust between the participants is the logical consequence (Friere 1972, pp.62–3).

The reaction of the audience watching Nassib's video was extremely emotional. The audience cried at the message that Nassib had conveyed. It was obvious that they connected to the story and sympathized with people living with HIV. The message was about the right to live life without fear or shame. It was unfortunate that the audience was not part of our survey demographic (which was gay youth, as described above), but we had the opportunity to receive face-to-face feedback from the audience concerning the videos and message. Some audience members approached us during breaks and after the event to discuss the videos and how they were touched by them.

Some of the audience members were relieved that the messages in the videos were not sex-oriented for a change, but concentrated on the struggles of GYLWH (e.g., Nassib in his scenario) in gaining the right to be loved and to live life the way they choose. The stripping of sexual overtones to see the individuals at a base human level appealed to the audience and facilitated constructive discussion.

The other point expressed by the audience that caught their attention was the surprise of seeing the ordinary lives of people living with HIV. The fact that the audience had never witnessed these stories intrigued them. The videos encapsulated the honest opinions of people living with HIV. These testimonies on the effect of stigma and marginalization by society in silencing and oppressing people living with HIV likely led to soul-searching by those not realizing that they were contributing to the problem.

After the screening event, the cultural counselors approached us to chat about the workshop and the work that had been completed. They were impressed and convinced of the importance of such work to provide GYLWH with creative processes to help them express themselves. They also liked the educational insights about the lives of people living with HIV in particular and the HIV pandemic in Lebanon in general.

Embassy representatives expressed interest in collaborating by offering funds for similar work in the future. They approached the NGO and talked

about future events for which they might provide help. There was talk about doing similar workshops for International Day Against Homophobia, Transphobia and Biphobia, which falls on May 17 of every year. The fact that stakeholders and decision-makers could witness the work of GYLWH and get them excited about possible future work was promising and exciting.

Lina Abbyad, a theater director and drama teacher at the Lebanese American University, was present at the event, saw the screened movies, and expressed her support for getting those stories out to the public. She held a discussion after the event about the effect of design and using different methods of creative expression to highlight issues hidden from the public. She shared with us her next play production project that deals with medical taboos, which includes HIV stigma among others. This showed yet another offshoot from our work using a different platform to talk about HIV stigma and its impact on Lebanese youth. The more people talk about HIV stigma, and share stories of GYLWH, the more it generates empathy and becomes accepted in communities.

6.0 Future research

When conducting research dealing with stigma, especially in Lebanon, social gender issues and basic human rights should be considered. The scope of this type of research is rich with possibilities.

Fighting stigma is best executed through education and awareness, which leads to the “normalization” of any social stigma. Further research and documentation is needed of design workshops with stigmatized groups of people so that solid workshop models can be created for future use.

One of the four strategies recommended by Restal's & Gonzalaz' for addressing HIV/AIDS stigma has been used in this thesis research project. More documented research with those strategies is needed for future analysis and adaptation to Lebanese society. One of the most important recommendations from Restal's and Gonzalaz' was the involvement of different stakeholders, especially people living with HIV (PLWH), so that the latter would influence future strategies. This recommendation is supported by participatory, community-based design research, which recommended the involvement of stigmatized and marginalized minority groups.

In Lebanon, more empirical research concerning GYLWH in particular, and PLWH in general, is needed. This will help to achieve a more holistic view of PLWH, which in return will help to provide the appropriate help needed. PLWH is a group that is hard to reach, therefore NGOs should put social involvement with this group on their priority list.

As we saw in the research, gender binary is a crucial issue embedded in the culture and remains the main cause of segregation. Further research on the effect of normalizing gender fluidity in Lebanese society, especially within the youth demographic is important for breaking gender binary and encouraging gender equality and accepting diverse sexual identity.

7.0 Conclusions

In this thesis research project, the opportunity to investigate the possibilities of nurturing empathy to create social cohesion were explored. The ripple effect that went from the micro level (GYLWH) to the macro level (society) became evident. At the micro level, there was a positive psychological evolution of the GYLWH who designed their experiences and communicated them to their gay community, then the effect of the stories on the gay community was demonstrated through their reactions to the designed videos and discussion of HIV issues. Finally, on a macro level, suggesting to NGOs that spreading awareness through the creation of videos that show the real stories of people living with HIV to Lebanese society, is an investment worth pursuing in the future. It is less expensive (as an activity) than all year long one on one psychological sessions and more involving, helping marginalized and/or stigmatized youth/people to immerse themselves in a creative dialogue with their community.

The creation of safe spaces for PLWHIV and LGBTQ social interactions and dialogue should be encouraged. One of the workshop participants suggested that NGOs should encourage training for PLWHIV to become spokespersons or representatives for their causes. Another participant suggested that future research could be conducted to train stigmatized/marginalized people to co-facilitate, or facilitate, empowerment workshops like the one completed for this thesis research project. This might encourage marginalized people to become activists and be more involved in their community.

As a researcher my primary objective was to maintain participants' anonymity as well as protect their stories. Since the participants' stories were in the forefront, my 'voice' was used solely to reinforce their messages.

Finally, during the video screenings, educators suggested that similar videos could be included in school curricula to increase social awareness and safe sex practices. It would be interesting to study reactions to the videos and their effects on high school students' attitudes.

The scope of the research included socio-cultural and political issues related to the gay lives in general and gay people living with HIV in particular. The research suggests that designing a way for gay youth living with HIV to express themselves and communicate their life experiences living with HIV can produce empathy to the cause, as well as encourage (indirectly) preventive safe sexual practices.

Applying Restal's and Gonzalaz' recommended strategy of addressing HIV/AIDS stigma—information in combination with contact with affected group—there was a glimpse of the fact that social change aimed at eliminating stigma is possible. The United Nations Department of Economic and Social Affairs (UNSD) and the sociological theories examined suggested that social change is a long process, and that a sustained effort at social intervention is needed to keep society informed about medical progress in the area. Keeping the momentum going is crucial. NGOs in Lebanon need to reinforce these social creative design activities, like the creation of video narratives or print publications, to encourage ongoing dialogue that can benefit both parties through education aimed at creating understanding and acceptance.

8.0 References

- Abboud, S., Nouredine, S., Abu-Saad Huijer, H., DeJong, J., & Mokhbat, J. [2010]. Quality of life in people living with HIV/AIDS in Lebanon. *AIDS Care*, 22(6), 687–696. <https://doi.org/10.1080/09540120903334658>
- Abu-Raddad, L.J., Akala, F.A., Semini, I., Riedner, G., Wilson, D., & Tawil, O. [2010]. *Characterizing the HIV/AIDS epidemic in the Middle East and North Africa: Time for strategic action*. Washington, D.C.: The International Bank for Reconstruction and Development / The World Bank. <https://doi.org/10.1596/978-0-8213-8137-3>
- Afshar, A., & Ahmadi, A. [2013]. The hand in art: Hamsa hand. *The Journal of Hand Surgery*, 38(4), 779–780. <https://doi.org/http://dx.doi.org/10.1016/j.jhsa.2012.12.010>
- Avert. [2016]. HIV and AIDS in the Middle East & North Africa (MENA). Retrieved September 1, 2016, from <http://www.avert.org/professionals/hiv-around-world/middle-east-north-africa-mena>
- Badin, A. [2016]. Between Men: Homosocial Desire and the Dynamics of Masculinity in the Novels of Rachid O. And Abdellah Taïa. *Contemporary French and Francophone Studies*, 20(1), 111–120. <https://doi.org/10.1080/17409292.2016.1120558>
- Baecker, D. [2013]. Systemic theories of communication. In P. Schulz & P. Cobley (Eds.), *Theories and Models of Communication*. Berlin: De Gruyter Mouton.
- Brown, B.T., & Wyatt, J. [2010]. Design thinking for social innovation. *Stanford Social Innovation Review*, Winter(Winter 2010), 30–35. <https://doi.org/10.1108/10878571011042050>
- Bruhn, J. [2009]. *The group effect: Social cohesion and health outcomes*. Springer. <https://doi.org/10.1007/978-1-4419-0364-8>
- Buccianti, A. [2016]. Arab storytelling in the digital age: From musalsalāt to Web Drama? In *The State of Post-Cinema* (pp. 49–70). https://doi.org/10.1057/978-1-137-52939-8_3

Cairns, G. (2014). *Noone with an undetectable viral load, gay or heterosexual, transmits HIV in first two years of PARTNER: study* Viral load suppression means risk of HIV transmission is "at most" 4% during anal sex, but final results not due till 2017. Retrieved from <http://www.aidsmap.com/print/No-one-with-an-undetectable-viral-load-gay-or-heterosexual-transmits-HIV-in-first-two-years-of-PARTNER-study/page/2832748/>

Canadian Association for HIV/AIDS Research. (2008). *Ethics Issues for Canadian HIV/AIDS Researchers in International Settings. Canadian Association for HIV research*. Toronto. Retrieved from <https://www.cahr-acrv.ca/wp-content/uploads/2012/10/cahrreportfinal.pdf>

Craig, R.T. (1999). Communication Theory as a Field. *Communication Theory*, 9(2), 119–161.

Dabbous-Sensenig, D. (2002). The Arab World And The Challenge Of Introducing Gender-Sensitive Communication Policies.

Donald L. Finkel, & Ar, W.R. (1995). The promise of a social pedagogy: paulo freire's culture circles. In *Education of freedom: The Paradox of Pedagogy* (pp. 85–118). Rutgers University Press.

Dukes, K (2009). The Quranic Arabic Corpus. Verse (17:23). Retrieved from <http://corpus.quran.com/translation.jsp?chapter=17&verse=23>

Eribon, D. (2004). *Insult and the Making of the Gay Self*. (M.A. Barale, J. Goldberg, M. Moon, & E.K. Sedgwick, Eds.). London: Duke University Press.

F.V.T. (2014). Gay rights in Lebanon. Retrieved March 6, 2017, from <http://www.economist.com/blogs/pomegranate/2014/03/gay-rights-lebanon>

Findeli, A. (2001). Rethinking Design Education for the 21st Century : Theoretical , Methodological , and Ethical Discussion. *Design Issues*, 17(1), 5–17.

Findeli, A. (2010). *Questions, hypotheses & conjectures: discussions on projects by early stage and senior design researchers*.

Frascara, J. (1997). Mapping the terrain. In *User-centered graphic design: mass communication and social change* (pp. 3–32). London: Taylor & Francis.

- Frascara, J. *Graphic Design: Fine Art or Social Science?*, 5 Design Issues 18–29 (1998). MIT Press. <https://doi.org/10.2307/1511556>
- Frascara, J. (2004). *Communication Design: Principles, Methods, and Practice*. New York: Allworth Press.
- Friedkin, N.E. (2004). Social Cohesion. *Annu. Rev. Sociol.*, 30, 409–25. <https://doi.org/10.1146/annurev.soc.30.012703.110625>
- Grace, A.P. (2015). *Growing into Resilience: Sexual and Gender Minority Youth in Canada*. Toronto: University of Toronto Press.
- Gubrium, A. (2009). Digital Storytelling: An Emergent Method for Health Promotion Research and Practice. *Health Promotion Practice*, 10(2), 186–191. <https://doi.org/10.1177/1524839909332600>
- Gubrium, A., & Harper, K. (2013a). Digital Storytelling. In *Participatory visual and digital research in action* (pp. 125–150). Walnut Creek, CA: Left Coast Press, Inc.
- Gubrium, A., & Harper, K. (2013b). Introduction. In *Participatory Visual And Digital Methods* (pp. 13–25). Walnut Creek, CA: Left Coast Press, Inc.
- Gubrium, A., & Harper, K. (2013c). Opening Up Data Analysis, Writing, and Research Products. In *Participatory visual and digital research in action* (pp. 183–196). Walnut Creek, CA: Left Coast Press, Inc.
- Gubrium, A., & Harper, K. (2013d). Participatory Film and Videomaking. In *Participatory visual and digital research in action*. Walnut Creek, CA: Left Coast Press, Inc.
- Gubrium, A., & Harper, K. (2013e). Participatory Visual and Digital Research in Theory and Practice. In *Participatory visual and digital research in action* (pp. 27–43). Walnut Creek, CA: Left Coast Press, Inc.
- Gubrium, A., & Harper, K. (2013f). Photovoice Research. In *Participatory visual and digital research in action* (pp. 69–90). Walnut Creek, CA: Left Coast Press, Inc.

- Gubrium, A., Harper, K., & Otañez, M. (2015). *Participatory visual and digital research in action*. [A. Gubrium, K. Harper, & M. Otañez, Eds.]. Walnut Creek, CA: Left Coast Press, Inc.
- Haddad, S. (2016). The Myth of the Queer Arab Life. Retrieved from <http://www.thedailybeast.com/articles/2016/04/02/the-myth-of-the-queer-arab-life.html>
- Hall, S. (2013a). Introduction. In J. Evans & S. Nixon (Eds.), *Representation* (pp. 1–47). London: Sage.
- Hall, S. (2013b). The Work Of Representation. In J. Evans & S. Nixon (Eds.), *Representation* (2nd ed., pp. 1–47). London: Sage.
- IDEO. (2014). *the Field Guide To Human-Centered Design. Igarss 2014*. <https://doi.org/10.1007/s13398-014-0173-7.2>
- Jaber, H. (2016). Crossing the Border: Rethinking Failure and Exile in Lebanese Musalsalat. *Kohl: A Journal for Body and Gender Research*, 2(2). Retrieved from <http://kohljournal.org/crossing-the-border/>
- Jenson, J. (1998). *Mapping Social Cohesion: The State of Canadian Research. Canadian Policy Research Networks Inc* (Vol. F13). Renouf Publishing. <https://doi.org/10.1007/s13398-014-0173-7.2>
- Kohut, A., Wike, R., Bell, J., Horowitz, J.M., Gross, E.M., & Barker, C. (2013). *The Global Divide on Homosexuality Greater Acceptance in More Secular and Affluent Countries*. Washington, DC. Retrieved from <http://pewglobal.org>
- Krayem, H. (1997). The Lebanese civil war and the Taif Agreement. Retrieved from <http://ddc.aub.edu.lb/projects/pspa/conflict-resolution.html>
- Krcmar, M., Roskos-Ewoldsen, D. R., & Koerner, A. (2016). What Is Communication? In *Communication Science Theory and Research : An Advanced Introduction* (pp. 18–35). New York: Routledge.
- Lambert, J. (2013). *Digital Storytelling Capturing Lives, Creating Community* (4th ed.). New York: Routledge.

- LaSala, M.C. (2011). Gay Men and Their Mothers: Is There a Special Closeness? Retrieved July 2, 2017, from www.comingoutcominghome.com
- Lockwood, D. (1999). Civic Integration and Social Cohesion. In I. Gough & G. Olofsson (Eds.), *Capitalism and Social Cohesion* (1st ed., pp. 63–84). London: MacMillan Press LTD.
- Massad, J.A. (2007a). Anxiety in Civilization. In *Desiring Arabs* (pp. 51–98). Chicago: University of Chicago Press.
- Massad, J.A. (2007b). Re-Orienting Desire: The Gay International and the Arab World. In *Desiring Arabs* (pp. 160–190). Chicago: University of Chicago Press.
- Massad, J.A. (2007c). Sin, Crimes, and Disease: Taxonomies of Desires Present. In *Desiring Arabs* (pp. 191–268). Chicago: University of Chicago Press.
- Massena, F. (2012). Is Lebanon on the path to decriminalizing homosexuality? Retrieved March 6, 2017, from <http://www.al-monitor.com/pulse/originals/2017/02/lebanon-judge-ruling-favor-lgbt-tolerance.html>
- Mitchell, C. (2011). *Doing Visual Research*. Thousand Oaks, Ca: SAGE Publications Ltd.
- Mitchell, C., & De Lange, N. (2012). Community-Based Participatory Video and Social Action in Rural South Africa. In Eric Margolis & Luc Pauwels (Ed.), *The SAGE Handbook of Visual Research Methods* (pp. 171–185). London: SAGE Publications Ltd. <https://doi.org/10.4135/9781446268278>
- Mortensen, N. (1999). Mapping System Integration and Social Integration. In I. Gough & G. Olofsson (Eds.), *Capitalism and Social Cohesion* (1st ed., pp. 13–37). London: MacMillan Press .
- Nammour, K. (2016, October). Judging Identities: Beirut Criminal Court’s Phobia of Homosexuality and Right to Privacy*. Retrieved February 27, 2017, from <http://legal-agenda.com/en/article.php?id=1738>
- National Academies of Science, Engineering, & Medicine. (2005). *Facilitating Interdisciplinary Research*. Washington, D.C.: The National Academies Press. Retrieved from <http://nap.edu/11153>

Peter McLaren, & Peter Leonard (Eds.). (1993). *Paulo Freire: A critical encounter*. London and New York: Routledge.

Pink, S. (Ed.). (2012). *Advances in Visual Methodology*. London: SAGE.

Restal, G., & Gonzalaz, M. (2014). *Strategies for Addressing HIV/AIDS- Related Stigma*. Retrieved from http://umanitoba.ca/faculties/medicine/units/medrehab/ot/media/Stigma_Report_-_2014-02-06.pdf

Rodger, A., Bruun, T., Cambiano, V., Vernazza, P., Estrada, V., Lunzen, J. Van, ... Lundgren, J. (2014). HIV Transmission Risk Through Condomless Sex If HIV+ Partner On Suppressive ART: PARTNER Study. In *21st Conference on Retroviruses and Opportunistic Infections* (p. abstract 153LB). Boston.

Rose, G. (2007). *Visual Methodology: An introduction to the Interpretation of Visual Materials* (2nd ed.). SAGE.

Schulz, P., & Cobley, P. (2013). *Theories and Models of Communication*. Berlin: De Gruyter Mouton.

Setayesh, H., Roudi-Fahimi, F., El Feki, S., & Ashford, L. S. (2014). *HIV and AIDS in the Middle East & North Africa*. Population Reference Bureau. Washington DC. Retrieved from <http://www.avert.org/professionals/hiv-around-world/middle-east-north-africa-mena>

Smit, P.J., Brady, M., Carter, M., Fernandes, R., Lamore, L., Meulbroek, M., ... Thompson, M. (2012). HIV-related stigma within communities of gay men: a literature review. *AIDS Care*, 24(4), 405–12. <https://doi.org/10.1080/09540121.2011.613910>

Strauss, C.F., & Fuad-luke, A. (2008). The Slow Design Principles. *Changing the Change: Design Visions, Proposals and Tools*, 1–14.

Taif. (1989). TAIF ACCORDS First, General Principles and Reforms. Retrieved from [http://peacemaker.un.org/sites/peacemaker.un.org/files/LB_891022_Taif Accords.pdf](http://peacemaker.un.org/sites/peacemaker.un.org/files/LB_891022_Taif%20Accords.pdf)

Tohme, J., & Ghanem, G. (2015). *Mental health of men who have sex with men in the Arab world*. Beirut. Retrieved from <http://m-coalition.org/portfolio-items/mental-health-of-men-who-have-sex-with-men/>

- Tolino, S. (2014). Homosexuality in the Middle East: An analysis of dominant and competitive discourses. *DEP (Deportate, Esule, Profughe)*, 25, 72–99.
- Tromp, N., & Bijl-Brouwer, M. van der. (2016). Introduction: Design Innovation for Society. <https://doi.org/10.21606/drs.2016.628>
- UNAIDS. (2014). *2014 Country Progress Report for Lebanon*. Beirut, Lebanon. Retrieved from http://www.unaids.org/sites/default/files/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/LBN_narrative_report_2014.pdf
- UNDESA. (2005). *Dialogue in the Social Integration Process : Building peaceful social relations — by, for and with people*. New York: Division for Social Policy and Development. Retrieved from www.un.org/esa/socdev/sib/peacedialogue/fnl_rprt.doc
- United nation. (1996). *Report of the World Summit for Social Development. United Nations publication*. New York. Retrieved from <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N95/116/51/IMG/N9511651.pdf?OpenElement>
- Van der Kolk, B.A. (2014). *The body keeps the score: brain, mind, and body in the healing of trauma*. New York: Penguin Books.

Videos

- Atallah, Bshara [Proud Lebanon]. (2016, Dec 12a). *We care* [Video File]. Retrieved from <https://www.youtube.com/watch?v=zxcbLod8xAM>
- Atallah, Bshara [Proud Lebanon]. (2016, Dec 21b). *We care-World AIDS Day 2016* [Video File]. Retrieved from <https://www.youtube.com/watch?v=LN4peSEllmw>
- [Online Production]. (2016, Jan 23). *Ishq al Nissa-episode 34* [Video File]. Retrieved from <https://www.youtube.com/watch?v=2tNSpmISTsQ>
- [AlNaharDrama]. (2016, Apr 12). *Samra Series-Episode 22* [Video File]. Retrieved from <https://www.youtube.com/watch?v=GzlhpaWcdLQ>

Figures

Baecker, D. (2013). Systemic theories of communication. In P. Schulz & P. Cobley (Eds.), *Theories and Models of Communication*. Berlin: De Gruyter Mouton.

De Fleur Model of Communication. (2012). *Communication Theory*. Retrieved 28 August 2016, from <http://communicationtheory.org/de-fleur-model-of-communication/>

Everaert-Desmedt, N. (2011). *Peirce's Semiotics*. *Signosemio.com*. Retrieved 28 August 2016, from <http://www.signosemio.com/peirce/semiotics.asp>

MENA. (2017) *En.wikipedia.org*. Retrieved 28 January 2017, from <https://en.wikipedia.org/wiki/MENA>

Mishra, S. (2017a). Retrieved 28 January 2017, from <https://www.businessstopia.net/communication/schramms-model-communication>

Mishra, S. (2017b). *Lasswell's Communication Model / Businessstopia*. *Businessstopia.net*. Retrieved 28 January 2017, from <https://www.businessstopia.net/communication/lasswell-communication-model>

The Design Process: What is the Double Diamond?. (2015, 17 March). *Design Council*. Retrieved 28 August 2017, from <http://www.designcouncil.org.uk/news-opinion/design-process-what-double-diamond>

9.0 Bibliography

- Atkins, S., Knill, P. J., Simoneaux, G., Abbs, K., Kalmanowitz, D. L., Huss, E., ... & Calderon, J. M. (2011). *Art in action: Expressive arts therapy and social change*. Jessica Kingsley Publishers.
- Boal, A. (2008). *Theater of the oppressed*. Pluto Press: Pluto Press.
- Cobley, P. (2013). Semiotic models of communication. In P. Schulz & P. Cobley (Eds.), *Theories and models of communication* (pp. 223–240). Berlin: De Gruyter Mouton.
- Hage, G. (2006). Migration, marginalized masculinity and dephallicization: A Lebanese villager's experience. In S. Khalaf & J. Gagnon (Eds.), *Sexuality of the Arab world* (pp. 107–129). Beirut: Saqi Books.
- Laurel, B. (2003). *Design research: Methods and perspectives*. MIT press.
- Merabet, S. (2014). *Queer Beirut*. Austin: University of Texas Press.
Retrieved from <http://ebookcentral.proquest.com/lib/ualberta/detail.action?docID=3571786>.
- Muñoz, J. E. (2009). *Cruising Utopia*. New York: NYU Press
- National Academies of Science, Engineering, & Medicine. (2005). *Facilitating interdisciplinary research*. Washington, D.C.: The National Academies Press. Retrieved from <http://nap.edu/11153>
- Subero, G. (2016). *HIV in World Cultures: Three decades of representations*. Routledge.

10.0 Appendices

Appendix A: Ethics application documents

Appendix B: Online surveys

Appendix C: Interview transcripts

1 Professionals and activists

2 Workshop participants

**Appendix D: Ethics Issues for Canadian HIV/AIDS Researchers in
International Settings**

1.1 Study Identification

All questions marked by a **red asterisk *** are required fields. However, because the mandatory fields have been kept to a minimum, answering only the required fields may not be sufficient for the REB to review your application.

Please answer all relevant questions that will reasonably help to describe your study or proposed research.

- 1.0 *** Short Study Title** (restricted to 250 characters):
Nurturing empathy for social cohesion
- 2.0 *** Complete Study Title** (can be exactly the same as short title):
Nurturing empathy for social cohesion: Participatory design-based community research with gay youth living with HIV in Lebanon.
- 3.0 *** Select the appropriate Research Ethics Board** (Detailed descriptions are available by clicking the **HELP** link in the upper right hand corner of your screen):
REB 1
- 4.0 *** Is the proposed research:**
Unfunded
- 5.0 *** Name of Principal Investigator** (at the University of Alberta, Covenant Health, or Alberta Health Services):
[Bahaa Harmouche](#)
- 6.0 **Investigator's Supervisor** (required for applications from undergraduate students, graduate students, post-doctoral fellows and medical residents to Boards 1, 2, 3. HREB does not accept applications from student PIs)
[Susan Colberg](#)
- 7.0 *** Type of research/study:**
Graduate Student - Thesis, Dissertation, Capping Project
- 8.0 **Study Coordinators or Research Assistants:** People listed here can edit this application and will receive all HERO notifications for the study:
Name Employer
There are no items to display
- 9.0 **Co-Investigators:** People listed here can edit this application but do not receive HERO notifications unless they are added to the study email list:
Name Employer Employer.ID
There are no items to display
- 10.0 **Study Team** (Co-investigators, supervising team, other study team members): People listed here cannot edit this application and do not receive HERO notifications:
Last First Organization Role/Area of Responsibility Phone Email
Name Name
There are no items to display

1.5 Conflict of Interest

1.0

*** Are any of the investigators or their immediate family receiving any personal remuneration (including investigator payments and recruitment incentives but excluding trainee remuneration or graduate student stipends) from the funding of this study that is not accounted for in the study budget?**

☐ Yes ☒ No

If YES, explain:

2.0

*** Do any of investigators or their immediate family have any proprietary interests in the product under study or the outcome of the research including patents, trademarks, copyrights, and licensing agreements?**

☐ Yes ☒ No

3.0

*** Is there any compensation for this study that is affected by the study outcome?**

☐ Yes ☒ No

4.0

*** Do any of the investigators or their immediate family have equity interest in the sponsoring company? (This does not include Mutual Funds)**

☐ Yes ☒ No

5.0

*** Do any of the investigators or their immediate family receive payments of other sorts, from this sponsor (i.e. grants, compensation in the form of equipment or supplies, retainers for ongoing consultation and honoraria)?**

☐ Yes ☒ No

6.0

*** Are any of the investigators or their immediate family, members of the sponsor's Board of Directors, Scientific Advisory Panel or comparable body?**

☐ Yes ☒ No

7.0

*** Do you have any other relationship, financial or non-financial, that, if not disclosed, could be construed as a conflict of interest?**

☐ Yes ☒ No

If YES, explain:

Important

If you answered YES to any of the questions above, you may be contacted by



1.6 Research Locations and Other Approval

1.0

*** List the locations of the proposed research, including recruitment activities. Provide name of institution or organization, town, or province as applicable**

The proposed research will take place at the Proud Lebanon office (<http://www.proudlebanon.org>) in Beirut, Lebanon. Proud Lebanon is a non-profit, non-religious, non-political, non-partisan civil organization that aims to promote sustainable social and economic development in Lebanon and the region and is working to achieve protection, empowerment and equality of marginalized groups through community service activities.

A participatory design workshop will be part of the support group program created by Proud Lebanon. The location is key in this scenario, as participants trust and are accustomed to the Proud Lebanon space and staff.

Recruitment of participants will also be through Proud Lebanon due to the stigma related to HIV and the gay lifestyle viewed as illicit and sometimes illegal, in the Lebanese society, and the need to protect the identities of participants.

- 2.0** * Indicate if the study will use or access facilities, programmes, resources, staff, students, specimens, patients or their records, at any of the sites affiliated with the following (select all that apply):
Not applicable

List all facilities or institutions as applicable:

- 3.0** Multi-Institution Review

- * 3.1 Has this study already received approval from another REB?
☐ Yes ☒ No

- 4.0** Does this study involve pandemic or similar emergency health research?
☐ Yes ☒ No

If YES, are you the lead investigator for this pandemic study?
☐ Yes ☒ No

- 5.0** If this application is closely linked to research previously approved by one of the University of Alberta REBs or has already received ethics approval from an external ethics review board(s), provide the HERO study number, REB name or other identifying information. Attach any external REB application and approval letter in Section 7.1.11 – Other Documents.

2.1 Study Objectives and Design

- 1.0** Date that you expect to start working with human participants:
10/15/2016

- 2.0** Date that you expect to finish working with human participants, in other words, you will no longer be in contact with the research participants, including data verification and reporting back to the group or community:
11/30/2016

- 3.0** * Provide a lay summary of your proposed research suitable for the general public. If the PI is not affiliated with the University of Alberta, Alberta Health Services or Covenant Health, please include institutional affiliation.

The study proposes to examine if creating and presenting stories of gay youth living with HIV (GYLWH) will generate empathy and reduce stigma within the gay community in Lebanon.

The study will engage GYLWH (participants) during their support sessions conducted at Proud Lebanon offices. Proud is a non-profit organization that holds support group sessions for the gay community and especially for GYLWH. I (the researcher) will conduct a workshop involving participants GYLWH in a narrative design process to transform their real life stories into designed products with messages intended for their community and aimed at generating empathy and reducing stigma.

The workshop will introduce GYLWH participants to creative tools and exercises that will help their creative thinking process while working on reconstructing their narratives, choosing their messages and producing them as designed products such as (posters, videos, collages...).

I will be a facilitator during the workshop. Stories will be transformed into designed products and shown to voluntary participants of the Lebanese gay community for feedback collected by a survey.

4.0 * Provide a description of your research proposal including study objectives, background, scope, methods, procedures, etc). Footnotes and references are not required and best not included here. Research methods questions in Section 5 will prompt additional questions and information.

Background: Being a gay Lebanese man myself, and familiar with the society, I have always been involved in the gay community and the issues related to GYLWH. Since my undergrad studies, I have been committed to bringing awareness to health promotion and education concerning the social issues of HIV/AIDS to help the wider community better understand the issue and to reduce the stigma associated with this medical condition. Proud Lebanon founder (Bertho Makso) pointed out many factors contributing to the rise of HIV cases in the gay community (6% of claimed cases), mentioning the negative reaction of the gay community towards the GYLWH. One of the risks for the rise of HIV cases in the youth demographic is the fact that because youth cannot identify with the disease, they still think that they are unaffected and beyond the risk of contracting the virus. As being HIV positive and being gay are both taboos stigmatizing and marginalizing youth in the Middle East and North Africa (MENA) region, this leaves youth, specifically gay youth, in a vulnerable situation fighting for their lives in isolation with neither guidance nor support.

The proposed research is in response to an invitation from the founder of Proud Lebanon to help raise awareness of the HIV issue and reduce stigma especially in the gay community. The research uses a participatory, community design-based approach that will allow me to check the effect of products designed by marginalized GYLWH, providing tools and a platform to tell their stories staying anonymous and protecting the disclosure of their medical status.

Scope and Objective: The purpose of this study is to investigate the effectiveness of participatory design work with marginalized participants. The study has three primary objectives. 1) to develop a participatory design model that can be adopted by non-profit organizations dealing with stigmatized youth 2) to help stigmatized youth engage with their community through a creative process by sharing their stories in a designed products created by them, and finally 3) to evaluate the response of the recruited members of the Lebanese GY.

Research approach: This study will follow the principles of community-based research (CBR) mirroring the human-centred design process. To follow the principles of CBR there will be a partnership involving me (academic researcher), Proud Lebanon social workers/activist allies and the community members (marginalized GYLWH).

The partnership with the Proud Lebanon facilitates recruitment of participants and provide a “safe” working space for conducting the workshop and connect to the GYLWH members (Planning Stage).

Then comes the Production Stage by engaging participants in a design workshop to create messages and designed products such as (posters, videos, collages...).

Next the Feedback Stage involves the sharing of the designed products to recruited members of the GY Lebanese community.

Research Methods: The research uses qualitative methods. The research process will be divided into three phases following the the CBR principles and the creative design process. There will be three semi-structured interviews used at the planning stage, two semi-structured interviews with GYLWH participants after workshop completion, and a survey with the recruited members of the GY community for feedback on the designed products.

Research Procedure: Planning stage: This stage will consist of interviewing three professionals: a social worker (in this scenario the founder of Proud Lebanon), a prominent activist, and a physician specialized in infectious diseases (chair of the Department of Medicine at the Lebanese University). The interviews will allow the researcher to identify the main focus of the subject matter used in study and the problems and considerations that need to be highlighted.

Production stage: At this stage I will conduct the design workshop that will consist of 6 sessions, one session per week. Each session will be 3 hours long (like many studio design courses), with a break after each working hour. The decision of having one session a week is due to the pre-arranged schedule of the support group held once a week by Proud Lebanon. After the workshop I will interview participants to provide me with feedback on the workshop and its effect on GYLWH participants.

Feedback stage: This stage it is about showing the results of the production stage to GY and getting feedback on the designed products. The survey will provide information on the effects of designed products and the messages they convey.

During all stages participants identities (GYLWH and GY) will be protected at all time.

5.0 Describe procedures, treatment, or activities that are above or in addition to standard practices in this study area (eg. extra medical or health-related procedures, curriculum enhancements, extra follow-up, etc):

Prior to initiating my research, I will work on building relationship with the NGO, social workers, activists and connect to the LGBTQ community in Lebanon. This will help in facilitating the flow of the research and will provide deeper insights on the problems occurring in the community. Drawing on my professional history, I am volunteering by helping Proud Lebanon in creating a short movie showcasing their field work. This short movie will be projected during the International World Aids Day event in Beirut, Lebanon on the 1st of December, 2016.

6.0 If the proposed research is above minimal risk and is not funded via a competitive peer review grant or industry-sponsored clinical trial, the REB will require evidence of scientific review. Provide information about the review process and its results if appropriate.

7.0 For clinical research only, describe any sub-studies associated with this application.



3.1 Risk Assessment

1.0 * Provide your assessment of the risks that may be associated with this research:

Minimal Risk - research in which the probability and magnitude of possible harms implied by participation is no greater than those encountered by participants in those aspects of their everyday life that relate to the research (TCPS2)

2.0 * Select all that might apply:

Description of Potential Physical Risks and Discomforts

- No** Participants might feel physical fatigue, e.g. sleep deprivation
- No** Participants might feel physical stress, e.g. cardiovascular stress tests
- No** Participants might sustain injury, infection, and intervention side-effects or complications
- No** The physical risks will be greater than those encountered by the participants in everyday life

Potential Psychological, Emotional, Social and Other Risks and Discomforts

- Possibly** Participants might feel psychologically or emotionally stressed, demeaned, embarrassed, worried, anxious, scared or distressed, e.g. description of painful or traumatic events
- Possibly** Participants might feel psychological or mental fatigue, e.g. intense concentration required
- Possibly** Participants might experience cultural or social risk, e.g. loss of privacy or status or damage to reputation
- No** Participants might be exposed to economic or legal risk, for instance non-anonymized workplace surveys

No

The risks will be greater than those encountered by the participants in everyday life

3.0 * Provide details of the risks and discomforts associated with the research, for instance, health cognitive or emotional factors, socio-economic status or physiological or health conditions:

The risk to research participants is minimal and not greater than what they may experience during their group support session at Proud Lebanon office. This is why the location of the research has been chosen to take place at Proud Lebanon space, due to our consideration of the cultural and social stigma against HIV and being of a sexual/gender minority.

Topics may arise during the workshop session that may cause participants to feel emotionally stressed or embarrassed when they are working on their narratives. Participant will be sharing private subjects. They might recall unpleasant situations where they felt bullied or stigmatized, or even rejected after disclosing their HIV status.

As well participants might feel a bit mentally fatigued due to concentrating on trying to understand the design exercise or trying to figure out how to apply certain drawing techniques.

4.0 * Describe how you will manage and minimize risks and discomforts, as well as mitigate harm:

To manage the risk of emotional stress or embarrassments arising from recalling unpleasant memories it was clarified and written in the letter of invitation that the workshop will be held in the usual support group time for participant familiarity and trust of the location and staff (psychiatrist and CEO) .

As well Proud Lebanon protocol during support group sessions includes the mandatory presence of Proud Lebanon psychiatrist, first aid personnel and the CEO to ensure the wellbeing of the participants at any moment, and provide immediate help if needed.

The participants will be notified and reminded at the beginning of each session that they can withdraw from any session at any time without consequences, and in case of mental fatigue, they can stop the work and relax or even leave the session if necessary.

5.0 * If your study has the potential to identify individuals that are upset, distressed, or disturbed, or individuals warranting medical attention, describe the arrangements made to try to assist these individuals. Explain if no arrangements have been made:

As mentioned, it was agreed with Proud Lebanon that the staff psychiatrist, the CEO and trained social worker, will be present at the on location during the workshop sessions and survey testing, to provide counselling or medical help if needed.



3.2 Benefits Analysis

1.0 * Describe any potential benefits of the proposed research to the participants. If there are no benefits, state this explicitly:

Participants may benefit from the workshop that they will attend by 1) learning skills related to design process (photo collage, photography tips, narrative building...). 2) learning problem solving techniques and tools that may help them in any of their fields of practice (creative thinking, mind mapping) . 3) of course being in a support group session participants will feel free to talk about any of their personal life experiences that they cannot share outside of Proud's non-judgemental, safe space. Most importantly 4) empower them by engaging them with their community and expressing themselves in a creative way while protecting their identities.

2.0 * Describe the scientific and/or scholarly benefits of the proposed research:

This proposed research will generate knowledge about understanding the scope of community design-based research practice with marginalized, stigmatized youth in Lebanon (which may be applicable to other groups). The research will test the effect of designed products, created by marginalized groups and inspired from their personal experiences, with the aim of creating social empathy. As well it will help build a model for this practice that will be shared publicly through a research report, so it can be a reference for similar design research.

3.0 **Benefits/Risks Analysis: Describe the relationship of benefits to risk of participation in the research:**

This proposed research can be a good reference for building a participatory design model that can be adopted by non-profit organizations dealing with stigmatized youth. The research will attempt to empower stigmatized youth by trying to engage them with their community through a creative process, sharing their stories in a designed products created by them.

The research will also examine the effect of the designed products (e.g posters, digital storytelling or short movies) in creating empathy to reduce stigma.

In this proposed research, the risk of mental fatigue and emotional stress from recalling unpleasant memories remain minimal and controllable. Given this, the potential benefits of the research outweigh the risks.



4.1 Participant Information

1.0 *** Who are you studying? Describe the population that will be included in this study.**

I will conduct the research with 3 main groups:

Group 1: 3 to 5 voluntary participants, gay Lebanese youth living with HIV (GYLWH), registered at Proud Lebanon. The GYLWH will work on representing their stories about living with HIV in a designed products (e.g posters, digital storytelling or short movies).

Group 2: 5 to 10 voluntary participants, Lebanese gay youths (GY) living in Lebanon, that will give feedback on the effect of the designed products.

Group 3: Field experts; activists, social workers and a doctor, to get their opinions on the relationship between the gay community and GYLWH in Lebanon.

2.0 *** Describe the inclusion criteria for participants (e.g. age range, health status, gender, etc.). Justify the inclusion criteria (e.g. safety, uniformity, research methodology, statistical requirement, etc)**

Group 1: GYLWH participants should be Lebanese, gay male youth, living in Lebanon, between the ages of 18 to 26, living with HIV and feeling marginalized by their community.

Group 2: GY participants, should be Lebanese, gay male youth, living in Lebanon, between the ages 18 to 26 and from various demographics backgrounds.

Group 3: Should be experienced in the field of research, have worked with the gay community in Lebanon and have some insight about the stigma happening in the gay community.

3.0 **Describe and justify the exclusion criteria for participants:**

Due to the rise of stigma and marginalization of Group1 (GYLWH) by Group 2 (GY) in the Lebanese gay community, my focus is specifically on those two groups.

Group 1: Any other nationality, age group, gender or sexual categories are excluded from this study.

Group 2: Any other nationality, age group, gender or sexual categories are excluded from this study.

Group 3: non-experts in the medical field, activists or social workers without experience and close work with the gay community, are excluded from this study.

4.0 **Does the research specifically target aboriginal groups or communities?**

☐ Yes ☒ No

5.0

*** Will you be interacting with human subjects, will there be direct contact with human participants, for this study?**

☒ Yes ☐ No

Will you be obtaining data from human participants (ie. Internet survey responses from human participants)?

☒ Yes ☐ No

*** Does this project SOLELY involve a review of health data (ie. Chart review, analysis of health data held in an electronic chart/database/repository, review of administrative health data)?**

☐ Yes ☒ No

6.0

Participants

How many participants do you hope to recruit (including controls, if applicable)

20

Of these how many are controls, if applicable (Possible answer: Half, Random, Unknown, or an estimate in numbers, etc).

If this is a multi-site study, for instance a clinical trial, how many participants (including controls, if applicable) are expected to be enrolled by all investigators at all sites in the entire study?

7.0

Justification for sample size:

The ideal number would be 5 voluntary participants for Group 1 (GYLWH), 10 voluntary participants for Group 2 (GY) and 5 voluntary participants for Group 3 (Field Experts). The minimum number of participants needed will preferably be as follows:

Group 1: The sample of the size of Lebanese GYLWH would ideally be 5 but no less than 3 participants, to be able to have 3 different stories of GYLWH from various demographics, to showcase the multiple form of stigma that is taking place in the Lebanese gay community.

Group 2: The sample of the size of Lebanese GY would ideally be 10 but no less than 5 to get as much feedback as possible on the designed products and its' effect on the target group.

Group 3: The sample of the size of field experts would ideally be 5 but no less than 3 to get data from 3 different field studies, activists, social worker and a doctor.



4.3 Recruit Potential Participants

1.0

Recruitment

*** 1.1 Describe how you will identify potential participants (please be specific as to how you will find potentially eligible participants i.e. will you be screening AHS paper or electronic records, will you be looking at e-clinician, will you be asking staff from a particular area to let you know when a patient fits criteria, will you be sitting in the emergency department waiting room, etc.)**

The recruitment of gay youth living with HIV (GYLWH) and gay youth members (GY) will be through Proud Lebanon (non profit organization). As mentioned Proud Lebanon will provide me with a list of voluntary interested members, who will call me directly before the start of the workshop sessions.

At the recruitment stage Proud Lebanon will inform voluntary members to choose a pseudonym before calling me, to give all participants the freedom not to disclose their identity with researcher. The chosen pseudonym, will be used all through the research process.

Proud will provide me as well with a list of interested participants for Group 3 (Field experts) by providing me with their names and emails.

1.2 Once you have identified a list of potentially eligible participants, indicate how the potential participants' names will be passed on to the researchers AND how will the potential participants be approached about the research.

Proud will provide me with the list of voluntary members (pseudonyms in this case) and they will call me directly for a debrief on the type of workshop and survey they will take part of. This will be for both Group 1 (GYLWH) and Group 2 (GY).

For Group 3 (Field Experts) participants will be contacted by email. Email addresses of interested participants will be provided by Proud Lebanon.

1.3 How will people obtain details about the research in order to make a decision about participating? Select all that apply:

Potential participants will contact researchers

Researchers will contact potential participants

Contact will be made through an third party or intermediary (including snowball sampling)

1.4 If appropriate, provide the locations where recruitment will occur (e.g schools, shopping malls, clinics, etc.)

2.0

Pre-Existing Relationships

2.1 Will potential participants be recruited through pre-existing relationships with researchers (e.g. Will an instructor recruit students from his classes, or a physician recruit patients from her practice? Other examples may be employees, acquaintances, own children or family members, etc)?

☐ Yes ☒ No

2.2 If YES, identify the relationship between the researchers and participants that could compromise the freedom to decline (e.g. professor-student). How will you ensure that there is no undue pressure on the potential participants to agree to the study?

3.0

Outline any other means by which participants could be identified, should additional participants be needed (e.g. response to advertising such as flyers, posters, ads in newspapers, websites, email, listservs; pre-existing records or existing registries; physician or community organization referrals; longitudinal study, etc)

4.0

Will your study involve any of the following (select all that apply)?
None of the above



4.4 Third Party or Intermediary Contact Methods

1.0

If contact will be made through an intermediary (including snowball sampling), select one of the following:

Intermediary provides information to potential participants who then contact the researchers

2.0

Explain why the intermediary is appropriate and describe what steps will be taken to ensure participation is voluntary:

The intermediary is more appropriate in this kind of proposed research because 1) Proud has a bigger more focused database of potential participants of GYLWH and GY, 2) to provide the potential participants the freedom of decision to call or not, as a voluntary act, without constraint or coercion.

3) Due to the sensitivity of the topic, a field expert in the gay community is highly advised to protect participants' identity.

1.0

*** Describe who will provide informed consent for this study (select all that apply). Additional information on the informed consent process is available at: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter3-chapitre3/#toc03-intro>**

All participants have capacity to give free and informed consent

Provide justification for requesting a Waiver of Consent (Minimal risk only, additional guidance available at:

<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter3-chapitre3/#toc03-1b>

2.0

How is participant consent to be indicated and documented? Select all that apply:

Signed consent form

Except for "Signed consent form" use only, explain how the study information will be communicated and participant consent will be documented. Provide details for EACH of the option selected above:

3.0

Authorized Representative, Third Party Consent, Assent

3.1 Explain why participants lack capacity to give informed consent (e.g. age, mental or physical condition, etc.).

3.2 Will participants who lack capacity to give full informed consent be asked to give assent?

☐ Yes ☐ No

Provide details. IF applicable, attach a copy of assent form(s) in the Documentation section.

3.3 In cases where participants (re)gain capacity to give informed consent during the study, how will they be asked to provide consent on their own behalf?

4.0

What assistance will be provided to participants, or those consenting on their behalf, who have special needs? (E.g. non-English speakers, visually impaired, etc):

Even though Lebanese society uses 2 or 3 languages in their education system (Arabic, English and French), in the case of non-English speaking participants, a copy of an Arabic information letter and consent form will be prepared for them to sign. I am from the same country and Lebanese Arabic is my first language. I can easily and clearly communicate with participants in their mother tongue.

In case of special needs, the researcher will ensure that all the necessary assistance will be available. Mobility impaired participants will be provided with an easy access.

5.0

*** If at any time a participant wishes to withdraw, end, or modify their participation in the research or certain aspects of the research, describe how their participation would be ended or changed.**

Participants may withdraw from any research activity at any time during the study without any consequences.

Participants GYLWH can withdraw at anytime if they feel discomfort. In case of withdrawal, I would ask whether participants wanted their collected visual artwork data withdrawn from the database and excluded from the study. If they did, their data would be withdrawn, and all participants' designed products, belonging to the withdrawn participant, will be packed in an envelope and left at Proud Lebanon office for them to collect. The designed products produced by GYLWH will not reveal their identities at any point during research. Participants identities will be protected at all times.

6.0

Describe the circumstances and limitations of data withdrawal from the study, including the last point at which it can be done:

For semi-structured interviews with GYLWH or expert activists, social workers and medical doctor, participants may request that their data be

Test Name Test Administrator Organization Administrator's Qualification the thesis document.

GYLWH participants data of workshop can be withdrawn at any time up until testing of the designed products with GY. The testing of the feedback is dependent on the design work done by GYLWH after the workshop. Therefore, GYLWH will have until the reflection stage to withdraw their designed products.

Participants will answer the survey anonymously, on computers/tablets present on location, without any name or pseudonym to identify them. The GY group cannot withdraw their data because of the anonymous survey style.

7.0

Will this study involve any group(s) where non-participants are present? For example, classroom research might involve groups which include participants and non-participants.

☐ Yes ☒ No



5.1 Research Methods and Procedures

Some research methods prompt specific ethic issues. The methods listed below have additional questions associated with them in this application. If your research does not involve any of the methods listed below, ensure that your proposed research is adequately described in Section 2.0: Study Objectives and Design or attach documents in Section 7.0 if necessary.

1.0

*** This study will involve the following (select all that apply)**

The list only includes categories that trigger additional page(s) for an online application. For any other methods or procedures, please indicate and describe in your research proposal in the Study Summary, or provide in an attachment:

Interviews (eg. in-person, telephone, email, chat rooms, etc)

Surveys and Questionnaires (including internet surveys)

Community-based Research

Participatory Action Research

Materials created by participants (eg. artwork, writing samples, etc)

2.0

*** Is this study a Clinical trial? (Any investigation involving participants that evaluates the effects of one or more health-related interventions on health outcomes?)**

☐ Yes ☒ No

3.0

If you are using any tests in this study diagnostically, indicate the member(s) of the study team who will administer the measures/instruments:

Test Name Test Administrator Organization Administrator's Qualification

There are no items to display

4.0

If any test results could be interpreted diagnostically, how will these be reported back to the participants?



5.6 Sound or Image (other than audio- or video-recorded interviews) or Material Created by Participants

1.0

Explain if consent obtained at the beginning of the study will be sufficient, or if it will be necessary to obtain consent at different times, for different stages of the study, or for different types of data:
It will be necessary to obtain consent from each group at the beginning of each method.

Experts Interviews, GYLWH workshop, GYLWH interviews and GY survey
As well it is important to explain the research process, background, and objectives, and give participants a copy of this information.

- 2.0 At what stage, if any, can a participant withdraw his/her material?**
Participants of the semi-structured interviews may request that their data, in the form of verbal comments, be withdrawn up to the preparation of the thesis document.

At the production stage, GYLWH during the workshop can withdraw their material at any time without consequences. The designed products will not reveal their identities.

As for the feedback stage GYLWH cannot retrieve their materials as the feedback and data collection will be related to their designed products.

The GY survey participants cannot withdraw their answers to the survey because they are anonymous and we will never know who answered what.

- 3.0 If you or your participant's audio- or video-records, photographs, or other materials artistically represent participants or others, what steps will you take to protect the dignity of those that may be represented or identified?**
Photos of participants will not be taken without their permission. The only way to show participants is by hiding their identification. I am aware of the society and cultural stigma against sexual minority and HIV. This matter will be clarified at the beginning of the group workshop. Therefore the consent will clarify that photos will be taken while concealing their identities, I will make sure to obscure recognizable features. I belong to the same community and I am fully aware of the consequences should identities revealed. That goes for both groups GYLWH and GY.

The designed products will be created without revealing the participants identities.

- 4.0 Who will have access to this data? For example, in cases where you will be sharing sounds, images, or materials for verification or feedback, what steps will you take to protect the dignity of those who may be represented or identified?**
Only the researcher and the supervisor will access the data.

Collected data will be shown in the Master's exhibition, thesis document and public presentations. Participants will only be identified by their chosen pseudonym. Participants will be informed by Proud the day of recruitment to choose the desired pseudonym (different then their real initials/names) for identification purpose during the research stage and into the thesis material.

- 5.0 When publicly reporting data or disseminating results of your study (eg presentation, reports, articles, books, curriculum material, performances, etc) that include the sounds, images, or materials created by participants you have collected, what steps will you take to protect the dignity of those who may be represented or identified?**
Collected data may be shown in the Master's exhibition, thesis document, reports and public presentations. Participants will only be identified by with their chosen pseudonyms.

Should the researcher quote any of their comments, researcher will use their chosen pseudonyms to ensure anonymity. Data will be kept in a secure place for 5 years following completion of the research, electronic data will be password protected and devices will be encrypted.

- 6.0 What opportunities are provided to participants to choose to be identified as the author/creator of the materials created in situations where it makes sense to do so?**
With the expert interviews, participants who choose to be identified may fill out a consent form.

The workshop and interviews with GYLWH participants will only be identified by pseudonyms (chosen by them) to ensure anonymity.

In the survey, participants will not be identified as the nature of the survey answers is anonymous.

- 7.0 If necessary, what arrangements will you make to return original materials to participants?**
The material will be sent to Proud Lebanon CEO, in an envelope with the designated pseudonym on the envelopes. The CEO will contact participants and will keep the envelopes secured in his office until participants collect them from Proud Lebanon office. As I will not collect participants' addresses, materials will be secured at Proud Lebanon office. All measures will be taken to protect participants' identities.



5.7 Interviews, Focus Groups, Surveys and Questionnaires

- 1.0 Are any of the questions potentially of a sensitive nature?**
☒ Yes ☐ No
- If YES, provide details:**
I will ask GYLWH during the workshop to talk about their experiences in the community, some emotional reactions may occur especially while recalling unpleasant memories of social stigma, or even failure of relationships because of disclosure of their HIV status.
- 2.0 If any data were released, could it reasonably place participants at risk of criminal or civil law suits?**
☐ Yes ☒ No
- If YES, provide the justification for including such information in the study:**
- 3.0 Will you be using audio/video recording equipment and/or other capture of sound or images for the study?**
☒ Yes ☐ No
- If YES, provide details:**
Audio recording will be used only to collect and analyze data in the semi-structured interviews. Audio recording will not be used in the Master's thesis exhibition and/or other presentations.



6.1 Data Collection

- 1.0 * Will the researcher or study team be able to identify any of the participants at any stage of the study?**
☒ Yes ☐ No
- 2.0 Will participants be recruited or their data be collected from Alberta Health Services or Covenant Health or data custodian as defined in the Alberta Health Information Act?**
☐ Yes ☒ No
- Important:** Research involving health information must be reviewed by the Health Research Ethics Board.
- 3.0 Primary/raw data collected will be (check all that apply):**
Anonymous - the information **NEVER** had identifiers associated with it (eg anonymous surveys) and risk of identification of individuals is low or very low
All personal identifying information removed (anonymized)
- 4.0 If this study involves secondary use of data, list all original sources:**

- 5.0 In research where total anonymity and confidentiality is sought but cannot be guaranteed (eg. where participants talk in a group) how will confidentiality be achieved?**
Participants will be assigned pseudonyms (eg. participant 1 or their chosen pseudonym) to maintain confidentiality. In addition, even though participants in the workshop (group session) might already know each other from previous support group sessions, participants will be reminded that they can keep confidential their identities during the workshop if they wish.



6.2 Data Identifiers

- 1.0** *** Personal Identifiers:** will you be collecting - at any time during the study, including recruitment - any of the following (*check all that apply*):
- Surname and First Name
Email Address
Age at time of data collection
- If OTHER, please describe:**
Pseudonyms will be chosen by participants for the group workshop. Participants who wish to keep their identities anonymous during the research process will use the pseudonym.
- 2.0** **Will you be collecting - at any time of the study, including recruitment of participants - any of the following (*check all that apply*):**
- There are no items to display
- If OTHER, please describe:**
- 3.0** *** If you are collecting any of the above, provide a comprehensive rationale to explain why it is necessary to collect this information:**
Pseudonyms will be chosen by the participants at the recruitment stage. Proud Lebanon CEO will ask participants to choose their own pseudonyms that will be used all through the research in order to protect their identities.
- The researcher will collect participants' ages to make sure that they fit the youth category in study.
- Proud will provide me with the emails and the names of potential field experts to interview, which will be my first mean of contact to the experts. Expert participants' names might be collected if they would like to be acknowledged for their participation in the research only after they sign the acknowledgement consent form. As for their emails, it will be good to have it incase I needed to touch base with them when I am back in Canada.
- 4.0** **If identifying information will be removed at some point, when and how will this be done?**
No identification will be added in any form, pseudonyms will be used throughout all published material, exhibitions and reports.
- If participants want to be acknowledged for designed products their chosen pseudonym will be used.
- 5.0** *** Specify what identifiable information will be RETAINED once data collection is complete, and explain why retention is necessary. Include the retention of master lists that link participant identifiers with de-identified data:**
All data collected will remain unidentified, ensuring the anonymity of the participants' identity especially GYLWH and GY, it is a very important criterion in conducting the proposed research.
- For the expert interviews, the data will be remain unidentified unless the expert participants sign the acknowledgment consent.

- 6.0 If applicable, describe your plans to link the data in this study with data associated with other studies (e.g within a data repository) or with data belonging to another organization:



6.3 Data Confidentiality and Privacy

- 1.0 * How will confidentiality of the data be maintained? Describe how the identity of participants will be protected both during and after research.

Protecting the anonymity of all people and treating them with courtesy and respect is essential in the proposed research. The privacy of all individuals involved in this research will be respected at all times.

Due to the nature of the group setting in the workshop anonymity cannot be guaranteed, however confidentiality will be discussed at the beginning of each and every research stage.

Participants will be informed that everything said in and done in the workshop will only be identified by pseudonyms. After the workshop all data will be documented using the chosen pseudonym.

As for the survey the participants will answer questions on computers and tablets set on location without any identification.

- 2.0 How will the principal investigator ensure that all study personnel are aware of their responsibilities concerning participants' privacy and the confidentiality of their information?

The researcher has no study personnel.

- 3.0

External Data Access

- * 3.1 Will identifiable data be transferred or made available to persons or agencies outside the research team?

☐ Yes ☒ No

3.2 If YES, describe in detail what identifiable information will be released, to whom, why they need access, and under what conditions? What safeguards will be used to protect the identity of subjects and the privacy of their data.

3.3 Provide details if identifiable data will be leaving the institution, province, or country (eg. member of research team is located in another institution or country, etc.)



6.4 Data Storage, Retention, and Disposal

- 1.0 * Describe how research data will be stored, e.g. digital files, hard copies, audio recordings, other. Specify the physical location and how it will be secured to protect confidentiality and privacy. (For example, study documents must be kept in a locked filing cabinet and computer files are encrypted, etc. Write N/A if not applicable to your research)

Visual, verbal and written data will be collected, documented and stored on an external hard-drive, with password protected encryption, and stored in a locked safe. The safe will remain at the researcher's dwelling.

- 2.0 * University policy requires that you keep your data for a minimum of 5 years following completion of the study but there is no limit on data retention. Specify any plans for future use of the data. If the data will become part of a data repository or if this study involves the creation of a research database or registry for future research use, please provide details. (Write N/A if not applicable to your research)

Data will be used for the Master of Design thesis document exhibition and in research papers. Data will be destroyed after 5 years following completion of study.

3.0

If you plan to destroy your data, describe when and how this will be done? Indicate your plans for the destruction of the identifiers at the earliest opportunity consistent with the conduct of the research and/or clinical needs:

Data collected will be destroyed, and digital files will be erased after 5 years following completion of study.



7.1 Documentation

Add documents in this section according to the headers. Use Item 11.0 "Other Documents" for any material not specifically mentioned below.

Sample templates are available in the REMO Home Page in the [Forms and Templates](#), or by clicking [HERE](#).

1.0 Recruitment Materials:

Document Name	Version	Date	Description
Experts first contact Email Script History	0.01	9/27/2016 3:49 PM	

2.0 Letter of Initial Contact:

Document Name	Version	Date	Description
letter of invitation from Proud Lebanon History	0.01	9/22/2016 6:57 PM	

3.0

Informed Consent / Information Document(s):

3.1 What is the reading level of the Informed Consent Form(s):
Grade 8

3.2 Informed Consent Form(s)/Information Document(s):

Document Name	Version	Date	Description
Experts letter of information and consent forms History	0.02	9/27/2016 2:38 PM	
GYLWH Interview letter of information and consent form History	0.02	9/27/2016 2:40 PM	
GYLWH workshop letter of information and consent form History	0.01	9/22/2016 7:01 PM	
GY Survey letter of information and consent form History	0.01	9/22/2016 7:02 PM	

4.0 Assent Forms:

Document Name	Version	Date	Description
There are no items to display			

5.0 Questionnaires, Cover Letters, Surveys, Tests, Interview Scripts, etc.:

Document Name	Version	Date	Description
Experts' Interview script History	0.02	9/27/2016 2:31 PM	
GY survey History	0.01	9/22/2016 7:04 PM	
GYLWH Interview script History	0.02	9/27/2016 2:33 PM	

6.0 Protocol:

Document Name	Version	Date	Description
GYLWH Workshop Content History	0.01	9/22/2016 7:06 PM	

7.0 Investigator Brochures/Product Monographs (Clinical Applications only):

Document Name	Version	Date	Description
There are no items to display			

8.0 Health Canada No Objection Letter (NOL):

Document Name	Version	Date	Description
There are no items to display			

9.0 Confidentiality Agreement:

Document Name	Version	Date	Description
There are no items to display			

10.0 Conflict of Interest:

Document Name	Version	Date	Description
There are no items to display			

11.0 Other Documents:

For example, Study Budget, Course Outline, or other documents not mentioned above

Document Name	Version	Date	Description
Arabic registration of Proud Lebanon History	0.01	9/22/2016	7:08 PM
English registration translation of Proud Lebanon History	0.01	9/22/2016	7:09 PM



Final Page

You have completed your ethics application! Please select "Exit" to go to your study workspace.

This action will NOT SUBMIT the application for review.

Only the Study Investigator can submit an application to the REB by selecting the "SUBMIT STUDY" button in My Activities for this Study ID: Pro00067905 .

You may track the ongoing status of this application via the study workspace.

Please contact the REB Coordinator with any questions or concerns.

INFORMATION LETTER

Group Workshop / GYLWH

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator:

Bahaa Harmouche
3-71 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
harmouch@ualberta.ca
+1 250 826077 (Canada)
+961 70 833109 (Lebanon)

Supervisor:

Susan Colberg,
3-98 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
scolberg@ualberta.ca
+1 780 492 7859

Background

- You are being asked to participate in this research because you represent the gay youth living with HIV (GYLWH) community. Your experience living with HIV will help in understanding the stigma attached to it.
- The results of this study will be used in support of my Master's thesis document and exhibition.
- Research participants include Lebanese social workers, activists, doctor, gay youth (GY) and gay youth living with HIV (GYLWH) in Lebanon.

Purpose

- This workshop (the research) aims to develop an effective participatory design model that can be adopted by non-profit organization dealing with stigmatized youth.
- The research will explore means to engage stigmatized youth living with HIV with their community in a creative process to share their stories through a designed products.
- The research will evaluate the effect of the designed stories on nurturing empathy to reduce stigma.

Study Procedures

- **You are being asked to participate in a narrative design-based workshop reflecting on your experience living with HIV. You will be participating in total 6 design/creative sessions. Sessions will be conducted once a week. The duration of each session is around 3 hours with a 10 minutes break every hour, and you are free to leave at anytime during the session. You will learn to creative thinking exercises and tools to help you construct your messages and stories in digital form. I ask your permission to take photos of you working. With your consent, photos will be taken and used while concealing your identity. You may request that your comments and work be withdrawn from the research before January 5, 2017 until the time of the testing stage of your work, as the testing is based on the workshop's designed products.**

(For your information, in addition to the workshop, I interviewed field experts; activists, social workers and a doctor, to get their opinions on the relationship between the gay community and GYLWH in Lebanon. At the end of the workshop, the designed products will be shown to GY for feedback on testing the effect of the products in generating empathy.)

Benefits

- Adding to the existing body of knowledge in design-based community research with marginalized/stigmatized youth in Lebanon.
- Evaluating the effect of storytelling in generating empathy for reducing stigma and producing sexual health education among youth in the gay community.

- Building a model for this practice that will be shared through a research document, so it can serve as reference for similar design research projects.
- Trying to create integration GLWH and GY communities in Lebanon.

Risk

- The risk to participants is minimal and no greater than what may be expected during regular discussions around gay community concerns and issues in daily life.
- There may be risks to being in this study that are unknown. If anything arises during the research that may affect your willingness to continue being in the study, you will be informed immediately.

Voluntary Participation

- Participating in this research is completely voluntarily and has no penalty or gain attached to it.
- You are under no obligation to participate in this study.
- Even if you agree to be in the study you can change your mind and withdraw without consequence your comments up to the time of the thesis document preparation.
- You may request that your comments and work be withdrawn from the research before January 5, 2017 until the time of the testing stage of your work.

Confidentiality

- Collected data may be shown in my Master's thesis document and exhibit, public presentations and in written articles.
- You will not be identified by name in the exhibit and thesis document, public presentations and in written articles.
- If it is necessary to use quotation, a pseudonym chosen by you will be used.
- Data will be kept in a secure location for 5 years following completion of research project, electronic data will be password-protected and devices will be encrypted. Data will be destroyed after 5 years.
- The data for all uses will be handled in compliance with the UofA standards.

If you would like to have a copy of my final research document, please contact me at harmouch@ualberta.ca

Further Information

- If you have further questions regarding this study, please do not hesitate to contact me, Bahaa Harmouche at harmouch@ualberta.ca, or my graduate supervisor Susan Colberg at scolberg@ualberta.ca
- The Research Ethics Board at the University of Alberta has reviewed the research plan, for its adherence to ethical guidelines. For questions regarding participants' rights and ethical conduct of research, contact the Research Ethics Office at (780) 492 2615. This office has no direct involvement with this project.

CONSENT FORM

Group Workshop / GYLWH

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109 Lebanon / +1 250 826077 Canada

Do you understand that you have been asked to be in a research study?	Yes	NO
Have you read and received a copy of the attached Information Sheet?	Yes	NO
Do you understand the benefits and risks involved in taking part in this research?	Yes	NO
Have you had an opportunity to ask questions and discuss this research?	Yes	NO
Do you understand that you are free to refuse to participate, or to withdraw from the research activity at any time, without consequence?	Yes	NO
Do you understand that you can change your mind after you participate, and withdraw your comments up to the time of preparation of the thesis document?	Yes	NO
Has the issue of confidentiality been explained to you?	Yes	NO
Do you understand who will have access to your information?	Yes	NO
Do you understand that anonymity cannot be guaranteed within a group and/or workshop setting?	Yes	NO
Do I have your permission to take photos of you working, while concealing your identities?	Yes	NO
Do you understand that you will be identified by your chosen pseudonym only?	Yes	NO

This study was explained to me by Bahaa Harmouche

I have read and understood the attached information letter and agree to take part in this study:

Pseudonym of Participant:

Signature of Participant:

Date (yyyy-mm-dd):

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator:

Date (yyyy-mm-dd):

You will receive a signed copy of this form to keep

INFORMATION LETTER

Semi-Structured Interview / GYLWH

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator:

Bahaa Harmouche
3-71 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
harmouch@ualberta.ca
+1 250 826077 (Canada)
+961 70 833109 (Lebanon)

Supervisor:

Susan Colberg,
3-98 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
scolberg@ualberta.ca
+1 780 492 7859

Background

- You are being asked to participate in this research because you represent the gay youth living with HIV (GYLWH) community. Your experience living with HIV will help in understanding the stigma attached to it.
- The results of this study will be used in support of my Master's thesis document and exhibition.
- Research participants include Lebanese social workers, activists, doctor, gay youth (GY) and gay youth GYLWH in Lebanon.

Purpose

- The research aims to develop a participatory design model (through the workshop conducted with GYLWH) that can be adopted by non-profit organizations dealing with stigmatized youth.
- The research will explore means to engage stigmatized youth living with HIV with their community in a creative process to share their stories through a designed products.
- The research will evaluate the effect of the designed stories on nurturing empathy to reduce stigma.

Study Procedures

- **You are being asked to participate in a semi-structured interview to give comments about your experience in the workshop. Your feedback will help in refining the content and the aim of the workshop for future use. The duration of the interview is around 40 minutes and you are free to leave at anytime during the discussion. You may request that your comments be withdrawn from the research up to January 5, 2017 the time of preparation of the thesis document. Please note that audio recording in the semi-structured interview will only be used to collect and analyze data, and that I will NOT use the recording in the Master's thesis exhibition and/or other presentations.**

(For your information, in addition to semi-structured interviews with you, I interviewed field experts; activists, social workers and a doctor, to get their opinions on the relationship between the gay community and GYLWH in Lebanon. As you know I conducted a workshop involving GYLWH participants in a narrative design process to transform their "real life" stories into creative designed products. The workshop introduced GYLWH participants to creative tools and exercises that helped their thinking process while working on constructing their narratives, choosing their messages and turning them in to designed products such as posters, videos or collages. The designed products will be shown to GY for feedback on testing the effect of the products in generating empathy.)

Benefits

- Adding to the existing body of knowledge in design-based community research with marginalized/stigmatized youth in Lebanon.

- Evaluating the effect of storytelling in generating empathy for reducing stigma and producing sexual health education among youth in the gay community.
- Building a model for this practice that will be shared through a research document, so it can serve as reference for similar design research projects.
- Trying to create integration GLWH and GY communities in Lebanon.

Risk

- The risk to participants is minimal and no greater than what may be expected during regular discussions around gay community concerns and issues in daily life.
- There may be risks to being in this study that are unknown. If anything arises during the research that may affect your willingness to continue being in the study, you will be informed immediately.

Voluntary Participation

- Participating in this research is completely voluntarily and has no penalty or gain attached to it.
- You are under no obligation to participate in this study.
- Even if you agree to be in the study you can change your mind and withdraw without consequence your comments up to the time of the thesis document preparation.
- You may request that your comments be withdrawn from the research up to January 5, 2017 the time of preparation of the thesis document.

Confidentiality

- Collected data may be shown in my Master's thesis document and exhibit, public presentations and in written articles.
- You will not be identified by name in the exhibit and thesis document, public presentations and in written articles.
- If it is necessary to use quotation, a pseudonym chosen by you will be used.
- Audio recording will only be used to collect and analyze data in the semi-structured interview. Audio recording will not be used in the Master's thesis exhibition and/or other presentations.
- Data will be kept in a secure location for 5 years following completion of research project, electronic data will be password-protected and devices will be encrypted. Data will be destroyed after 5 years.
- The data for all uses will be handled in compliance with the UofA standards.

If you would like to have a copy of my final research document, please contact me at harmouch@ualberta.ca

Further Information

- If you have further questions regarding this study, please do not hesitate to contact me, Bahaa Harmouche at harmouch@ualberta.ca, or my graduate supervisor Susan Colberg at scolberg@ualberta.ca
- The Research Ethics Board at the University of Alberta has reviewed the research plan, for its adherence to ethical guidelines. For questions regarding participants' rights and ethical conduct of research, contact the Research Ethics Office at (780) 492 2615. This office has no direct involvement with this project.

CONSENT FORM

Semi-Structured Interview / GYWLH

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109 Lebanon / +1 250 826077 Canada

Do you understand that you have been asked to be in a research study?	Yes	NO
Have you read and received a copy of the attached Information Sheet?	Yes	NO
Do you understand the benefits and risks involved in taking part in this research?	Yes	NO
Have you had an opportunity to ask questions and discuss this research?	Yes	NO
Do you understand that you are free to refuse to participate, or to withdraw from the research activity at any time, without consequence?	Yes	NO
Do you understand that you can change your mind after you participate, and withdraw your comments up to January 5, 2017 the time of preparation of the thesis document?	Yes	NO
Has the issue of confidentiality been explained to you?	Yes	NO
Do you understand that you will be identified by your chosen pseudonym only?	Yes	NO
Do you understand who will have access to your information?	Yes	NO
Do you understand that audio recording in the semi-structured interview will only be used to collect and analyze data, and that I will NOT use the recording in the Master's thesis exhibition and/or other presentations?	Yes	NO

This study was explained to me by Bahaa Harmouche

I have read and understood the attached information letter and agree to take part in this study:

Pseudonym of Participant:

Signature of Participant:

Date (yyyy-mm-dd):

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator:

Date (yyyy-mm-dd):

You will receive a signed copy of this form to keep

INTERVIEW SCRIPT

Semi-Structured Interview / GYWLH

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109 Lebanon / +1 250 826077 Canada

Supervisor: Susan Colberg, 3-98 Fine Arts Building University of Alberta Edmonton, Alberta, T9G 2C9 scolberg@ualberta.ca, +1 780 492 7859

Hello,

Thank you for your participation, the responses received may be shown at the master's thesis exhibition and report, as well as other presentations and written articles. The research aims to develop an effective participatory design model that can be adopted by non-profit organizations dealing with stigmatized youth. The research will explore means to engage stigmatized youth living with HIV their community in a creative process to share their stories through designed products. The research will evaluate the effect of the designed stories on nurturing empathy to reduce stigma.

In addition to semi-structured with you, I interviewed field experts; activists, social workers and doctor, to get their opinion on the chemistry between the gay community in Lebanon and the GLWHI. Because you were part of the workshop that was done few weeks ago, you are being asked to participate in a semi-structured interview to give your opinion on your experience in the workshop. Your feedback will help in refining the content and the aim of the workshop for future use. The designed products will be shown for feedback on testing the effect of the products in generating empathy.

The risks of participating in this semi-structured interview are minimal. The interview will take around 40 minutes. Please note that your participation is completely voluntary, and you are free to leave at any time during the discussion without consequence. There is an audio recording of your responses, but it will only be used to collect and analyze data. You are free to ask me to withdraw your data from the study up to January 5, 2017 the time of preparation of the thesis document. Your information will remain anonymous, and will be identified by your chosen pseudonym if needed.

Do you have any questions regarding the study?

1. Let's begin our discussion
2. Which part in the workshop you liked the most? Why?
3. Would you change anything about the process? Why?
4. What were the benefits of the workshop?
5. Would you recommend this workshop to friends?

Do you have any comments?

Thank you for your participation, the responses received may be shown at in the Master's thesis exhibition and document, as well as other presentations and written articles using your chosen pseudonym only.

INFORMATION LETTER

Semi-Structured Interview / Activists, social workers and doctor

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator:

Bahaa Harmouche
3-71 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
harmouch@ualberta.ca
+1 250 826077 (Canada)
+961 70 833109 (Lebanon)

Supervisor:

Susan Colberg,
3-98 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
scolberg@ualberta.ca
+1 780 492 7859

Background

- You are being asked to participate in this research because of your experience with/understanding of activism with the Lebanese gay community will help me understand the cause of stigma related to community members living with HIV.
- The results of this study will be used in support of my Master's thesis document and exhibition.
- Research participants include Lebanese social workers, activists, doctor, gay youth (GY) and gay youth living with HIV (GYLWH) in Lebanon.

Purpose

- The research aims to develop a participatory design model (through the workshop conducted with GYLWH) that can be adopted by non-profit organizations dealing with stigmatized youth.
- The research will explore means to engage stigmatized youth living with HIV with their community in a creative process to share their stories through a designed products.
- The research will evaluate the effect of the designed stories on nurturing empathy to reduce stigma.

Study Procedures

- **You are being asked to participate in a semi-structured interview concerning the cause of stigma against GYLWH from within the gay community. The duration of the interview is around 30 minutes and you are free to leave at anytime during the discussion. You may request that your comments be withdrawn from the research up to January 5, 2017 the time of preparation of the thesis document. Please note that audio recording in the semi-structured interview will only be used to collect and analyze data, and that the recording will NOT be used in the Master's thesis exhibition and/or other presentations.**

(For your information, in addition to semi-structured interviews with you, I will conduct a workshop involving GYLWH participants in a narrative design process to transform their "real life" stories into creative, designed products. The workshop will introduce GYLWH participants to creative tools and exercises that will help their thinking process while working on constructing their narratives, choosing their messages and turning them in to designed products such as posters, videos or collages. The designed products will be shown to GY for feedback on testing the effect of the products in generating empathy.)

Benefits

- Adding to the existing body of knowledge in design-based community research with marginalized/stigmatized youth in Lebanon.
- Evaluating the effect of storytelling in generating empathy for reducing stigma and producing sexual

health education among youth in the gay community.

- Building a model for this practice that will be shared through a research document, so it can serve as reference for similar design research projects.
- Trying to create integration GLWH and GY communities in Lebanon.

Risk

- The risk to participants is minimal and no greater than what may be expected during regular discussions around gay community concerns and issues in daily life.
- There may be risks to being in this study that are unknown. If anything arises during the research that may affect your willingness to continue being in the study, you will be informed immediately.

Voluntary Participation

- Participating in this research is completely voluntarily and has no penalty or gain attached to it.
- You are under no obligation to participate in this study.
- Even if you agree to be in the study you can change your mind and withdraw without consequence your comments up to the time of the thesis document preparation.
- You may request that your comments be withdrawn from the research up to January 5, 2017 the time of preparation of the thesis document.

Confidentiality

- Collected data may be shown in my Master's thesis document and exhibit, public presentations and in written articles.
- You will not be identified by name in the exhibit and thesis document, public presentations and in written articles.
- If it is necessary to use quotation, a pseudonym chosen by you will be used.
- If you choose to be acknowledged for your participation in this research, you may fill out a Consent for Acknowledgment form that I will provide.
- Audio recording will only be used to collect and analyze data in the semi-structured interview. Audio recording will not be used in the Master's thesis exhibition and/or other presentations.
- Data will be kept in a secure location for 5 years following completion of research project, electronic data will be password-protected and devices will be encrypted. Data will be destroyed after 5 years.
- The data for all uses will be handled in compliance with the UofA standards.

If you would like to have a copy of my final research document, please contact me at harmouch@ualberta.ca

Further Information

- If you have further questions regarding this study, please do not hesitate to contact me, Bahaa Harmouche at harmouch@ualberta.ca, or my graduate supervisor Susan Colberg at scolberg@ualberta.ca
- The Research Ethics Board at the University of Alberta has reviewed the research plan, for its adherence to ethical guidelines. For questions regarding participants' rights and ethical conduct of research, contact the Research Ethics Office at (780) 492 2615. This office has no direct involvement with this project.

CONSENT FORM

Semi-Structured Interview / Activists, social workers and doctor

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109 Lebanon / +1 250 826077 Canada

Do you understand that you have been asked to be in a research study?	Yes	NO
Have you read and received a copy of the attached Information Sheet?	Yes	NO
Do you understand the benefits and risks involved in taking part in this research?	Yes	NO
Have you had an opportunity to ask questions and discuss this research?	Yes	NO
Do you understand that you are free to refuse to participate, or to withdraw from the research activity at any time, without consequence?	Yes	NO
Do you understand that you can change your mind after you participate, and withdraw your comments up to January 5, 2017 the time of preparation of the thesis document?	Yes	NO
Has the issue of confidentiality been explained to you?	Yes	NO
Do you understand who will have access to your information?	Yes	NO
Do you understand that audio recording in the semi-structured interview will only be used to collect and analyze data, and that I will NOT use the recording in the Master's thesis exhibition and/or other presentations?	Yes	NO
Do you choose to be acknowledged for your participation in this research? If you answer YES, please fill out a Consent for acknowledgment form.		

This study was explained to me by Bahaa Harmouche

I have read and understood the attached information letter and agree to take part in this study:

Name of Participant:
Signature of Participant:
Date (yyyy-mm-dd):

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator:
Date (yyyy-mm-dd):
You will receive a signed copy of this form to keep

INTERVIEW SCRIPT

Semi-Structured Interview / Activists, social workers and doctor

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109
Lebanon / +1 250 826077 Canada

Supervisor: Susan Colberg, 3-98 Fine Arts Building University of Alberta Edmonton, Alberta, T9G 2C9
scolberg@ualberta.ca, +1 780 492 7859

Hello,

Thank you for your participation, the responses received may be shown at the master's thesis exhibition and document, as well as other presentations and written articles. The research aims to develop a participatory design model (through the workshop conducted with GYLWH) that can be adopted by non-profit organizations dealing with stigmatized youth. The research will explore means to engage stigmatized youth living with HIV with their community in a creative process to share their stories through designed products. The research will evaluate the effect of the designed stories on nurturing empathy to reduce stigma.

In addition to semi-structured interviews with you, I will conduct a workshop involving participants GYLWH in a narrative design process to transform their "real life" stories into creative designed products. The workshop will introduce GYLWH participants to creative tools and exercises that will help their creative thinking process while working on constructing their narratives, choosing their messages and executing them into designed products such as posters, videos or collages. The designed products will be shown to GY to check if it was a catalyst for generating empathy.

You are being asked to participate in this research because your experience with understanding of activism for the Lebanese gay community will help me understand the causes of stigma to the gay community members living with HIV.

The risks of participating in this semi-structured interview are minimal. The interview will take around 30 minutes. Please note that your participation is completely voluntary, and you are free to leave at any time during the discussion without consequence. There is an audio recording of your responses, but it will only be used to collect and analyze data. You are free to ask me to withdraw your data from the study up to January 5, 2017 the time of preparation of the thesis document. Your information will remain anonymous, unless you choose to be identified. If you would choose to be recognized in this research, you may fill out a Consent for Acknowledgement form.

Do you have any questions regarding the study?

Let's begin our discussion:

1- Why do you think we are witnessing stigma against GYLWH from the gay community?

2- How do you think stigma affects:

. Gay youth living with HIV? and

. The gay community?

3- In your opinion, what could activists, social workers and specialist doctors do to minimize stigma? Is there something you are doing?

Do you have any comments?

Thank you for your participation, the responses received may be shown at in the Master's thesis exhibition and document, as well as other presentations and written articles.

CONSENT FOR ACKNOWLEDGEMENT

Semi-Structured Interview / Activists, social workers and doctor

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109 Lebanon / +1 250 826077 Canada

Consent to acknowledge your participation:

As a participant in the research study: 'Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV', you have the opportunity to be credited for your contributions to this research by having your name featured in the Master's thesis document and exhibition. It is anticipated that the exhibition will be in August 2017, and the thesis document available by September 2017.

Please indicate with an (X) below that you would like to be acknowledged for your participation in this research:

_____ Verbal statements (Participant in semi-structured interview)

My signature on this Consent for Acknowledgement form means that:

I want my name used to acknowledge my participation in this research. (By default, if you do not sign this form your information will be anonymous)

Please write your name (exactly how you would like it to be used), sign and date below

Name of Participant:

Signature of Participant:

Date (yyyy-mm-dd):

You will receive a signed copy of this form to keep.

If you have any further questions regarding this study, please do not hesitate to contact me, Bahaa Harmouche at harmouch@ualberta.ca, or my graduate supervisor Susan Colberg at scolberg@ualberta.ca

You will receive a signed copy of this form to keep

Evaluative Digital Survey / GY

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator:

Bahaa Harmouche
3-71 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
harmouch@ualberta.ca
+1 250 826077 (Canada)
+961 70 833109 (Lebanon)

Supervisor:

Susan Colberg,
3-98 Fine Arts Building
University of Alberta
Edmonton, Alberta, T9G 2C9
scolberg@ualberta.ca
+1 780 492 7859

Background

- You are being asked to participate in this research because you represent the gay youth (GY) community. Your experience being from that community will help me research the effect of designed products, created by gay youth living with HIV (GYLWH).
- The results of this study will be used in support of my Master's thesis document and exhibition.
- Research participants include Lebanese social workers, activists, doctor, gay youth (GY) and gay youth living with HIV (GYLWH) in Lebanon.

Purpose

- The research aims to develop a participatory design model (through the workshop conducted with GYLWH) that can be adopted by non-profit organizations dealing with stigmatized youth.
- The research will explore means to engage stigmatized youth living with HIV with their community in a creative process to share their stories through a designed products.
- The research will evaluate the effect of the designed stories on nurturing empathy to reduce stigma.

Study Procedures

- **You are being asked to participate in this research through a survey where your answers will be anonymous. The answers will be sent anonymously from the tablets and computers set on location. The survey will revolve around the designed products that you have seen and watched. Your feedback will help in evaluating the effect of the designed stories in nurturing empathy and reducing negative attitude towards GYLWH. As well it will help in evaluating the clarity of the messages created during a design-based workshop with GYLWH. You are free to leave the online page at any time. If you leave the page without completing the survey, your comments will not be included in the research.**

(For your information, in addition to evaluative survey, I interviewed field experts; activists, social workers and doctor, to get their opinion on the chemistry between the gay community and the GYLWH in Lebanon. I conducted a workshop involving participants GYLWH in a narrative design process to transform their “real life” stories into creative designed products. The workshop introduced GYLWH participants to creative tools and exercises that helped their thinking process while working on constructing their narratives, choosing their messages and turning them in to designed products such as posters, videos or collages. The designed products will be shown to you for feedback on testing the effect of the products in generating empathy.)

Benefits

- Adding to the existing body of knowledge in design-based community research with marginalized/stigmatized youth in Lebanon.
- Evaluating the effect of storytelling in generating empathy for reducing stigma and producing sexual health education among youth in the gay community.
- Building a model for this practice that will be shared through a research document, so it can serve as reference for similar design research projects.
- Trying to create integration GLWH and GY communities in Lebanon.

Risk

- The risk to participants is minimal and no greater than what may be expected during regular discussions around gay community concerns and issues in daily life.
- There may be risks to being in this study that are unknown. If anything arises during the research that may affect your willingness to continue being in the study, you will be informed immediately.

Voluntary Participation

- Participating in this research is completely voluntarily and has no penalty or gain attached to it.
- You are under no obligation to participate in this study.
- For the digital survey, it is NOT possible to withdraw data as it is totally anonymous.

Confidentiality

- The digital survey is completely anonymous.
- Collected data may be shown in my Master's thesis document and exhibit, public presentations and in written articles.
- You will not be identified by name in the exhibit and thesis document, public presentations and in written articles.
- If it is necessary to use quotation, a pseudonym chosen by you will be used.
- Data will be kept in a secure location for 5 years following completion of research project, electronic data will be password-protected and devices will be encrypted. Data will be destroyed after 5 years.
- The data for all uses will be handled in compliance with the UofA standards.

If you would like to have a copy of my final research document, please contact me at harmouch@ualberta.ca

Further Information

- If you have further questions regarding this study, please do not hesitate to contact me, Bahaa Harmouche at harmouch@ualberta.ca, or my graduate supervisor Susan Colberg at scolberg@ualberta.ca
- The Research Ethics Board at the University of Alberta has reviewed the research plan, for its adherence to ethical guidelines. For questions regarding participants' rights and ethical conduct of research, contact the Research Ethics Office at (780) 492 2615. This office has no direct involvement with this project.

CONSENT FORM

Evaluative Digital Survey / GY

Study Title: Nurturing empathy for social cohesion: Participatory designed-based community research with gay youth living with HIV

Research Investigator: Bahaa Harmouche, University of Alberta, harmouch@ualberta.ca, +961 70 833109 Lebanon / +1 250 826077 Canada

Do you understand that you have been asked to be in a research study?	Yes	NO
Have you read and received a copy of the attached Information Sheet?	Yes	NO
Do you understand the benefits and risks involved in taking part in this research?	Yes	NO
Have you had an opportunity to ask questions and discuss this research?	Yes	NO
Do you understand that you are free to refuse to participate, or to withdraw from the research activity at any time, without consequence?	Yes	NO
Do you understand that you can change your mind after you participate, and withdraw your comments up to the time of preparation of the thesis document?	Yes	NO
Do you understand that you will be identified by your chosen pseudonym only?	Yes	NO
Has the issue of confidentiality been explained to you?	Yes	NO
Do you understand who will have access to your information?	Yes	NO
Do you know that you are free to leave the Digital Survey page at any time, if you leave the page without completing the survey, your comments will not be included in the research?	Yes	NO
Do you know that it is NOT possible to withdraw data as it is totally anonymous?	Yes	NO

This study was explained to me by Bahaa Harmouche

I have read and understood the attached information letter and agree to take part in this study:

Pseudonym of Participant:

Signature of Participant:

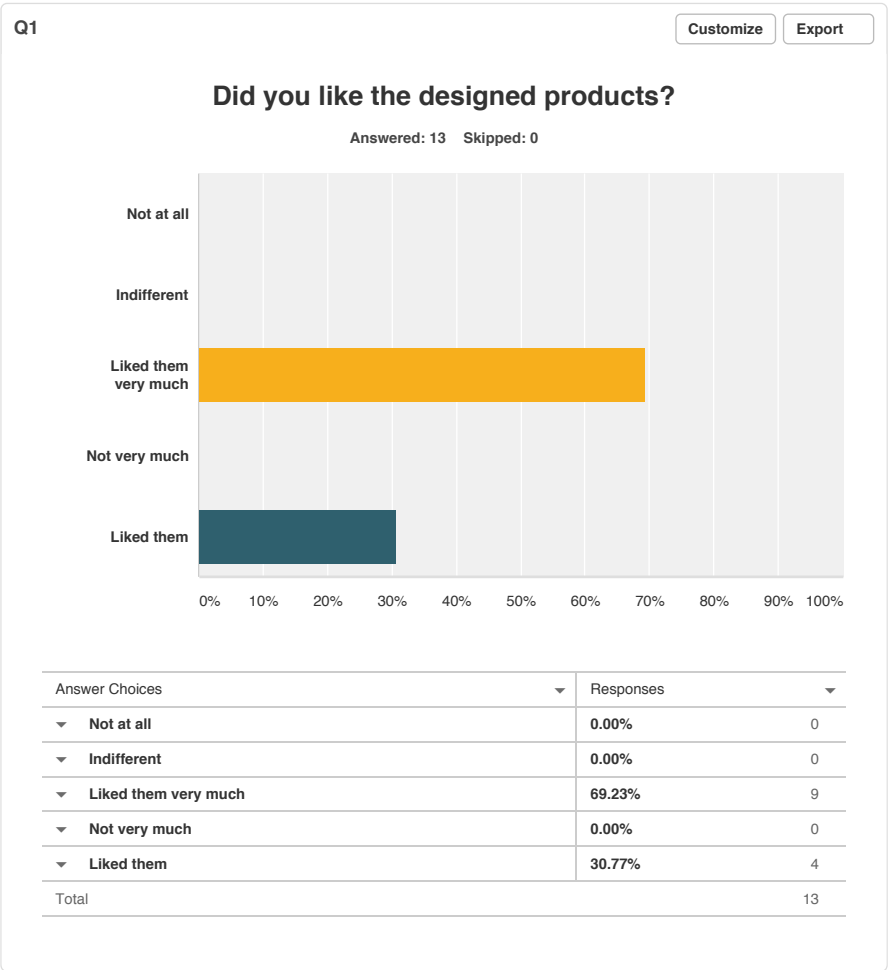
Date (yyyy-mm-dd):

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator:

Date (yyyy-mm-dd):

You will receive a signed copy of this form to keep



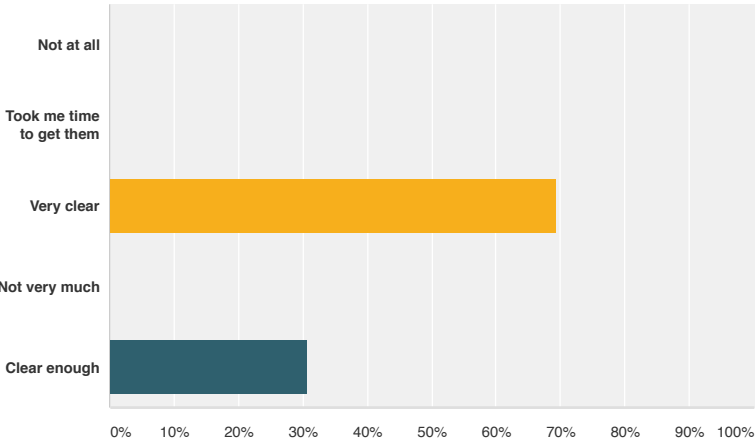
Q2

Customize

Export

Did the messages of the stories came across clearly?

Answered: 13 Skipped: 0



Answer Choices	Responses
▼ Not at all	0.00% 0
▼ Took me time to get them	0.00% 0
▼ Very clear	69.23% 9
▼ Not very much	0.00% 0
▼ Clear enough	30.77% 4
Total	13

Q3

Export

In your own words, what did you learn from those stories?

Answered: 13 Skipped: 0

Responses (13)

Text Analysis

My Categories

PRO FEATURE

Use text analysis to search and categorize responses; see frequently-used words and phrases. To use Text Analysis, upgrade to a GOLD or PLATINUM plan.

Upgrade

Learn more »

Categorize as...

Filter by Category

Search responses

?

Showing 13 responses

That people should be equal and deserve to be loved.

12/2/2016 5:02 PM

View respondent's answers

Everyone is already facing their own battle alone. They are faced with enough hate from themselves and others. We should show support and love and take care after one another. ACCEPTANCE IS KEY.

12/2/2016 10:10 AM

View respondent's answers

More support and love is needed

12/2/2016 10:06 AM

View respondent's answers

the strong impact of stigma and discrimination against plhiv specially gay people who face double discrimination

12/2/2016 10:05 AM

View respondent's answers

We shouldn't stigmatize hiv+ individuals and we should accept people with these cases more

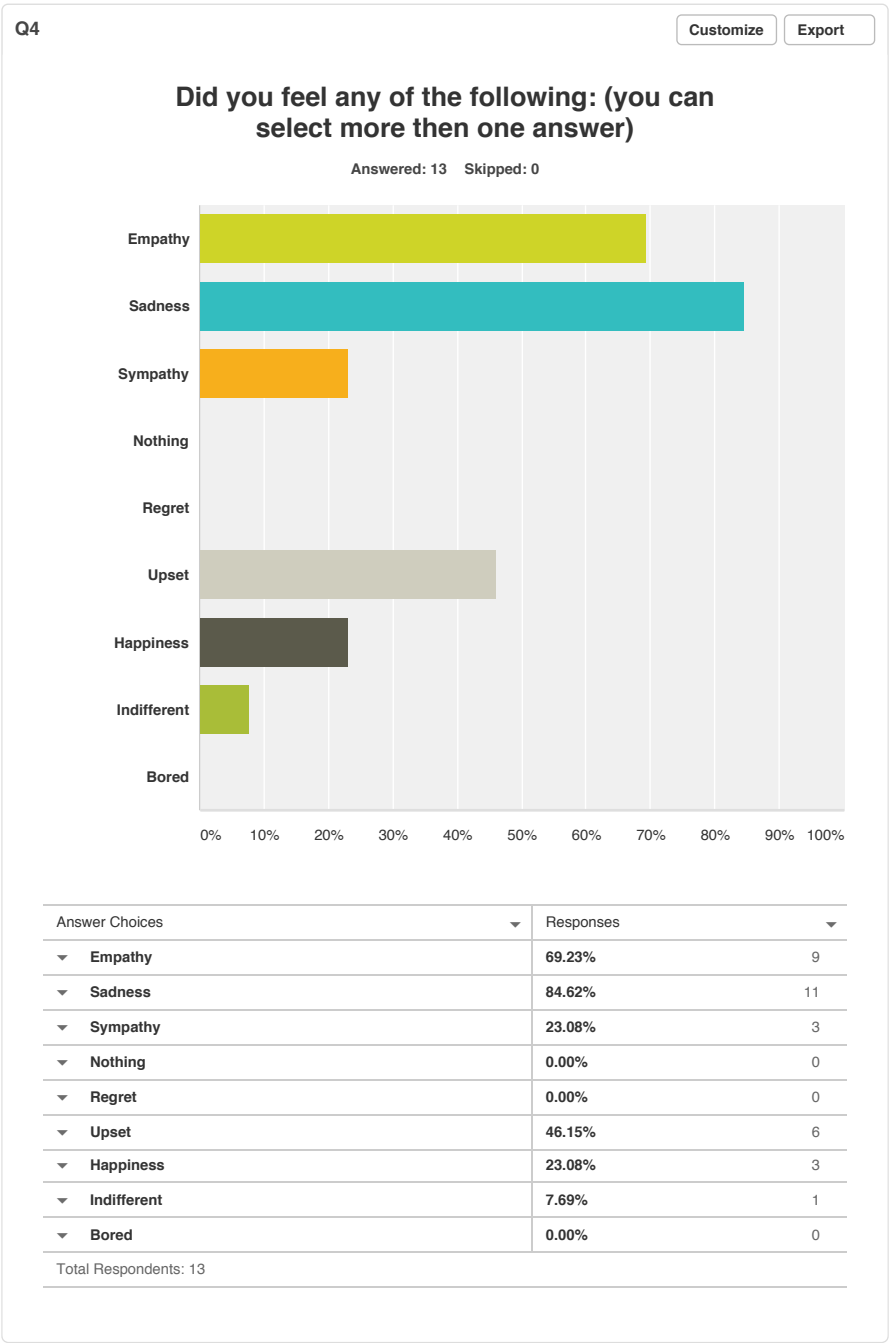
12/2/2016 10:05 AM

View respondent's answers

They exposed people suffering from HIV something I know and expect yet they didn't inform me ways to survive those conflicts and such suffering they didn't expose or discuss any solution on the social medical psychological levels and they didn't not inform me about protections and ways to avoid having this illness

11/30/2016 11:48 AM

View respondent's answers

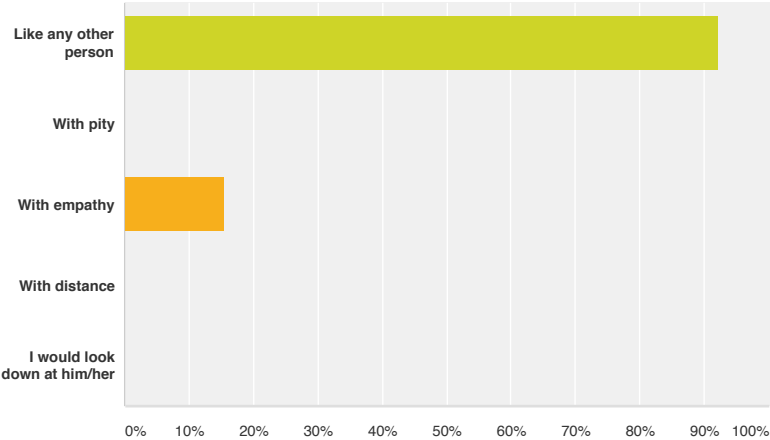


Q5

Customize Export

After seeing the designed products, if you met a person living with HIV, how would you treat them? (you can choose more than one answer):

Answered: 13 Skipped: 0



Answer Choices	Responses
Like any other person	92.31% 12
With pity	0.00% 0
With empathy	15.38% 2
With distance	0.00% 0
I would look down at him/her	0.00% 0
Total Respondents: 13	

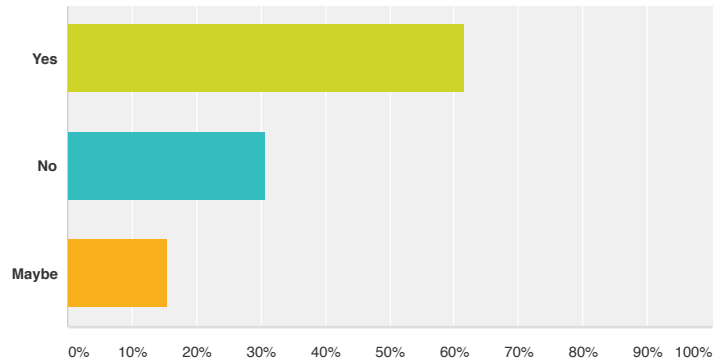
Q6

Customize

Export

Do you know of anyone (close to you) living with HIV?

Answered: 13 Skipped: 0



Answer Choices	Responses	
Yes	61.54%	8
No	30.77%	4
Maybe	15.38%	2
Total Respondents: 13		

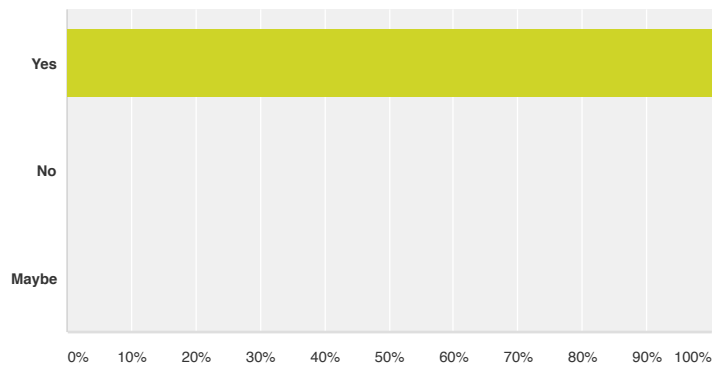
Q8

Customize

Export

Would you hug a person living with HIV?

Answered: 13 Skipped: 0



Answer Choices	Responses	
Yes	100.00%	13
No	0.00%	0
Maybe	0.00%	0
Total	13	

1. Professionals and activists

Why there is stigma between the gay society and the gay youth living with HIV? Why do you think, in your opinion that we have this stigma instead of having empathy between minorities, because we are a minority?

Well, I am not an expert in answering this question, but I can tell you that it is likely that like in any community, group, population there's always discrimination against someone, the weakest in the group, and obviously someone who is HIV infected will behave as the one who doesn't want everybody else to know because that will decrease his homosexual attractability. I see it, in addition to that, in every society, and I'm not an anthropologist, but I think you can check on that in every time in history a society faces a crises, and the gay community has been facing a crises forever because of the discrimination against homosexuality, and against homophobia, so we already have that, the presence of HIV increased this defiance, this fear of the gay community being the source of HIV, because unfortunately, the original cases were in the gay community while we know now that it has nothing to do now with being gay but needless to say the idea of HIV has always been in the mentality of people who have been exposed to western media it is associated with being gay, whereas in Africa it has nothing to do with being gay. But in the rest of the world, particularly in our neck of the woods where we are exposed to western media we consider anybody with HIV equals being gay. The gay community looks at anybody with HIV as a person who has made worsened the behavior of people towards them. Because of these several issues, being gay is discriminated against, being HIV positive increased this discrimination and decreases your sexual attractability, so there is always, and since it's a small community, close community, and people know each other, especially in Lebanon a lot of people know each other I think people become the victims of gossip and discrimination because of that, definitely, I don't see any other thing right now.

You've always been like a protector for your patients, I've known you for a long time, and you've kind of an activist towards them, what do you think we should do as activist or experts in making the life of HIV patients easier for them rather than being a burden for them?

I personally believe that the attitude, talking about HIV to start with. That the problem is that HIV was used by the gay community in the western world, in north America and northern Europe, it was used as a spring board to talk about gay rights, same thing in Lebanon, same thing everywhere,

talking about HIV, fighting for HIV activism about HIV has been primarily used as gay rights and that's why people still insist that HIV and gay and they kept, they put and they forced people, particularly homophobes to be more discriminatory and more fighting against gays and against persons who have HIV in general. So HIV suffered as a virus and as a medical entity suffered from the discriminations against gays and all well good thinking people, looked at gays, looked at sex in general in a very condemning way, as if they never have done sex so because of that and in any sexual transmitted diseases, and we know from history that syphilis, herpes, have always suffered from discrimination by the good thinking, right thinking, righteous catholic, the key issue is what we need is to trivialize , de-exceptionalize HIV, I think we have to fight for it. The problem of HIV right now, first HIV should not be a problem anymore, because now it is virtually curable, you keep on taking medications, let's say, they don't discover the final cure, let's say in ten years, 20 years, 60 years, we don't discover the final cure , we have right now a decent therapy that would maintain someone alive for the rest of his life, without the need of anything, I think we do have that. The problem is that there are many, many people and societies and groups and activists and all different stuff that are making a living out of HIV, so now it has become an economic decision to trivialize HIV, HIV has become a profitable institution, there are huge loads of money spent, not for medications, very frequently not for condoms, or for proper techniques in prevention, ok, instead of working on improving education, and really working from childhood on education from childhood we are still working on displays, ok, unfortunately importing things that are done in the West for the gay community, for the highly sophisticated, highly educated, highly cultured gay community of North America and northern Europe and importing it for the regular village sex worker in down town Africa.

Where the hell do you want this activity to be impacting this activity so that's why I think we really have to look at HIV in a very standard way, like any other sexually transmitted infection to teach about the safety of sex, to teach about the safety of preventing needle use, etc. etc.

And that's it, once we trivialize, once we de-penalize, once we de excetionalize HIV, I think it will be excellent, but unfortunately there are plenty of financial interests behind it, and I think its going to be difficult to do that.

Last question, in Lebanon, what kind of policy do we need to trivialize HIV?

It doesn't depend only on Lebanon, I think we are doing a rather good job in

Lebanon as compared to other countries, believe me, even as compared to western countries. Despite the fact that we are complaining all the time, we really are doing much better. But despite that the epidemic is spreading, we have now a concentrated epidemic in the gay community so why??Why?? Despite the fact now that we have zillions of societies that are making shit loads of money just from HIV just for the gay community, that are doing money for health for the gay community, and despite that HIV is spreading, something is wrong, ok, something is wrong, why?? I think because we are not spreading the information good enough period we are working on focuses, because international organizations that give you money, give you money for specific projects....

And no one is doing something for a general project, so what we need is to look at the big picture, and not work on details, and not focus on a group of 30 people but instead focus on the whole community I think we have to work a lot, and in general, and certainly one of the most important things is to de-penalize decriminalize homosexuality, we have to get rid of that, I personally would even go to the maximum, and I already wrote an article in the newspaper promoting gay marriage, they told me, we're talking about gay marriage and being gay is illegal in Lebanon, so I think we have reached a stage where we can start talking about somewhat being a homosexual, being accepted in society, and then eventually talking about gay marriage Because I'm convinced that gay marriage will reduce, let's say, will not eliminate but will reduce extra marital affairs. In one way or the other, so as a public health measure, I don't care, people can have sex the way they want to, everybody is free with his own sex, that's not my problem, I mean why do I have to worry about the sexuality of people, I mean this is something between the person and his bedroom, it has nothing to do with society, it doesn't impact society, you have great people who have always been fantastic in society, in art, in literature, in politics, in military, in everything that have been gays or not gays, I don't care, ok, alright, there are even...., I was going to say a joke, but I'll skip it because you are recording , but I mean, so.... It's nonsense, so forget about sexuality, let everyone have sex the way he wants, but then, or she wants, the only problem is that definitely we need to decriminalize we need to de-penalize, and then eventually reach the stage of teaching the gay community to think about more prevention in their behavior. I believe that partousing. And I think that people have to be aware about the reduction of that what happened in the 1970's, what happened in Lebanon

in the 1990's and 2000, we are reproducing what happened in the 1970's in America, I think we have to understand that we are not allowed anymore to do that, it is to God dam fucking dangerous, and the mixture of drugs, particularly a lot of....., we worry about injecting drugs for HIV, but there are, it's much more worrisome in the non injecting drugs because it decreases your inhibitions and it decreases your understanding about the prevention and the techniques you have to use to protect yourself so because of all that we really need....., I personally believe that we need a very strong education, very very strong education, from a very young age, in schools, in universities, in clubs, in places where the young people are sitting, that's where we have to target, and very aggressively, and very very seriously, and be open, God dam it, sex is occurring, so why not give them condoms, why not make condoms available, why not talk about condoms, why not distribute condoms, and then be open about it, making stupid laws and regulations etc. is totally nonsense. The Arab countries are the countries that are doing the maximum as far as laws and visa regulations and all kinds of stuff, and what do we end up with? The only places in the world where the epidemic is still growing is in the Middle East. How come?

Thank you so much

b. Interview with George Azzi

I'm trying to build this conversation between the gay community and gay youth with HIV. Why do you think we are witnessing stigma against youth with HIV?

From the community?? I think its because of the whole stigma around HIV, I think the whole strategy around HIV in the 80's was to scare people from HIV and not raise awareness. This mentality continued throughout the years and till now, I think with HIV or learn that they are HIV positive; there is this fear of the end of life. I remember once I went with someone to collect his confirmation test, I remember the doctor said " I cant give it to you "3am a3teek war2it na3weh" (an obituary announcement), so I think there's fear around it, you know in the community there is very low self esteem as a gay person, because there is very little maturity as a community, yet I think its easier to discriminate against HIV where we already discriminate based on the masculinity, on different issues and I think HIV adds to that, the whole fear of HIV, this is why I think that specifically youths are still been discriminated against for being HIV positive.

Stigma affects many members, it affects the individuals, and it affects the individual with HIV and the gay community in general, lets start with the youth. How does it affect the youth, how does it affect the gay person living with HIV?

Definitely, they are much less motivated to seek help the less they are exposed to their HIV status the better, so there's the partner notification is completely... so they can't blame them, it doesn't happen at all, seeking help from a community based service is also becoming challenging because the problem is that they will probably meet other gays there, even collecting the medication their treatment from the ministry of health is a form of exposure, so I think that people are less prompt to seek help, assistance and medical support, when they are HIV positive which has of course lots of consequences on their lives. And the same applies to the community in general since people don't talk about HIV, since it's a taboo, if I were to ask someone to wear a condom that would mean that I am HIV positive, people still ask " Why do you want to wear a condom? Are you HIV positive?" so I think that this misconception, they don't speak about HIV, if they speak about HIV , they're afraid that people might think that they are HIV positive, and this is why the number of infections is growing year after year.

You said something about the medication. Are they getting their medication, or do they pay somebody to go get it for them.

There are options, you can get it through an organization SIDC, there are some who can get the medication for you, there's a centre specifically for..... and I'm not sure this is a good idea, but they created different centers for HIV positive people, with good intentions, its better equipped with councilors who can answer questions, and instead of going with the diabetic person, they call your name and the name of the medication, they think offering them a specific place for people living with HIV is a good option, but at the same time, if you go there, you are already labeled as HIV positive and people will be scared to do so ,so there's always you know the pros and cons to this.

... it's ridiculous. But it reminds me of the gay clubs when they started in the 90's , they were not labeled as gay friendly or gay clubs but yet it was like ...

They were not too friendly in the 90's, they kicked you out of the door if you looked too gay, if you were a group of men without women, they would not let you in, they were the only possible places to go to, but they were not friendly at all (sheikh man2oush, Acid back then).

How does stigma affect the gay community itself? We know how it's affecting the people living with HIV, how about the community?

I think because it's a taboo, people don't speak about it honestly, and I think then there's this issue, if I use condoms with you, then I don't trust you, there's this fear,it's not a normal conversation to have, probably I'm HIV positive, probably you are HIV positive, let's use a condom, I think this conversation is not taking place yet because there is this paranoia around HIV.

We talked about it, because I'm married and there's time in the relationship where we have to be open and talk about it we decided that no matter what, we don't want to bring something foreign to our house. And this is where, the..... If you want to do something, like..... Married people don't say these words, because monogamous, we don't want to do anything, but yet with that monogamy we had to have this talk with a counselor, which was amazing, here we don't have it ,

I think people here don't want to admit that they're having sex in general, **It's not a taboo, sex is good.**

In your opinion what could an activists, because you are an activist, so what could an activist, social worker or a specialist doctor, these are the three categories, do to minimize stigma, and is there something you are doing right now about it, you and your NGO?

I think when we first started the work at Helem and Marsa, The problem with most HIV programs were condom distribution, lube distribution and interviews, and the problem was never the accessibility of condoms, ok condoms can be expensive, but if they have the condom, that doesn't mean that they are going to use it. Because most of the people, especially the young ones, they have sex in cars sometimes, they don't have available places, so it really happens fast, it needs to be anonymous, quick, because you know people have this shame around sex as well, so going to the pharmacy buying a condom or coming to a place for a condom, that means that you have the intention to have sex, and this was the issue, I think the first thing we need to do is to normalize sex. MARSa is a sex friendly place, we speak about sex mostly, before speaking about SCI's, we speak about pleasure, we need people to feel comfortable with sex in general, and I think this is what we tried to change in the conversation about HIV, when we started Marsa, not to speak about an illness, but to speak about sexual pleasure, and sexual pleasure comes with protection and knowing that you don't want to have any infection.

And its just part of something you do every day, and you need to be careful about, and this is still not yet mainstreamed in Lebanon, they think that if it's happening in the gay community, it's not happening outside it, because most of the NGOs don't want to adopt this discourse, It's about sex, and I've been to many regional conferences about HIV and people don't want to talk about sex, I've on a panel where I had to say the words "penis", "vagina", and people reacted negatively, but this is a sexually transmitted disease, so we need to talk about sex first, then speak about the infection.

This was one thing, speaking about sexual pleasure, and the other thing is to demystify HIV, and this where I think people were, the sole image of HIV being something scary, people will die if they have HIV

This needs to change

Nowadays HIV is not as petrifying as having Hepatitis C, but now they are creating something for hepatitis C, so I guess there's an anecdote that's going to happen, but at the time HIV virus could have been more oppressed than the Hepatitis C, because Hepatitis C in the long run is going to ruin, and I remember I had a talk with Dr. Mokhbat, like it's funny enough that they don't care about Hepatitis C, But they are scared of HIV.

But there's no money there.....

Exactly, right? it's weird, the same word you said "demystify" Mokhbat said

,.....than lies. I just use the word “normalize” not like it’s ok, but normalize, like you can talk about it, I like the word “demystify”

Because it’s scary for people, that’s why they need to demystify, as well as homosexuality is scary, and you need to demystify it as well by making people more visible. I think what we need to do is to have more people with HIV going out publically, not in the dramatic way they present it on TV, so if someone wants to go on TV with a hidden face and scared, and talking about how miserable his life is, which could be possible, but this is not what we want people to see, he likes to be invisible because of stigma, because of HIV, and this what the media doesn’t know how to cover yet the issue. This has been changing recently, and we insist to control the narrative, and we say this how we need to present things, some of the media has been cooperative with us, the issue is that most of the mainstream HIV organizations, they still don’t have an issue with scaring people because if people are scared enough not to have sex, that’s fine with them, but of course people will not stop having sex, they will keep doing it the wrong way, **exactly, the fact**

It’s something normal, you can ask me not to drive a car in Beirut, it’s safer, and you can walk, fine I can do this, but you can’t ask me not to have sex. Whoever believes that you can oppress people’s sexuality?

I’m going to ask you, as your opinion: we didn’t go to the narratives yet, we’re going to the narratives on Saturday, but in my brain, I don’t want to talk about sex, as because I had sex I contracted HIV, and that’s why the free talk on Wednesday, like it’s ok to have sex, we all have sex, we all have our needs, and it’s great when it is more romanticized and it’s done in the “whole” way, everyone has his own way. Do you think that the narratives always deal with the sides of how I contracted the virus? Or what I felt when I contracted the virus, I don’t want to oblige them, because this is part of the participation, not to oblige anyone.

I am not sure what they are more comfortable in presenting, I don’t think its important how the contracted it, the fact is that they have it, and when everybody goes on TV, they say that they had a blood transfusion and this is how they got it, and the last time that this happened in Lebanon was in the 80’s ,.....we know that this person had sex, but the problem is when people living with HIV is like when Gay people go on TV here, most of the time they narrate what people want to hear, when a gay man goes on TV here, he says he was raped when he was a kid and this is why I’m gay , and they reproduce the stories and narratives that they heard before, this is something that we are trying to change with the media centers, train people to tell their

stories as they think it is, not as the people want them to say it.

That's what I'm trying to push them to do actually

It's important in this context to encourage them to tell their stories, as they'd wish to tell it, not as not how people would react to it.

So you have Any other comment?

You've met people with HIV, right? **Yes.** It's interesting when you see the more people are comfortable with their sexuality in general and in the relationship with other people, the more comfortable they are with their HIV status and they speak about it. so It's all connected. Most of the time people are ashamed of their HIV status, because it means that they admitted that they had sex, so it's the whole...., well it's as basic asslut shaming is still common in the gay community. People think that when they are in a relationship, they need to copy the exact same relationship their parents lived in the heterosexual world,....let's get married and live like wife and husband have children.....that's not necessarily what everybody wants, and the thing that these details that people should start accepting, that there are different forms of relationships and sexualities, people who want more sex than others, people who eat more than others, I think this will directly affect the stigma around HIV as well.

It's interesting because that talk was yesterday after the workshop, a reunion with friends, husbands and wives, and I don't know why I talked about that, and it was interesting to see the straight community, how they're fine with it, and they're fine with the experimenting of new things ... which takes us back to the word you said , the more we talk and have this discourse between different members of the community, the more it becomes normal ...

Thank you

c. Interview with Eli Ballan

Thank you for taking the time to make this interview. I would like to start with the following question: why do you think we are witnessing stigma in the gay community?

Stigma of HIV they go together for as long as HIV has been known. First of all because HIV has been known as the gay disease, the grid and from there on the stigma stayed there, and the fact that it is a virus related to sex, that adds to the taboo. In our community, the Lebanese community before going into the Lebanese gay community, the stigma against the virus first is ignorance of the fact that you are going to die in matter of seconds, people still fear that it is highly contagious, and third that it is because it is related to sex, and everything related to sex is a taboo is a "haram" it is something that we wouldn't be talking about.

And in the gay community itself, well because there is a lack of understanding of what it is of where we have come right now, how you can live a completely normal life, healthy life, and actually not be contagious and not be able to transmit the virus, especially if you have an undetectable viral load, with the lack of those basic information this is what people stigmatize about, this is what people are scared of what they don't know.

We know that the effect of stigma has dual effect, it has an effect on the gay living with HIV and the gay community in general. Can you identify those effect on each side?

The stigma practiced on those living with HIV, it attacks a very personal space in them, their confidence their courage, their stamina and stepping out and being who they really are, and being who they want to be and aspire of who they want to be. I know a lot of young youth who because of stigma they lost their spark, they lost their will, they are scared all the time and all of them they wanted to be with people who are HIV positive. And not because it makes everything easier or not, just because they will feel less judged, they will be with someone that completely understand them and they will not give them the same bullshit as the other people. That is just on the surface, on a deeper level it affected sometimes their sex life their sex performance, the way they are in the community, those who they were once bold you see them now being shy, staring in the corners, you know and what really hurts more is that everything HIV is brought up, as a subject they coil and get petrified, and each word that is said about them, the words are a stabbing knives pointed at them although no one knows about their status, but they will be sitting there

in the community feeling the impact of those knives. This is the role of the rest of the community comes is that these people are throwing the knives sometimes without even knowing that their friend is positive, but these thrown knives are leaving scares and scares that even though they are healed but they still leaves scares.

For the rest of the community I think it is just gives more fear, it gives more ignorance instead of going and seek the truth and finding out what really matters or not, how it is transmitted how you can be protected from it, how you can live with it, because you don't have this information just hearing the stigma against the other people makes them fear it even more, "oh what will happen to me, they will stop talking to me the same way, I can't be like this, I have to protect myself". One group of people told me like, no I think every person who is positive should tell everyone, we have the right to know who we are sleeping with. I told them no you don't have the right to know, you only have the right to cover up your dicks before fucking someone.

Exactly, how did it affect the gay community in general?

With 3 charging wireless it is spreading more fear, it is making people alienate others, judge others, and you have this horrible horrible phenomenon where people just say, "oh I think this guy has HIV, can you see his forehead?" And will go "what is wrong with his forehead?" They reply "he has flat forehead". And I will go "don't we all have forehead?" Ya this is something I investigated very deeply into it, and apparently if someone has been on ART for a very long time, it start effecting their heads here that they become a little bit with curved or like a whole, but this is something we talk about it something very advanced, something very.....but for someone who grasp the tip of the iceberg and here is that every time they see someone with a flat forehead they woe per between themselves "OMG he has HIV".

Well in the old days there was the fat appearance on the body that was in lumps and people used to identify it on the beaches, now we have a new thing, ok.

Well that increases fear, and I mean we live a culture of gossip, a culture of people they talk about each other, about blaming, shaming, shading and humiliating each other, sometimes it is just for fun, but although we all do it for fun, we need to know the thin line between hurting someone and just laughing together about it, and if you are laughing about someone behind their back, you are not laughing with them, that isn't laughing at them and that it just increases that, and it creates more groups, and the groups become

further apart, and then we are just not unified, and then whenever we have something to deal with on a national level as a community, we want to work for our right we want to fight for our equality, for freedom or whatever, we can't, because together we can not get unified on one thought, how about being unified against government or the laws.

In your opinion, as I know you are an activist, because I know you work in M-coalition and you are working to spread the education about HIV and beating close to the community, what can we do to minimize stigma? And is there something that you are doing right now you would like to talk about it and share it?

Stigma will always be there in a society controlled by religion, controlled by taboo, controlled by ignorance. A culture that would not open a book if they want answered but rather go ask a neighbour, at the simplest. If things if someone is sick and he has something, instead of first thing go and see a doctor, they will have a family reunion and each member will become a doctor or the pharmacist and they start sharing antibiotics and start sharing recipes and witch crafted and voodoo, and later on when the person is in a severe case they call a doctor when it is too late. So I think this summarizes what happens in our community in general, the first thing we need to do and because we are activist, because we work in this all the time, we sort of thought that we are a little bit ahead then we are, especially with the larger community and the gay community, I mean we thought that people know about HIV, they know they need to test, they know to wear a condom, basic knowledge. OK they don't know what viral load is, undetectable is, that is fine one step at a time, but going back to what we are doing recently and asking the community recently, they know shit about anything "zirait el kussa" (zucchini plantation) you know I mean it is ridiculous.

When someone tells you I don't know if I kiss someone on the cheek if I get HIV, if I shake someone's hands, and this has just happened in past 2 weeks, personally I was so shocked, it was nothing even close to what I imagined, and I just realized and we talked about it with several of my activist and colleagues, I said I think we are going about this all wrong, we are trying to work on such an advanced level for some advanced people, but we are way back in the dark ages, we need to start by the simplest of messages, shaking hands does not transmits HIV, hugging someone does not transmit HIV, HIV is not AIDS, AIDS is different, AIDS is a case HIV is a virus, it has to be back at this, the point is awareness and no matter how much you try to work on awareness still there are certain parties that will fight you back, I mean one

organization few years ago they tried to do something very nice, which was an awareness and anti-stigma campaign, which included priest and sheikhs and different religious people, who came and said stop stigmatizing HIV, people with HIV are not sinners punished by God, they are not condemned to the hell as a repercussion of their sins, it is all not that. it is a virus like any other thing in the world that has come to our life, that has destroyed humanity for sometime and we are working on to find it.

On what we are working to do at the moment, we do have one awareness campaign that we are working on, we do try to work on stigma on almost every project, in spreading the awareness to the people you are working with or you are working with for the first time, even if you are working with a printing press sometimes, and the see the material you are working on, you open up a conversation, I is these one on one conversations with taxi drivers, with people to make them understand that it is not as horrible as we thought. And the second step is the awareness, now we are trying to inhabit a little bit of satirical a bit comic so that people will see their mistakes and someone will laugh at you if they heard you. So a little bit of satire with a little bit of shaming, not too much shaming, just shaming enough so that people would stop and think, but not to distribute them because we are not fighting fire with fire here. But we just want them to stop and think that this behaviour is destructive for other, for yourselves. what examples are you giving for the younger generation or for the other people around you when you act this way. I can give you tons of examples on stigma that is happening in our country and in our medical field which is known to be the best in the region. Still their are some private institution that have done great work with HIV and I will keep them unarmed for their protection because they have been doing great work and they are others, like putting a patient in a room closing the room and putting a sign on the door saying "please to not enter do not communicate HIV" I mean I thought they only did that to witches.

So talking communication and discoursing, that is a salon du the', I always thought the right place to discuss those things, tarek the places where it clicks with people, more then any other time. Nice I can't agree more. Ok do you have any other comments?

Good luck in your project, you are marching into turmoil territories, but they are controllable, the things that keeps me going personally is that as much as there is ignorance and as much as people are afraid of it, when you sit down and talk to someone and they ask their questions from the heart they change, and funny enough that change does have a ripple effect on them on their friends.

Yesterday I had this focus group and I gave them that awareness, I was soaking in it at some point I become so poignant, and they were asking and asking and asking the questions with a BUT, like I will say something and they go "but I heard this and I know that" and then, I knew I was going to say it at some point, but I left it to a very critical point where I just slammed my hand on the table and told them: "I am HIV positive, I have been living with HIV for the past 10 years and here I am in front of you, I am healthier than anyone of you on this room" at this point they all sat and were quiet, they thought of it their questions changed, they saw something different because the idea they have in their minds is the same idea people had about AIDS in the 80s, where if you have HIV it means you are going to be a white skeleton with purple blots on your face, open wounds, your teeth are out, and you are shivering all the time. I think we are watching too much of the exorcist. but then when they saw me like that, and they saw that I am healthy and I am strong and that I am talking, their questions changed and I can see it in their eyes, that when they were leaving, they were different people, they were not scared of it anymore. I talked to them by sums after they left I was like "thank you for coming", they were no thank you for giving us the light, because we were living our lives scarred, our sex lives were affected, our love lives were affected, we were just moving with so much caution, I wasn't enjoying it anymore and know you just gave us an opportunity to breath, and I think this is what people needs to know. It comes about how you approach awareness, when you go to people and you preach them, wear a condom wear a condom wear a condom, due if you keep saying that they don't wanna use condoms. And I heard something from someone a scholar who said something who was giving a workshop and he said something beautiful, "don't give people one choice and force it on them, give them all safe choices, tell them all about their options for safe sex including having unsafe sex with undetectable viral loads of people on treatment on people on Prep, give them the choices so whenever choice they make it is always the right choice." They will feel that they have the power to choose but they are not forced to do it.

Thank you Eli it has been a pleasure.

2. Workshop participants**a. Interview with Houssam****Let us begin our discussion, which part of the workshop you liked the most and why?**

The thing I liked the most was when we were assembling the story at the end during the editing part. I felt that the results are appearing and the things that we worked on are seeing the light. That is the thing that we were saying are indeed happening not staying on paper. That someone might see it or we can show it to somebody if we want to. That it is all documented now, the paper could be hidden but this one (the video) can be sent and used in particular ways.

So that is the part where you set on the computer and compiled everything is the most effective to you?

yes

Would you change anything about the process ? why?

I wouldn't change anything in the process. Only if there were more time as time was tight. Or maybe the amount of the participants, if they were less we could have focused better, like the time when we were two.

Ok what were the benefits from the workshop?

I now feel more confident to talk a bit about myself; I am a person who doesn't like to talk about himself or his feelings, now I feel I can talk about what I am passing through. Which is an add on, that was the most beneficial thing in here was that you made me open up and talk about myself.

What else you think this workshop gave you?

There was something very nice which was the bonding between the participants. I knew the people here before, but during the workshop, when we started collaborating in certain activities, some participants became friends, not best friends but we got to know each other more, like we started understanding each other's personalities. So on the social level it was perfect.

Would you recommend this workshop to friends?

Of course it is replicable and it doesn't have to be only for HIV stigma, it can be used for another subject... and the process of digital storytelling was super nice and convenient for people that are not used to talk about their problems or personal issues, there is a lot of people that hide their problems, it was a good chance for people to express themselves.

These are all the questions that I prepared, do you have any comments or any idea that you want to add?

I liked that we were not only working on storytelling but we learned skills, we used softwares and we did brainstorming to solve visual. We saw what other people did before through the presentations that you showed us. As well we learned from each other and even people visit us from outside the group to give us their opinion which was very positive.

On the level of being a gay youth living with HIV what insight did this workshop provide for you?

Being part of the people that are responsible for the support group in Proud Lebanon, the workshop highlighted things that I can use in future support groups. Like I should check what people want sometimes and it is not always what you think other people need is what they really need. That was a good point to let people open up and say what they want to say, and not assume what they want. I used to think that I want 123 that mean other needs the same too, which it is not the case in reality. We can think that people need this particular thing but in reality they need something completely different. You created a space where people could express themselves, and no body stopped anyone like “don’t say that” it was really open and everything was accepted, there were not a small restriction. There were no limitations adding to that everyone was able to reach into stages they wanted to reach even you asked us at the end “what did this video gave you”. It was worthwhile to think why I did this video? What did i get out of this video? What did it do to me? I thought of all theses questions even after we finished the workshop; it was good to think of these thoughts?

Thank you very much

b. Interview with Nassib

Let us begin our discussion, which part of the workshop you liked the most and why?

The first exercise where we had to answer questions with photos and the video, we expressed what we were holding inside of us.

“The video” you mean the shooting or the edit? and why?

The edit, I told you why, because we expressed what we have inside in a different way, we were not there only to talk. We benefited from the message that we sent to the world.

How did you benefit?

We felt like we accomplished something. We saw ourselves where we were, how we started, what we became and where we are heading.

You mean like a reflection

Yes

Would you change anything about the process ? why?

What I would have done is develop it, by training the participants to become conductors as well so they can use this workshop in different situations.

That will be hopefully a next step. OK what were the benefits from the workshop?

I think I answered it in the first question. It was like a turning point, where you are in a situation and you don't feel it, through the work I was able to look at my situation and connect to it. Like seeing where was Nad before and where is he now? Where was I in 7 months and where am I now? The way of thinking now, the acceptance of my situation, living with the situation.

Would you recommend this workshop to friends?

Of course, to experiment what we experimented. To experiment this turning point that I went through. I tried to invite a lot of people but they were late.

Thank you very much

b. Interview with Ihab

Thank you for taking this interview. I am meeting you because i want to have some feedback about the workshop, and talk about the benefits and etc.

The first question is which part of the workshop you like the most and why?

The first part, the one with the questions that we had to answer through visual (photo voice). The questions about our favorite sanctuary the places we like and the places we don't like. It was really nice. It just let me express myself in a better way.

I was free to do whatever I want, when you asked about our sanctuary I was free to do whatever i want and show whatever I want. There were no restrictions. Not that there were restrictions after but the questions were open ended because later we had a topic to talk about this exercise was with no topic, open-ended.

Great, thank you. Would you change anything about the process and what?

If i needed to change something that means there was something that disturbed me, but I wasn't disturbed by anything therefore I have nothing to change. For me it was good enough and you were very interactive with us, which was very nice too.

Ok then what are the benefits for you?

The benefits are that I started to talk more about my inner feeling, because I wasn't used to talk much or express myself. I don't know how to explain it... to be honest I wasn't prepared to reconnect with the HIV story and bring it back to my life again, because it was a stage in my life and left it long time ago. In the workshop it came back and brought up a lot, even though I didn't like it, but by bringing it back and started working on it through the sessions, it became something I am talking about... I am showing it to people. It was a benefit.

Did you feel that you reconciled with yourself?

I was already fine with myself but it definitely made me more accepting with myself. I became more open about the HIV, before I had some negative ideas towards the HIV and I didn't use to talk about it and didn't think of it 100%, now I let the negativeness go completely.

Great I am glad, do think there is other benefits that you want to talk about?

Socializing more and I learned iMovie, I learned a new way to express myself, and I learned new stuff, which was nice.

Would you recommend this workshop to anyone?

To everyone

Why?

Because there is a lot of people like me that don't know how to express themselves. Because I used to no know how to express my feeling and self, now I found a way to be able to express myself, and the person who knows how to express himself he should be able to do it. Everyone needs this in my opinion, and everyone loves Art and it is Artistic.

Did you like the art component into it, not only just the narrative?

Of course it wasn't only about the writing there was something more that I was enjoying, and when you see the reaction of the people when they see it, and they don't know who you are, it gives you a satisfaction about there was something that is bugging me inside and said it or showed it. It was something really good.

I will be a bit specific, where does the satisfaction comes from? does it come from you have been heard or that you did something and put it out?

The satisfaction is that you did something and put it out there and everybody heard it.

ok great got you.

Do you have any other comments to add?

The negative part about me is that when I needed help I didn't come to you or asked you at the time, the technical parts.

Thank you so so much for your participation it was a pleasure for me.

Appendix D:
Ethics Issues for Canadian
HIV/AIDS Researchers in
International Settings

The document is available here: <https://www.cahr-acrv.ca/wp-content/uploads/2012/10/cahrreportfinal.pdf>

