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## Managing Illness through Creative Engagement: Women, HIV, and the Stitches Doll Project

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### Abstract

The Stitches Doll Project is a community-based initiative that enables women and girls to express their feelings about living with HIV/AIDS through creating a doll that speaks for them. In a very personal and powerful way, women and girls are able to tell their stories both visually, through their dolls, and verbally/non-verbally, through their dolls' monographs. The completed dolls become part of an online and traveling oral history exhibit. Based on an analysis of the dolls and their monographs, interviews with doll contributors and project coordinators, and archived Stitches materials, this paper explores the meaning making and identity work/repair articulated through textile creation and the cultural transmission of oral histories. Our analysis reveals four recurrent message themes: making sense of infection, the impact of HIV, the role of social support and connection, and educating others. These themes speak to the nature of the oral history the artists transmit via their dolls. As they design their contribution to the project at Stitches workshops, the healing benefits of creative engagement through textile artwork is made available to them. It is these two components of the project in combination that afford doll makers a unique opportunity to engage in a process of meaning making and identity work/repair. In the process they help advance public education efforts by challenging cultural beliefs regarding "the face of AIDS," the experience of living with HIV/AIDS, and ultimately who is at risk for acquiring the virus and by poignantly calling attention to the variety of social factors (e.g., poverty, domestic violence, and sexual abuse and assault) that put women at risk for contracting HIV.

### Keywords

HIV/AIDS, Adapting to Illness, IdentityWork, Textile Art, Social Support, Education

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### Acknowledgements

As Kathy Gerus-Darbison is the director of the Stitches project, she has the copyright authority for the images and quotes used in this paper.

## Managing Illness through Creative Engagement: Women, HIV, and the Stitches Doll Project

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*The Stitches Doll Project is a community-based initiative that enables women and girls to express their feelings about living with HIV/AIDS through creating a doll that speaks for them. In a very personal and powerful way, women and girls are able to tell their stories both visually, through their dolls, and verbally/non-verbally, through their dolls' monographs. The completed dolls become part of an online and traveling oral history exhibit. Based on an analysis of the dolls and their monographs, interviews with doll contributors and project coordinators, and archived Stitches materials, this paper explores the meaning making and identity work/repair articulated through textile creation and the cultural transmission of oral histories. Our analysis reveals four recurrent message themes: making sense of infection, the impact of HIV, the role of social support and connection, and educating others. These themes speak to the nature of the oral history the artists transmit via their dolls. As they design their contribution to the project at Stitches workshops, the healing benefits of creative engagement through textile artwork is made available to them. It is these two components of the project in combination that afford doll makers a unique opportunity to engage in a process of meaning making and identity work/repair. In the process they help advance public education efforts by challenging cultural beliefs regarding "the face of AIDS," the experience of living with HIV/AIDS, and ultimately who is at risk for acquiring the virus and by poignantly calling attention to the variety of social factors (e.g., poverty, domestic violence, and sexual abuse and assault) that put women at risk for contracting HIV. Keywords: HIV/AIDS, Adapting to Illness, Identity Work, Textile Art, Social Support, Education*

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### Introduction

*Without stories there is no articulation of experience. Without stories a woman is lost when she comes to make the important decisions in her life. She does not learn to value her struggles, to celebrate her strengths, to comprehend her pain. Without stories she cannot understand herself. Without stories she is alienated from the deeper experiences of self...she is closed in silence. (Christ, 1995, p. 1)*

There is a tradition of women and marginalized/disenfranchised groups using textile art, often in the form of quilts, as a means by which to express themselves, record their stories, commemorate status passages (e.g., birth, marriage, death) and create alternate historical records (Aptheker, 1989; Carocci, 2010; Collier, 2012; Ferrero, Hedges & Silber, 1987; Fry, 2002). Through their textile work "women...not only [are] witnesses to but active agents in important historical change" (Ferrero et al., 1987, p. 11) transforming their

“experiences into ways of knowing” (Aptheker, 1989, p. 43). They create meaning, a cultural record of their experience, with which others can share and learn. The typical group/community nature of such work – the joining together with others for “sewing and protest...[uniting] women in ties of work and creative expression” (Ferrero et al, 1987, p. 11) – provides women with the strength and support necessary to persevere adversity and face life’s challenges (Reynolds, 2004).

The Stitches Doll Project is a contemporary example of women creating alternative history through textile art. This community-based initiative provides HIV+ women and girls the opportunity to share their stories through creating a doll that speaks for them. The completed dolls are anonymously contributed to the project and are then made available for public consumption through the Stitches website and travelling doll exhibits. Through analyzing the dolls makers’ contributions to the project and Stitches exhibit visitor response cards, this paper explores the meaning making and identity work/repair articulated through textile creation and the cultural transmission of oral histories (Aptheker, 1989). As with their 19<sup>th</sup> century sisters whose “needles became pens and quilts their eminently expressive texts” (Ferrero et al., 1987, p. 11), the creation of dolls provides these women and girls with the opportunity to reflect on their personal feelings and share their ways of knowing and the reality of their daily lives. It “allows those most involved to provide context and meaning to their situation” (Wright, 2003, p. 29), work towards healing, and in the process educate their audience and challenge popular constructions of persons living with HIV/AIDS (PHAs).

### **Textile Art**

The creation of cloth-based/textile art forms, particularly by women, has a long global history (Gillespie, 2010). Through the textile arts of North American indigenous people, the storyquilts of the agrarian Hmong, the 3D arpilleras or cuadros of South America, African Kente cloth, and the American Antebellum slave quilts we see the historical cross-cultural use of textile art. Created by hand, using familiar materials (e.g., scraps of cloth, yarn, notions, etc.), often in collaboration with others, textile creations are “personal and communal” and serve “aesthetic and functional” purposes (History in Quilts, N.D.). Despite their different names and/or forms, textile creations are typically made by women for a variety of purposes: for warmth, to decorate, to commemorate life events, to express political views, to pass on oral histories, to express oneself (Carocci, 2010; Gillespie, 2010; History in Quilts, N.D.).

One of the most well-known North American examples of recording stories and history through textile art are the antebellum slave quilts. According to Fry (2002, p. 1) “denied the opportunity to read or write, slave women quilted their diaries, creating permanent but unwritten records of events large and small, of pain and loss, of triumph and tragedy in their lives.” Such textile projects are used as a means to share and record stories for future generations. As exemplified by contemporary quilting projects (e.g., The Sisters in Spirit Traveling Quilt, The Living Healing Quilt Project, The Native American AIDS Quilts, The Names Project AIDS Memorial Quilt), they can communicate hope and healing through weaving together stories, experience, and memory (Carocci, 2010). The typical communal nature of such projects also provides women the opportunity to come together, connect and give meaning to their shared experiences (Aptheker, 1989; Collier, 2012).

The Sisters in Spirit Traveling Quilt, Living Healing Quilt, Native American AIDS Quilt and NAMES Project AIDS Memorial Quilt are examples of contemporary North American community-based storytelling initiatives. All involve the use of textiles to tell stories – stories that often conflict with mainstream understandings of the issues faced by a marginalized group. The Living Healing and Sisters in Spirit Quilts are Native Canadian

projects. Both are designed to record painful histories and promote healing. The Sisters in Spirit Quilt “‘provides an avenue’ for Indigenous peoples to express their reaction and emotional response to the ‘unfair treatment and abuses suffered by [their]...people’” (Anonymous, 2008, p. 122). The Living Healing Quilt reflects more specifically on the Canadian residential school experience<sup>1</sup>, providing direct and intergenerational survivors with a venue to share their stories (Robertson, 2009). In contrast, the U.S based Native American AIDS and NAMES Project Quilts speak specifically to the impact of HIV/AIDS. Both Quilts, which have been publically displayed together in Washington D.C., serve as memorials to lives lost to AIDS-related illnesses and as a testament to the impact of such loss. They provide their panel creator(s) with a medium through which to commemorate loved ones and help to recast “mainstream understandings of AIDS” (Lewis & Fraser, 1996, p. 434).

By sharing trauma and loss through textiles, the process of quilt making preserves a legacy of stories and promotes healing for the quilt maker and the community (Lewis and Fraser, 1996). When such textile art projects are made public, the stories of the artists/contributors and/or those represented in the quilt panels are provided with an audience – of the artist’s product and the lives/stories shared. The interactions between quilt panels and audience members that occur at public displays “provide a medium through which many micro-level interactions take place. Within each of these interactions a relationship between the quilt and viewer is established” (Lewis & Fraser, 1996, p.447) and the story of the quilt/panel maker is witnessed, passed on and preserved.

Given the benefits derived from such textile art projects for the artist, it is not surprising to find a growing body of literature exploring the healing power of art therapy and artistic engagement (Collie & Kante, 2011). A key aspect of art therapy is providing a forum for expressing emotions that may not be expressible through words (Naumburg, 1987). In a review of the current literature on the connection between art and healing, Stuckey and Nobel (2010) note that engaging with artistic activities/creative engagement can have a positive impact on physical and psychological well-being and the healing process, leading to improvements in quality of life. With regard to textile-art, Reynolds’s<sup>2</sup> research illustrates how this form of art helps women deal with “the threats to self and identity” (Reynolds, 2004, p. 59) that accompany physical impairments and chronic and terminal illnesses. Such art making is restorative in nature, allowing women to not only express themselves, but manage their illnesses, experience joy and connectivity. According to Reynolds “creative artwork may hold particular potency for reclaiming self and identity” (2003, p. 113), for people experiencing chronic illness and may serve as a “vehicle for symbolic expression and achievement of a renewed, robust sense of self” (2002, p. 20).

It is through the creation process that we express ourselves and engage in meaning making and identity work. Such identity work is important as a disruption in biography and identity accompanies chronic and terminal illness (Bury, 1982). “Sustained symptoms, immediate medical crises, and lasting stigma undermine an established self-concept. Intermittent bodily sensations, implicit negative messages, and liminal identity questions may erode taken-for-granted images of self” (Charmaz, 2002, p. 305). People experiencing such

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<sup>1</sup> Beginning in the 19<sup>th</sup> century through to the mid-1960s aboriginal, Inuit and Métis children were removed from their communities by the Canadian government and forced to attend church-run government-funded “residential schools”. The stated aim of the schools was to assimilate Canada’s aboriginal peoples “into mainstream Canadian society by adopting Christianity and speaking English or French” (A History of Residential Schools in Canada, May 16, 2008). Over the years these children were forced to live in substandard conditions, abandon their cultural languages and practices, and were subject to emotional, physical and sexual abuse. More information on Canadian residential schools and the impact on the aboriginal, Inuit and Métis people can be found on the CBC website <http://alturl.com/4hr7c>

<sup>2</sup> Reynolds (2002, 2003, 2004), Reynolds, Vivat and Prior (2008), Reynolds, Lim and Prior (2008).

illness are forced to confront changes in their physical being, including not only the way they look and physically feel, but in what they can do and how others view them. The impact on the self can be monumental. As Charmaz (1991) notes, chronically ill people engage in identity questioning as a result of being immersed in illness or social isolation. Such questioning “involves wondering if the present identity founded in illness will become permanent and override other sources of identity” (Charmaz, 1991, p. 101). Artistic/creative engagement provides an avenue through which those experiencing chronic illness can engage in the identity work necessary to the healing process. According to Collier (2012, p.14), “the use of textile-making presents an amazing opportunity for growth, development, and psychological wholeness in women.” When created in a group setting, textile art enhances both ones sense of self and collective identity (Riley, 2008) and can enhance self-esteem (Reynolds, 2004).

The Stitches Doll Project is a contemporary textile-based therapeutic art project for women and girls living with HIV. By contributing to this travelling exhibit, participants are provided the opportunity to work towards healing through sharing their stories, expressing their feelings and experiences as PHAs, challenging popular (mis)understandings of AIDS, and educating others. Using the Stitches dolls and monographs, the data from interviews with project coordinators and several doll makers, and comment cards from doll exhibit visitors, this paper explores the meaning making and identity work articulated through textile creation and the cultural transmission of oral histories. In particular, it examines how this textile-based art project provides a forum for the voices of women and girls impacted by HIV, a means by which to share their experiences via expressing raw emotions, telling stories and sharing silences, and engaging in identity work and repair. In doing so, this paper adds to the literature on the role of textile art in the identity work processes of women living with chronic and terminal illnesses.

## **Methodology**

### **The Project**

The Stitches Doll Project originated in July 1999. It is a community-based initiative that provides the opportunity for women and girls to express their feelings about living with HIV/AIDS through creating a doll that speaks for them. The vast majority of doll makers create their dolls during doll-making workshops hosted by local service agencies. The remainder of them make their dolls at home on their own.<sup>3</sup> At doll-making workshops, in addition to providing the basic textile doll<sup>4</sup>, the Stitches Project makes available the basic materials from which each individual contribution to the project is developed (e.g., decorative materials and notions). Each doll maker is asked to design a doll that represents herself and to develop a monograph to accompany the doll that answers the question “if my doll could talk what would she say?” Once completed,<sup>5</sup> the dolls then become part of a traveling and online

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<sup>3</sup> Doll workshops are the primary means by which women participate in the Stitches Project. Women and girls wishing to make a doll on their own, however, can request a doll be sent to them. No such requests have been received since 2006.

<sup>4</sup> In 2008 the basic doll provided to contributors changed. Prior to 2008 the dolls were approximately 12 inches high, flexible, with long skinny legs and arms. The post-2008 dolls are shorter and thicker with no wires inside to pose them. Both, however, are made of a similar cloth that can be dyed to the skin color doll makers wish to project. This change was made because the cost of the original style doll became too expensive for the project. Stitches is a not-for-profit organization that provides the dolls and design materials free of charge to contributors.

<sup>5</sup> Once dolls are completed it is up to the maker if she wants to contribute her doll and what information she wishes to provide about herself to the Stitches Doll Project. Initially a number of the dolls were never returned.

exhibit where they carry the message of their makers to the larger community. By contributing to the project, each artist is afforded the opportunity to express themselves and help the viewing audience better understand the reality of living with HIV/AIDS.

### **Archiving the Dolls**

The research project involved archiving the dolls, monographs, Stitches display viewer comments, media coverage of the Stitches Project as well as conducting interviews with the Stitches founders/coordinators and several doll makers. Archiving involved photographing the dolls and inputting the monographs and viewers comments into spreadsheets that were then coded for analysis. Interviews were audio recorded, transcribed and coded. All dolls were assigned a code name to allow photographs and monographs to be cross-referenced. Media coverage of the project was scanned into a data-base for ease of access.

### **The Dolls Collection**

The current doll collection contains 400 dolls from all over the United States, one doll from South Africa, five from India and seven from Canada. Although we have some basic demographic information on many of the doll makers, it is up to each individual to choose what she wishes to reveal about herself to the Stitches Project and/or to the public. There are advantages and disadvantages of allowing women to remain confidential and/or anonymous. The obvious advantage is that they can participate in a project for women and girls with HIV without revealing who they (and their family) are. The project provides them with the opportunity to have a public “voice,” while at the same time keeping their identities private.

The disadvantage of this policy is that we are not able to capture all the nuances of the demographics from the doll makers. Although all contributors to the project must sign a release waiver stating that their doll becomes the property of the Stitches Doll Project, many of them choose not to disclose their personal contact information and limit the amount of background information they provide. This leaves us with many “unknowns” in terms of demographic data. The current data set contains basic demographic information (age, racial background, state and sometimes city of residence) for approximately 85% of the doll contributors. However, because most dolls are made in a group setting (i.e., at doll workshops through social service agencies), we have a general idea of the background (e.g., state of residence, racial background), of most of the doll makers, even for those who do not disclose. Other socio-demographic information (e.g., education, socio-economic status, marital status, sexual orientation, job, parenthood and number of children, etc.) tends to be left out by most contributors.

At present the demographic information we have is as follows: at the time of their submission, doll makers ranged in age from 6 to 82 years old. The median age was 35-45, but over one quarter were in the late teens/early 20s. They predominately identify as black or African American women. Approximately one eighth identify as Caucasian, a few as Hispanic/Latina, Indian, Native American, and as multi-racial. Almost one quarter of doll makers did not indicate they identified with any particular racial/ethnic group. The majority of the North American dolls (147) were made in Michigan, the location of Stitches headquarters. The new dolls joining the Project seem to be made overwhelmingly by disenfranchised minority women who live in urban areas. It is these women in particular who

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Since 2006 all project contributions have been made in doll workshops and all artists have contributed their dolls at the completion of the workshops.

face the daily health challenges and associated stigma that result from the intersection of racism, sexism, classism/poverty and ageism in our society.

## **Findings**

An analysis of the data collected for this project reveals the variety of ways that doll creators use their dolls to share their experiences with HIV and engage in identity work. Some doll makers use their participation in the project to express raw emotions or sort through their feelings and others to tell a story -- their story. Whichever form of expression they choose, the oral histories they create deal with a variety of issues, some that are extremely hard to face (e.g., illness, death, loss, suffering, betrayal, sexual assault). In a very personal and powerful way, women and girls are able to tell their stories both visually, through their dolls, and verbally (and non-verbally), through their dolls' monographs. The dolls poignantly call attention to the variety of social factors (e.g., poverty, domestic violence, racism, sexual abuse, assault) that put women at risk for contracting HIV. They also speak to the disproportionate representation of women of color among those infected with the disease.

We found a variety of messages are communicated via the dolls and their monographs. Our analysis is organized around the four recurrent message themes that emerged: making sense of infection, the impact of HIV, the role of social support and connection, and educating others. These themes speak to the nature of the oral history the doll makers transmit via their dolls. There is no strict one-to-one correspondence between doll makers/dolls and themes and as illustrated below, many dolls and monographs fit into more than one. Instead, we find the messages communicated, and the Stitches Project more generally, are multi-vocal in nature, speaking to the varied positive and negative experiences of women living with HIV. By juxtaposing the positive and negative experiences, the doll project helps us to understand aspects of the doll makers' lived experience -- pre, at point of, and/or post diagnosis -- which is connected to managing illness, identity work processes, and healing.

### **Making Sense of Infection**

The doll maker's desire to make sense of their infection and their health status is a common theme in project contributions, especially for those more recently diagnosed. For example, Angel Unaware (TX) tries to explain how she got infected despite her "Christian life":

She shows the Christian life I always lived.  
If my ex (minister) and I had NEVER divorced I would NEVER had this illness.  
But I would rather I had this and be an example to others and so my 3 sons  
will always take precautions  
(Angel Unaware, TX).

And Tbird (NY) attempts to grapple with her current health issues resulting from HIV status. What the hell am I doing here? I am in a wheelchair and I want to get out! (Tbird, NY). A number of the dolls are entitled "WHY ME?" and some version of the question "why or how did this happen to me?" is prevalent in the monographs. In these types of monographs we hear the doll makers thought processes as they try to make sense of why they contracted the virus, how they got to be where they are in their lives. Why Me's (MI) monograph illustrates this:



For someone that has had three sex partners. Why me!  
 I have had two husbands and one sex partner, one time.  
 I was never a street person. Why me!  
 I was always a housewife. Why me!  
 But I still will try to live as long as I can with Jesus [sic] help.

Despite the nature of the question, “why me?”, we do see some positive outcomes to this exploration. Why Me (TX) reports:

When I learned of the HIV disease, I was sad, unhappy and kept asking  
 “Why Me?”  
 But I’ve learned that life does go on.  
 With the support of my family, and faith in God,  
 I’m able to go through life now with the hope of someday, saying  
 “I AM NOT SICK”

Although Victory’s (MI) monograph starts with “Why? Why? Why? Why?” it goes on to say, “Let’s get a cure going-on. Let’s get busy. Let’s live until we die. Be happy, don’t worry.” Based on the doll’s name, Victory, this transformation is not surprising. It is monographs such as Why Me (TX) and Victory (MI) that illustrate how an HIV diagnosis can serve as a turning point in some women’s lives. Some project contributors’ lives were a downward spiral of tragedy, grief, and poverty prior to receiving their diagnosis. Such “stories of self reveal beliefs about essential attributions of self—both lost and gained through illness. They often mark a transformation of self that emerges through suffering and subsequent struggle to maintain a moral status” (Charmaz, 2002, p. 315). For example, Leotie (FL) tells us:

I am Leotie, I am the woman that has been born through all of Deborah's past and present experiences. The changes that we have made has [sic] become a strong positive force with the universe. My HIV will not end my existence, it will only help me live a better life (Leotie, FL).

And Lady M (FL) reports:

...In my past I was infected with HIV but today I am not living with HIV, HIV is living with me. I know that I cannot change what has happened to me in the past, but I have accepted my past for what it was worth. By doing so I can move on with my life so that I can live in today which is the present with respect and love for myself. I can build my future with self-dignity because I am no longer a victim. I am a survivor (Lady M, FL).

Part of making sense of their HIV infection involves identifying the underlying issues that put women and girls at risk of infection. The overarching issues for women all around the world coalesce into a daily struggle with sexism, classism/poverty, racism and ageism. Although the doll makers come from different walks of life, many speak to the intersection of these issues and how they put them at risk. Sexism is an important risk factor. Culturally dictated gender roles and expectations typically place women in an inferior position to men. This is a dangerous place as it makes women more vulnerable to male sexual advances, often feeling unable to refuse unprotected sex or sexual relations generally. In November 2009,

The Foundation for AIDS Research (AmFar) reported that 80% of newly diagnosed HIV-positive women contracted the virus through heterosexual sexual activity.

Through the dolls we hear stories from women who know they were infected through sexual relations with their spouse or partner or through sexual violence. Disco Lady's monograph and doll speak of feeling violated by a non-disclosing partner. This is illustrated by the placement of the multiple hands touching the dolls body (including the ones on her back that are not visible in this photo).

I was once a beautiful disco lady.

Met a man – married him, he put  
his dirty hands all over me – Now  
I [sic] got HIV.

Goddess (MI), in contrast, discloses her experience with rape:

“I am a 40 year-old African-American female who got infected through a sexual assault. I felt my world had been destroyed and I felt utterly alone.”



And Phoenix (MI) reflects on the experience of multi-victimization.

I am called Phoenix because I have been knocked down to nothing but ashes and rose again over my trials and adversities such as sexual abuse, physical abuse, verbal abuse, and homelessness. But just when I thought I was soaring high like a bolt of lightning, I was hit with the news that I was HIV positive. I found that this was the hardest blow. Thinking that I would not rise this time. This attack came from the man I loved, my husband.

Poverty is another of the main HIV risk factors for women around the world. According to by Krishnan, Dunbar, Minnis, Medlin, Gerdtz and Padian (2008, p. 101), “poverty and gender inequities operate cyclically: the myriad manifestations of poverty – insufficient income, restrictions in educational attainment and access to labor markets, and minimized decision-making autonomy – are fueled by inequities in gender-based norms and values and thus reinforce women’s lower socio-economic status.” Women who are prisoners of poverty often feel they have little choice but to yield to the demands of male partners, family members, strangers, social service providers, etc. in order to ensure economic security (see Andreeff, 2001). As the monograph that accompanies Honey (Show me the money!!!) (TX) illustrates, once women are HIV+ economic concerns can become even more pronounced, putting these women in an even more vulnerable position.

When I have to stop working due to my illness, where am I going  
to get the money I need for Rent? Food? Telephone? My Cats?  
When the time comes for me to “retire”, how am I going to pay off my  
Credit card bills? My dental care?  
Please, show me the money!

The importance of helping women become economically independent is the focus of many efforts that seek to improve the lives of women and reduce their risk for contracting HIV (for example see Forbes, 2011). Statements made in the monographs echo the experiences of

many other women, those who are/were not able to protect themselves because of fear of reprisal, poverty, inability to physically escape, or lack of access to information and resources. The reality of how women are (mis)treated and manipulated by the men they love and trust and by institutionalized forms of oppression become all too apparent in the doll monographs.

The stories shared by doll makers speak to the myriad of circumstances that they perceive lead to their diagnosis. Through questioning and sharing experiences of betrayal and victimization, we see the doll artists actively seeking to make sense of their HIV infection and to life with HIV. Those earlier in their diagnosis tend to focus more on how or why they contracted HIV and their struggle to deal with the challenges ahead of them. In contrast, those who have had some time to process their HIV status are more likely to share their journey with HIV. For some of these women it is a journey from devastation to enlightenment/optimism and for others it is a story of redemption, self-discovery and healing. Despite individual differences, the oral histories transmitted speak to circumstances that precede an HIV diagnosis and the difficult struggle that can follow it.

### **Communicating the Impact of HIV**

Doll makers communicate both positive and negative impacts of HIV through sharing their experiences, stories and silences. As noted by Charmaz (2002, p. 302) “stories and silences simultaneously frame and constitute meanings among people who experience disrupted lives” and are part of the process of “reconstructing life after disruption and loss” (Charmaz, 2002, p. 306). In terms of positive impacts we hear of people finding peace, community, and love as they deal with their HIV status. This is illustrated by monograph comments such as:

Happiness is living with AIDS and still enjoying a normal life” (Karen Loving, VA).

HIV has given me the ability/tools to see life in a different light. To see that the things that are important are stopping to smell the flowers, staying strong, finding support, remembering family and friends, work hard for what you want, and always show love” (Grace, TX).

We find similar positive, hopeful commentary in the dolls entitled “Hope”, hope for the future, hope for a cure, hope for the(ir) children, and hope for people living with HIV. This is evident in the poem “Shattered” that accompanies Hope (NY).

...I can only find comfort  
And hope,  
Hope for a cure.  
And hope that I am on a journey  
And when my destination arrives  
God will call my name  
And I will be waiting so patiently.

For I will be going  
To a better place  
A place for all eternity  
Where there will be no more suffering

But happiness and joy forever.

In the meantime  
I hope for a cure.  
Keep your hopes high,  
Don't give up.

In line with Baumgartner's (2012) work, positive impacts appear to be more typically expressed by women who have had more time to process their HIV status, its impact on self and identity. The narratives communicated via the dolls and monographs "illuminate...aspects of the complex process of reclaiming a positive identity through artistic occupation during chronic illness" (Reynolds, 2003, p. 125). In the monographs that accompany these dolls we hear the journey the doll maker has gone through, the identity work they have engaged in, ultimately arriving at a positive sense of self. Monica's doll Christina (FL) tells us:

I am done running. I have no reason for guilt and shame. I am proud of myself. Now I am living and a survivor of HIV-AIDS. I can say now that I love life and I'm living life to the fullest. I have no more time to waste running away because life is always there. I'm done and staying strong celebrating new life as free as a bird. Lasting and staying strong. That's me Monica I'm proud to be ME.

For some dolls, the focus is solely on the end result of the journey. For example, the Maker of Life (DC), notes,

If my doll could talk she would tell you, I have HIV. HIV doesn't have me I am not my HIV. If you look at the virus you won't see me. You won't see the strong, loving, compassionate young lady I am. You must live life, don't let HIV live it for you.

Similar to Reynolds (2003, p. 122) we find some women describing making a "relatively deliberate decision to act positively" at some point post diagnosis. For example, Untitled (TX) tell us:

I'm cleaning up my life,  
taking charge calling my kids,  
going back to school so that I can have my kids back with me.  
Flying like a butterfly on the winds of life with God's help.

Time appears to play an important part in achieving a positive sense of self/identity and/or orientation to HIV. It is the artists who knew their HIV status the longest whose dolls expressed more positive outlooks on their health and their lives. In contrast, negative impacts of HIV are often the focus of women earlier in their diagnosis. In terms of negative effects, the dolls that say very little or nothing express some of the most poignant negative effects of all. For example, both "Untitled" (MI) and Silverstar's (MI) monographs indicate that they "don't want to talk." As Charmaz (2002, p. 203) notes, such silences signify "an absence – of words and/or perceivable emotions," suggesting the overwhelming nature of their diagnosis on their lives (see also Reynolds, 2004; Reynolds, Lim, & Proir, 2008). Silverstar's monograph goes on to tell us that "Last year our support group had 25 women. Now we only



I have a beautiful daughter (the pink princess) and we enjoy each day we are together. I encourage anyone who is HIV+ to take charge of things and work at maintaining good health. Having joy in your life will keep you alive!

In her monograph, we hear how Amelia moves from the initial traumatizing and debilitating impact of her diagnosis through to her current hopeful and positive orientation to life. Through this and other monographs we see the important role that length of time since diagnosis plays in the identity work and repair process and the significant role social support and connection plays in one's orientation to HIV.

The juxtaposing of negative reflections of HIV with the positive ones provides visitors to exhibits the opportunity to see the varied experiences of PHAs and the process PHAs go through to achieve a positive sense of self. In doing so, they allow the viewer to connect with the doll makers and other people with HIV and in some cases, inspire action.<sup>6</sup> As one visitor noted,

The emotions conveyed through the dolls are evident. Hope, strength, despair, all the sides of HIV/AIDS are present and made all the more real. I'm glad I came today because I've gotten the chance to hear about the feelings, questions of someone who has HIV and AIDS and not just from a pamphlet. I will continue to talk about this disease and help create awareness (Female, 22).

Another viewer wrote,

Never have I learned more about HIV/AIDS.... The stories of the dolls allowed me to connect with the women with AIDS in a way that is almost similar to hearing them personally (Male, 24).

Creating a connection between the dolls and their audience also appears to encourage reflection -- on the day-to-day struggles of people living with HIV as well on one's own life orientation. This is illustrated in the following visitor's comment,

I hope that through this and other future exhibitions that they [the doll makers] will continue to be heard. Through their voices they give hope, comfort, empower others and show you are not alone. It helps to show the brighter side that people see when they are given such devastating life-altering news. Finally, those girls are breaking down the stigma and are going to bring awareness (Female, 36).

### **The Importance of Social Support & Connection**

People living with chronic and terminal illnesses such as HIV/AIDS often experience a shrinking of their social networks and/or sense of social isolation/disconnection (Charmaz, 1991; Lennon-Dearing, 2008). Such loss of social support and connection can negatively impact health, as support is essential to the process of illness, stigma and identity management and physical and emotional well-being (Baumgartner, 2002; Lewis, 2000;

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<sup>6</sup> Visitor reflections are collected at Stitches Doll Project displays through the use of comment cards, which are one source of data for this paper.

Poindexter & Shippy, 2008). We hear in Loneliness' (MI) monograph, the isolation one can feel in relationships that pre-date their diagnosis.

I feel lonely all the time. It feels like no one cares. When I'm in a place with friends I'm their [sic] but I feel invisible. It feels like people can see right through me. The D [in the pendant on her necklace] represents the depression I feel. The broken Heart [on her chest] is how much love and hate is in my body. The flowers represent how many people have broken my heart and have tried to repair it (Loneliness, MI).



In contrast, Egypt (NY) and Nanny (NY) report the benefits that can be derived from such relationships.

...Living with AIDS is easy for me since I have been fortunate to have a lot of support from my family and friends. That support alone made me not ever want to give up! (Egypt, NY).

I've been positive since 1998 and I'm still here to tell my story. I appreciate everything this agency has done for me. At first I was scared, thought my family would reject me – had no one to talk to. Yet they treat me no differently than before I told them I had the virus. I'm blessed with a supportive family. I am not afraid any longer because I am not alone in this... Thank you for listening (Nanny, NY).

Although some people find pre-existing significant other (familial and friendship) networks helpful, it is the support derived from interacting with experientially similar others (Thoits, 2011) that plays a key role in accommodating to life with HIV (see Baumgartner, 2012 and Lewis, 2000). In fact, it was such networks that helped Nanny (NY) (see monograph above) to discover the support available through her familial network. According to Lewis (2000, p. 111), interacting with "similar others is important for...facilitating the process of status adjustment and identity.... reconstruction" following an HIV diagnosis. As Watkins-Hayes explains (2013, pp. 83-84),

over the years, HIV-focused support...and advocacy groups have been critically important in helping people cope with their diagnoses As "framing institutions," ...[they] shape the form and tenor of individuals' coping trajectories by offering initial information about one's HIV status, a conceptual framework for understanding what it means to have HIV, language to talk about one's condition, and resources to begin restructuring one's life in the wake of a diagnosis.... These institutions are especially powerful for women.

The sense of belonging that can develop through such affiliation widens one's network enhancing personal and social well-being (Riley, 2008). Grace's (MI) monograph illustrates the role supportive networks can play:

After being diagnosed 3 years ago, HIV positive, I needed help coping with my family. I was afraid, angry, lonely, and depressed. I joined a women's



support group through Wellness AIDS Services, Inc. in Flint, Michigan. Feeling as though you are the only one in the world who is going through this makes matters worse. So they helped me by putting me in touch with others in my same position and by keeping me up to date on helpful information about our disease. Support groups can offer important help by allowing you to blow off steam in a safe place where others have gone through what you are going through. And accept you without being critical.

In Stitches doll workshops women come together to make their dolls. Sometimes the workshops take place within pre-existing support groups and other times they bring women together for the first time. As noted by the makers of Joseph (MI), Lisa (MI) and Susan (MI), regardless of whether the women know each other at the start, Stitches workshops provide opportunities for socially supportive interactions to take place and supportive and informative relationships to develop with experientially similar others.

I enjoyed the project, it is a way to get some new friends, everybody was friendly, we laughed and forgot about our status. It is so good to meet with all these people who have the same problems as you. It is a good activity to keep you busy. Thank you (Joseph, MI).

I think this experience was wonderful. Thank you. I hope more will be able to come in the next years. I really feel a sense of belonging (Lisa, MI).

I learned more about HIV and AIDS and being more careful by creating this doll (Susan, MI).

That CeCe (NY) was completed and submitted by her designer's support group after the death of her creator is a testament to the power of the relations that develop between these HIV+ women in such groups and the role a finished doll can play in confirming a positive identity (Reynolds, 2003).

Carolyn died before she finished her doll, but her sister gave permission for her doll to join the "Stitches Doll Project" journey. As soon as Carolyn began her doll she said,

"She's got to have a crix belly like me."

All through her illness Carolyn grieved the changes in her body and talked about being scared. The doll has a big heart just like Carolyn, who was always thinking of others and spoiling us with incredible fried chicken. We remember her wonderful laugh, her warm smile, her jaunty hats and tremendous strength.

With love from her doll-making sisters of the Positive Moms Support Group Westchester County, New York.





In addition to the connection and support doll makers reported finding among peers and supportive family members and friends, our analysis of the doll monographs reveals that many of the doll makers find support and comfort through their faith in god or a belief in a higher power. This is not surprising given the research that shows a relationship between religion and physical and emotional health (see Ironson, Stuetzle, & Fletcher, 2006; Koenig, 2012; Koenig and Larson, 2001). According to Koenig (2012), religious beliefs and practices can reduce the onset of physical and mental illnesses, reduce mortality, improve immune function, enhance social support, and overall health and well-being. The benefits derived from the support found through their religious beliefs is evident in a number of the preceding monographs and the following excerpts from the Stitches collection: “However by God’s grace he has kept me alive for 13 years” (Untitled, TX). “But through the love of my family and my faith in God and prayer I have a better appreciation for Life” (Goddess of Hope, MI). “I’ve learned the key to life is a positive attitude, FAITH, and GOD as your foundation” (Grace, TX). “Believe in God, he heals all!” (Amari, NY).

The stories shared by the doll makers illustrate that adapting to life with HIV and incorporating HIV into ones identity is enhanced by the support of/connection with significant others, religion and/or god, and experientially similar others (see Baumgartner, 2012). Support groups, with experientially similar others, are particularly important in this regard as they can be a valuable source of information--about the illness, treatments, and resources—and a source of empowerment. This is especially significant earlier in one’s diagnosis as “empowerment developed through community involvement...enables individuals to not only confront and challenge mainstream understandings of HIV and PHAs, it may also...enhance their health and well-being” (Lewis, 2000, p. 120). Phoenix’s (MI) monograph provides a nice illustration of the intersection and benefits of the various forms of social support and connection.

Through the grace of my god, Jehovah, my husband, daughter, and friendship of women who I met through the positive support group such as the one at Wellness, I have risen again. Stronger and Better than before (Phoenix, MI).

## **Educating Others**

The dolls and monographs not only speak to the importance of having access to supportive networks (e.g., family, friends, religion, HIV support groups) and what the doll makers themselves have experienced/learned via such connections, they also provide messages of support and encouragement for their viewing audience – strategies for avoiding infection, stories of lessons learned, ways to stay healthy once infected, etc. Making a doll that will speak for them, who will continue to provide the artist with a voice to share her story even after she is gone, is part of the Stitches Project mandate. According to the website:

The Stitches Doll Project was created so that the diverse stories of women living with HIV could be preserved for future generations to learn from.... The completed dolls become part of a national traveling exhibit and, in that way, educate the general population about the risks of HIV infection. (Stitches: Our Mission. N.D.)

In the oral histories passed on through the dolls and monographs we hear messages that share what the artist has gone through, a legacy that can educate/instruct the viewing audience, both those who are HIV negative and positive. This is evidenced in monographs such as *My Life After Death* (MI):

After the death of my one true friend, trying to save her life I unwittingly put myself in harm's way. I too at first thought I would lose my life. But with the grace of God and his purpose for me I'm still here. After 11 years of loneliness I know [sic] longer feel alone and this is a true blessing. I wish for others not to have to wait so long. It's been a long journey and hopefully my life after a death may make someone else's not so long.

Dolls and monographs that articulate educational messages, are often framed as messages designed to spare others the suffering and shame the doll maker has experienced. In their monographs, the artists share many important ideas, concerns, warnings, hope, and love with the greater community. Through analyzing the monographs and interview transcripts, we find such educational messages can be subdivided into 3 categories, all of which are framed as messages of encouragement and that speak to the importance of taking care of oneself and of social and individual responsibility. The first encourages the audience to protect themselves and others from infection. Some of these messages provide the audience with specific information on what to do and what to avoid.

Be safe – take care of you.  
Don't put yourself at risk; unsafe sex, using IV drugs.  
I used to think I was invincible but that wasn't the case of course  
(Native Hawaiian, TN).

People around the world take care of yourself – safe sex (Pac Woman, TX)

Teach young people about how to love each other and protect themselves from the  
harm and dangers in the world (Brenda Washington, VA).

The second category of educational messages encourages those individuals who are at risk to get tested. These messages are typically practical and hopeful in nature and speak to the benefits of “knowing” one's HIV status and of the future for HIV positive individuals.

Please everyone go get tested! Please practice safe sex. God will find a way to help us  
fight this battle. Also be strong and take your medicine (Me, VA).

Upon my journey of life I took a HIV/AIDS Test.  
Nov 1995 my life changed for the better.  
Because the seeds of growth started coming my way.  
If a person waters their garden fruits will grow if not it will die.  
That is how HIV/AIDS is seeking knowledge....  
Education is the KEY!!! (Knowledge, TX)

Get tested, it's a win-win situation. If the results are positive - you win. You know to  
seek treatment immediately (Guardian Angel of Life, MI).

The third category of educational messages are directed toward PHAs, encouraging them to take care of themselves, physically and emotionally.

I am Leslie and living with the virus. I am happy to be living  
and learning about my life with AIDS.

I thank God that I am living with this and still have a happy  
normal life and you can too.  
Stay healthy and be strong (Leslie, VA).  
I encourage anyone who is HIV+ to take charge of things and  
work at maintaining good health.  
Having joy in your life will keep you alive! (Amelia, NC).

HIV is a virus that says you must take your medicines every day – because  
if you don't you will die" (Ola, NY).

The importance of having a positive attitude is emphasized in these messages as illustrated in Faith's (MI) monograph when she explains why she is smiling.

You may ask why Faith is smiling? You live the life you choose--and you can either let all this bullshit get you down, or you can wake up each morning, put your best foot forward, and hope for love, peace and tranquility to enter your day. And a HUGE sense of humor doesn't hurt either...

As we move through the 3 categories of messages we see the consequences of not heeding the advice contained in the first type of message (things to avoid) and we see the reality of living with HIV. We also hear messages that are directed to a diverse audience – those who are negative, at risk, and those who are positive. The effectiveness of the women's voices, their messages, is clear in the comment cards completed by viewers at Stitches displays. Viewers talk about the educational power of the dolls:

STITCHES is a wonderful teaching tool! People can learn about AIDS as both a global and personal issue. Everyone should have the opportunity to engage with it (Female, 54).

They describe the personal impact of viewing the display:

This experience has been absolutely life changing for me. The dolls and narratives of these women/artists have spoken to me on a personal level. AIDS is a reality. Most importantly these women have taught me about life. We can learn from these dolls. Thank you for creating an opportunity for these voices to be heard (Female, 23).

And, as the following two quotes illustrate, viewer comments detail how they are inspired by the exhibit.

These women's narratives really inspire me to reach my full potential (Female, 30).

Very powerful and moving. Art always expresses experience so much more viscerally. The dolls which emphasized having to live your life to the fullest no matter the circumstances were particularly inspiring - they really help those who aren't living with HIV/AIDS to put things in perspective. Very grateful to have been able to share the exhibit (Female, 49).

## Discussion

*Love yourself to the fullest, my journey with HIV has taught me to fall in love with me! To accept myself for all my faults and celebrate the great things about me! In my arms is [sic] 6 roses for my babies I hold dear to me. I have on shades because my Future is Bright. My mouth is big because I want to educate and empower women everywhere. I'm sexy and sassy and fabulous! When the road was dark on my journey I knew God would see me through 34 years of Sunshine! For I know the plans I have for you says the Lord, plans to prosper you and give you hope and future (Victory, MI).*



The mandate of the Stitches Project is to provide women and girls with HIV “the opportunity for their ‘voice’ to be heard in a safe, confidential and educational manner.... [and to] educate the general population about the risks [and reality] of HIV infection” (Stitches: Our Mission, N.D.). Our analysis of the dolls, monographs and visitor comment cards suggest that the project is achieving its goals. The doll collection, pieces of art created by disenfranchised women, share their creator’s emotional state and/or story, their meaning making and identity work/repair processes, so that others may benefit from their experiences and hard-earned wisdom. Through their contributions to the project the artists provide a “connection between oral tradition, storytelling, the invention of meaning, and the preservation of cultural identity” (Aptheker, 1989, p. 42) of women with HIV/AIDS. The type and tone of message is often related to length of time since diagnosis, with longer time “allowing for adjustment to illness” (Baumgartner, 2012, p. 17). The nature of the messages contained in the oral histories are usually multi-vocal, incorporating one or more of the four recurrent themes we identified: making sense of infection (how they acquired HIV, factors that increase risk); the impact of HIV on their lives (the challenges they have faced, how being HIV+ has impacted their lives, their journey post diagnosis); the importance of social support and connection (the role familial, friendship, religious/spiritual, and social support networks play in adapting to life with HIV, the isolation experienced in the absence of such networks); and the importance of educating others (both those negative and positive about the experiences of PHAs, how to avoid infection, how to maintain healthy once infected).

By contributing to the Stitches Doll Project women and girls are able to communicate their emotions, stories and silences both visually, through their dolls, and verbally/non-verbally, through their dolls’ monographs. The cultural transmission of both positive and negative life experiences articulated through textile/doll creation ensure that the artists’ life histories and the life histories of women and girls living with HIV/AIDS are recorded, witnessed and remembered. Similar to quilting, doll creation enables women “to pass on knowledge, experience, [and] legacy through stories...tied in with the dailyiness of their lives...[and] women’s ways of knowing...[to provide] evidence that there is and always has been another point of view [from the dominant culture], another social reality” (Aptheker, 1989, p. 74).

The unique form of artistic expression offered by the Stitches Project, enables contributors to engage in a form of public education and activism while maintaining their anonymity. Their efforts help advance public education efforts by challenging cultural beliefs regarding “the face of AIDS,” the experience of living with the virus, and ultimately who is at risk for acquiring the virus. The dolls poignantly calls attention to the variety of social factors

(e.g., poverty, domestic violence, and sexual abuse and assault) that put women at risk for contracting HIV. By combining “real life” with “textile art” the Stitches Project and its contributors are able to illustrate the impact on women of the intersections of class, race, gender and age in an accessible, non-threatening manner. Based on the comments left at Stitches doll displays, the audience impact of the dolls parallels those of memorials for other contested social issues (Lewis & Fraser, 1996; Wagner-Pacifici & Schwartz, 1991), provoking “feelings, thoughts and emotions of a variant and private nature” (Wagner-Pacifici & Schwartz, 1991, p. 393).

Through bridging the public-private divide the Stitches Doll Project creates a personal and public outlet of expression (see Lewis & Fraser, 1996). As the artists design their contribution to the project at Stitches workshops, confronting their illness, cultural and personal views of HIV/AIDS and of themselves as a PHA, defining and redefining who they are, what it means to them to have HIV, the therapeutic/healing benefits of creative engagement through textile artwork is made available to them. It is these two components of the project in combination – sharing experiences, stories and lessons learned via a process of creative engagement (i.e., the creation of a doll and monograph, typically during a doll making workshop with other women with HIV) – that affords doll makers a unique opportunity to engage in a process of meaning making and identity work/repair. As noted by Stuckey and Nobel (2010, p. 261), “through creativity and imagination,” they find their identity and “reservoir of healing.”

For those of us consuming the artist’s stories we “learn something about their lives, and about courage, patience, devotion, love, beauty, grief, strife, resourcefulness, failure, survival, and struggle. The stories...form a legacy of strength, of endurance, of astonishing will” (Aptheker, 1989, p. 44). We can also see parallels between this and other textile creation projects. Similar to the Antebellum slave quilts, the Sisters in Spirit and Living Healing quilts, the Stitches Project doll makers are able to pass on important information/messages and be part of a legacy of survivors. Like the NAMES Project AIDS Memorial Quilt, the portability and accessibility of the doll project adds to its impact as it widens “the interactional context in which...the meaning and message” (Mueller, 1995, p.19) of the dolls and the doll project are communicated. And, in line with Collie, Bottroff, and Long’s (2006) research, the traveling nature of the displays satisfies an important element of the art making process, that is, for such artistic endeavors to have their full impact, it is important that there be an audience to receive it and acknowledge the person who created it.

Building on the success of the Stitches Doll Project, since the completion of this study, Stitches has expanded to include five other doll creation projects. Under the umbrella of the Stitches Women’s Initiatives, the project now reaches out to a more diverse range of marginalized/disenfranchised groups, providing them with the opportunity to express themselves, share their experiences, work toward healing and educate others through creating a doll. The new projects focus on: women with bleeding disorders (The ClotNot Project), women who have experienced domestic violence or sexual assault (The Victory Against Violence Project), transgendered people (The Transitions Project), orphaned children (The Orphans Project), and at risk youth (Youth @ Risk Project).

## **Strengths and Limitations**

This research project highlights the importance of viewing cultural artifacts, such as textiles (verbal and non-verbal recorded history), as sources of qualitative data as they provide alternative records and means of understanding social life. In particular, our analysis of the Stitches Doll Project adds to the literature on the role of textile art in the identity work and repair processes of women with chronic and terminal illnesses (see Reynolds, 2002,

2003, 2005; Reynolds et al., 2008; Riley, 2008; Stuckey & Nobel, 2010). However, rather than interviewing artists, this study focused on the artists' creations and audience reactions. As evidenced through the juxtaposing of positive and negative message, our findings speak to the importance of the passage of time on adapting to life with HIV and the incorporation of HIV into one's identity (see Baumgartner, 2012). In highlighting the self-expressive nature of oral history creation via textile art, especially when created in the company of experientially similar others, this research points to the various benefits that can be derived from such endeavors (e.g., for HIV+ women having the opportunity to express oneself, record one's history/experiences, pass on messages regarding means of infection, the impact of HIV, the importance of supportive relationships, and public education) and remind us of the importance of textiles in the lives of women and the recording of women's experiences.

While this study highlights the importance of using cultural artifacts to study social life, there are limitations to relying solely on this type of data. Without speaking to the artists, it is not possible to directly engage with them in order to explore the textile making process, and their life outside of their textile work. Although the few interviews we conducted with doll makers help reduce some of these limitations for our study, future research would benefit from including both the artist and the artifact. In particular, research on the impact of textile creation should focus more attention on the meaning of the artifact to its creator, perhaps incorporating a journaling component that has the artist reflect on her creation pre and during the creation process and after the project's completion.

With regard to the Stiches Project, adding a doll workshop observational component and interviews and/or focus groups with Stiches artists shortly after having completed their dolls, would facilitate developing a more nuanced understanding of the artists' motivations for participating in the project, of their experiences creating a doll, choices for doll design and monograph content, their understanding of their role in the project and the message they pass on. It would also be beneficial to interview or conduct focus groups with a group of artists over a period of time, at each point of contact having them reflect on their dolls, in order to obtain a richer picture of changes in their meaning making processes (see Baumgartner, 2002) and the role that other forms of time (historical, chronological, social – see Baumgartner, 2012) play.

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### Author Note

Jacqueline Lewis is an Associate Professor in the Department of Sociology, Anthropology and Criminology at the University of Windsor. Her research interests are in the areas of crime, deviance and socio-legal studies and health and illness. Her research explores the impact of public policy on the health and well-being, identity and stigma management, adapting to illness, drugs and drug policy. Over the course of her academic career she has conducted four studies that explore issues related to HIV, including individual and collective adaptations to illness. The most recent of these studies are two collaborative projects with her co-author on this piece, Kathleen Gerus-Darbison, a long-standing activist in the HIV-community. Since the mid-1990s, Dr. Lewis has also led three federally funded studies exploring the impact of public policy on various forms of sex work.

Kathleen Gerus-Darbison is the Founder and Director of the Stitches Doll Project, which began in 1999. Her research with women and life threatening issues subsequently propelled her to pursue her Master's degree in Sociology at the University of Windsor, Canada. She now works as an adjunct professor at two community colleges in the Detroit area where her focus is the intersection between gender, sexuality, and health. She is active in



the statewide Michigan HIV/AIDS Council, whose charge is to ensure that funding expenditures reflect the demographics of the HIV epidemic in Michigan. Ms. Gerus-Darbison has been a long-time activist for both HIV/AIDS and hemophilia-related issues. She served on President Clinton's HIV/AIDS Advisory Council, has co-authored a book with her daughter, Stephanie, called "My Parents Have HIV/AIDS: Some Advice From an Eight-Year-Old," and has been featured in several independent films in the last decade. She has served as Chair, Vice President, and a board member for the National Hemophilia Foundation over a span of 16 years.

As Kathy Gerus-Darbison is the director of the Stitches project, she has the copyright authority for the images and quotes used in this paper.

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