

The Use of Survival Stories to Empower HIV + Women of Color

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Abstract

Survival stories are a narrative approach which involves understanding the stories of people's lives and recognizing the strength that can be achieved by the narrator in telling and re-telling these stories. This article reports on the use of a narrative approach to describe the common experiences faced by a group of minority low-income women living with HIV in two Texas communities. Survival stories were analyzed to identify patterns of survival based on themes or trends in the data. Specific categories and subcategories were identified: Support systems (family members, significant others, friends, other support systems), inner strengths, history of survival, skills specific to survival, quality of life (emotional well-being, social well-being, spiritual well-being), emotions specific to HIV status (anger, frustration, ambivalence in emotions), parenting issues, mental health issues (depression, suicidal thoughts, domestic violence, substance abuse), rural issues, urban issues, healing (hope, future perspective, motivation to change), medical adherence, barriers/challenges, care coordination (support provided by staff, peer navigators, motivation to change). Survival stories can: a) provide information on how women survive difficulties and challenges in life; b) be used to empower women and to enhance behavior change; and c) be useful to evaluate local efforts to retain women in care. Practice and research implications are also discussed.

Keywords: Survival Stories, HIV+ Women of Color, Narrative Approach

1. Introduction

As we enter the fourth decade of the HIV epidemic, receiving a positive diagnosis continues to present psychological challenges (Do, Rosenberg, Sullivan, et al., 2014). Not only because an individual is confronted with a perceived threat to his or her health and life but also because the diagnosis continues to be highly stigmatizing, marginalizing, and discriminatory (Sandelowski, Lambe, & Barroso, 2004). Among the psychological consequences, a HIV positive diagnosis may result in what White (2004) refers to as the shrinking of the territory of a person's identity and a sense of losing touch with a "particular and valued sense of who they are" (pg. 46). Although there are many psychological challenges associated with HIV as with other chronic illnesses, there are also opportunities for psychological growth. (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). Survival stories are a narrative approach which involves understanding the stories of people's lives and recognizing the strength, resilience and power that can be achieved by the narrator (patient/client) in telling and re-telling these stories. Kleinman, (1988) and Riessman (2013) state that it is not necessary that the story represents absolute truth but it must hold psychological truth and meaning for the narrator. Although illness tends to be unpredictable and associated with the experience of loss of control, narrating stories about illness allows the narrator the opportunity to preserve a sense of identity and a sense of control in the face of a profound life disruption (Garro, 1992). By telling or writing about the experience of living with HIV/AIDS, one might repair damage the illness has done to the affected person's sense of self and life purpose (Frank, 1995).

This article provides an overview of the use of survival stories at two demonstration sites in Texas funded under the Special Projects of National Significance (SPNS) initiative, "Enhancing Access to and Retention in Quality HIV Care for Women of Color" conducted from 2009 through 2014. In addition, the article provides practical suggestions for using survival stories in HIV care and discusses potential areas of future research. The stories were originally implemented as part of local evaluation. It became evident that the stories could fulfill three objectives: a) provide information on how women survive difficulties and challenges in life; b) be used to empower women and to enhance behavior change; and c) to evaluate local efforts to retain women into care. The stories empowered women by creating an opportunity to reflect on their own ability to survive difficulties. Women became aware of their strengths, realizing that they can overcome barriers associated with their HIV+ status. Several benefits of the survival stories were identified during the project. By sharing their stories and listening to others the women built strengths and resilience. The stories provided information about their life experiences which was used in individualized treatment plans. In addition to empowering women, the themes of the survival stories were used by the sites to identify specific focus areas to increase knowledge of team members through training, thus potentially improving care. The survival stories provided valuable information to develop assessment instruments and evaluation tools. For example an instrument to explore spirituality was developed.

2. Overview of Projects

2.1 Special Health Resources for Texas

Special Health Resources for Texas, Inc. (SHRT), whose SPNS Project is known as "Survival of the Fittest", developed an effective model to link, engage, treat and retain HIV infected women of color in quality medical care, in a timely manner through a variety of avenues. SHRT implemented an intensive strengths-based case management intervention model to address barriers identified in existing literature with regard to why HIV positive women of color wait too long to be tested, do not follow through with care, or drop out of care (Eastwood, Fletcher, Quinlivan, Verdecias, Birnbaum, Blank, 2014). To address these barriers, SHRT utilized the skills of a master's level social worker and three bachelor's level intensive case managers. Face to face visits were conducted in the office or home. Patients and family members were educated about the need for sustained HIV care. By using strengths-based interventions, women became experts, actively participating in their care, whereby empowerment and personal catharsis could occur. SHRT established a partnership with Stephen F. Austin State University's School of Social Work to provide local and multi-site evaluation. One hundred and twenty nine women in 23 rural counties were enrolled in the project.

2.2 The University of Texas Health Science Center at San Antonio

The University of Texas Health Science Center at San Antonio (UTHSCSA) Division of Community Pediatrics collaborated with two community agencies, the Alamo Area Resource Center (AARC) and the University Health System's Family Focused AIDS Clinical Treatment Services (FFACTS) Clinic to implement project Women's HEART. The geographical catchment area included three rural and Anurban County.

Bexar is the most populous, includes San Antonio, and is the epicenter of the regional HIV/AIDS epidemic. UTHSCSA and its partners implemented a multi-component intervention for its minority, low income HIV+ women consisting of intensive outreach, medical patient coordination, patient navigation, and the “prevention with positives” intervention known as Healthy Relationships (Kalichman, Rompa, Cage, et al.,2001) integrated into an existing local network of HIV care. Over the course of the SPNS initiative, Women’s HEART enrolled 186 women.

3. Research Design

In this study, the authors used a qualitative narrative approach and case study design to describe the common experiences faced by a group of minority low-income women living with HIV in two Texas communities. The design provides the methodology for researchers to study complexities (in this study HIV+ status, life circumstances and illness) within a specific context. The design is based on the perception of the research participant’s (HIV+ women) world and a construction of her own reality (Baxter, & Jack, 2008).The major benefit of the design is that participants can tell their own story. In this specific study women were considered the experts of their own life situations- a principle strengthened by the case study design.

3.1 Sample

A convenience sample including 58 women from both sites were drawn from the 315 Texas women who took part in the SPNS initiative. The sample included English and Spanish speaking women of color. See Table 1 & 2 for the demographics of the women.

3.2 Data Collection

The survival stories were collected by meeting with the women individually once or twice during the 18 months of SPNS participation. Most stories were shared with staff during clinic or home visits and some stories were written by women at home. Initially the idea was to meet with the women at the beginning and the end of their 18 months of participation. However, this was not practical and the aim was to at least collect one written or audio taped story from each woman. SHRT developed a consent form and protocol and also identified four guiding questions used to engage patients in the writing of their survival story. The questions were (1) what was your life prior to HIV/AIDS, (2) how has HIV changed your life, (3) what has helped you to survive and (4) what ideas do you have that we can use in your treatment? Upon IRB approval, SHRT case managers and various HEART clinical staff () were trained at their respective sites to collect survival stories in the same manner ensuring consistency of data collection and trustworthiness (validation) of the qualitative process. The training protocol was developed by the SHRT project evaluators and director in collaboration with the Women’s HEART’s project evaluator.

3.3. Data Analysis

The raw data (survival stories) were analyzed per individual story. NVivo (Version 9.0) was used to identify specific categories of data (nodes), compare data from different external sources (in this case the survival stories) and conduct a content analysis of the different nodes and sub-nodes. Themes were identified to represent the data of both sites. Separate themes were developed for the sites and were then compared to develop the final set of themes. Themes similar to specific sites as well as those different to the two sites were identified. Only themes that showed similarity between the sites were used for this paper. Themes were matched with direct quotes from the survival stories. The quotes in the results section of this paper were not altered in any way. Using direct quotes provided the advantage of observing women’s realities as experienced. Qualitative data is subjective and the researcher’s framework of analysis and perceptions influence analysis and theme development. Researchers can interpret the data in different ways. The project team therefore reflected on the themes throughout the process to ensure consistency and agreement of the data interpretation. See figure 1 for the research process.

3.4 Categories of Data (Nodes)

Specific categories and subcategories were identified: *Support systems* (family members, significant others, friends, other support systems), *inner strengths*, *history of survival*, *skills specific to survival*, *quality of life* (emotional well-being, social well-being, spiritual well-being), *emotions specific to HIV status* (anger, frustration, ambivalence in emotions), *parenting issues*, *mental health issues* (depression, suicidal thoughts, domestic violence, substance abuse), *rural issues*, *urban issues*, *healing* (hope, future perspective, *medical adherence*, *barriers/challenges*, *care coordination* (support provided by staff, patient navigators, motivation to change).

4. Results

The results of the study focus on the women's strengths and abilities to cope and heal, and to remain in care and become medically adherent.

4.1 Women's Strengths and Abilities to cope and Heal

Spirituality centers on a positive relationship with God. Being connected with God and other people of the same religious affiliation is important to the women. The individual connection with God enabled women to forgive the person who infected them. The connection with other people with the same religious affiliation provided the social support, which is an important part of the healing process. The women in the study were all Christian, thus the reference to God. A sense of purpose gave meaning to life and being HIV positive. Women verbalized the importance of finding purpose even though they were ill. Finding purpose was connected to a belief that God is in control. Women survived everyday difficulties by feeling they belonged – this is a result of being accepted by family or community. Close relationships with family members were reported. The closest relationship reported consistently was between the patient and her mother. The women (specifically African-American women) reported that their closest relationships were with their mothers.

“I finally got the strength to tell my mother, it was not bad as I thought. My mother and aunt actually embraced me and they all cried, but reassured me that they did love me”.

Upon disclosure of diagnosis, the women experienced initial shock, denial, hurt and anger followed by feelings of depression, fear, loneliness and hate towards the person who infected them. Secrecy and depression was evident and resulted in ongoing isolation.

“My initial reaction was shock because I never did drugs or anything”

“When I found out my status, I felt like it was the most devastating day of my life”

Conflicting thoughts about dying (death or suicide) resulted in questioning the ability to survive and despair. Thoughts about death were often connected with the feeling and perception that the HIV+ status is a death sentence in itself. In contrast, several women indicated that they realized it is not a death sentence.

“I cried all the way home and made up in my mind that I was going to commit suicide. I did not want to live...”

“I had planned my suicide out and was going to actually kill myself that night”

“I automatically took it as a death sentence”.

“I will live it (my life) to the fullest because I realize that it is not a death sentence.”

Gratefulness for being alive generated hope and resulted in a positive attitude about the future.

“I am grateful for everyday and I realize the importance of life and being positive and I am trying to live that way each and every day.”

Self-acceptance was the basis of survival -understanding that she was still the woman she was before she was diagnosed with HIV/AIDS.

“At this time, I continue to take one day at a time with my family and friends and try to keep abreast of the new and upcoming things pertaining to HIV.”

Specific structure in the daily schedule of activities promoted day to day survival and gave meaning to everyday life. It seems that having structured activities during the day helped the patients prevent depression and negative feelings.

4.2 Women Remain in Care and Become Adherent

Program staff played a significant role in enabling women to deal with challenges. The encouragement and motivation provided by the project team members empowered women to address barriers.

“I have met people in my life (HEART staff) like the doctors, my nutritionist, my counselors, I mean they, they’re great encouragement, they’re great help.they help me to want to get be able to cope and deal with my situation”.

“Case managers (at SHRT) let me know my life isn’t over...there is a lot of support”

The support provided by staff encouraged women to cope with the daily barriers to healing. The narratives reflected the importance of support provided by case managers, social workers, patient navigators and medical staff. Navigators played an important role in empowering women to seek opportunities for change. Women initially reported being overwhelmed by the HIV diagnosis but it seems that navigators were able to provide important guidance.

5. Discussion

Themes based on these women’s stories are similar to those found in prior qualitative studies about the experience of living with HIV (Dalmida, Holstad, Diiorio, & Laderman, et al., 2012). Despite the presence of negative themes (e.g., suicide, depression, anger), most were positive and life affirming including a sense of purpose and meaning in life, gratefulness, hope and a feeling that it is worth living. The importance of a connection with God and with others who share similar beliefs observed among our women has also been noted in other studies of HIV infected individuals (Ironson, Stuetzle, & Fletcher, 2006 and Prado, Feaster, Schwartz, et al., 2004). Several studies suggest a positive although not clearly understood relationship between spirituality and health among HIV infected individuals (Ironson, Stuetzle, & Fletcher, 2006). Ironson and colleagues reported an increase in spirituality/religiousness following HIV diagnosis within a subgroup of their sample, which was predictive of slower disease progression and independent of coping, social support, or health behaviors. Social support, particularly provided by mothers/family, was also important in these women’s lives. Prior research has identified social support as an important determinant of quality of life among HIV infected women (Gielen, McDonnell, Wu, et al., 2001). Further, perceived family support may protect against the experience of loneliness, coping, and depression among HIV positive women (Serovich, Kimberly, Mosack, et al. 2001). Other positive themes reflected in the stories are related to finding meaning and purpose in one’s life. Although “meaning” is characteristically challenging to define, much research has been conducted on meaning making in relation to highly stressful situations, including being diagnosed with HIV. Most evidence supports a positive association between meaning making and better adjustment (Park, 2010). Similarly, having a purpose in life appears to reduce mortality risk (Hill, 2014). From our experience we note that survival stories have both practice and research implications and that generating survival stories can serve both purposes.

6. Practice Implications

Patients’ personal narratives of their HIV experience can be useful to both the health provider and the patient. Asking a patient to share her story and truly “listening” to the story may strengthen rapport between the two. The provider may gain a clearer understanding of the woman and her subjective experience of the illness and the information gleaned can enhance treatment planning. Telling the story about one’s HIV experience, like other expressive therapies and modalities, may have health and therapeutic benefits for the patient (Hill, 2014). Petrie, Fontanilla, & Thomas (2004) suggest by telling her story, the HIV infected woman may adjust to, cope with, and find meaning in the experience of becoming HIV infected as well as come to terms with her identity as a person living with HIV (Macapagal, Ringer, Woller, et al., 2012). According to Plattner, & Meiring (2006) this can be an empowering experience for the patient. It provides an opportunity for catharsis, much needed after diagnosis and during treatment. Having women tell their stories may also benefit their peers. Survival stories can be collected as written documents or as audio recordings for sharing with other patients at a future time (Cantrell, Sutton, & Gaur, 2014). Listening to others going through the same experiences can help women to understand that other people survived the same difficulties they are experiencing. It is important to obtain the permission of the women to share their stories. This in itself can be empowering. Women know that their own stories can help other women.

The stories can provide reassurance and hope to patients whose own life story may have been recently disrupted by receiving an HIV diagnosis. However, respect must also be shown for the prospective recipient's readiness to receive such a story. The women's stories suggest that health care providers may help their patients by considering ways to incorporate spirituality and religious beliefs in the healing process. Religious activities shared with other people provide women with the social support needed as part of the healing process. For instance, providers could routinely inquire about a woman's spiritual beliefs and practices and assist her in obtaining related services (e.g., finding a non-judgmental congregation or worship center to attend) or developing a plan to meet her spiritual goals. In view of the importance of social support as a buffer against depression and a predictor of improved quality of life, if themes of fractured social support or isolation arise in a woman's survival story, the provider may encourage the woman to re-establish or solidify familial relationships or explore ways to acquire new sources of support. Survival stories can be used to empower HIV+ women. The unique experience of sharing a story with a clinical team member provides an opportunity for the patient to reflect on her own history and recognize her strengths and ability to survive and adapt. Through the survival stories women can recognize that they are the experts of their own lives. A collection of survival stories can also be useful to a team to provide specific information to the women they work with. Themes identified through the survival stories can be used to develop intervention strategies and evaluation tools. Knowledge development and training can be based on the themes. Through an increased understanding of the specific patient population, the team can be empowered.

7. Implications for Research

On the basis of some of the predominant themes emerging from the stories told by this subgroup of marginalized, stigmatized, and vulnerable women, we believe that telling HIV survival stories was an empowering intervention for many of them. Future research could combine qualitative with quantitative methods to clarify the therapeutic effectiveness of the experience per se. For instance, one could measure various types of psychological functioning (e.g., self-efficacy, hopefulness and purposefulness) as well as engagement and retention in treatment in a sufficiently large group of minority women randomly assigned to tell their survival stories versus those who receive a "control" intervention. Future research could also assess the longitudinal impact of repeated story telling on psychological functioning as well as retention in treatment. Such research could also address whether the experience of telling one's HIV survival story at various points in time influences the narrative itself as well as psychological and adaptive functioning. This study was essentially an exploratory one that included both urban and rural women, Hispanics and African-Americans, and women shared their stories at different times in their HIV illness trajectory. Future studies may focus on exploring differences as well as commonalities in narratives based on these factors. Any differences that emerge could have implications for tailored treatment planning.

8. Conclusions

When women get the opportunity to tell their stories, reflect on their life trajectories, and recognize that they have been able to overcome incredible circumstances to reach the point in their lives when they can accept social support from others, profound life transformations become possible. While originally conceptualized as an evaluation activity for the respective Texas sites, the strategies and concepts reported here for engaging women through their survival stories fulfill three objectives. The narrative approach provides evaluation outcomes and may serve as a successful therapeutic modality to engage and retain women in services. By accomplishing these three objectives the survival stories framework has the potential, when adopted by others, to evolve into a potential best practice for engaging vulnerable women. It is not often that a research concept fulfills these multiple purposes while not requiring additional resources. Practices should consider adopting the survival stories approach and sharing their experiences so that a body of evidence can be accumulated to validate this as a best practice. "This publication was made possible by grant numbers H97HA15147 and H97HA15154 from the U. S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's Special Projects of National Significance Program. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the government."

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