Visually storying living with HIV: bridging stressors and supports in accessing care

S. M. Schrader1*, E. N. Deering2, D. A. Zahl3 and M. Wallace4

1Department of Oral Biology, Indiana University School of Dentistry, Indianapolis, IN 46202, USA, 2Department of Communication Studies, Indiana University School of Liberal Arts, Indiana University-Purdue University Indianapolis, IN 46202, USA, 3Office of Dental Education, Indiana University School of Dentistry, Indianapolis, IN 46202, USA and 4Ryan White Part A Director, Ryan White Services Program, Marion County Health Department, Indianapolis, IN 46220, USA.

*Correspondence to: S. M. Schrader. E-mail: sschrade@iupui.edu

Received on March 15, 2010; accepted on March 15, 2011

Abstract

This paper examines how visual narratives may bridge relational understandings between people living with HIV/AIDS (PLWH/A) and future oral health care providers. Borrowing from literature in participatory visual methods such as photo elicitation and photovoice, we explored how PLWH/A visually choose to represent their daily lives. This study uses a grounded theory action-oriented approach in examining the thematic analysis of 257 photos and 12 related reflective participant journals. Ten collaborative themes emerged from the participants’ analysis of their photos. These themes of social support, places, family, staff, group, recovery tools, transportation, friends, medications and food exhibited the indivisible characteristics of stressors and supports commonly found in accessing care. Further researcher reflections also found three meta-themes of stigmatization, maintenance of positive mental health and the development of pride in managing one’s health. PLWH/A need to share these visual themes of supports and stressors with future dental providers so that they may hopefully acquire an understanding of chronic illness that is more personalized and relationship centered rather than merely numeric and detached.

Introduction

Individual lives can be understood as a story that for some is disrupted by disease [1]. People living with HIV/AIDS (PLWH/A) experience life with chronic disruptions. This photo elicitation project employs a participatory method of photovoice to create positive social change for PLWH/A by exploring how participants live with chronic disruptions due to disease [2]. Photo elicitation is characterized as a postmodern dialogic conversation whereby authority on the imagery rests with the originator rather than with the researcher [3]. Photovoice is a participatory action research method in which participants photograph their everyday realities [2] whereby people can identify, represent and enhance their community through a specific photographic technique [4]. Both photo elicitation and photovoice share the perspective that authority and expertise reside with the subject taking the photo.

The method of photovoice is specifically being used because it stresses placing cameras in the hands of participants so they can “act as recorders and potential catalysts for change, in their own communities” [4]. Our project participants were invited to record and reflect how they live within their communities. The intent is to promote critical and collaborative dialogue about important local issues between participants and the research team, so as to reach policy and decision makers who
impact community members [4]. Grounded in critical reflection and data collection, this project aims to empower the communities being evaluated by inviting local PLWH/A to explore how they choose to represent the telling of their visually cocreated context-bound daily stories [5]. Participants were, therefore, asked to record a visual accounting of their daily life and to keep a reflective journal to explore sociocultural meanings related to the selection and composition of their photographs.

This participatory photo elicitation project [3, 6] examines the emergence of critical visual themes that may limit or enhance a PLWH/A’s ability to access health care. The participants’ visual experiences are analyzed because they have the potential for representing a powerful form of memorable yet also ordinary narrative [7]. These reflections of their everyday moments raise “the question of what parts of [their everyday] identity are not visible” [3] as past research has often sought out distinction and dissimilarity rather than highlighting how their lives are at times routine and even mundane. The retelling of these more commonplace narratives is meant to invoke empathetic responses and understanding in health care providers [8], by not just providing more disease-centered information but by highlighting common ground found between patients and providers [9]. This visual project is intended to offer future dental providers with the everyday visual voices of PLWH/A. Their imagery will hopefully provide dental students with a greater understanding of the daily biopsychosocial complexities and challenges involved in living with HIV/AIDS.

**Literature Review**

**HIV/AIDS patients’ unmet dental needs**

PLWH/A are frequently in need of seeking out, securing and maintaining a dentist because dental needs are critically important. HIV/AIDS patients have highly medically and dentally complex conditions [e.g. xerostomia (dry mouth), mucositis, (mouth sores) and periodontitis] [10, 11]. Oral health implications can ultimately affect how an HIV/AIDS patient swallows or chews, thereby influencing nutritional status or ability to adhere to medications [12]. It is essential that these patients have regular access to dental care in an effort to maintain overall oral and systemic health care.

PLWH/A’s access to dental care is often limited. In 2002, 24% PLWH/A in Indiana ranked dental care as a most needed service [13]. However, the Indiana State Department of Health reported that in 2002, 58% of PLWH/A in Indiana reported not getting any dental care and 44% of respondents in 2005 had trouble accessing dental care at least once in the past year [13]. In 2005, dental care was ranked as the third most important needed service [13], illuminating this continued unmet need.

**Barriers and stigmatization in seeking oral health care**

There are several explanations for unmet oral health care needs of PLWH/A. These barriers, however, often run deeper than simple logistical limitations and instead unveil intricate psychosocial barriers. According to Sontag [14], ‘AIDS makes explicit, as few diseases could, the complex interaction of social, cultural and biological sources’. Although the introduction of antiretrovirals has significantly increased the lifespan and quality of life of PLWH/A, social stigma and barriers in accessing care have unfortunately continued for some [15].

Rosenberg [16] argues that a disease is a socially constructed biological state. Our understanding of HIV/AIDS is represented as a multiplicity of connotations that are legitimized as they are collectively lived by the various participants [17]. These connotations may lead to stigma. Stigma takes place when a person’s experience and value is ‘reduced in our minds from a whole and usual person to a tainted, discounted one’ [18]. This stigmatization is performed between people when one or both parties are focused, in part, on the many negative stereotypes surrounding HIV/AIDS or on the attributes of the disease and not on the people living with this illness [19]. A dental health provider’s focus when interviewing a patient may, for instance, involve ‘an obsession with discovering the origin of
the disease rather than the means of controlling it’ [19]. Stigma can cause HIV/AIDS patients, thereby, to have devalued self-images and to not want to share their lived experiences [20]. Therefore, it is imperative that this project’s visual narratives provide a glimpse into the everyday lives of PLWH/A to illuminate any potential barriers or stigmas that may otherwise go unnoticed, unaddressed and/or misunderstood between those living with the disease and those providing care.

These complex and at times stigmatizing barriers have consistently impacted the HIV/AIDS community. Back in 2000, one of five PLWH/A reported unmet oral health care needs within the past 6 months [21]. Other studies in 2003 reported that lower income PLWH/A have concerns about their access to oral health care [22, 23]. Even as recent as 2007, Rintamaki et al. [24] reported that some dental providers still panic when confronted with HIV-positive patients, in effect limiting their dental access. Even though refusal to treat HIV patients can result in charges of discrimination [25], some dentists may still remain reluctant to treat PLWH/A [26]. Providers also express concerns that they themselves might become stigmatized if they treated PLWH/A [27]. Even if PLWH/A are actively pursuing dental care, psychosocial barriers and stigma play an integral role in the hindrances that impact both providers and patients.

Appreciating PLWH/A’s socially constructed illness narratives

Living with, managing and treating HIV all involve socially constructed health care interactions; therefore, it is important that these interactions are aided by mutual understanding and empathy. Some PLWH/A may feel uneasy with certain dentists, so these narratives help to create meaning with practitioners, community members and each other [28, 29, 30]. In order, in part, to reduce these socially developed feelings of discomfort, one needs to consider increasing empathy and appreciation for the ‘other’—the dentist and PLWH/A alike. Constructionist theorists have proposed taking a relationship-centered approach in exploring one’s self through ‘the discovery of the other’ [8]. One highly valuable medium through which to discover and understand ‘the other’s’ perspectives and values is by exploring visual narratives through photo elicitation because photographs can at times evoke deeper levels of human consciousness than words alone [3].

The exploration and sharing of specific HIV patients’ visual and verbal illness narratives through the photo elicitation process may help providers to explore their own levels of caring, consideration and compassion toward this particular patient population. We hypothesize that the sharing of written, spoken or even visual illness narratives can assist dental providers in reframing the often depersonalized and enumerated patient relations into a more personable relationship. Health care educators expect that the observing, listening to and/or reading of these narratives stimulates self-reflection in health care students so that they more critically consider their own approaches, prejudices and values regarding their care for HIV/AIDS patients [8].

Photo elicitation bridges relational understandings between patients and providers

While some may view visual projects as ‘soft’ among more traditional medical education curricula [8], this qualitative educational approach taps into the experiences of the patient and his or her own intimate knowledge of the disease [31]. Many research projects have effectively employed traditional qualitative research techniques of interviews or focus groups [32, 33, 34] to explore the private lives and stigma experienced by PLWH/A. Using a photo elicitation approach provides an additional complement to this body of literature by lifting out the visual narratives behind stories not yet fully told. Using photos can possibly sharpen participants’ memories and reduce the areas of misunderstanding between researchers and participants, while exploring complex social conditions, such as stigmatization [3].

According to Turner [35], ‘Disease is a language’, ‘the body is representation’, and ‘medicine
is a [socio-] political practice’. Photovoice [2, 4, 36] can be a critical methodological tool by which to explore language, body and politics. Photovoice can assist in bridging the gaps between emotionally laden daily stories and culturally distinctive worlds [3], such as a dental office and people living within various HIV communities.

Therefore, as researchers at the Indiana University School of Dentistry, we needed to develop a community partnership with the local HIV/AIDS patient community in order to understand how this population does or does not choose to represent their daily lives to future dentists. To better understand how PLWH/A’s physical, social, political, economic and occupational environments influence their health [37], we began working with the Bethlehem House, a local care coordination site for PLWH/A.

Researchers began visiting the Bethlehem House in 2006 to work with their community members to act as simulated patients (SP) in our objective structured clinical examination (OSCE) curriculum. Based on this ongoing partnership, we began to collaboratively develop, with a subset of our SPs, a photovoice project that is intended to assist our students in better understanding the lived experiences of our local HIV patient population.

We are expressly interested in how PLWH/A visually choose to represent their normal practices, challenges and complexities in living with the disease. Verbally or visually we take the position that all people act as storytellers and one’s shared visual narrative provides access into a person’s private and public identity, personality and relational communicative role with others [38, 39]. Visual narratives can unveil one’s socially constructed reality based on the ‘manipulation of symbols, words, meanings, and languages’ [20], demonstrated in participants’ photographs, discussions and accompanying journals.

Photovoice can tell numerous public and private stories as it combines and mixes multiple imagery [40], thereby suggesting why it is an appropriate method through which to voice the complex psychosocial stories of PLWH/A. Throughout human history, stories ‘represent the most effective vehicle that human beings use to communicate’ a lived experience [8]. A visual story like verbal and written narratives is a way of ‘ordering and presenting a view of the world through … characters, actions and settings’ [41]. Photography allows any of us regardless of our gender, ethnicity, education or other sociocultural groupings to make observations that can record such narrative abstractions [4, 36, 40, 42]. A photo elicitation process [4] helps us to make observations that we might not normally make and assist us in connecting core definitions of ourselves with those placed on us by society, cultures and history [3]. Borrowing from the literature of visual narrative [40, 41], photo elicitation [3, 42] and predominantly the participant action research method of photovoice [2, 4, 36, 40, 46], we worked with PLWH/A to explore the voices behind the representation of their digital images. This study, therefore, asks the question: How can visual methodologies help in the development of educational materials that will teach dental students about the everyday lives and experiences of PLWH/A?

Methods

Visual voice protocol

The protocol used was informed by photo elicitation, photovoice and photo narrative research and more specifically by the research of de Lange et al. [47], Wang and Burris [4], Baker and Wang [2], Wang [46] and Harper [3]. Fifteen Bethlehem House participants self-identifying as living with HIV or AIDS signed an informed consent and media release form previously approved by Indiana University School of Dentistry and the Indiana University Board of Review. They were then each given a disposable digital camera because this was the most durable and cost-effective technological option available since two cameras went missing and needed replacing and several were dropped without breaking. Also, this project hoped to illuminate that unpracticed photographers, with modest equipment, could perhaps make impactful visual statements about their everyday lives.
Only 12 participants completed the project and 3 dropped out. One felt that the time commitment required would be too taxing, another participant received the camera and did not return and the third participant did not want to come out to the community as someone living with HIV/AIDS. Prior to the study, participants were oriented to the study and instructed on how to effectively and ethically use a camera, which excluded photographing minors or incriminating activities.

In order to facilitate participation, participants were given bus passes for transportation to and from meetings; they were also given a photo CD of their photographs and hard copies of their images. Over a period of the next 4 months in 2009, participants were given two assignments which included: (i) to photograph events, people, places and things involved in their daily living with HIV/AIDS and (ii) to keep a reflexive field journal about: (a) where, when and with whom the picture was taken and (b) the socio-cultural meaning associated with each photograph.

Two months into the study, two communication researchers and one bioethics researcher engaged participants in a photo elicitation SHOWeD focus group technique to discover emergent themes from the participants’ pictures and their accompanying critical reflections [46]. After the photos were developed in hard copy and on disk, the participants and researchers collaboratively reviewed each photo together to foster ‘photofeedback’ regarding the images [48]. Researchers next asked out loud at each group meeting, the meaning of each photo and meanings were negotiated in groups separately from what had been written previously in reflective journals. Finally, upon completion of the entire study, they were each provided a gift card to a national retailer.

**Participatory visual action research analysis protocol**

A study of visuals helps those participating to open up interesting spaces for innovation and collaboration [49]. Therefore, we worked closely with participants for three months in creating a thematic analysis of their visuals to develop a rich portrait of who they are [50], what they value and how they ultimately see themselves fitting into their various social worlds.

Participants and researchers used grounded theory [51] to develop preliminary themes that emerged from the discussion through the SHOWeD technique: an acronym detailing the questions of what do you ‘see’; what is ‘happening’; how does it relate to ‘our’ lives; why does this ‘exist’ and what do we ‘do’ about it? [46]. Researchers facilitated a narrative analysis [52], which identified themes within and across the group’s thematic story. Although the researchers were intent on later applying these themes to teach dental students about the everyday lives of PLWH/A, they remained completely open and accepting of all of the collective participants’ thematic analyses throughout the process. Researchers later used appropriate HIV/AIDS literature to help recontextualize and apply the participant group’s thematic findings [47]. Eventually, the completed analysis was presented back to the group for their final interpretation and critical feedback.

**Participatory group characteristics**

Twelve participants took part in this project (see Table I). General socio-demographic data were collected at the onset of the study using a brief survey in order to learn more about the socio-cultural traits of the participants. The group was comprised of seven women, four men and one person who self-identified as being transgender by explicitly writing down this term to describe him/herself in the margins of the survey instrument. There were 10 African-Americans, one Latino and one multiethnic participant. Most reported as having completed high school (five) and as having gotten an associate degree (three). The participants’ sexual orientation consisted of six identifying as gay, five as heterosexual and one as other. The majority of participants reported being single (seven). Half reported making less than $5000/year and four reported making between $20 000 and $29 000/year. Also, most reported being unemployed and getting...
Finally, most (11) reported having a mental health diagnosis of depression and 4 of the 12 also stated they experienced panic attacks.

Collaboration at times was made more challenging by the group’s frequent open reporting about their struggles with addictions, mental health concerns and financial stressors, which occasionally took time and focus away from the project. Some participants also struggled with seemingly low levels of formal educational literacy and health literacy, hindering their abilities to write photograph descriptions. These barriers furthered our appreciation for the usefulness of self-directed photography and collaborative verbal feedback [4]. Additionally, as a medically and psychosocially complex group with highly scheduled antiretroviral and other medication regimens [9], they tended at times to fall in and out of adherence with the project’s objectives depending on their daily mental, physical or emotional state [53]. Because of these challenges, participatory photo elicitation was an appropriate approach since this process elicits comprehensive interview conversations while taking into account participant fatigue and boredom that may be exacerbated by less engaging methods [3].

Additionally, the participants reported most often having been diagnosed with HIV back in the 1990s (seven) and some much more recently in 2002 (four). They self-reported their CD4 count; the lowest count provided was 265 and the highest was 1056. There was a significant range of self-reported viral loads from undetectable to a high of 4000. Meanwhile, half (six) of the participants had not been told by a health care professional that they have AIDS, while five had been informed that they have AIDS (see Table II).

Photographs

In all, the 12 participants captured 257 photographs over the course of 2 weeks (see Fig. 6). Each camera provided to a participant was capable of capturing 25 photographs. On average, each participant took 21 photos. The minimum number of pictures taken by a participant was 12 and the maximum was 25.
Participatory results

The group of participants in collaboration with the research team identified 10 core themes from within the collection of 257 photographs. The themes consisted of social support, places, family, staff, group, recovery tools, transportation, friends, medications and food (see Fig. 1). These general themes encompass several subthemes and complexities that require clarification. ‘Social support’ entails people who provide PLWH/A with several forms of support. ‘Places’ describes one’s home and other physical venues for relaxation as well as places that foster spirituality and elicit peace and stability. ‘Family’ suggests biological and social ‘families’ and also includes pets. ‘Staff’ is a theme that includes the personnel at care coordination sites and social service agencies, such as mental health facilities. ‘Medication’ represents the individuals responsible for providing HIV-related medications, as well as the medications themselves and how they may interact in one’s body (see Fig. 3). The theme of ‘group’ refers specifically to the Bethlehem House support group. ‘Recovery tools’ include various resources that help participants stay sober and calm in an effort to avoid drug and alcohol abuse and mismanagement of general frustrations. ‘Transportation’ refers to the means by which participants get back and forth to their appointments and home. ‘Friends’ consist of support personnel at HIV care coordination agencies who have become friends to the participants and it also includes fellow PLWH/A in support groups. Lastly, ‘food’ is characterized as playing an impactful role in the maintenance of general health and fulfillment.

While these 10 themes detail sources of support, these same 10 themes were also described by participants as sources of stress. These reciprocal and at times indivisible themes unveil the symbiotic relationship between support and stressors within the life of a PLWH/A. Not all components of the themes, however, offer equal elements of support and stress. The level at which these themes impact the participants varies and affects each participant differently.

During the process of constructing themes, participants specifically noted supportive and stressful attributes of particular themes. Some of the supportive and stressful attributes discussed were in reference to staff, medication, transportation and places.

Table II. Community participants’ HIV status

<table>
<thead>
<tr>
<th>When diagnosed?</th>
<th>1990s (7)</th>
<th>2002 (4)</th>
<th>1980s (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-reported CD4 Count</td>
<td>Mean = 538</td>
<td>Min = 265</td>
<td>Max = 1056</td>
</tr>
<tr>
<td>Self-reported viral load</td>
<td>Mean = 1161</td>
<td>Min = Undetectable</td>
<td>Max = 4000</td>
</tr>
<tr>
<td>Has a health professional ever told you that you have AIDS?</td>
<td>No (6)</td>
<td>Yes (5)</td>
<td>Prefer not to answer (1)</td>
</tr>
</tbody>
</table>

Fig. 1. Community action-oriented themes.

Staff

The participants mentioned that staff members are supportive, provide relevant and helpful information, direct them to the ‘right places’ and help get PLWH/A Medicaid (see Fig. 2). Participants also detailed that ‘staff’ assist in getting housing, food and mental health resources, and they even help with mail.
However, participants also detailed that ‘staff’ at varying care coordination sites can at times be a source of stress. Participants noted that staff members are not always helpful; some are viewed as ‘lazy’. One person said that one ‘can’t reach them when needed’. In defense of the staff members, some participants stated that support agencies are at times understaffed, requiring clients to constantly change case managers. It is often ‘frustrating’, one person stated, to continually get new people in your life, rather than maintaining some consistency with support staff members and health providers.

**Medication**

Medications were generally reported as facilitating health but were also viewed by some as complicating one’s life and leading to discomfort. The participants noted that medications support their immune system, improve mental health, assist in getting good lab values (e.g. positive CD4 counts) and that medications are something that one ‘hope[s] keep viral loads down’.

On the other hand, medications ‘don’t [always] work’ and cost a lot of money. They can cause constipation, diarrhea, headaches and dehydration. The participants spoke of needing a ‘drug holiday’ away from the reliance on multiple daily medications that can lead to these taxing side effects.

**Transportation**

Transportation for some was a source of independence. It allowed the participants to attend health-related appointments on one’s own terms. The agency staff at times was noted as helping clients without a car get where they needed to go. For some with a car, driving was viewed as a peaceful and
restful time. Owning a car means one does not have to rely on the scheduling of public transportation and one no longer has ‘to wait on the bus!’ Transportation allows for PLWH/A to adhere to their medical regimens by getting them to their frequent health care appointments. However, the participants also alluded to the stressors induced by various transportation resources breaking down. They expressed their stress in not having any gas money, having to wait for the bus’s arrival, the feelings of disappointment when the ‘bus driver passes you by’ and owning a car that requires the use of a ‘screwdriver’ and other assorted tools just to start the engine (see Fig. 4).

Participants also noted that once on a bus, the stressors are still present. Fellow passengers may at times be ‘rude’, ‘smelly’ and listen to ‘too much music’. Using public bus transportation also requires substantial amounts of time and accurate timing in order for transportation to be a source of support rather than a source of stress.

Places (home)
Home was mostly described as a place of peace and comfort, in which one can ‘get away’. Participants shared their feelings of gratitude to ‘have a place to live’. Home was a concept that elicited pride for participants who had this valuable resource. For some, however, home was also viewed as a sizable stressor. Participants struggled to pay their bills, get food and keep homes clean. Some lived in the ‘PJs’ (projects) and one woman with walking difficulties was required to climb ‘forty f-ing steps’, just to get to her door. They also report living in homes with someone who ‘nags’ them; some of them claimed to share their facilities with mice and bed bugs. Within their communities, there were also common sightings of drug addicts, prostitutes and ‘cluckers’ (crack addicts).

Discussion
Based on the researchers’ further analysis of the participants’ photographs, their reflective journals and relevant literature, three key meta-themes emerged as telling indicators of the stressors and supports facing PLWH/A. Eventually, these meta-themes were presented to the participants and their feedback was used in the reflections that follow. With a greater understanding about how stigma, maintenance of mental health and pride play a role in the lives of PLWH/A, one can begin to better grasp the social barriers and complexities that limit an HIV patient’s access to dental care. In turn, dental providers can then hopefully facilitate increased access to oral health care for PLWH/A and create stronger personal connections with their HIV patients.

Stigma
HIV disease has several negative connotations that involve stigmatizing the disease and the personage of those living with the disease. The imagery of HIV is still viewed by some as one of constant immoral, promiscuous, riskier, sexual behavior and drug abuse, which ultimately will lead to one’s death. If PLWH/A are to help the rest of us recast these negative associations, PLWH/A need to assist in reframing themselves to society as having a ‘normal’ identity [54]. This public projection of ‘normalcy’ is not meant to detract from one’s unique and at times idiosyncratic nature. Instead, it is meant to help establish a sense of pride in one’s self as possibly being different, while also coming out vocally and visually as someone just like the
rest of us in conducting daily mundane activities (e.g. food shopping or visiting a health provider). Therefore, this project is intended to expose some of the duality involved in a PLWH/A’s representation of self as both normal and stigmatized. Health providers may not get an opportunity to fully appreciate the struggles facing PLWH/A since they may possibly appear outwardly normal in one’s dental operatory chair, while facing a myriad of private social barriers hindering access to care.

One participant writes about his lived dialectic experiences with normalcy and stigmatization in stating, ‘I’m an attractive six foot tall single African-American male. Along with the virus that lives within me, I also struggle with substance abuse, mental health, nerve damage, COPD, congestive heart failure, major depression … [yet] I receive no disability or SSI because I am not sick enough or close enough to death’s door according to the government’. While this participant expresses his outward attractiveness as positive and ‘normal’, he keeps invisible and private the potentially stigmatizing struggles that exist ‘within’ him. Only until he was asked to critically reflect on his self-portrait, did he begin to come out to the public about his conflictual feelings. While his narrative explains his complex mental and physical health challenges, his outward physical presence is likely viewed by us, as he suggests himself, as ‘normal’.

He would consistently remark that he appeared to have things ‘all together’. He wrote in his journal that his life was considerably out of balance and that social agencies and society only saw his well-groomed projection of normalcy but not his feelings of being stigmatized due to his various psychosocial conditions (e.g. a self-reflection as a depressed, poor, African-American, gay PLWH/A).

Another participant discussed a different mirroring of stigmatization. She noted in her journal that she wanted to take another picture of her boyfriend because he frequently reminds her of ‘how much he love[s] me and [it] doesn’t matter to him that I [am HIV] positive’. This reflection unveils the participant’s anticipation of societal stigma by implying differently than the previous participant that most people would view her negatively due to her positive status but that her boyfriend sees their relationship as ‘normal’ (see Fig. 5).

Another participant values living with her pets more than some of the people in her life because pets do not stigmatize her. She writes that ‘I can go off, or confide in my dog without her judging me … she’ll just listen’. Her characterization of her pet’s active listening skills seemingly illustrates that her dog is more accepting than some people may be.

**Maintenance of mental health**

Individuals living with HIV often have complex and at times convoluted histories that include traumatic
events [55, 56, 57] that may consist of sexual assault, sexual abuse, physical abuse, neglect or death of a loved one. Occurrences and recurrences far exceed the level of trauma for the general population [58]. As an example, one of our participants noted that her picture of a friend held particular significance to her. It was a picture of the first person whom she saw ‘moments after I found out my son had been killed’. This public reflection about her photo to the group opened up an opportunity for the group to further explore the various elements of trauma existing within their past and present daily lives.

This prevalence of trauma in PLWH/A’s histories produces lifelong effects on the health and behavior of those impacted by such factors as higher levels of mental illness, anxiety, depression and personality disorders [57]. Mental illness is often linked to poorer medication adherence [58, 59, 60] and has been associated with less safe sexual practices and drug use [61, 62]. This helps to provide some explanation for why some PLWH/A might engage in riskier health behaviors and offers health providers a deeper understanding for why maintenance of mental health is not only important for a patient’s general quality of life but is important in maintaining a PLWH/A’s systemic health care and medication adherence.

The participants involved in this study discussed various ways that they struggle and cope with mental illness, sobriety and anger. One participant writes that his hot tub acts as a mental health ‘stress reliever’. Another participant uses exercise as a tool to maintain mental health and sobriety. He writes that his weight training ‘makes me feel strong and helps my blood to pump and feel ready to face the day. [The exercise] helps fight depression for me’. This same participant shared that being around his loved ones also ‘helps me to be happy most of the time, now that we don’t drink’. His reference to family illustrates the role that psychosocial support can have in one’s maintenance of mental health and sobriety.

Several participants noted that alcohol and illegal drug use were coping mechanisms for controlling anger. However, many struggle to maintain their mental health without drugs. One participant notes that a local care coordination site is a place ‘where I go for anger management … I have [been] 115 days sober and I am calmer and want to manage my life without drinking. I need help getting it right,’ amidst feelings of anger and addiction. Another participant writes that through support, she is ‘learning how [to] control [her] temper’, in order to ‘keep out of trouble [with drugs]’. Other participants also praised the role that psychosocial support played in their ability to stay sober and control their anger, thereby improving their overall mental health.

Finally, participants noted that care coordinators provide support in assisting maintenance of good mental health. One participant wrote that her care coordinator, ‘give[s] me hope when my days are cloudy and [I] can hardly walk’. Another participant called her care coordinators her ‘women of hope’, who help to provide an HIV/AIDS support group ‘where I can go and let go, [and] vent about my problems’.

Pride

The final meta-theme that emerged from this project was the role that pride played in PLWH/A’s feelings of ownership about their lives and health. A participant stated that sharing his artwork helps to ‘make me feel good and worthwhile’ and that he and his partner ‘feel proud to display it in [their] home’. This sense of accomplishment and ownership can possibly be a significant motivator in addressing the health care needs of PLWH/A. Several participants expressed the joy they experience when they are in charge of someone’s or something’s care. One person wrote that ‘plants help me feel good [and] that I’m needed to care for something’. A different participant spoke of celebrating his garden because ‘gardens [are] a sign of living … no matter the adversities’.

Plants and gardens are not the only source of pride for our participants. Several participants also felt they were actively involved in their health care through the food they provided for themselves and their family. A participant took a picture of dinner that consisted of ‘a balanced meal with my meds’ since several medications must be taken with food.
Another expressed pride in ‘eating healthy [because it] keeps the weight on’ when losing weight is often a challenge for PLWH/A.

This demonstrates that several participants actively take pride in maintaining their mental and physical health. Yet another participant writes of his desire to become an even more active and prideful participant in his own health. He states, ‘I must be a major person in decision-making concerning my health along with my providers’. Taking pride in negotiating his own health care relationships will hopefully lead to greater trust between himself and his providers and greater adherence to treatment regimens [63].

Conclusions

By comprehending the role that motivators and barriers like stigma, the maintenance of mental health and pride play in the lives of PLWH/A, future dental health care providers can begin to develop a more relationship-centered focus in interviewing, diagnosing and treating HIV/AIDS patients.

Limitations

There was a considerable amount of energy, resources and logistical support needed to complete this project. Therefore, it is possible that this project was for some physically and/or emotionally taxing, which is why we saw some participants’ involvement wane over time. The intensity and complexity of the project could also have contributed to the lower numbers of people wishing to participate. We also struggled as a research team with the ethical considerations of how to construct reasonable rules for protection of subjects’ rights versus participants’ self-determination to tell their own story. For example, we urged the group to critically reflect on how presenting explicit photos in public could place them in legal and socially compromising positions. Although we alone could have crafted restrictions about imagery content, we decided that throughout the entire photovoice process that we would collaboratively negotiate with the group to discuss and develop group norms based on thoughtful and critical considerations.

Future directions

During spring 2010, the researchers, with reflections from the study participants, developed three, four feet by five feet, photo narrative posters that each outlined a meta-theme from this photovoice project. This multi-media presentation provides a robust complementary position to the pervasive biomedical and clinical science knowledge routinely integrated into dental education and it encourages dental students to ‘acquire an understanding of chronic illness that is personal and immediate rather than abstract and statistical’ [64, 65] by promoting ‘the personal relationship which develops between student and patient-storyteller’ [8].

In the future, we intend on continuing each year with the experiential learning process described earlier in which multi-mediated storytelling is woven together to provide students with a rich sociocultural context for how people in our community live with HIV/AIDS. We also intend to produce more photo narrative posters based on the other themes identified by the study participants. Researchers hope to redesign these multi-mediated materials, and some previously collected related video materials into a comprehensive podcast, web-based educational site and/or DVD that expresses the supports and stressors commonly facing this group of PLWH/A in accessing services. We hope that this newer educational design will be used in teaching not only dental students but possibly other dental providers (e.g. hygiene, residents, staff, faculty and clinical faculty), in order to affect greater relationship-centered cultural change within the dental community. Additionally, it would be advantageous to suggest an evaluation of educational outcomes by assessing how students specifically feel they would apply this education material in their upcoming clinical practice and how the education materials influence direct patient care with PLWH/A in OSCEs and in real clinical settings. Another evaluation might assess how study participants feel they have influenced students’
clinical practice. Overall, it is essential that we enhance the vividness of our educational HIV/AIDS materials for future health providers, so the next generation of clinicians appreciates, embraces and empathizes with both the uniqueness of a particular patient population and the connections we all have with a patient’s everyday life.

Funding

This work was supported by a Title XXVI HIV Health Care Services Program 1, 2 Part A, Emergency Relief for Areas with Substantial Need for Services grant from the United States Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau [2H89HA07938].

Acknowledgements

We would like to thank the following people for their support in this project: Mr Mike Wallace, Director of the Ryan White Program, Marion County Health Department; Mr Nate Rush, Executive Director, Bethlehem House, Indianapolis; Mr Isaac Spain, Program Director, Bethlehem House, Indianapolis; Dr Susan Zunt, Chair, Department of Oral Pathology, Indiana University School of Dentistry, Indianapolis; Dr Lawrence Garetto, Dean, Office of Dental Education, Indiana University School of Dentistry, Indianapolis, and most importantly, we would like to thank our Bethlehem House group for their dedication, enthusiasm and thoughtful reflection throughout this project and for their willingness to share their lives with us and others.

Conflict of interest statement

None declared.

References

Visually storying living with HIV


