

Enhancing Client Retention & Empowerment ... the “Positive Journey” Project

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ST. JOHN'S
RIVERSIDE HOSPITAL





A Positive Journey

living life with HIV

Photo stories by Clients of The HOPE Center
of St. John's Riverside Hospital

20 Years of Leadership
A LEGACY OF CARE



20th YEAR WHITE ALL GRANTEE MEETING AND 10TH ANNUAL CLINICAL CONFERENCE

Origins

- Early HIV/AIDS epidemic associated with many artists, performers, youth culture
- Activism in symbols and designs
- Emergence of photojournalism stories depicting illness, death

HIV/AIDS: Icons & Images



Memorial Quilts from 1985



Princess Diana 1987



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Act Up demonstration, 1988.

Photo © Ben Thornberry



Icon; Keith Haring 1989



Public Awareness



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Pieta, Benetton



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Magic Johnson Announcement 1991



1993, the beginning of an era...



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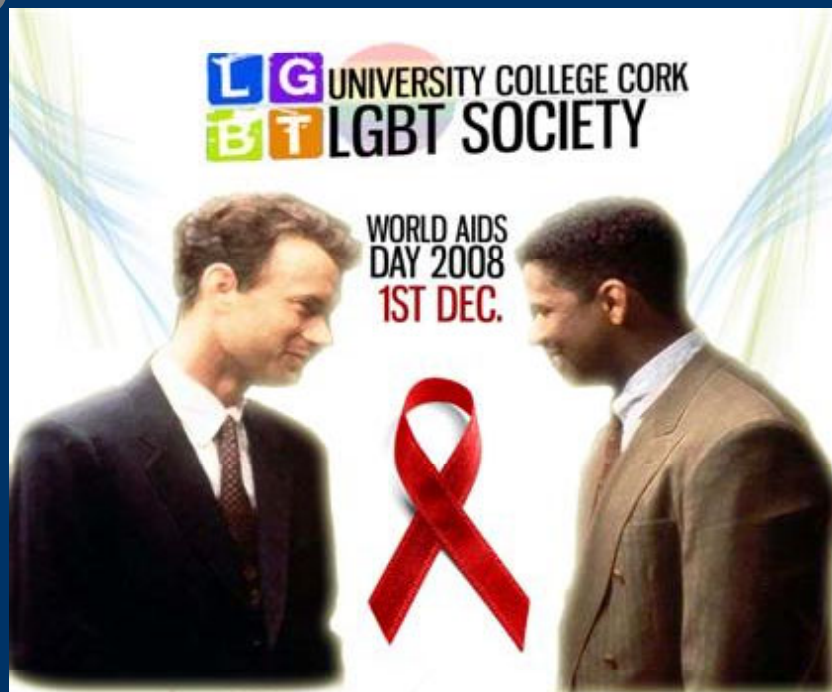


2018 RYAN WHITE ALL GRANTEE MEETING AND 15TH ANNUAL CLINICAL CONFERENCE

“Gotscho Kissing Gilles” Nan Goldin, 1993



Academy Award winner 1993



I WAS BRUISED AND BATTERED
AND I COULDN'T TELL WHAT I FELT
I WAS UNRECOGNISABLE TO MYSELF
I SAW MY REFLECTION IN A WINDOW
I DIDN'T KNOW MY OWN FACE
OH BROTHER ARE YOU GONNA LEAVE ME
WASTIN' AWAY
ON THE STREETS OF PHILADELPHIA

SEE THE OSCAR-WINNING CLASSIC.
PHILADELPHIA. MONDAY 1ST. ORB 2.12. 7PM
CHARITY RIBBONS ON SALE MONDAY IN BOOLE BASEMENT: €2

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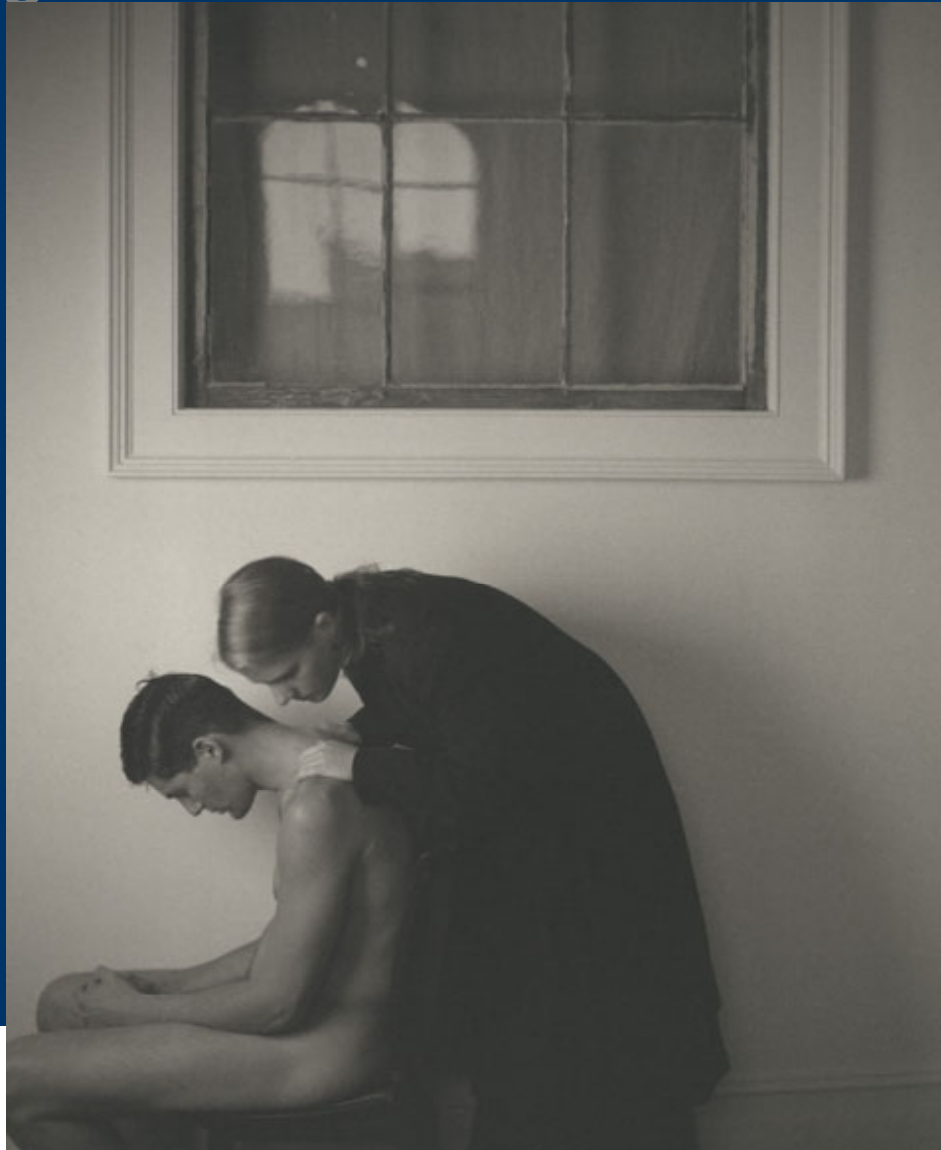
Photo by Tom Stoddart



Photo by Giles Mendel, Africa



“My Spirit Tried to Leave Me” John Dugdale 1994



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Photo by Darcy Padilla 1994



Photo © 1994 Darcy Padilla

Child with HIV/AIDS in Cambodia



Meds as art – hivine.com



A New Disclosure?



“Listening to Myself: Open” 2002 Richard Sawdon Smith; The Body



Vanity Fair Magazine 7/2007

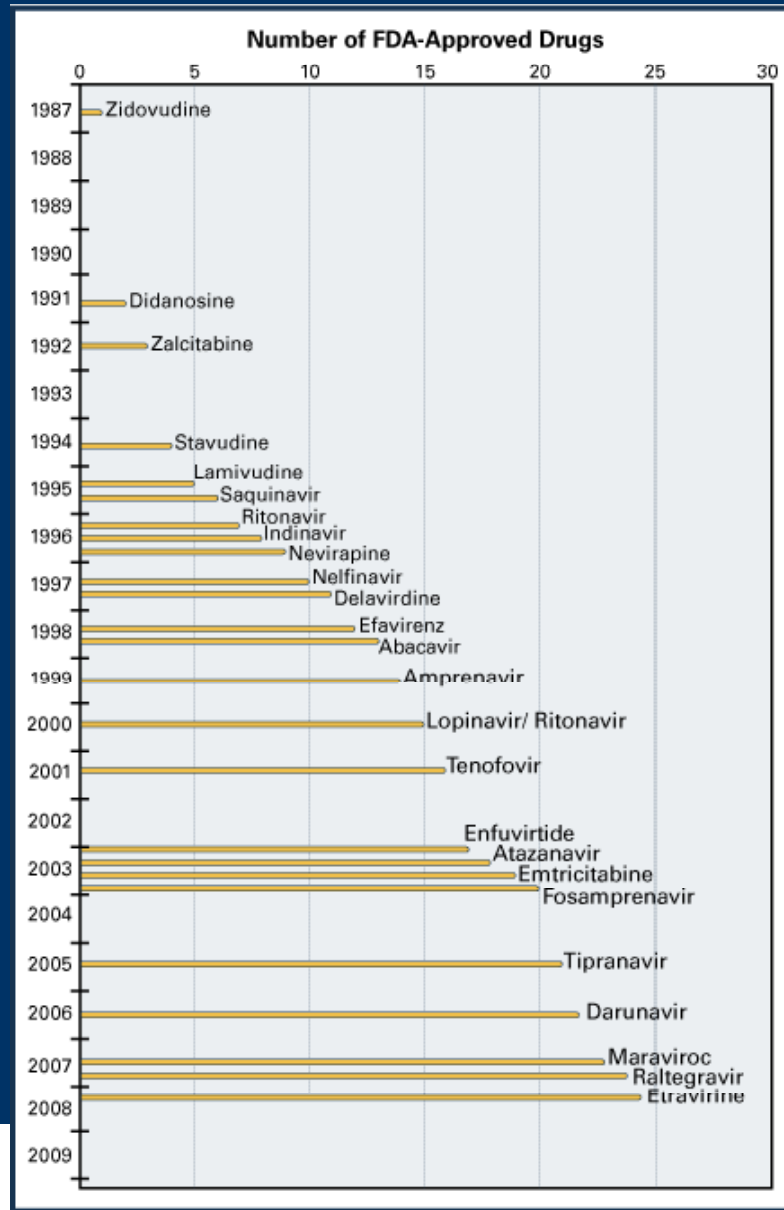
Photo by Antonin Kratochvil



On The Issues Magazine 5/2008



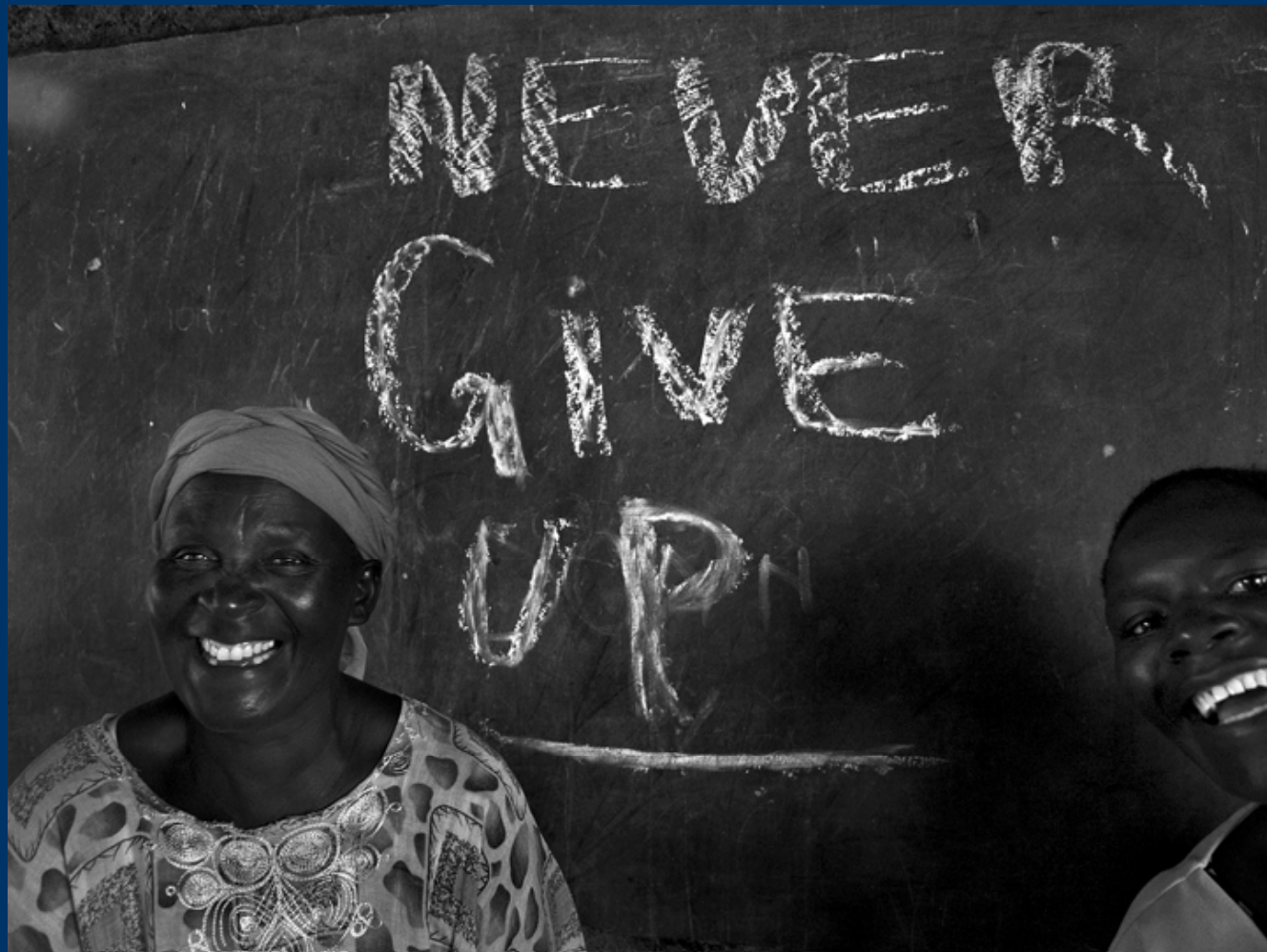
Timeline



An Aging Population, Epidemic



Photo by Patti Gower



Evolution & Self-reflection

- Development of treatments and care facilities has changed lives
- Change in the culture of HIV/AIDS
- Focus shift from imagery of devastation to survival to health
- Photography as a tool to start locally and reach globally

Creating a Photography Project

- Timeline
- Resources
- Institutional issues
- Goals, target audience
- Portraits, collages, narratives, designs

Timeline 1

- Approximately one year from idea to final exhibit.
- Identification of willing participants (15)
- Discuss where project will be displayed
- Disclosure assessment, obtain consents
- Discuss availability and commitment

Timeline 2a

Small group sessions (5 per group)

- Portraits with photographer
- Discuss feelings about being photographed
- Presence of lights, filters, screens
- Appearance
- Time

Timeline 2b

Small group sessions (5 per group)

- Collage preparations
- Distribute cameras
- Discuss basic camera use (flash, aim, lights)
- Discuss photography techniques
- Distribute worksheets to stimulate ideas for collage photos

Timeline 3a

Photography sessions with photographer

- Portraits
- Multiple shots per client
- Discuss concerns

Timeline 3b

Review of photos for collage

- Audio recordings – interview clients about their photos
- Review of photos: subject matter, style, significance
- Review of general themes, emotions
- Discuss layout

Timeline 4

- Obtain consents for those photographed in collages (special considerations for minors, those with personal disclosure issues).
- Prepare for exhibit
- Assess emotional issues, conflicts, concerns about public disclosure

Timeline 5

Final exhibit

- Location, location, location
- Resources, scale of event
- Media issues

Timeline 6

Beyond the first exhibit

- Consider volume of photos, frames, etc.
- Traveling or permanent collection?
- Consider internet resources
- Linkages

Resources

- Available staff, volunteers
- Money & time
- Cameras
- Photographer
- Graphic Designer
- Developer
- Framer
- Facilities



Institutional Issues

- Validation of care
- Perceptions
- Advertisements
- Cultures



Goals, Target Audience

- Participants
- Institution
- Community
- Media



Self-Reflection

- Guide participants to express themselves
- Elicit emotions, thoughts beyond the superficial
- Provide perspective on health, feelings about medical care, staying sober, disclosing status, etc

Analysis – Use of Narrative & Content Analysis Methodologies

An Analysis of the Images & the Spoken Word

Qualitative Research Methodologies

- Narrative
 - Inductive
 - Storytelling
 - Highly ‘local’ to the sample (nongeneralizable) – it gives you the sound of individual ‘voices’ that may be lost in experimental research methods
 - Does not ‘objectify’ knowledge; rather privileges the knowledge of the interviewee – what they ‘know’
 - This may or may not represent others in the population
 - What does “health” meant to this particular set of people in Yonkers, NY in 2009?

- Interpret the data within the context of the locality
- Emphasizes the meanings that people give to concepts and events
- Strength – first hand account of the issue

Sample

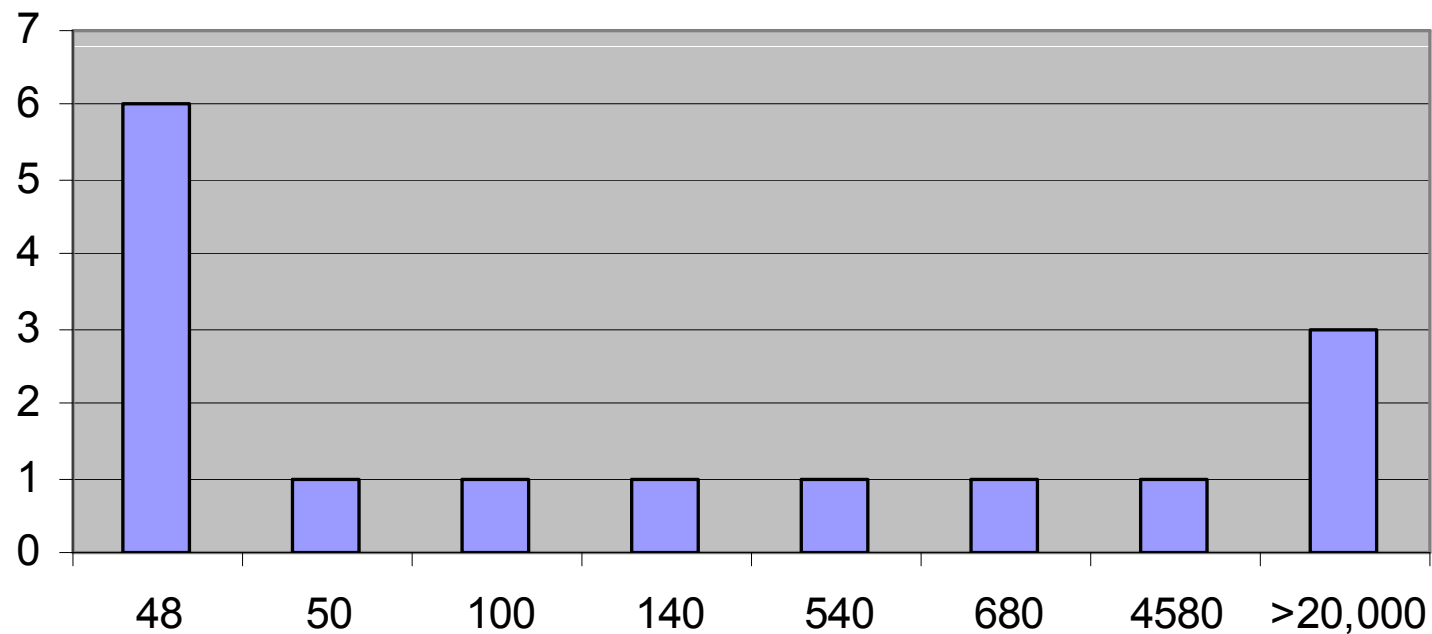
- Purposive; 15 clients of HOPE Center, St. John's Riverside Hospital
 - Subgroup of clients chosen because they are doing well on medications and with their medical care
 - 'Strengths perspective'
 - Question – *What helps you stay healthy?*
- Look at outliers – the 'other' perspective

Demographics

- **Sex:** 1 Trans (M to F), 7 Females, 7 Males
- **Race/Ethnicity:** 7 African Americans, 6 Hispanics, 1 Caucasian
- **Mode of Transmission:** 6 Heterosexual, 5 MSM, 2 MSM, 1 Transfusion, 1 Sexual Assault
- **Average Time Since Diagnosis (n=13):** 11 years (range: 9-29)

9 AIDS Diagnosis; 6 HIV+
Average CD4: 478 (66-1102)
VL: mean = 7126, median = 100, mode <50

Range of VL Among Participants



How “I” Impact the Narrative: Who Am I?

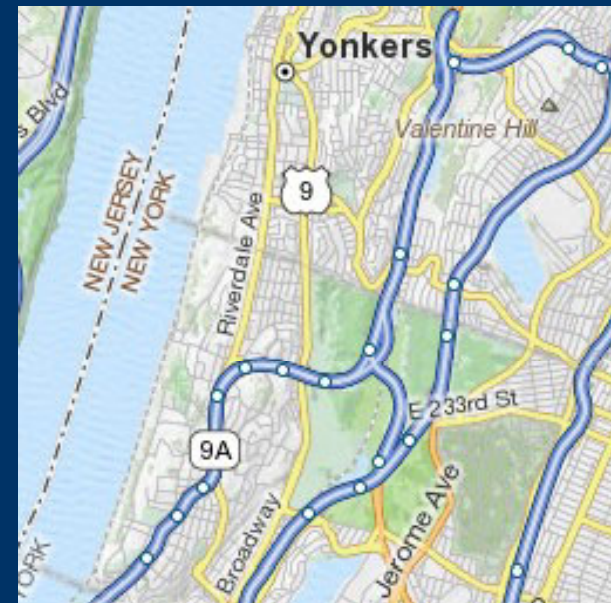
- Race/Ethnicity
- Gender
- Who am I in relation to this HIV+ person?
- What culturally dominant ideas do I bring to this work?
- What led me to decide what I included in the narrative analysis?

Stance of the 'Researcher'

- Must be identified & made 'transparent' in narrative
 - Who am I?
 - What do I bring to this discussion?

Context

- Yonkers, NY –
 - Among the highest growth areas in the country (Hispanics & other immigrants account for much of that increase)
 - Majority minority/ring suburb
 - 196,086
 - 26% Hispanic (Puerto Rico)
 - 16% African American
 - HIV disproportionately impacts African Americans
 - AIDS incidence – 673.75/100,000





- 4th largest City in NY State
- HIV is still very stigmatized
- Economically – very wealthy and very, very poor; majority of cases of HIV are among the very poor
- High intensity drug-trafficking area (58% of AIDS cases attributed to IDU; increase in cases among MSM, particularly those of color).





I don't want anybody to see their faces because they're smaller



He has the attitude of "if they know you are sick I don't care"



My kids are my gold in life, why I should live



I took this picture to show myself how I look, now and how I will look in a year from now when I accomplish my goals



look at the sky and thank God for another day for Him giving you life



With my faith in God, it helps to live



This is the medicine that's what helps me to stay cleaner for my children



I took a picture of a school - that's one of my goals



I don't like the way I'm living in that building, I want better than that for my children



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This is the family, there's nothing but love here



*Look at my beautiful congas!
I used to play in a band!*



*The dogs are my babies, they have balls
and everything!*



This is my baby, we've been together 10 years!



Look at the faces we're making! It's my tradition - making faces



My stepdaughter



That's my daughter, look at her, how beautiful she turned out



The reception desk at the Hope Center



This was at the Living Together Picnic

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This is the yard in the back, where you can go and sit and meditate, it's very peaceful.



I've gone through so much turmoil in my life and I survived it.



I'm in a good place, I'm blessed.



There are some people that still haven't got the message, they're killing themselves, I bring them back here, I try to pass the word that finally got to me.



Come in and get some help, can help is there for you man. Once upon a time when you were diagnosed, three days later you were dead, but now you get help.



I need to take all these medications, now I'm down to just one a day.

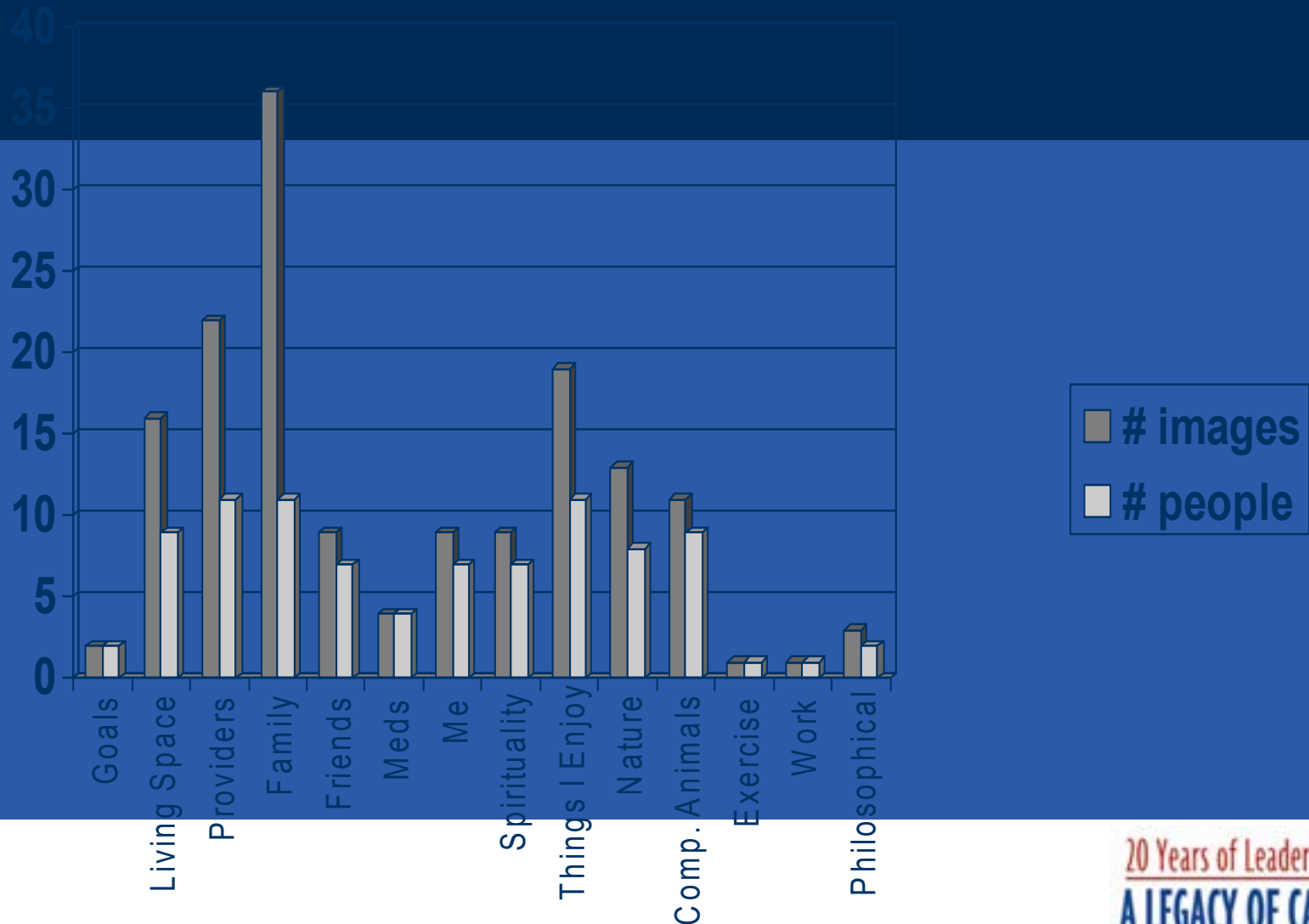


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Content Analysis – *What Clients Say “Keeps Them Healthy”*



What Literature Says

- Consideration of psychosocial factors can enhance our understanding of quality of life in individuals living with HIV (Gielen, AC, McDonnell, A.W., Wu, P, O'Campo, & Faden, R., 2001).
 - Support from family & friends influences perception of quality of life (Demmer, 2001).
 - Increased support of family & friends predict life satisfaction among those living with the virus (Demmer, 2001).

- Spirituality is a major factor in the ability to cope with illness (Tuck & Thinganjana, 2007, Chou, F. & Holzemer, W.L., 2004; Flybert & Reinert, 1999, Highfield, 1999, Koenig, 2004, Koenig, Pargament & Nielsen, 1998; Sowell et al., 200, Targ & Levine, 2002; Tuck, McCaine & Elswick, 2001).
- Spirituality is a significant factor that affects the psychosocial outcomes of HIV disease (Tuck & Thinganjana, 200, p. 152).

- Self-education & ability to manage and monitor symptoms of HIV are important self-care processes for clients (Chou, F. & Holzemer, W.L., 2004).

Disclosure & Stigma

- Disclosure = act or instance of disclosing or making something known that was previously unknown or concealed.

Merriam-Webster Online Dictionary (2010)

Disclosure

- Major concern of the team working on this project
- Meetings with clients individually & in groups to talk about & anticipate the impact of the disclosure (client, family & friends)

Potential Consequences of Disclosure (from the literature)

Eustace & Ilagan, 2010, p. 6-7.

■ Potential Positives

- Greater social support, particularly in families
- More frequent use of safer sex
- Improved medication adherence

■ Potential Negatives

- Anxiety over outcome
- Fear of rejection & distrust
- Negative labeling
- Loss of social support
- Potential abandonment, violence, imprisonment
- Impact on family functioning

Publicity & Online Comments - Newspaper Article

"The article leaves out an important part of the story. Exactly how much of this cost is on the tax payer. I guess the reporter either conveniently left it out or perhaps political correctness doesn't allow the

"EWWWWWWWWWW!!!!!!

YUCK!!!!!!!!!!

They are not normal human
beings.

We were not ment to live this
way.

Stigma

- **Concealable Stigma** – Identity that can be kept hidden from others but that carries with it social devaluation. (Ex: substance abuse, HIV/AIDS, mental illness)
- **Associative Stigma** – Stigma that a person possesses because of his or her close connection to a stigmatized other



Why They Disclosed

"I felt it was time for me to share my story with my community. I know if I had someone like me telling their story I might still be negative."

"I think it will help the

The Fears

"It was worst case scenarios, you know. It was ... everyone I ever had unprotected sex with will know and they're

Impacts on the Family

"His big fear was, 'Who will see it?'
... At his job all his friends know
me & they don't think I'm sick or
have HIV. They think I'm female.
It affected him that way ...
everyone would know I'm
transgender & they'd know I'm



This is my 46-inch flat screen TV I like the white channel. I watch on it



I like looking at animals, nature, fishing the fish



This is my highest scoring my favorite



Whenever I get a letter, I always smile and I always have a good time and they always lift my spirits!



This is Timmy



This is my niece I like watching her smile



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“As with people reporting personal stigmas, those reporting associative stigmas were also affected by the anticipated stigma, centrality and salience of the identity” (Quinn & Chaudoir, 2009, p. 648).

Processes that Mediate the Impact of Disclosure

- Social support
- Supports changes in social information

Quinn & Chaudoir, 2010, p. 240

Lessons Learned

1. Don't underestimate the emotions of the clients & staff involved in the process.
(Consequences of disclosure during exhibit.)
2. Be clear in contracting with outside photographers.
3. Be aware of and supportive of the ongoing impact of the process on the clients.

4. Impact of the process on the treatment.
5. Be aware of and consider the ethical & power issues if a client should request their picture be removed later in the process.
6. Using the data – family & involvement in medical goals for clients.

Images for 'A Positive Journey'

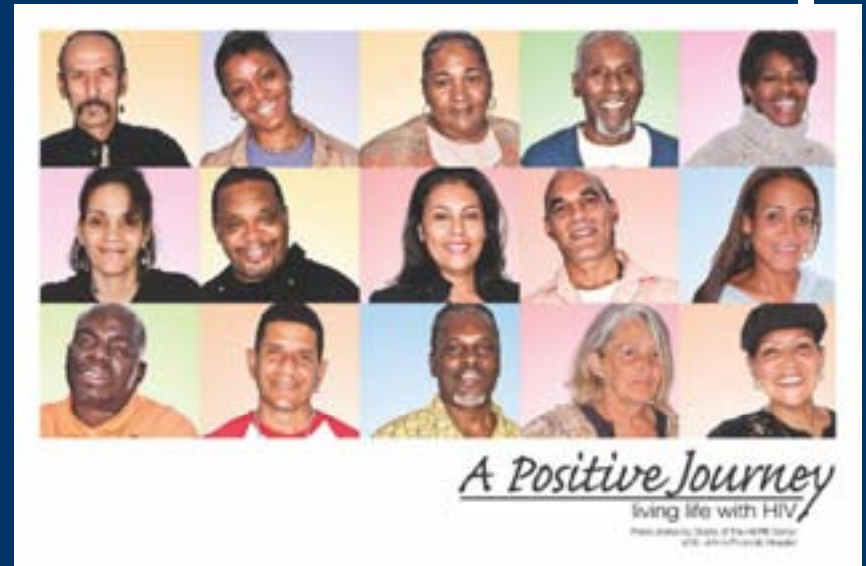
Raeford Dwyer
of
Raeford Dwyer Photography,
Peekskill, NY –
<http://www.raeford.net/>

Thank You to the Project Supporters

- Undertone Networks -
<http://www.undertone.com/products/undertonevideo.php>
- Sunrise Pharmacy, Yonkers, NY 10703
- AIDS Combat International -
<http://aidscombatinternational.com/>
- Dr. Girish R. Trivedi & Aarti Foundation -
http://aartifoundation.org/index.php?option=com_content&view=frontpage&Itemid=53

Thank You!!!

To all the individuals & their families & friends who had the courage & were ready to participate ... Thank you for allowing us to share your 'positive journey.'



Questions?

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