

## Poetry as Data Analysis: Honoring the words of research participants

*Poetry was used as one method to highlight the findings from a qualitative study of twenty older, minority HIV-affected caregivers. Semi-structured interviews were designed to solicit the participants' perceptions and experiences. In order to honor the strengths and uniqueness of each individual and to preserve their inspirational stories, a "poem" was created by arranging their words into a format which highlighted the essence of each respondent's comments.*

by  
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From January to August of 1997, I and two other researchers conducted interviews in the Chicago, Illinois, area with twenty older, minority persons who provided care to grandchildren or adult children who are infected with Human Immunodeficiency Virus (HIV), the virus which causes Acquired Immune Deficiency Syndrome (AIDS). These semi-structured qualitative interviews were designed to solicit the participants' perceptions of what it was like to be an HIV-affected caregiver. All but one interviewee was female; 18 were African-American; ages ranged from 44 to 80.

The neglect in scholarly literature of HIV-affected elderly caregivers is remarkable, although this care situation is becoming more common. Because of the stigmatized nature of HIV, many older, minority HIV-affected caregivers are not disclosing their needs or situation to their churches, to traditional aging programs, or to the AIDS service networks. Furthermore, there are few services or social programs which are designed with this hidden population in mind. This research project was therefore intended to "give voice" to a

population which is not often heard.

I was not new to the consideration of HIV caregiving of older persons. Before embarking on this research, I had been working as a social worker in the HIV service, education, and policy arenas for nine years and was a social worker in the field of gerontology for eight years prior to that. This research interest came from years of professional and personal observations of older, minority caregivers whose lives were both disrupted and enriched by caring for adult children and grandchildren who were affected by the HIV epidemic. I had also provided personal care to my best friend, who died of AIDS. I therefore did not bring neutrality or a fresh perspective to this task. The lens through which I viewed this research was as an advocate, a case manager, an educator, and a caregiver. Throughout the process I strived to ensure that my experiences, opinions, and emotional responses contributed to a more accurate portrayal of the phenomenon than would be possible with a less informed person as data gatherer and analyst and hope that they enlight-



ened more than they obscured the data.

However, I was always afraid that I would not be able to sufficiently give voice to the caregivers' stories and to translate their experiences in a way which would be useful and meaningful. I felt throughout the data collection phase as if I were being freely offered an enormous gift of wisdom and intimacy and that I had a tremendous responsibility to honor it and be an ambassador for the interviewees. I was aware that they were counting on me to tell their side. For example, halfway through my interviews, a participant handed me the urn containing her only child's ashes and asked me to hold it. I realized clearly at that moment with how much I was being entrusted. I felt burdened by this responsibility and incapable of adequately fulfilling the function of translator. I wanted my research to be a tribute to the participants' wisdom and grace, but found that there was no way to sufficiently paint that picture.

I was perpetually saddened and touched by what I was hearing in the interviews. I had to work very hard to develop enough perspective to see the broader picture; I felt immediately, personally, and intensely connected to the interviewees. I emerged from this research project being awed and inspired by the respondents' resilience, wisdom, and ability to transcend suffering.

**A**s the research assistant on this project, I was responsible for coding all inter-

views and identifying themes and patterns. As I began the search for commonalities and differences across the sample, I worried that this reduction of the data would not preserve the uniqueness of each of the respondents. Therefore, in an effort to honor the strengths of each individual and to preserve their inspirational stories, I created a "poem" for each of the participants after having read of this idea in a qualitative research text (Miles & Huberman, 1994, p. 110).

In order to clarify our intention to be respectful to the respondents and to their communication styles, and before I explain how I used poetry to analyze the data, I must comment on the treatment of names and language in this project. During the interviews, the researchers referred to the respondents by their last names and titles (e.g., Mrs. Johnson). They were assigned first names (which are pseudonyms) in the transcripts and poems for the purpose of making them more real to the readers. In transcribing the tapes and in reproducing their remarks, we tried to be true to the words, phrases, styles, and pronunciations of the interviewees. We did this out of a desire to represent them accurately, to convey the tone and affect of their statements, and to celebrate the elegance of their expression. In no way was any disrespect or mockery intended.

The process of developing the poems was as follows: as I coded each transcribed interview, I copied phrases, sen-

tences, or paragraphs which seemed to highlight the unique personality or perspective of the respondent and transferred them into another computer document. At the end of that process, I arranged the respondent's phrases into stanzas which seemed to me to best represent him or her. The result was a "poem" in the actual words of the interviewee. Although I arranged the words in an order which seemed to best represent the narrative flow and meaning, no changes were made to what the respondent had actually said.

On the following pages are three examples of the twenty poems that I have created using this process. Each one is a testimony not only to the grief of these older minority persons who are caring for their children or grandchildren with AIDS, but to their resilience, spirituality, and wisdom.

## REFERENCE

- Miles, M. B. & Huberman A. M. (1994). *Qualitative data analysis* (2nd edition). Newbury Park: Sage.

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**It's God's change (Lacy)**

I heard tell of HIV happening to other people.  
No, I didn't think it was coming to my family.  
But since it did? I've got to deal with it.

I've kind of accepted what's wrong.  
It was hard at first.  
They first told me, I went to my knees.  
I just went to the Lord.  
And prayed.  
Until I got my strength back.  
God's will, thy will be done.  
In my life. No matter what.

Sometimes life seems unfair and unfit.  
But He's a just God.  
He don't do no more to you than he do  
to others and what he do for others.  
You just got to accept his will.  
Because you cannot change it.  
It's God's change.

I just look at it like another sickness.  
Another illness.  
Just like cancer, leukemia, whatever.  
Something you can't help.  
Something you didn't ask to have.  
But it's there.  
That's the way I look on it.  
I don't shy nobody.  
You never know what you're gonna have.  
It's best to always treat people right.

Sometimes she thinks that if certain peoples knew they would talk about her or something.

But I tell her, "It don't matter. What the peoples say. As long as I love you. Don't you worry about them because they don't do nothing for you anyway."

I don't see any reason to be sad. You can make your own self sad. But I want to stay out of that rut. Where I got to set around and mope.  
No I don't. I'm thankful. Because things could be much worse than they are.

That's one thing that I would wish that people would not do. To see sick peoples as a burden. 'Cause think about those good times and you was with them and happy.  
When they get so they can't do for themselves,  
I don't see it as a burden.

I've learned—to feel other people's pain.  
I've learned to share other people's sadness.

Just a little love and a hug and a kiss  
can do a lot for a person.  
It can do a lot.  
It can do more sometimes than medication.

**Lessons learned hard are best learned (Jen)**

It's a shame when you have to learn

all lessons the hard way.  
Lessons learned hard are best learned.

It's the worse thing that ever happened to me.

It's hard.  
One thing I believe, from the bottom of my soul,  
is that you can die from a broken heart.

I am a cream puff, I'm telling you.  
What would I do if he died?  
They would have to lock me up, I know.  
I would not be able to deal.  
I would be nuts!

I give out this air that I'm so strong,  
but AIDS will knock you to your knees.  
The thought of the person that you love  
more than anything in the world...  
And as you can see,  
I can't talk about it long without crying.





See how healthy he looks?  
As long as he look like that,  
I'm not going to dwell on AIDS.  
I'm going to dwell on God.  
God is good.

You just have to join the real  
world.  
You know, like, you're in denial.  
So gettin in denial ain't made  
the AIDS go away.  
So, I just have to make up my  
mind to make it.

Cause there's no situation in the  
world like this.  
Cause when you turn your back  
on somebody for having it,  
and you're supposed to love'em,  
that destroys people.

And this is Hell.  
This is the worst thing that I see  
that happened  
in this lifetime.  
I just hope God makes a way for  
a cure,  
for everybody,  
you know.

### **I wish I could put her back in- side me (Celeste)**

I don't have any friends.  
I don't go around anybody I  
used to associate with.  
Because I don't feel the same.  
Because I know that they'll be  
going on with their lives,  
and none of my friend's children  
have HIV.

They stopped coming over  
since they found out she had it.  
And they sit around talking  
about  
people with AIDS.  
And they put you down, and I  
can't talk

about it anymore like  
that.  
Yeah, they put um down.

HIV, that's something that I  
worry about  
all the time and have the blues.  
Cause I'm just wishing  
that I could take a magic wand  
and just make everybody's go  
away.

I'm hoping that they can come  
up

with some kinda cure.  
I mean, there's gotta be some-  
thing  
that they can come up  
with  
to keep these people from startin  
to die.

Cause I just don't know what  
I'm going to do if she...

is she gonna get any worse than  
this?  
Is she gonna get worse?  
Is it gonna get worse?  
I just don't think I can stand it  
if she gets any worse.

When she told me she was HIV,  
I just wanted to die,  
I just wanted to die.  
I swear to God.  
Why does my baby have it?

There must be something that  
we were put here for.

I wish I could just ball her up  
and put her back inside me.□

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