

Shadows and Sunshine: What Metaphors Reveal About Aging With HIV

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Using narrative inquiry, the researchers interviewed 5 older adults on 5 occasions over a period of 3.5 years about their experiences of aging with HIV. The participants' stories were analyzed for metaphors. Individual metaphors reveal a complex, unique struggle: living between tensions of uncertainty and hope, facing death and living in the moment, and suffering hurt amidst the joys of evolving identity. The tensions are fluid, although time and life experience facilitate a shift towards reconciliation. An overarching metaphor across this group of survivors is shadows and sunshine: to survive and live in a fragile state, balancing multiple shadows such as stigma and side effects with joyful experiences of support and belonging. The findings suggest that when nurses invite stories of life experience and listen for language used, they build compassion and gain understanding of what support is most needed to honour the personhood of older adults who are HIV-positive.

Keywords: metaphors, HIV, aging, narrative inquiry

D'ombre et de lumière : ce que révèlent les métaphores sur l'expérience de vieillir avec le VIH

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Utilisant une approche axée sur l'enquête narrative, les chercheuses ont réalisé des entrevues auprès de cinq aînés, à cinq reprises, sur une période de 3,5 années. Les entrevues portaient sur leurs expériences en tant que personnes vieillissantes vivant avec le VIH. Les récits des participants ont fait l'objet d'une analyse en vue de relever les métaphores. Les métaphores individuelles révélaient une lutte complexe et unique issue de tensions provoquées par le fait de vivre de l'incertitude et de l'espoir, de côtoyer la mort, de vivre dans l'instant présent et d'éprouver une souffrance parmi les joies découlant d'une identité en évolution. Les tensions sont fluides, bien que le temps et le vécu facilitent un virage vers une réconciliation. Une métaphore commune présente dans le groupe de survivants était celle de l'ombre et de la lumière, qui traduisait l'expérience de survivre et de vivre dans un état de fragilité, de composer avec plusieurs côtés sombres, comme le stigmate et les effets secondaires, et de vivre des expériences heureuses, comme le soutien et le sentiment d'appartenance. Les résultats de l'étude indiquent que les infirmières qui invitent les patients à partager leur vécu et qui portent attention au langage utilisé acquièrent un sentiment de compassion et comprennent davantage le type de soutien qu'elles doivent dispenser pour honorer l'identité individuelle des aînés séropositifs.

Mots clés : métaphores, VIH, aînés, personnes vieillissantes, enquête narrative

Context

Human immunodeficiency virus (HIV) and HIV-associated diseases have been known for three decades, and in that time many advances in care and treatment have been made. The advent of antiretroviral treatment in the 1990s and the success of highly active antiretroviral treatment (HAART) have enabled affected persons to survive to age 50 and beyond.

The impact of being HIV-positive on older populations is gaining new attention from researchers, public health organizations, and clinicians worldwide. This is in stark contrast to the situation only 10 years ago, when such older adults were an “overlooked” and “forgotten” population (Whipple & Scura, 1996). “Older adult” has been defined as a person age 50 or over by the Centers for Disease Control and Prevention: AIDS (Kirk & Goetz, 2009). By 2015 approximately half of adults with HIV in the United States will be 50 or older (Kirk & Goetz, 2009; Patel & Crane, 2011). The increasing prevalence of persons 50 to 59 with HIV infection is expected to grow: those with HIV are experiencing longevity, and the number of new HIV infections in those over 50 is increasing (Centers for Disease Control and Prevention, 2008).

These numbers have led to a shift from the conception of an HIV diagnosis as imminently life-threatening to an emerging conception of HIV as a chronic but manageable disease (“B.C. Centre for Excellence,” 2012). Yet this view may be misleading as extended life expectancy makes aging with HIV a relatively new phenomenon, the implications of which are only now emerging. Medications may increase longevity, but aging with HIV can be unpredictable and challenging. Those aging with HIV experience the infection as a complex chronic disease with significant comorbidities (Patel & Crane, 2011) and an ongoing sense of life threat. Although life expectancy has improved, persons living with HIV/AIDS have increasingly complex needs as the immune compromise and associated stigma and discrimination may affect their emotional and physical health, quality of life, financial status, and independence (Public Health Agency of Canada [PHAC], 2012). More specifically, Eisenberger, Jarcho, Lieberman, and Naliboff (2006) found that individuals who experienced social rejection reported more social distress and physical pain. While HAART helps reduce viral load, these medications can produce hypertension, dyslipidemia, and insulin resistance (Heath et al., 2001) and can foster cognitive decline (Vance & Burrage, 2006). There is also a recognition of disease-related clinical concerns, such as increased cardiovascular risk, HIV wasting, and HIV-associated immune activation (Falutz, Hardy, & Kotler, 2010). Dognin and Selwyn (2010) report a recent HAART-era trend in the United States of concurrent HIV and

cancer. Unique to the older adult with HIV is that, in addition to bodily changes resulting from the infection and the medications, are the layered aspects of the normal aging processes.

This has brought a new crisis: the “Greying of AIDS” (Gough & Karapita, 2011), or the “Greying Epidemic” (Berry, 2009). The day-to-day experiences, realities, and challenges of affected individuals remain largely misunderstood or invisible, and for this reason it is important that their stories be illuminated. To “story” is to “language” and give voice to, and when a person gives voice there is an opportunity to make sense and meaning of their experience, to cope, and to be as well as possible while living with illness. The language we use and how we speak about HIV and aging needs attention and intention if we are to better understand and support those living this new reality.

Introduction

The complex figure of speech known as the metaphor has been described as a “device of the poetic imagination and the rhetorical flourish — a matter of the extraordinary” (Lakoff & Johnson, 1980, p. 3). As one of four master tropes, along with metonymy, synecdoche, and irony, the metaphor is created when “two different and disparate subject matters are mingled to rich and unpredictable effect” (*Stanford Encyclopedia of Philosophy*; <http://plato.stanford.edu/entries/metaphor/>). An example can be found in Shakespeare’s *Romeo and Juliet* (2.2.2–3): “But soft! What light through yonder window breaks? It is the east and Juliet is the sun.” Metaphors help create meaning as ideas embedded in and conveyed through them arise from our world and reflect beliefs and values; they create expectations, influence decisions, and are a powerful way to increase understanding of things and processes (Geary, 2009). While metaphors help us make sense of our world, they can also be ironic and paradoxical tricksters in that they act as symbolic shorthand and as a way to *not* say precisely what we mean. The way that a metaphor analogizes or likens one subject to another (e.g., Juliet and the sun) is important and tenuous within illness experiences, as the most effective metaphors often compare two unlike things and we soon come to speak of and think of the secondary thing as if it were the primary. For example, we may initially think of disease or a virus as the enemy — “she is fighting cancer” (Lakoff & Johnson, 1994) — and then come to think of and treat a person living with a particular virus in the same way, as if she is under attack or is a valiant combatant heading into battle. Caution is required, as linkages made between two subjects — in this case, cancer and war — reveal one aspect of the subject explicitly, while other aspects remain implicit or concealed. Because they are so powerful, metaphors can hurt,

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hinder, or mislead when taken for granted, such that they blanket the particular and can flatten the very idea that is being conveyed.

Metaphors can also be generative, be playful, and inspire change for the good. They have the ability to evoke what can be described as an aesthetic way of knowing, as the trope creatively links two unrelated objects in a new and different way. Aesthetic knowing in nursing, initially conceptualized as knowing through the senses (Carper, 1978), is referred to here in an expanded way, as a dynamic pathway of knowing nursing through a relational interaction that reflects the art of nursing (Boykin, Parker, & Schoenhofer, 1994). By stimulating thoughts and imagination, metaphors can impact how we perceive the world and ourselves in it, in the present moment and in the next moment of our lives. Many authors describe the magic that can result when two unlike objects are likened. Baldick (1990) emphasizes the new combination of ideas to create more powerful understandings, Geary (2009) refers to the element of “combinatory play,” and Janesick (1994) speaks of how metaphor de-familiarizes the familiar as it “creeps up on you and surprises” (p. 209). For Patton (1990), metaphor is an effective rhetorical tool that helps a researcher describe complex experiences in an evocative way. Rorty (1979) speaks of the imaginative power of metaphor and challenges current thinking by suggesting that if we go beyond representation and seek new ideas, new metaphors, and new language, this will help with intellectual and moral progress. Scholars such as Barry and Purnell (2008), Gaydos (2005), Greenwood and Bonner (2008), and Watson (1999) point to the important role of metaphor across nursing. Malinski (2009) echoes the view that the metaphor has transformative potential: “change your metaphor of the world, change your worldview” (p. 310).

The intricate relationship between metaphor and illness is explored in Sontag’s (1978) classic, *Illness as Metaphor*. Sontag describes how metaphors for cancer and tuberculosis can ostracize, objectify, and produce an oppositional us/them mentality. In a later work (Sontag, 1989), her critique is expanded to include metaphors for AIDS, as will be discussed shortly. Yet because language is inherently metaphorical and only approximates embodied experience, scholars such as Biro (2010) posit that persons living with chronic illness and pain *must* use metaphors as a way to understand and talk about their illness experience. Frank (2011) agrees that metaphors are critical in stories of illness, especially chronic illness, where the experience is not linear or neat but most often complex and surreal, where “narratives have a problem with endings” (p. 189) and metaphors offer “expressive possibility” (p. 182). For the listener, paying attention to metaphors in illness narratives helps open up many possibilities of interpretation and thus ensures that he or she does not presume to know an individual or what it is they are experiencing.

For the teller of the narrative, the language serves to reveal, but they also may learn for themselves who they are, even if they might be unsure. We draw on the words of Jan Zwicky (2003) to illustrate this idea:

The experience of struggling with illness is the experience of the fundamentally metaphorical nature of self: one is, and one is not, one's body. Music can also teach this: but it teaches it as harmony, not paradox. In illness, we grasp how the self approaches the condition of language. Compassion for the self: the most difficult language. (p. 35)

This deep-rooted influence of language in illness is found in metaphors associated with living with HIV, where our focus now shifts.

Literature Review

HIV-related metaphors permeate the literature and are seen as influential and disturbing. Sontag (1989) describes the metaphors used for HIV/AIDS as invasion, pollution, contamination and mutation, punishment, retribution, a plague, a death sentence, and "hard death." She describes how AIDS has been used politically: a metaphor for terrorism and international political evil. Her concerns resonate some 25 years later as many countries opt for a criminal view of HIV illness. The crime of "exposure without disclosure" results in charges such as assault, aggravated sexual assault, criminal negligence causing bodily harm, and attempted murder. This metaphoric likening of persons with HIV to violent criminals reinforces stigma, fosters the view of persons with HIV as bad, undesirable members of society, and raises complex public health and human rights concerns (Canadian Association of Nurses in HIV/AIDS Care, n.d.).

Hillmer (2007) found frequent use of the phrase "illness is warfare" in texts describing how the immune system functions in HIV/AIDS. Hillmer concurs with Sontag (1989) that such metaphors are dangerous, "encouraging strong drugs and surgery without heed to side effects, focusing attention on the disease rather than the patient, and leading to unnecessarily frightening images" (2007, p. 30). Others have explored HIV/AIDS as a broken narrative and as silence (Drakos, 2008). Lather and Smithies (1997) cite the metaphors "leper" and "demon" used to describe a person with HIV/AIDS. Mooney (2005) refers to the AIDS discourse itself as an epidemic. In a more positive light, Gosselink and Myllykangas (2007) examined leisure behaviours of older women with HIV/AIDS and found that each woman showed resilience in overcoming barriers and came to see leisure as a metaphor for the meaning of life. Jones (2002) studied the experience of HIV-positive nurses aged 28 to 52 and found the metaphor "double-edged sword" to represent the benefits and disadvantages of taking HIV medications. A year later she

studied 10 adults aged 35 to 58 taking HAART, and found the metaphor “a bitter pill to swallow” (Jones, 2003).

Metaphors for HIV, whether harmful or helpful, impact how an individual tells about and lives the illness experience. They convey how the illness of HIV is influenced and socially constructed by fear and ignorance. A focus on HIV illness through the lens of warfare emphasizes the aggressive aspects of the disease and generates fear while keeping lesser-understood aspects hidden. Metaphors that instil fear can lead to discriminatory behaviours. Vance, Brennan, Enah, Smith, and Kaur (2011) found that adults aging with HIV face adversity and stigma. This population also faces depression (Jang, Anderson, & Menten, 2011), social withdrawal (Vance & Burrage, 2006), and a need to negotiate secrecy. This is a concern. A study by Lourdes et al. (2008) found that while the prevalence of HIV in older adults is increasing, sexually active older adults with HIV may be engaging in high-risk behaviours for transmission and that perceived stigma is associated with inconsistent condom use.

There is a small body of literature emerging related to aging with chronic life-threatening illness and the role of metaphors. Metaphors analogize aging as a negotiation between decline and progress (Hammond, Teucher, Duggleby, & Thomaset, 2012), as contrasting the “sinful decay” of illness and aging as “romantic” (McCallum, 2001), as resilience (Clark, Burbank, Greene, Owens, & Riebe, 2011), as frailty and deterioration, and as a journey, fulfilment, and renewal (Kenyon, Birren, & Schroots, 1991). Pervasive Western views of aging tend to add a layer of stigma and oppression; they fail to capture the complexity in individual lives while perpetuating a culture of ageism that further devalues and distances us from aging and old bodies (Calasanti, 2005). Metaphoric language reveals an even stronger link to stigma for those with HIV. For adults who are living with HIV and aging, we do not fully understand what metaphors arise, how stigma may or may not present, or whether the stigma is unique to HIV or a reflection of aging in general.

Aging with HIV is a new area of concern and, in this new millennium, nurses are being called upon to support and care for greater numbers of HIV-positive older adults. As we gain more understanding of the experience as lived, we will be better able to provide meaningful and high-quality care. This timely study addresses three questions: *How are metaphors for aging with HIV experienced? What do these metaphors reveal? What might nurses learn from metaphors embedded in stories of older adults living and aging with HIV?* This focus on the power and use of metaphors within stories of living with HIV will add to nursing knowledge by providing access to the narratives of individuals who live at the margins and are not heard, thus generating insight into and understanding of the experience and illuminating social facets of living with HIV

that metaphors reveal, and by illustrating the potential of narratives and “storying” in the nursing relationship.

Method

Narrative inquiry (Riessman, 2008), framed within social constructionist theory, was used to engage participants in the co-construction of stories about their experience of aging with HIV. Four commonly accepted concepts within narrative guided our approach. The first was meaning-making, the belief that stories hold meaning (Kleinman, 1988) and that storytelling generates sense-making and identity (Riessman, 2008); Josselson (2011) refers to stories as “the core meaning-making systems of real people” (p. 33). The second concept was close study of the “particular” within individual stories as a means to illuminate universals in human experience (Charon, 2006; Riessman, 2008). The third underpinning concept was social constructionism, the belief that the teller and the listener of a story influence one another such that meaning is co-created and co-constructed by them (Crotty, 1998). Stories and the language within are seen as a complex representation containing plural voices from one’s social and cultural environment. This powerful interplay between individual meaning-making and the social world influences, shapes, and constructs how individuals make sense of everyday experience. The fourth interrelated concept that guided our approach was a belief in the role of metaphoric language within stories as a way to reflect influences and understand and talk about one’s illness experience (Biro, 2010; Frank, 2011). Guided by these beliefs, we synthesized raw data from the participants’ stories to capture aspects of the experience in their own words.

Sample

The study involved five Caucasian urban participants, three male and two female. Participants were 50 or older and living with HIV for at least 10 years. Two had been diagnosed with AIDS in the past. At the time of the final interview, participants were 55 to 62 (average 58.2). Number of years since diagnosis ranged from 13 to 24 (average 17.6). The participants were part of a purposive convenience sample of 32 adults recruited for a broader study on the narratives of life-threatening illness (www.uvic.ca/illnessnarratives). All five consented to have their data used for secondary analysis and to participate in an additional interview focused on aging. This allowed for more in-depth access to the experiences of aging with HIV across time.

All aspects of the study were approved by a university human research ethics board.

Data Collection

A semi-structured, in-depth approach was used to interview participants five times over a period of 3.5 years, except for one male who chose to be interviewed three times over that period. Each face-to-face interview was conducted by a nurse in the role of research assistant, who began by saying, "Tell me about your experience of living with HIV." The interviewer referred to an interview guide of gentle probes such as *Tell me more. What was that like for you?* and *Can you give me an example?* These prompts were seamlessly posed in a conversational exchange that was relational and discursive and intended to generate detailed accounts (Riessman, 2008). The first interview focused on building rapport and eliciting the participant's story of living with illness in whatever way that unfolded. In the second and third interviews the interviewer confirmed what was heard previously, posed exploratory questions to understand in more depth, and asked about new developments. The fourth interview was an opportunity to reflect on the interviews to date and the final one focused on the experience of living with HIV past the age of 50. The interviews varied in length from 1.5 to 3 hours and were audiorecorded. The generated narratives were transcribed verbatim.

Immediately following each interview, the interviewer audiorecorded spontaneous reflections on and impressions of the exchange, describing non-verbal communication, the physical environment, and the emotional energy. These recordings, which were transcribed as field notes, informed and added depth to the analytical process by illuminating context and affording our research team a way to reflexively examine our own assumptions.

Data Analysis

We followed a case-centred approach to narrative inquiry that emphasizes individual agency, particularities, and context (Riessman, 2008). "Case" is understood as a participant's narratives that, once transcribed, form the unit of analysis. This approach entailed close analysis of each participant's narratives to identify metaphors embedded within stories. Metaphors were not always evident, and the researchers read each participant's set of transcripts closely and repeatedly. The primary researcher (first author) identified metaphors used by each participant, then synthesized them into a short descriptive narrative, all the while conferring with the other researchers to validate identified metaphors. We returned to the transcripts and field notes repeatedly as a way to continually inform this iterative consolidation process. The research team then shifted the analysis to the sets of transcripts across the five cases and generated an overarching metaphor of "sunshine and shadows." Analysis involved finding a balance between description and interpretation.

Findings

The narratives were rich in metaphor as participants drew upon analogy as a way to express self and describe the reality of their experience across many areas of their lives, from diagnosis and treatment to experiences of death and loss, depression, secrecy, altered identity, and adapting to the life journey itself. We wove the metaphors used by each participant into a small story as a means of illustrating the findings. Each story, then, is a synthesis of the participant's words constructed by the researchers. The dense metaphors within each story help illuminate the many aspects of what it is like to age with HIV. Given that metaphors often slip into language undetected, we invite the reader to engage with the stories slowly, paying attention to and reflecting on the variety and depth of metaphors used, what they might reveal or conceal, and how a particular metaphor may evoke, in the reader, a connection or deeper understanding.

Aging With HIV: A candle flame dancing to the music of life

(Nancy, age 58, positive for 24 years)

The day I was diagnosed, my life took a turn. It hit me in the stomach. I went home and climbed into bed waiting to die. HIV is chaos; it is to lose your way and walk on unknown land with nasty pitfalls until you get your feet back on the ground. HIV is loss of innocence; it sits within me as tightness, down here, and is with me every day, a backpack I cannot put down unless I find safe ground. It is to live halfway between A and B — I'm not really healthy and not really sick. I have memories of walking in candlelight vigils in the '80s with people throwing things at me, as if stoning us. Even after 24 years, I feel the stigma and fear and humiliation. HIV erodes my confidence. For safety, I disclose that I am positive only when I'm in a group or with a witness. To be age 58 with HIV is a lonely place; I'm cut off from sexual relationships and the threat of being called a criminal is very real. And yet these are bonus years: I have survivor energy and love. My lessons learned are abundant, lessons about global compassion. I believe in this world; we are each other, we are one. And in the face of the challenges I have with aging with HIV, at times I am a phoenix rising from the ashes, reborn. I am dancing as fast as I can to the music of life, my best dance.

Aging With HIV: A yo-yo of life lessons

(Judy, age 60, positive for 20 years)

HIV is a changed death equation. For me it was a death sentence when I was diagnosed; now it's a yo-yo — I'm unsure if I'm dying or not. My plot and stone are paid for and ready. I adhere to my medication regime because the pills take care of the HIV, they save me, although they are not

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a cure, you don't get your life back. The cocktail is hope, but I can't trust how long this family of meds will work. The meds are a life raft and I am a guinea pig being experimented on. For me, HIV is fatigue. I often lie on the couch and feel useless. I have a bug in my blood, living, trying to kill me, although there is less in me now. HIV is a reminder for me from the universe to pay attention and be thankful. I see myself as no different from anyone else my age; we all deal with challenges. HIV has become a smaller part of my life, and yet to age with HIV for me is to live with fear and sometimes panic; I live with a secret that is not coming out for fear of stigma by my non-HIV contemporaries who will judge me as having the naughty disease, the dirty disease associated with sluts, drugs, and prostitutes. And yet I feel lucky to be on disability and live in a subsidized home, a place I have created over 20 years and where I belong, but it is contingent on keeping my HIV a secret. I live with fear but I keep blooming, like my plant; it is to volunteer at a local HIV agency and feel safe there, to be out about my status, where I do my turn, have a sense of purpose and feel needed. At age 60, HIV is about being the expert, about doing my own inner work even as the old tapes keep playing over and over, about self-forgiveness and about the mind, body, and spirit coming together. To tell my stupid, sad story is cleansing, like cleaning out a closet; it's the easiest story to tell, of lessons learned on the road.

Aging With HIV: Rainbows, confetti, and tea and cakes

(Leonard, age 62, positive for 18 years)

Diagnosis: 2 years to death. Terminal. I saw the box on the assessment form ticked off. I face depression: a horrible dark place, filled with stigma and pain; it makes me a leper on the precipice, and is more difficult than HIV. I have attempted suicide, a turning point, rock bottom. I have come out of the closet three times: being gay, having mental illness, and having HIV. HIV owned me, a tattoo. BIG. It was number one on my Rolodex list of things to worry about. HIV is pain buried in a very deep, dark place. HIV is pity, ignorance, hurt, name-calling (fag, queer), and hiding (in the closet). For me, it has been secrets, little pieces of information that owned me, that kept germinating. It was stigma that made walls go up, made everything bigger than the earth. It was living on the edge, hard, fast, being self-destructive in a new world I didn't know how to enter. Living positive for 18 years has changed how I experience HIV. Now, HIV is no secret. To tell is to let it go down to little bits, to look people in the eye and see your soul and not deceit — it is to be the face of HIV, to make it mundane like tea and cakes. To age with HIV is to be a mentor, a substitute father, an uncle, a sage, a societal elder, a gay grandpa, a less intimidating member of society. Everyone smiles at me! It is a time of my third

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act, of self-strength and wisdom, of getting rid of material things. It is to age gracefully, to be privileged, eccentric, to no longer mould to societal norms, to be thankful for the HIV as a blessing, a gift. To enjoy bonus years and see myself as a long-time survivor. To live normally, a rebirth, to live a balanced life in sync with the planet, to not fight it but accept a natural order to life. HIV is about volunteering and giving back, being useful, helping others; it is kindness first. To volunteer at the local HIV agency is like coming home, my place, my rock, no tippy-toeing, a starting place for who I am and not an end point. I am at the bookends of my life, my story has no ending; telling my story is a mirror of my own thoughts and the truth will set you free.

Aging With HIV: A rollercoaster ride with face into the wind

(Rick, age 56, positive for 13 years)

Memories of the 1980s are painful for me, fresh and easily retrieved. I recall living in Vancouver's West End: ground zero, an emergency, trench lines, ugly, terrifying paranoia, five pages of friends who died, full of ghosts. It was going through the wars with friends, evictions, short-term death sentences, overdoses, obsessions with meds, blurred faces on ads, secrecy, and anonymous testing. Today, aging with HIV for me is about following a drug regime; it's a numbers game, like the stock market, the numbers up, down, on edge, the trend, the downward slope, the steady rise, the high, the blip. My numbers are currently high, high, high, phenomenal, triple digits. I'm on my fourth cocktail and talk of the fifth is like looming death. My options are decreasing. HIV is not chronic illness; you take the harsh chemicals, you strike a bargain and have a responsibility to take the regime, you play the hand you are dealt. I feel lucky, pure dumb luck, in balance despite side effects. I have taken the mask off and become a face of HIV, no veneer, no more secrets; I come out of the HIV closet to everyone. There's a freedom in being totally open and upfront, to not care, to belong to the gay and positive community, to a family of choice, to have a circle of friends, and to be part of my local neighbourhood. I live the lesson that we are all part of one community, part of the mix. For me now, it's a different world, to live with an attitude of survival, to feel settled, confident, and in balance. I volunteer at the local HIV agency in ways that do not put my hurt on the line. It is to be on a life journey, facing forks in the road, making decisions about retirement and downsizing my home with my partner, reinventing myself and having my life go forward. To age with HIV is also to have money issues and enter a new level of poverty. There is no "Freedom 55"; stress means I'm dancing as fast as I can at times, still facing a black well of depression at times, like being on a rollercoaster, rocketing around; so many layers to the onion. Post-traumatic stress is ever

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present, yet I'm a survivor, I put one foot in front of the other. And this aging is a time of beauty. I have all these years of experience and knowledge that take me forward.

Aging With HIV: A lab rat on a running wheel

(Norm, age 55, positive for 13 years)

My experience of aging with HIV is medications: a double-barrelled shotgun. I know the meds are miraculous and life-giving, yet I push the envelope, can't trust them, an awful bunch of stuff, toxic and brutal. To age with HIV is to be a lab rat on my own. You step your way through it. I refuse to follow the party line, to swallow the bitter pill. I know there's an instruction manual but prefer to read between the lines. I know if I don't take them I'm dead. But let me be clear: they are not vitamins; they make me sick as a dog. I make a lousy patient, a long-term patient. It's a balancing act, I walk a fine line. HIV is living by the numbers of my blood work; I fool around with the numbers, my CD4 count, viral count, WBC. For me, there's uncertainty about the future; the future doesn't exist. I live in the moment, in the present, on a different plane from my friends. I'm apart from other people. I live outside the box and don't sweat the small stuff, the everyday bullshit. Stigma is real. I face everyday ignorance in the form of comments that suggest I'm on meds and therefore cured! That I should be grateful to be alive, or if I am sick why don't I look like Tom Hanks in Philadelphia? So I pick and choose who I spill the beans to, protect myself. HIV is to live two roles, a public and a private. I wear a tattoo, a brand, a pox on my name. HIV is to hide a secret, to pretend, to lie, to be a spy and not blow my cover. It is to live behind a façade and act as if all is okay, to hide behind a cover of happiness, to put on a good face. I am a pariah, an untouchable. I face depression, what I call a grey zone and a black zone. The journey has been one of difficulty, a big, long road, a grind. I'm frustrated, keeping the inner turmoil inside, turning inward, insular, cutting myself off, being a loner. To age with HIV is a life sentence, a constant struggle, a fight. I have fought back from AIDS and have a guardian angel with me; it's not my time. I'm older and I'm a survivor and the key to it all is my cat, my best friend, my spirit animal companion, a quiet private innocent just like me.

Discussion

Our participants used metaphor as a device to help them “language” the experience of their complex lives, and to “language” or give voice to something can help one make sense of it and understand it (Johnson & Lakoff, 1980). Associations made through metaphor were subtle at times

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and not so subtle at other times. Some metaphors had the capacity to support living well, while others remained as stark reminders of associations made through metaphor that can hurt, cause rejection, and foster stigma and discrimination.

Each metaphor reveals and can be considered a small personal and profound story unto itself. Metaphors, as social constructions, offer a way to see how knowledge is constructed through everyday language (Crotty, 1998). Through their influence, metaphors have the ability to shape, constrain, expose, liberate, or illuminate how one experiences a disease. In this research, metaphors within stories of older adults aging with HIV illuminate how having the “bonus” of added time and life experience impacts day-to-day living and the challenges of living beyond life expectancy.

Participants’ metaphors reveal the experience of aging with HIV to be one of living between dichotomous tensions such as sadness and joy, darkness and light. The fluid and non-linear nature of these tensions makes life fragile. For most participants, aging afforded a shift in the tensions and an evolution towards sense-making and reconciliation as they, as older adults, drew upon rich life experiences and adapted as best they could to living in transitional spaces. Unique metaphors for individual participants reflect this: a candle flame that burns brightly but is fragile and needs protection; life lessons that hang by a tattered string, going back and forth, like a yo-yo, between secretiveness and openness; a rainbow life attitude following years of a harsh storm, a time when old secrets fall away like confetti and aging with HIV is as normal as having tea and cakes; a rollercoaster ride with twists, turns, and fear but also joy and freedom that feels like fresh air upon an unmasked face; and a laboratory rat, trapped, going on and off medications, feeling unwell and dizzy yet unable to find firm ground. These metaphors support and extend findings reported elsewhere on experiences of living with HIV (Jones, 2002, 2003) and yet differ in degree within the context of aging.

The metaphors reveal that to age with HIV is to live and struggle in the inescapable shadow of disease over time. The availability of HAART, extended years, and the move to HIV being considered a chronic disease were unthinkable at the time of diagnosis; yet these achievements have not erased the real and raw hurt, fear, secrets, and the need to gauge truth-telling that stigma generates. For some, the metaphors are extreme and embodied; an older adult may take on the identity found in a social metaphor such that they begin to see themselves as viewed as tattooed, untouchable, or having a dirty disease (Mooney, 2005). Consequently, some have, over time, developed coping strategies such as taking off their mask, telling everyone they meet about their HIV status, and eventually

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being proud to be a face of HIV. Tension lies in living between the desire to be free of secrets and live with honesty and the underlying uncertainty about the safety of disclosing.

All have faced the reality of continual, cumulative loss and death, in particular the harshness of dying with AIDS, and now live with hope tempered by tension and uncertainty, wanting to take the drugs in order to live yet knowing these are toxic, trusting their cocktail will continue to be effective yet knowing its effectiveness may end, wanting to live in the moment yet anticipating an early death. These tensions exist within social contexts of living with few resources, sometimes in poverty, with uncertain access to community supports; the dance of aspiring to live in the moment and apply life lessons learned, to adopt an attitude of gratitude, to have a sense of a gift and being lucky, and yet knowing it is all tenuous as the attitudes of others and inner depression can upset the fragile balance at any time. Metaphors also provide insight into a sense of belonging, of having arrived at a place, or a sense of community, this being quite solid for some and under threat for others. There are expressions of the beauty and joy of aging, of embracing new roles such as that of long-time survivor and elder or uncle; these identities help counter negative social attitudes while also generating a sense of seeing self as seen, as reconciling who they are now as less threatening older adults.

As a result of major antiretroviral advances, an increasing number of people with HIV are living into older adulthood (“B.C. Centre for Excellence,” 2012). Findings from this study deepen our understanding of experiences of this emerging phenomenon.

The research team also engaged the imagination with in-depth knowing across the group to arrive at an overarching metaphor that transcends the individual: shadows and sunshine. This metaphor allows for simultaneous tensions within experiences. The representation of shadows raises questions about the role of language in the construction of stigma. Aging survivors of HIV in the Western social context feel the cool, dark shadow of what we will call omnipresent *S* factors: harsh and harmful social factors that slip in and salt a wound, such as stigma and stereotypes, but also secrets, shame, slurs, stupidity, struggle, stress, side effects, suicidal thoughts, sorrow, spiralling, and being stuck. The breadth and depth of this dark side is unique to HIV conceptualized as a chronic illness, and is emphasized with the passage of many years. The dual aspect of sunshine holds light and joy, helpful, healing *S* factors such as sense of safety, support, self-assuredness, successful strategies, and soul-searching. Each of these factors has the power to ever so easily tip the personal experience from a high to a despairing darkness that affects well-being.

The metaphors identified in this study contribute to a growing scholarship (Barry & Purnell, 2008; Biro, 2010; Frank, 2011; Malinski, 2009) that illustrates how metaphors can help us understand the tenuous experience of another.

Nursing Implications

An awareness of metaphors and how they function in stories can deepen one's understanding of the complex experience of aging with HIV and thereby enrich nurses' ability to be supportive, compassionate, and effective. Metaphors help communicate and make aspects of experience more visible and recognizable, allowing us to hear and interact with them, possibly to be humbled and to move closer to understanding another's life experience that we can never truly know. The insights and understanding that nurses can glean from listening for and inquiring about metaphors embedded in the stories of those aging with HIV can have far-reaching implications. Understanding an individual's unique reality invites sensitivity and compassion into one's nursing approach, which in turn supports the timely, effective, and person-centred tailoring of care and services. Nurses are called upon to cultivate curiosity and solicit stories about everyday life experience, to create spaces to ask *What is this like for you?* and then listen with an acute ear, an open, non-judgemental attitude, and an attentiveness to language that helps reveal — in essence, to bear witness. To ask about a metaphor that arises in conversation and check interpretations with the person may uncover further meaning, self-understanding, or socially constructed challenges of aging with HIV, such as poverty and stigma, that metaphors help express. Once communicated, these can be addressed as appropriate. It is important that nurses take the role of stigma into account, given that it may adversely affect health (PHAC, 2012), social ease, and ratings of pain (Eisenberger et al., 2006). The presence of stigma makes aging with HIV different from aging with chronic conditions that do not carry the same negative associations.

Nurses must also pay attention to metaphors that they themselves may be using and be aware of how certain words can avert silence or adversely influence the person before them. This "aesthetic" way of knowing, which illuminates the art of nursing and perceptual sensibilities (Boykin et al., 1994), also offers a way into conversations that build insight and illuminate the challenges, beliefs, hopes, fears, and sense of identity that may not be easily expressed but that are part of living and aging with HIV every day. Informed understanding leads the way for nurses to feel confident about providing, and able to provide, a genuine presence and the support needed to promote access to resources and care.

Conclusion

A diagnosis of HIV changes everything, forever. The force of its rupture follows one through life into older adulthood. To age with HIV is to live with shadows and sunshine, to live between myriad fluid tensions associated with the disease and its treatment, aging, and the social context of stigma. To age with HIV is to shift closer to a balance and a reconciled sense of identity and belonging, although this is ever tenuous and variable and is unique to each person. When nurses listen for and understand metaphors embedded in stories, they can more fully support older adults in facing shadows and letting in the light.

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