

Stories of Aging with HIV: (Un)Certainty and Sense Making

by

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B.N., University of Manitoba, 1981
M.N., University of Victoria, 1996

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Supervisory Committee

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Dr. Laurene Sheilds, (School of Nursing and Faculty of Human and Social Development)
Co-Supervisor

Dr. Anne Bruce, (School of Nursing)
Co-Supervisor

Dr. Donna Trueit, (School of Nursing)
Departmental Member

Dr. Marie Hoskins, (School of Child and Youth)
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Abstract

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To live HIV positive and age into older adulthood is a new phenomenon. Research is helping to identify how the body is biologically impacted by the complex convergence of the virus, antiretroviral drug treatment, and aging. And yet there is more. One has to live in their body. Believing that stories of living with illness hold meaning, we also need to understand the lived experience of persons aging with HIV. When we engage and listen to stories of everyday lived experience, we are afforded a way to gain insight into particulars of aging with HIV, and this in turn generates understanding and compassion that can connect and teach all of humanity about the broader experience of life.

The intent of this dissertation is to present the narrative inquiry I have undertaken over a five year period. I begin with an introduction to the phenomenon of aging with HIV and then present four manuscripts, two that highlight research findings related to metaphors and themes within stories, and two that focus on the interview process and narrative practice. In a concluding chapter I weave together my emergent understanding of what it means to age with HIV, narrative inquiry, and discuss implications of the findings that may take nursing and nursing care forward.

In the first manuscript I address tensions that arose and troubled my narrative interviewing approach. Tensions arose when a) presence was tempered by performance, b) power by equality, c) leading by following, d) insider by outsider, e) being non-influential by social influences, and f) trust tempered by responsibility. These tensions, which I refer to as a dynamic process of breathing in the mud, can act as catalysts that ignite clarity and advance narrative interviewing. In the second manuscript I explore metaphors within the stories of 5 adults' experiences of aging with HIV. Metaphors reveal a complex struggle of living in-between tensions of uncertainty and hope, of facing death and living in the moment, and of hurt amidst joys of evolving identity. The overarching metaphor of "shadows and sunshine" reveals that to age with HIV is to survive and live in a fragile state, balancing multiple shadows such as stigma and side effects with joyful experiences of support and belonging. In the third manuscript I present results of a narrative analysis exploring HIV and aging stories of five adults, age 55-62, who have lived with HIV for 13-24 years. In analyzing the co-constructed stories, six common storylines were identified: the illness embodied, the journey of sense making of, intimacy with death and loss, ongoing secrets and stigma, evolving identity, and living in connection. These findings illustrate the vitalness of telling one's illness story, as sense making happens in the telling and supports one to adapt. The final manuscript is a call to action and emphasizes cultivating a narrative sensibility in nursing practice. I offer the mnemonic **STORIED** to help nurses weave together essential elements of a narrative practice approach: Subjective, Tell/Listen, Openness, Reflection, Invite/Intention, Engage, and Document.

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Dedication

Dedicated to my dear husband Rod
who has been my shining light
and steadfast grounding strength.

To my family who always cheered me on
nourished me with love
and believed in me
even when my own way forward wavered.

And to friends,
who kindly asked
generously showed interest
and offered words of encouragement.

In memory of departed kindred spirits
Sue Wonneck and Jenny Daniels,
And dear Ryan James
whose stories were interrupted too soon.
They continue to inspire
with their legacy of courage
and desire to live life
fully
with beauty and grace
while facing adversity.

I am filled with gratitude and love.

The Participants

It is an honour for me to introduce to you to the very real individuals whose generosity of time and courage of spirit made this research possible. To help point to the complex experience of aging with HIV, I consolidated each participant's words into a short narrative. My hope was to create exemplars that are accessible, memorable, and evocative. May these stories generate insight, remind us of why we serve, and inspire us to be more relational in our practice and in our lives.

Leonard's Story of Aging with HIV

My life is beautiful right now. I'm in my early 60s and aging gracefully with HIV and mental illness. I had no life plan and didn't think I'd live past 55 because no male in my family ever has, but the curse has lifted. This third chapter is exactly where I want to be. I'm naturally in the right place at the right time. But it's not been an easy journey...

Now, I am able to give back and I am willing to be the face of HIV. And it's difficult to find people that are willing but they do need a face the public can recognize and identify with. I think they see me as someone they never thought was HIV positive, you know, I don't look homeless, drug addicted, you know, all the clichés that go with being HIV positive. And the virus doesn't discriminate, it doesn't care who the host is. And I find I have this new persona which is funny but wonderful...I am treated like a societal elder! I get respect that is given to elders. People consider me a long time survivor and a gay grandpa, and I like that, talking to young people about ideas. I'm happy to fulfill the role of grandpa in young people's lives, but someone suggested to me we gay grandpas should fight one more battle. I said no, we don't have it in us, it is our turn to relax. Many of us are still suffering post traumatic stress and we won't be fighting any longer. But aside from that, I've taken the role of uncle and adapted it to my entire life. I embrace the role and even sign my emails that way! I mean the honorific of uncle usually goes to straight society not gays, we are often ostracized and have to create a new family, so yeah, I love it. I'm thankful to this disease for getting me back on track and on this trajectory. It feels wonderful to be returning something to the next generation and to the planet.

It surprises me that it took so long, to arrive at this bookend of my life. I am where I am supposed to be and delighted to be here. And it's all bonus time. It's been a strange course to get here but I like being where I am. My life is full and it's the first time in a long time that I like who I am. I am honest and open, not worrying about being hurt. Let's just say I am evolving and love being eccentric! I have fun, I walk, I swim, I

bicycle. I am taking up ball room dancing! And at this time, with being retired, society expects me to play. I love it! I have passion in my life, I love flowers, always have. They are part of me. I love the secret language of flowers. I'm doing oil painting and finding joy and artistry. I am keeping my mind open to things I have never done before. I'm very interested in HIV and aging because I am really the first group that has been able to age, gracefully I might add! I have balance in my life, in my mind and physical body and spirit. Everything is in order and I am in order. I have naturally come to that point where I have a sense of spirituality in my life. I was at a conference and got to hang with 300 other people with HIV and felt like a small fish in a big pond. And they talked about aging, but it was all negative about progression and it was so depressing. I actually said to the guy facilitating, "Will there be any good news coming?" I didn't realize they were going to dwell on the negative to that degree. I couldn't stay because again it could trigger depression.

Having HIV now after 18 years is no big deal, it's a chronic, manageable condition like diabetes and I live with it, I don't think about it like I used to. It no longer defines me. I can live my life normally with HIV. Before, I felt I was HIV. It owned me; it was as if I had toxic waste tattooed on my forehead. So I had to come out of the closet, because secrets germinate and grow inside you and eventually define you. The thing you are most afraid of must be said or you can't get beyond, you know the disease was owning me until I didn't give it any more power. It used to be the number 1 thing on my rolodex list of top 10 things to worry about. I had no life plan for this segment of my life. You had a death sentence, truly. I lost 14 of my friends and I'm still here, they're not, and so I see it as a blessing, there's no reason I shouldn't live to a normal age. My health is good. I'm having pre-diabetic testing done and yeah, it's a normal geriatric condition! And my life is meaningful and beautiful right now. I don't feel diseased any more. It's the most enjoyable part of my life because I don't have to care about what people think of me. I don't have to work, I volunteer. I recognize the enormous strength it has taken me to get here and I feel I am finally getting some wisdom and it feels good. And I am passing it along. I went from taking 30 odd pills twice a day down to 13 to 5 to 3 and now I'm on one at night. Back then it was horrible, with the first antiretrovirals I took I felt like the walking dead. And yet that was a blessing too, because I was a business owner I was able to get the meds quickly and start even though my CD4 count was still high. Now I take more meds for depression so HIV is the lesser of the two. I would love to be the first person to go from HIV positive to HIV negative. They're doing a study in Seattle and I applied to be in it. The stress of secrets is gone and that has been freeing, heavenly. I have stopped caring about material things and that is freeing too.

There is still stigma for sure, HIV is still marginalized in terms of the hierarchy of diseases. HIV is way down there and it's considered a disease you gave yourself and um you're a worthless human being because you contracted it. Stereotypes are alive and well. And the stigma with mental disease is even more difficult in our society, people won't admit they have it. But you look in their eyes and you see the pain they're in and you see them isolating themselves and trying to think it through and you can't, I know that doesn't work. And this opportunity to tell my story has been good for me. I don't get to articulate these things that often and when I'm telling you I'm telling myself too.

It's like until I heard the words come out of my mouth it was the first time that I believe it and knew it was true, they sound true in a good way. It's truer than when you just banter back and forth in your mind or tippy toe around the subject with a friend. I'm realizing that the truth will set you free and you will feel better about it. It's the only way to let a deep dark held secret go, to talk about it, to let it become the mundane. And I am living with less stuff, less baggage. Funny how it takes a lifetime to get less. It's still baby steps but I expect the future to unfold brightly. I enjoy life, the most I've ever enjoyed it and I absolutely, absolutely love it. I would say now that living with HIV is like living without it. It is rewarding only, and has been a big blessing. I've come to see the gift in it. I can honestly say it is through HIV that I have found my social conscience, humanitarianism, my volunteerism and humility. And I want to say on this subject, I am sometimes amazed how some people take ownership of all the negative signs of the disease and I almost want to say, it is HIV positive not negative! You know, you really need to see the positive in the positive, yeah. So thank you for the opportunity to articulate living with HIV.

Judy's Story of Aging with HIV

I was diagnosed with HIV in the early 90s. The day I was told of my diagnosis it was really hard to let in. I thought the doctor was joking. I never thought I'd be the kind of person that could get it. And I thought it was a death sentence. I was seriously sad. But then the medicines came out in around '96 and I started taking them very diligently. And I was afraid to hope. I didn't want to let the hope in and then be disappointed to find out that there was nothing to it.

The longer I live with HIV, it gets easier. Everyone's life has traumatic pieces in it, HIV is a part of me. I don't think of it as a death sentence any more. I was declared disabled and get disability. And I lucked right out and got a housing subsidy and moved into a nice place. I doubt if there's anybody living on welfare that has been as lucky as I have. I know a lot of people in the building, but I've been afraid to tell them I have HIV. Although I have gained a lot of people's respect, you never quite know where they're going to come out of left field on you and I don't want to move. So I am a little fearful. I feel like one day it will come out and we'll see where it goes. And I know that in order for people to change their ideas about HIV it kind of relies on us to come out and say something to change that. It takes a lot of courage. But I don't feel like taking it on. I feel like staying exactly the way I am and not telling. No secret is forever though, the truth always come out. If I end up dying in this house, I hope it does come out and they get to think about it. If I can help with my sad, stupid story, that's about the easiest thing I can do all day. But living here, I keep it secret. I just tell everyone I am disabled and leave it at that.

My health. Well, I have other illnesses, diabetes and osteoporosis, my thyroid is out, my ribs keep popping. And when I get a cold it goes on forever. I've reached the stage where I'm afraid of my next illness 'cause I've been down so long this past year. I don't mind getting older but I think I am getting older ahead of my time. It's either HIV or the meds that prematurely age you, I heard this from a talk two weeks ago. I know they are

no cure, and they keep you alive but then they kill your liver and kidneys off. We're going through with liver failure, kidney failure, and I have osteoporosis, hyperthyroid, diabetes and the taste alterations I told you about. I've had a couple of falls and because of my osteoporosis I usually break something. And I wish there wasn't facial wasting in my face. Thank goodness I haven't had any Hep C medicine yet, but who knows, it might be on my form, coming. I'm lucky, I'm still on the front line of regular meds, but they're still learning from us and so that means I'm still a guinea pig. But the meds really help. So I'm very good at remembering and taking them and follow a routine absolutely. Before I had the meds I thought you die at the end of this, and I was so tired hoping for and hoping that I wouldn't. And at first the meds were like throwing us a life raft, I was a little bit wary and not really sure I should trust because I had accepted I was going to die and now they were saying I'm not. So my acceptance of the meds was very gradual, I thought I don't want to go through the whole process of accepting that I'm dying over again. But when you're on the meds for 16 years you're doing okay. And everything happens for a reason. You never know how long you have. The key is to remind myself to be thankful to be alive. Life lessons, to be thankful, to love one another, and to be careful what you ask for! I think I wasn't thankful enough, and HIV teaches me to be thankful. I do peer counselling and I teach the people that come in. I tell them it's not a death sentence, it's still terminal but manageable. Take your meds, be good to yourself and be healthy. I tell them don't be ashamed, and don't spread it. I don't believe in condomless sex, wear a condom. The disease is not symptomless, and pills are not a cure. And so I'm still useful, I volunteer as much as I can.

Other people don't understand. It makes me so mad. A lot of times I get down and I spend a lot of time on the couch. I tell them I have no energy, and they don't understand. Some of my friends think they know the HIV experience, and they don't. They say, "why don't you get your shoes and coat on and go for a walk around the block?" And it's starting to grate on me a little bit. No one understands. But I know exactly what to expect. I'm an expert when it comes to HIV. I've deal with it for 20 years. And there isn't anybody better to take care of myself than me.

Um so back to back to HIV I guess. You know the longer I live with it the less it affects my life. Can I say that? Like it was, when I was first diagnosed, it was more on my mind. It was on my mind a lot. It seemed to play a part in most of my thoughts. And it's not like that anymore. It's just something I have, like somebody has diabetes. It's no more, no less. It's a disease that you're living with and managing as best as you can. If I had to think of something that represents my HIV it would be this plant, because it's not a thing but it's alive. My HIV is alive, it's trying to kill me and if I fertilize myself and water myself and take care of myself well I'll end up blooming. It reminds me to get the best that life has to offer and I might even be able to bloom a few times. So that's it. I've kind of gotten used to the thought that you don't know when the end of life is coming again. They thought you could predict it before the meds but now it's a different equation and sometimes it blooms and sometimes I bloom and sometimes I'm on the couch and not blooming. Um, my doctor says that I do get depressed. I beg to differ with him sometimes but I have seen myself a little depressed. But I'm not a wallflower. I'll get out and do a project. But it does hit me. I found that being in the house a lot in the winter

is hard, and I've noticed my mind is starting to say stuff like, again, at the end of this is death. And there's uncertainty. Like what do I tell the grandchildren? I wonder, at one point do you tell them Gran's got HIV? I don't know.

Aging is not so bad. For me, I mean it's different for everybody and every body. HIV doesn't change things, you still have life happen, it's just one extra thing. I mean the disease will kill me one day. I find that as I'm growing older I am able to let the anger out, let it go. I had always blamed myself for everything, like I am such an idiot to get HIV. I'm you know, who's so stupid to do all those things you know? So there are issues, and it's, I'm coming to an age where this stuff is wanting to explode out of me. And I'm finding that things that happened to me were unpleasant and a lot more traumatic on my life than I realized. It changed my life. I didn't look at it that way before, I just thought it was unfortunate. But things are starting to make a lot more sense now. I am learning self forgiveness. It is not easy, there is no button you can push, but I am trying to forgive myself and accept my imperfect self. I believe in God and try to be strong in my faith and put it first, I think it's easier to go that way than on your own. So HIV has become the smaller part you know. Now, in my sixties, I'm surprised to be here and have lived with HIV for 20 years. Yeah, I don't think anybody can prepare for aging, like it kind of comes upon you and you go, oh darn. And I am doing what everybody does my age, I am looking for answers and stability in my life, a balance. And I want for nothing really except a healthy relationship with my children is about all I would like. With aging, everybody deals with life illness challenges, some earlier, some later, so you just go with it. And I notice a shift. I think I have way more energy now. The first ten years I was always tired, always, always tired. Now I don't push myself as much. I don't have days where I can't get of the couch too often. I can actually say I experienced more days out of chronic fatigue now. I feel like "oh yah I'm in my 60s" and it's great! But I have to take my rest days. I rationalize that maybe I just have less HIV in me now or less symptoms of HIV, but I don't think that's true really, I don't know. And I'm starting to think a little bit more about dying. I have a plot and stone, and I was thinking of looking for one of those canisters, you know the one they used to sell knitting stuff in, and use it for an urn so all the ashes fit it, but they might not let me because they have certain standards, you know. Might as well get it done now. It'll be ready when for me when I get there. Welfare will bury you but I don't think they buy urns. And I want it to be as easy on my kids as possible.

But one thing concerns me. Why are people still getting infected with HIV? Because I led a foolish lifestyle, but after all these years, aren't they being more careful yet? Like it's not necessary. It just concerns me. I can't believe it's still going on, when it's a preventable disease. And the stigma to HIV. There's not a stigma to kidney disease or cancer. HIV is still the naughty, the naughty disease, and dirty disease. You must have been bad to catch it. And I wish that would change.

Nancy's Story of Aging with HIV

When I tell my story I always go back to the beginning and the beginning goes back a long time because it's been more than 20 years since I was diagnosed. I had been

travelling abroad and when I got back I wanted to get checked for everything. I don't even remember talking about an HIV test. My doctor phoned and told me I was HIV positive and it was like boom, like you just got hit in the stomach hard. I was just in this total, total fog and I was sure I was going to die. I caught the bus home and just got into bed because I thought you must die in bed! I had this attitude I was going to die and there was nothing I could do about it and it was so terrible. And I was shocked I didn't die right away... So I was basically in denial for about 7 years and then I became so tired and got so sick I had to quit working. I did go the full tumble to AIDS and was in hospital. They sent me home with a palliative care binder and I was prepared to die...

HIV has put me on a whole different life trajectory. It makes me think of an embroidery I have of a phoenix rising from the ashes. And it's kind of what I see because this disease comes with a huge wall of stigma and has really severe implications and yet it allows me a commonality with people everywhere. So I can envision myself rising out of the ashes, of having another chance at doing what I want to do. A friend was the first one to help me recognize I was part of the changing story of HIV. And I have been involved in various ways, teaching and telling my story because I do want to influence and impact change for the better. And it is not always easy, I want to do so much and it strikes me as urgent to get health care to people for something that is treatable. But at times I feel I'm pushed to the brink and that the world is crumbling, I feel overwhelmed. Part of me feels I need to figure a way around these roadblocks and another part of me feels depleted and I just want to fall back and rest. I have faced depression but I have also started recognizing that life is about the yin and yang. You might get smacked in the face in the morning but you may have somebody kiss you tonight. I know that each struggle doesn't go on forever.

Now, in my late 50s, I am focusing less on my work, taking a step sideways although that is a challenge, and I'm really working on my own health, my physical health and psychiatric health. I'm dealing with all those things that everyone my age has to think about but I have to put it into the framework for living with HIV always. What does that mean and how does that make it any different? I've always looked after my whole self and have been proactive, I mean it is about taking responsibility for self care because it's more than just staying alive. And it makes no sense to expect medicine to do it all, there is no magic bullet. I still take meds. I take 5 a day and one needs to be refrigerated so it's kind of a problem when you're traveling. And I have tried many alternative treatments. It's frustrating at times, you do everything and are yet no better. And there's old stuff that keeps coming up that I need to deal with that I haven't, it's easier often not to deal with it, and a lot of things are difficult. I did a collage art recently, and it came out looking like chaos, and I thought that's what I do want to illustrate, there is chaos in all of this too. So for the most part I have been well and balanced in my physical body and in my spiritual body, and often feel more like 30 years old. My CD4 count was the highest it's ever been, 1200! Right on the high end of normal so it was just kind of amazing. And I couldn't believe it, I turned 40 and then I turned 50! I had to celebrate. Anything past 40 to me are bonus years. But lately my health has imploded, it's not that good. Maybe it's all the stress because I think the psychological and the physical are closely linked. I've got a lot of issues on my mind, thinking about what I'm going to do

for money once I'm no longer on disability and thinking about retirement. So let's see, I have had blood in my urine, and a sinus infection. And I had some little tests done because I'm worried about my memory. And the other is osteopenia. I don't know what's really going on and I'm not as good as I was a while ago and it doesn't feel like its HIV, maybe something else. It seems health wise it goes up and down and it's just a fact of life.

The stigma of HIV is still so great, you live with fear that you might pass it on. And having HIV is not like having diabetes, you cannot date, and it now has this criminal element and it is stigma personified. Your identity is changed forever. And the criminalization of HIV is just making it more stigmatized and less likely that people will get tested. Like I feel really alone and I want to be in another intimate relationship, to have sexual intimacy, but relationship for me is fraught with concern about disclosure. This issue is huge and I'm scared of it, it adds more fear about entering a new relationship when you already have enough fear when you're my age. It's an ugly problem and I feel humiliation, it has really eroded my self confidence. I've tried to meet someone and can't. The stigma is always there, the threat of it. It's like always wearing a back pack, I'm never sure when I can take it off and set it down on safe ground. I want to live my life open and honest but I cannot trust, there is fear. It stops me from living my life. I can no longer live with innocence. When I meet someone new, I never disclose at a first meeting. I have to gauge if it is safe to tell and so as a safety I always tell people I am HIV positive in a group so I don't get beaten up by somebody reacting, or I have a witness, so there's safety in who I am and where I am. The stigma creates so much pain.

I'm beginning to realize that that's the biggest health thing, self-esteem, because when we have low self esteem we are most vulnerable. And this is a sexually transmitted disease or a blood borne infection and the disease gets spread because of uncertainty, because young people are not able to be clear about boundaries. And that's what we need to teach. When I think of what happened in the 80s and 90s, all the deaths, I think there was a whole bunch of compassion and awareness that came into being, that it was a real eye opener for the world that there is a group of incredible people here and globally who are totally vulnerable and human beings like the rest of us. This is such an opportunity for compassion. And I don't think we can succeed as a person until we do community work, we are not only what's inside our core but we are our relationships with our communities. And it's that relationship that helps me so much, living with HIV, the community work that I do.

I am aging. I am aging! And I live with the threat of HIV all the time, it's always with me. It sits in my body as a tightness, like a tightness when you clench your fist. It's about so much loss, you know, the loss of partners, of innocence, of learning to live with grief. There's an uncertainty about living and there's an uncertainty about dying too. I don't totally trust what the long term situation will be, we don't know the effects of taking these drugs over years is going to be. So I am dancing my dance, my best dance, to the music that is life, and I'm trying to relax but I am not there yet. Joys of aging? Yes, so many, the joy of being alive, of breathing, of every little thing because I do

remember being on the brink of death. And to be this age is pretty amazing. HIV positive... that's pretty amazing.

Telling my story is important for me, there's lots of self counselling when we talk and that's helpful. I feel confident in the information I have shared but I still feel like a guinea pig and I'm not certain what might help others, everyone's story is so unique and always shifting and changing, and that's a good thing, but I hope it creates a space for others dealing with HIV to feel not as alone and that they may find some gems.

Norm's Story of Aging with HIV

Here it is, my thesis of living with HIV. I'm in my mid fifties and have been positive for 13 years, yeah, 13, and I'm proud of that, surviving. It's about uncertainty. The future does not exist for me. Sure there are so called "outstanding" drugs my doctors keep preaching at me to take, but let's be honest, they're brutal and they are no cure. More like a life sentence. No breaks ever from the drugs, you're on them for the rest of your life. If I don't take these things I'm going to be dead. I trust the doctors but not the drugs. Someone says to me, "oh just take them like vitamins." Yeah, right. They make me feel sick. I get diarrhea, I'm nauseous, my nights are rotten. And I barff a lot. I have no appetite. I got the double whammy, HIV and hep C, so I have malaise. So yeah, it may seem crazy but I don't always take my meds, sometimes for months... I have never felt at ease with them. I think there's some psychological aspect to it because once you realize how toxic they are, they're harder to take. When I was first diagnosed I was interested and passionate about sticking to the routine, but now I'm a long term and I got burned out by the whole process, the blood and the numbers and doctors and drugs all the time. I just say "F" it, screw it all. I'm a guinea pig in my own experiment. And this mystifies my doctors and friends, that I push the envelope so to speak but I know when to stop. I fool around with the numbers a bit because it keeps me sane, and I know I can get away with it. And I feel deep deep guilt and feel I am letting people down, letting the doctors down, but I just sort of walk a fine line. I almost died with pneumocystitis pneumonia in the 90s -- that scared me, so don't want to go there again. But taking the drugs, I'm on my fifth cocktail, it's hard. It's mostly a mental thing. At times I live in a black zone and crawl into a hole, and then sometimes I feel inspired. But mostly I live in-between, in a grey zone of inner turmoil. And emotionally you just think, God, I don't know if I can keep doing this.

And the worst part is it's my own fault. I don't play victim. I used IV drugs, cocaine, everything when I was a fool years ago. It's not sympathy I want but a little empathy would be nice. No one understands me, people don't care. It scares them, it's because they're afraid you know. Their eyes get glassy when I tell them about my numbers, they're not interested. Sure my doctors understand the numbers, but no one gets the psychological aspect of the illness. The best health care in the world and yet you don't know me, you don't know who I am. Everyone is mostly ignorant about the whole thing. I've given up on people understanding. Yet it's all about the numbers for me, that's how I have to live, by numbers. Viral load, CD4 count. Everyone expects me to act like it's all okay, so I play along, put on a façade. I lie instead of explaining, it's easier than

facing reactions all the time. And I'm a wise guy, I have a sixth sense and choose who I tell, one of the few dignities I have left. But I'm tired of it all and its not that I think about it day to day or constantly, I don't, but then it crops up and it's almost like it all falls apart and you have to build yourself up again. There's still stigma and fear. People are uncomfortable. I know darn well the stigma of HIV has not changed in probably 30 years, since 82. I am a pariah. If I visit someone in their home and tell them, they throw out the glass I used when I leave and freak out, "he ate off my dishes!, did he use the bathroom?, I touched him!" People today wear cancer on their sleeve, not HIV. If you have cancer and survive you're a hero. If you live with HIV for 13 years, they say "well at least you're alive." It's a tattoo on you, a brand, a pox on your name. There's a whole bunch of ignorance out there. People say, "oh you're on meds now, and your viral count is undetectable, oh, so you are cured." And I just shake my head at that. I don't make this stuff up. I know it is the truth. And HIV is out of the picture now, so people stay ignorant.

All this... it's a real grind on me, wears me down. One big long road. I say to people, you have no idea how lucky you are. How do I cope? It's an inward illness. Lots of turmoil. I've cut myself off. I have to protect myself from letting it out there. So I play two roles, my private self dealing with HIV and my public self. I've really come to protect my privacy about it. And my personality has changed. It's made me more reticent, more insular. I'm apart from people in a way, you know. The most basic fundamental of this whole thing is the fact that you're, you're different from everybody. I can't connect with people talking about everyday things like money, and trivial things like the price of gas. I have no one to confide in really, except a brother. I mean I do engage people. If I'm in the grocery line up I am open to people but not all the time. I mean, just because someone's a stranger doesn't mean you shouldn't talk to him otherwise the whole of society becomes closed. But I socialize little. That's the thing, this illness is physically tough. Mentally it's probably just as tough, I'm not going to say tougher, but just as tough. You know, I mean I don't know what's worse. The doctor says I'm depressed, and I'm starting to believe it. And my social well being is directly related to my mental well being. They are all interconnected. And here's another one. This is what really gets me, is everybody avoids the question of sex. Ha. There are no longer women in my life. Used to be, and I miss that. Now I'm stuck. I'm an untouchable. If I meet someone, I disclose I have HIV, I always do and they are fascinated because they've never met anyone like me and they want to become friends and then it fizzles out, they kiss me on the cheek, on the cheek you know, always, and they're gone. You get nervousness. I don't like it worth a damn. Wears me down, makes me more cynical. All I have is my work, I'm still keeping it going somehow. And I have my cat Charlie. He's the key to it all. He doesn't tell me to take my meds! He reminds me of me, a survivor. I prefer him over humans by far, by far. We're both kind of private, he's quiet like me, and he doesn't have a lot of cat friends. He's 18. He's always here for me, he sleeps with me, purrs, bashes his head against me. My best friend without a doubt.

I hate this existence and accept it... I am content knowing this is my life, it won't change. I'm used to it. There is a kind of cleansing, a relief in not having to worry about or look

to a future that's not there. No pension worries. I've stopped worrying about what people think. I don't worry about a lot of stuff anymore. If I do worry, it's about like, am I going to live the next 2 years?

I live in the moment. I have faced death and won, some guardian angel was over me. When I got sick and was in hospital years ago, no one could figure it out, and it was AIDS. I remember looking at all the faces around my bed and thinking, the worst thing is not dying but everyone will know... I think about death more than most people. When things aren't going well I think about the pneumonia and "oh god, am I going to get slowly worse?" and that freaks me out. If I don't take my meds I'm going to die a horrible death and I know that because I almost did. So I do take them though it may be a bit loosey goosey. I'm being compliant in my own way, kind of a balancing act. As I've gotten older, I see it's not a linear path. I'm frustrated for sure. It's becoming a more negative experience, I believe so. I don't have a sense of the future as I said, and that's a rotten way to live – something I wouldn't want to have anybody deal with. My doctor says I could live 10 more years if I was more compliant, but it's tough to think I'll be sick as a dog for the next 10 years on those darn things. I don't know. And I don't expect it to get much better, to tell the truth you know. It's my responsibility to live 'cause I've invested 13 years in this. But I am not giving up at all. At all.

So that's it, I wish I could give you more positive stuff. Thank you, I love the fact that you are interested.

Rick's Story of Aging with HIV

I live among you and yet you don't know me. I feel it is my duty to become a face of HIV and tell you how I experience living HIV positive as a gay man in his fifties. Death touches me, too much certainly. I've seen a lot of people die in some pretty awful ways and have to experience some pretty awful things. I lived in the West End in the late 80s and saw many friends die of AIDS. The trauma still sits within me, a shock that continues to reverberate. I cannot forget, and you must remember --- this that took place not so long ago.

Today, I am absolutely terrified of my own dying because I know the range of possibilities. I know the reality that is kept at bay by the powerful cocktail of pills I force myself to take. I'm on my fourth cocktail and now a fifth is being discussed. I've chosen to follow the medical model and pay heed to the numbers: my CD4 count is high and my viral load is undetectable, and it never fails to remind me of how my immune system is holding up and I am holding on. The side effects are relentless: migraines, vivid dreams, elevated cholesterol, and so more pills to swallow. I also have an ulcer and I get an upset tummy. Yet I am lucky that I have the cocktail. And I don't have to follow a special diet or anything like a diabetic might, so I'm not preoccupied with it. I mean I am aware of being positive but life is not bad and HIV is not an issue. For me. I mean I know it is still urgent in other areas, the north, and in the street community. For me, I'm a survivor of HIV, I'm a survivor of my life. And I will continue to survive the best that I can.

In many ways I am surprised that I've lived to be the age that I am. On the outside you see me as a pretty normal guy. I have a job, I pay my bills, I have a partner, I have a cat, I have friends. Let's see.... I'd say I have less energy and need to nap more, and my memory of the past is very fresh but not as much so for the present. And all the drama of youth has fallen away! I feel more settled in myself and more confident. And I am more open, like I am on Facebook and I speak in public, I don't care if people know. Yet I don't like confrontation either, like how will people react? I'd say I just try to live my life by example. I feel I have a responsibility because I lived through the death of the 80s, you know, I do my part to advocate but in a different way now, I got too burned out I the past.

Life now has a different kind of drama, more the drama of life and death. On the inside, I face episodes of depression as anniversary dates of so many losses merge with new stresses, like caring for my partner. I find myself on a roller coaster of emotion and stuff. Yet I'm getting on with the rest of my life because I don't know how much of the rest of my life I have. I am grateful to live here, in this city that affords me access to the best doctors and treatment and support. Not all are so lucky. I don't keep my HIV a secret any more. I am tired of secrets. Be damned really, this is me, my life. We're all dealing with something, everyone here in my neighborhood. The lady next door has diabetes, the other neighbor just had a hip replaced, and another fellow died of heart problems. And I have HIV. It's a disease, it is not easy and yet I carry on, experiencing being positive and living my life with intensity. I am a face of HIV, and I am of part of the mix of this community.

Chapter 1. Inquiry into Understanding Narratives of Aging with HIV

As I began this doctoral journey in 2009 I prepared to enter two worlds, one being that of stories with underpinning concepts of language, experience, and social influences, and the other being the world of aging with HIV. Of course they are not two separate worlds, but as a novice researcher my starting place of making sense began with a mental separation as I delved in.

This dissertation begins with an introductory chapter that reflects embryonic ideas I held at the inception of this inquiry, ideas which evolved over the course of time. I think of a larva hatching from an egg, shedding old skin, ingesting nourishment, and growing. The four ensuing middle chapters focus on the research process and findings generated. Time spent immersed in the research and writing, chrysalis like, supported the final chapter to emerge. The final chapter brings together my learning, focuses on contributions to nursing knowledge, and serves as a closure. And yet it is more, a place of endings and beginnings and the beauty of butterflies.

This introductory chapter is set up as follows. I situate myself in the inquiry with a personal note on narrative inquiry and HIV. As background and grounding I next share a timeline of HIV/AIDS and the story of HIV as understood in statistical numbers. A review of the literature follows with a focus on HIV in relation to aging, metaphors, and stigma, as well as narratives of illness and what illness narratives do. Under the section on methodology I explore my early understandings of the concepts of narrative, stories, experience, narrative inquiry, and social constructionism. Secondary analysis is also addressed. Lastly is an envisioning of four manuscripts meant to guide this inquiry and

form the body of this dissertation.

Personal Note on Narrative

To write about narrative with a focus on stories of illness invites a tension that sits alongside passion. I ride a roller coaster of elation imagining how the world might be, tempered with a realistic knowing of the challenges facing health care. In nursing today, I am unshakable in my belief that a narrative approach may be the Nightingale lamp that casts light on the human experiences of illness and on human engagement between those who are ill and those who bear witness to suffering and angst. I want to proclaim this and hold it high like a saving grace yet am hesitant and pay heed to Paley and Eva's (2005) caution that a tendency to romanticize narratives may undermine necessary vigilant analysis. Yes, we yearn for the trust of those who are ill, a return to kindness, and truth in our quick claims of patient centeredness.

Yet while nurses demonstrate vitality and creativity in response to opportunities that present themselves, I believe a disruption of current ways of being and knowing can take place when we emphasize understanding through narrative. It bumps up against promises of our dominant digital era that emphasize data and privilege systems designed to collect fragments of illness stories in tight boxes. I am not suggesting data is bad or unnecessary, far from it. Many advances in today's health care are due to our ability to access and transform data into remarkable care treatments, and this has meant pain and suffering associated with illness can be delayed or ameliorated, quality of life improved, and lives extended. This is a blessing to many who face illness as most everyone in this situation does want to live...to live longer. Like Gaydos (2005), I suggest that nursing is at a critical time to introduce balance to the reductionism that can creep in and distort the

personal. Frank (2002) refers to this as a “triumph of science and a lapse of humanity” (p. 27). Quality care is about technical and clinical skills, as well as engagement. An overemphasis on this one aspect of knowing impedes us as we come to see, know, and understand those living with illness in only one dimension. While we see the bodily person before us our focus may slip away from seeing them fully and hearing their story.

This is all we have, the stories that we tell of our life and who we are. I believe most individuals facing illness desire to live and continue to experience life; to have more of all the messy everyday comings and goings that equate to the humanness of experience. This applies to young friends living with cancer and to my 80 year old father. It is not that he still has things he wants *to do*, he explains, “I just like being here, with all of you.” We all have experiences and tell of them as a way to make sense. When we in health care negate or reduce stories, when we assume they fit only or predominantly into unmovable and known frames, a discrepancy occurs that puts us on the verge of doing harm. The person in all their humanity before us, as a living breathing body subject, becomes more object and the nurse also becomes less relational, more impersonal, and objectified. And yet this innocently happens every day. For example, I attended a presentation about findings from a new international data instrument to be used with elderly persons in the ER. The speaker stated the tool takes ten minutes to complete, “If you can ignore and get past all that they’re trying to tell you about their dog and problems with their kids and so on!” It was meant to be comical and the audience laughed, sharing a collective sigh of “we know what you mean!” Implied is that in the name of efficiency and compliance, the best approach is to get past, go around, cut through, downplay, ignore, shut down, and use every communication skill the nurse has

to silence stories and generate succinct responses. Sakalys (2003) draws on Freedman and Coombs (1996) to suggest nurses most often listen analytically versus narratively; we are socially constructed to “listen with a diagnostic and pathologizing ear, listening for facts rather than meaning” (p. 234) and to convert the ill person’s story to a diagnosis and treatment plan. I wonder, if not when a person is facing illness and vulnerable, then when is a good time for them to speak of who they are and what matters to them?

The reality is that our world is complex. We need multiple ways of thinking, listening, and knowing and the discernment to use each wisely. Tension lies in figuring out how to illuminate narrative inquiry as important in health care such that doors to considering it are not closed. How can one promote narrative as a way of knowing for and in nursing that sits alongside more analytical ways of knowing and is not dismissed as too soft for our challenged health care environments? For now, I place these thoughts in a pocket close to my heart, tucked away but not forgotten, and enter into narrative.

Personal Note on HIV

My entry into the complex world of HIV as a researcher began with interviews I conducted as part of a narrative research team from 2009 to 2011 (Sheilds et al. 2014). From this starting place I pursued an in-depth entry into literature on HIV and metaphors that culminated in this inquiry about the experience of living and aging with HIV.

Like most nurses I knew a little about HIV and AIDS, yet my knowing was in many ways that of a naive outsider: a somewhat narrow lens of privilege and socially mediated exposure. My view was that of a white, middle class and middle aged female nurse working in an urban health care setting. I believe my understanding of HIV was similar to that of many nurses: outdated and knowing enough to get by. At the peak of

the epidemic in the late 80's and early 90's I worked as a community nurse and cared for many individuals dying of AIDS in their home. After that time I had not formally kept current of significant changes taking place. At the outset of this inquiry I paused to reflect on my positioning. I acknowledged my sharp anticipation and curiosity as to the journey ahead, these feelings tempered with uncertainty and a hesitancy, maybe anticipatory fear of the pain and magnitude of suffering, ugliness, and complexity I might tumble into. I imagined I would be forever changed by the experience, that innocence and naivety would be lost and there would be no returning to my not knowing self. As I prepared to bear witness to the narrated experiences of individuals living with and in the world of HIV today, I reflected on and discerned personal shifts by journaling emotions experienced as I dared to near another.

Of the vast number of diseases that are chronic yet life threatening, I responded to a sense of calling and the pull of the stories of those living with the illness of HIV (*human immunodeficiency virus*) for several reasons. I was appalled by the legacy of stigma that HIV has not been able to shake off, and could easily recognize that HIV received less attention than other illnesses in the media. I was fascinated that it has been three decades since the virus responsible for HIV was identified, and how over time ARV (antiretroviral) drug treatments have vastly extended lives. I realized that most clinicians today have little contact with persons living HIV positive, as for the most part they live well and are in a sense invisible from mainstream healthcare and society, entering our acute health care system only when faced with advanced disease. I was inspired and disturbed by Sontag's work *AIDS and its metaphors* (1988). She highlighted metaphors associated with AIDS and emphasized how illnesses can be powerfully influenced by

social constructions. This led me to wonder what metaphors older adults use as they story their experience of aging with HIV in this new millennium.

I wanted to better understand the experiences of living with a deadly disease that over time has become treatable and shifted to a chronic disease. I imagined it not easy to live with let alone express aspects of this experience through story. And yet individuals living with the HIV do speak of their experience, and their stories often have the power and potential to teach, inspire, inform, and connect us all as humans to suffering and life. It seems critical that we hear stories of living with HIV as affected individuals are now living to older, unanticipated ages. By 2015 approximately half of adults with HIV in the USA will be 50 and older (Kirk & Goetz, 2009; Patel & Crane, 2011). Aging with HIV has brought forth new challenges -- what some have termed a new crisis. My research contributes to this evolving understanding of HIV from a death diagnosis to one of aging with chronic but life threatening illness, and helps untangle the intersections of aging, illness, and social influences. By focusing on metaphors that arise from stories of aging with HIV, this research gives voice to individuals who often live at the margin, it adds to the body of nursing knowledge in this emergent area, and it illustrates the potential of narrative inquiry and story in the nursing relationship.

(Note: Throughout this dissertation I use the term “patient” in the broadest sense to include all individuals across all settings who seek health care and nursing services.)

Aim of Research

The primary question guiding my research is: What might nurses learn from the stories of older adults living and aging with HIV, and what do metaphors reveal about their experience? My aim is to more fully understand the experiences of living with HIV

now that the illness has shifted from imminent death to living with chronicity. I use narrative inquiry to interpret narratives of older adults (age 50 +) living with HIV for at least 10 years. The findings are presented in this manuscript style dissertation. Key questions to be addressed include: what are the stories about living and aging with HIV, what metaphors are used by these older adults to convey their illness experiences, what is the experience of being a narrative interviewer engaging with and co-constructing illness stories, and what implications can be drawn from this research for nursing practice?

Background

Timeline Retrospective of HIV/AIDS

I begin with a brief timeline of HIV/AIDS (acquired immune deficiency syndrome), summarizing the retrospectives by *WebMD* (2011) and *Avert* (2012). The AIDS epidemic is now 30 years old and responsible for 30 million deaths worldwide and counting. Today, in North America, more than 1.1 million people live HIV+. When the first case of AIDS was recognized by the US Center for Disease Control (CDC) in 1981, it was believed to be spread in contaminated blood. The CDC initially identified four high risk groups: gay men, injection drug users, Haitians, and people with hemophilia A. Canada recorded its first case of AIDS in 1982. The virus responsible for the syndrome (a lentivirus, species *Human immunodeficiency virus*) was isolated in 1983 and by 1986 became known as HIV. By 1985, as death spread across heterosexuals and homosexuals, fear and hysteria mounted. 1986 was the year that the HIV was differentiated into HIV-1 (most prevalent) and HIV-2 (less virulent, more common in western Africa, and closely related in structure to SIV of monkeys; HIV-2 seemed to be less easily transmitted and the period between initial infection and illness is longer with HIV-2.). In 1987, the first

antiretroviral drug AZT was approved by the US FDA (food and drug administration) and in Canada in 1990. By 1988 a lack of funding and attention prompted increasing AIDS protests and the first World Aids Day on Dec 1 came to life.

In the early 1990s more public attention was generated as famous people succumbed to AIDS, the red ribbon was introduced as a symbol of solidarity, and the first rapid HIV test was licensed. Awareness campaigns promoting the use of condoms flourished. In spite of these efforts, delayed accessibility to all treatment meant that in 1992 AIDS became the leading cause of death for Americans aged 25 to 44. The trend continued to 1995. In 1996/97, hope surged due to a treatment breakthrough and the release of the AIDS drug cocktail: highly active anti-retroviral therapy or HAART. The treatment could cut HIV viral loads to undetectable levels and deaths declined by more than 40% in the USA. HIV treatment was shown to extend life by 24 years. Challenges continued though as the gold standard of HAART drug treatment meant many pills with serious side effects needed to be consumed daily.

Over the next few years, new drugs were trialed and efforts were stepped up to ensure drug treatments were available in other parts of the world where death tolls climbed and the majority of those affected had no access. Tensions ran high between activists and pharmaceutical companies perceived as limiting the availability of drugs. In 1999, the extraordinary degree of genetic diversity of the virus type one and the increasing complexities of new sequences led to changes in the nomenclature system: four types of categories were used to refer to the major HIV-1 lineages: groups, subtypes, sub-subtypes, and circulating recombinant forms (CRFs). By 2002, AIDS became the leading cause of death worldwide for people aged 15 to 59 predominantly due to

increasing prevalence in developing countries with delayed or minimal access to treatment. Efforts continued to develop a vaccine and in January 2012 a vaccine again advanced to the human clinical trial phase in Canada (CBC, 2011).

Today there is real hope that a cure may be possible given advances in gene therapy and the case of a Berlin man, Timothy Rae Brown, who is thus far the only person known to have been apparently cured of HIV following a bone marrow transplant (Cohen, 2011). While such advances may further impact the evolution of HIV and social understandings of the disease, in the interim, the reality is harsh. While death rates worldwide peaked in 2004, death continues and the new infection rate also climbs most notably among young gay men. The majority of those affected worldwide go without treatment. The disparities are noted most markedly between individuals living HIV+ in North America and Western and Central Europe and those in developing countries, most notably southern Africa: 68% of all people living with HIV reside in sub-Saharan Africa. Factors such as poverty, mistrust of western medicine, superstition, and government policies prevent or delay access to and adherence with treatment.

In America, attention has shifted to a new crisis, that of shifting demographics reflecting a “greying of AIDS.” Data trends from the 2008 *Centers for Disease Control and Prevention: HIV Surveillance Report* indicate that by 2015 approximately half of adults with HIV in the United States will be 50 and older (cited in Kirk & Goetz, 2009). Also, as the epidemic has taken on a chronic disease profile for those with access to care, 2009/10 saw concerns focus on “let us not forget.” Globally, new infection rates continue to fall and more people than ever are starting treatment. UNAIDS (2011) reports 6.6 million people are now receiving treatment in low and middle income

countries: nearly half those eligible. While the number of people becoming infected with HIV worldwide continues to fall, the number of people living with HIV continues to rise. In Eastern Europe and Central Asia, the number of people living with HIV rose 250% from 2001 to 2010. This timeline emphasizes the evolution of HIV and AIDS and illustrates why it remains a real and major problem, and why ongoing attention, research, and funding are needed.

The HIV Story in Numbers

The impact of the HIV virus continues to be devastating across the world, as evidenced in statistics collected regarding death rates, overall number of cases reported, and new infection rates. My focus is on North America and when possible, more specifically on Canada. An estimated total of 24,300 deaths are attributed to HIV-related illness in Canada since data collection began in 1987, with the most current Canadian statistics from the Public Health Agency of Canada (PHAC) surveillance report for 2011 (PHAC, 2012). Statistics offer hope in reflecting a decrease in HIV death rates of all ages over a five year period: 1.2 deaths per 100,000 population in 2004, up to 1.3 in 2005, and declining since then to a rate of 1.1 in 2008 (Statistics Canada, 2011). The PHAC emphasizes that the statistics provided understate the magnitude of the HIV epidemic and do not represent the total number of people infected with HIV (prevalence) or the number of people newly infected each year (incidence). Some reasons for this include the fact that surveillance data are subject to delays in reporting, underreporting, and changing patterns in HIV testing behaviours (who comes forward for testing). In addition, surveillance data can only tell us about persons who have been tested and diagnosed with HIV or AIDS and not those who remain untested and undiagnosed.

Furthermore, because HIV has a long latency period, many persons who are newly infected in a given year may not be diagnosed until later years.

Despite the continuing death toll, there are glimmers of hope. The number of new HIV infections in Canada in 2011 is estimated at 3,175 people, and this number has remained stable or is insignificantly lower than estimates of 2008. While anyone can contract HIV, Canada's reality is that key populations are disproportionately represented among those living with HIV/AIDS. In 2011, the group defined by the broad epidemiological term describing a behavior (men who have sex with men), MSM, is still the leading risk exposure in Canada. Of all people living with HIV in Canada, this group represents 50% (PHAC, 2012). People who used injection drugs (IDU) represent 20%, people whose HIV status was attributed to heterosexual sex represent 33%, those whose status could not be attributed to sex or injection drug use represent less than 1%, Aboriginal people represent 9% and continue to be over-represented in part due to poorer health and socio-economic conditions, and females represent 23% of all people living with HIV (PHAC, 2012). In addition, Aboriginal peoples are being infected with HIV at a younger age than the non-Aboriginal population. While there has been concern over the past 10 years regarding an increase among specific population groups including younger females, Aboriginals, and Canadians over the age of 40, in 2011 it was found that the number of new HIV infections may be decreasing among people who inject drugs, females and Aboriginal people (PHAC, 2012). As fewer infected individuals die in this HAART era, the PHAC estimates indicate that the number of people living with HIV (including AIDS) in Canada continues to rise: approximately 71,300 by the end of 2011, an 11% increase since 2008. An estimated 17,980 people living with HIV

remained undiagnosed in 2011. This represents 25% of the estimated number of people living with HIV. This number is slightly lower in the USA, with 21% of those with HIV remaining undiagnosed (Goetz et al., 2011).

To summarize, the numbers used to capture incidence and prevalence of HIV begin to portray a dramatic change in the HIV story in North America. The convergence of a decreasing death rate for all ages, a slight decrease in the overall number of cases reported, and a stabilizing new infection rate mean an overall increase in the number and age of individuals living with HIV. Also on the rise is the number of those unaware of their HIV+ status. I next shift attention to the significance of this changing face of HIV.

Significance of HIV Numbers

The steady evolution of understanding, detection, and treatment of HIV over the past three decades have culminated in this millennium into new hopes and a tangible shift in the once dismal if not downright deadly trajectory of HIV. Today, life expectancy for persons with HIV continues to increase, making aging with HIV a relatively new phenomenon that is only beginning to be fully understood. As the older population of Americans at risk for—or living with—HIV/AIDS grows, the day to day experiences, realities, and challenges of their lives remain largely misunderstood or invisible. At one time, a diagnosis of HIV meant an untimely death. Today, Toffler's (1970) idea of “durational expectancies” or our cultural assumption about how long time to death is supposed to take has shifted dramatically for this group, and society has not yet fully embraced or understood the implications of this. The unknowns in these successes are the long-term consequences of the disease and the effects of antiretroviral medications on an individual over time as they age.

Aforementioned statistics are significant as they highlight the changing reality of HIV's older demographic and point to why health care providers need to be aware and consider ways within research and practice to improve the quality of life of this aging group. Clinicians and the public, policy makers, funders, educators, all must be ever aware of changing realities and incorporate what we know into optimal care and support. In this regard, Canadian nurses have made significant contributions through the Canadian Nurses Association (CNA) and The Canadian Association of Nurses in AIDS Care (CANAC). CNA (2006) published a key report entitled "Nurses at the Forefront of HIV/AIDS" and CANAC hosts annual conventions in their commitment to foster excellence in HIV/AIDS nursing, promote the health, rights and dignity of PLWHA, and prevent the spread of HIV infection. Most recently they published a position statement addressing HIV criminalization (CANAC, 2013). Nursing is well positioned to continue contributing as we enter this new era of aging with HIV and face new challenges.

There needs to be increased awareness of the implications of longer survival and the emerging view of HIV as a chronic illness. And there is danger in this view:

"A widespread misconception exists that with medication, HIV/AIDS is a manageable disease. In fact, for many—particularly as they age—HIV/AIDS is an unpredictable, marginalizing and frequently life-threatening illness for which there is no cure" (Gough & Karapita, 2011).

This new crisis, the coming together of HIV and emerging chronic health problems as one lives long and beyond expectation with the disease, is not so easily reconceptualised as chronic and manageable. Harsh yet subtle realities of living this new phenomenon are often invisible. For example, infected individuals often have little money as they never saved in same way as one would who had a long term plan. Writes Dreier (2011):

“Some 15 years into the era of protease inhibitors and drug cocktails, the first large group of AIDS patients to go through the aging process is facing a host of unexpected medical conditions, not to mention psychological and financial challenges they never thought they would live to see.”

These factors that are changing the face of HIV and shifting the many challenges facing those who live HIV+ raised questions for me about the stories of older individuals living with HIV and the language they use to express this experience. The approach of seeking understanding through stories is also of significance, as within nursing and beyond there is a growing emphasis on illness narratives. To unravel this emerging reality and further inform my research question, a literature review was undertaken.

Literature Review

I conducted a literature review of key concepts that would underpin my research: aging with HIV and metaphors within HIV. The concept of illness narratives, what they do for us, and how they contribute to understanding the experience of illness was also reviewed.

Literature Review: HIV and Aging

Current trends in HIV are fueling a focus on older adults. This warrants a closer look at how older adults are defined and categorized with HIV related data and the impact of HIV and its treatment on the body over time.

Those who study HIV categorize individuals who are 50 years plus as being “older.” Kirk and Goetz (2009) clarify that this demarcation has been in place since the epidemic began and reference this to the original source, the *Centers for Disease Control and Prevention: AIDS* (1998). While HIV/AIDS has generally been viewed as a disease affecting younger people, it is becoming apparent that older Canadians are not only affected by but are also at risk of HIV infection. The PHAC released a report *HIV/AIDS*

Among Older Canadians in 2010. In this document, "older" continues to be defined as 50 years of age and older, and includes those infected after the age 50 as well as those infected at a younger age and surviving into older age. Due in a large part to HAART, more HIV+ individuals are surviving longer, and this is reflected in the prevalence rate.

The burgeoning interest in the adult age 50 or older has been dubbed “the Greying of AIDS” (Gough & Karapita, 2011), the “Greying Epidemic” (Berry, 2009) and so on. As the disease known as HIV turns 30, the impact of living HIV+ on older populations is gaining new attention from researchers, public health organizations, and clinicians worldwide. It has in essence become a movement. This is in stark contrast to only 10 years ago when older adults living with HIV were part of the HIV/AIDS epidemic but not focused upon, and indeed were considered to be an “overlooked” and "forgotten population" within this infection group (Whipple & Scura, 1996). Those aging with HIV today, and having a life span extended beyond original hopes, experience the infection as a complex chronic disease often with multiple comorbidities.

The attention to persons aging with HIV is not unwarranted, as the number of persons diagnosed with HIV infection in the demographic of age 50-59 is increasing in North America (CDC, 2008). Further data trends from the 2008 *Centers for Disease Control and Prevention: HIV Surveillance Report* indicate that by 2015 in the USA it is expected that 50% of those with HIV/AIDS will be 50 years of age or older (Kirk & Goetz, 2009; Patel & Crane, 2011). And this number is expected to grow for two reasons: those with HIV are experiencing longevity, and the number of new HIV infections over the age of 50. One factor impacting the rate of HIV infection and adding to the graying of HIV/AIDS is the beliefs and misconceptions about sexual activity

among older adults. The Administration on Aging (2012), a federal USA agency that advances concerns of older adults and their caregivers, explained it this way:

“The misconception that older adults do not have sex and cannot get HIV has led to a lack of HIV testing among this population. HIV risk doesn’t stop at 50. In fact, men and women over age 50 account for 17% of all new HIV and AIDS diagnoses. In 2009, people aged 50 and older accounted for 23% of AIDS diagnoses in the United States. Yet older adults are often overlooked in the ongoing HIV/AIDS conversation. Lack of public education about HIV/AIDS targeted at older people means this demographic is less knowledgeable about how to protect themselves against infection” (p. 1).

In addition to risk factors related to sexual activity, Schmid et al. (2009) also cite physicians’ failure to consider HIV as a diagnosis in this older population.

Closely related to the greying of HIV is the shift towards reconceptualising HIV as a chronic illness. Persons living HIV+ in North America can now expect to age with the illness and are in many ways becoming the changing face of HIV. The reality of being infected with HIV has shifted markedly from preparing for death to facing an uncertain future, with HIV being newly considered as a chronic illness due to advances in treatment and care options: “chronic but manageable in most cases” (Montaner, 2012). While the view of HIV as a chronic disease associated with significant comorbidities (Patel & Crane, 2011) is a wonderful indication of lives not lost, the language of chronicity is problematic and of concern within the HIV/AIDS community as the new metanarrative may mean funding is negatively impacted at a time when numbers of persons living with HIV continues to increase. HIV must now compete with the UN General Assembly’s new global health priority, non-communicable diseases (NCD’s), which includes diabetes, cancer, lung, and heart disease (Morrison, 2011). Yet the reality is that although life expectancy has increased, persons living with HIV/AIDS (PLWHA) continue to have increasingly complex needs related to immune compromization,

treatment side effects, as well as stigma and discrimination; all of which may affect emotional and physical health, quality of life, finances, and independence (PHAC, 2012). More specifically, Eisenberger, Jarcho, Lieberman and Naliboff (2006) found that individuals who experienced social rejection reported more social distress and also higher ratings of physical pain. While HAART therapy has helped to extend lives by reducing the virus production, these medications can unfortunately produce hypertension, dyslipidemia, and insulin resistance (Heath et al., 2001) and foster cognitive decline (Vance & Burrage, 2006). There is also recognition of disease-related clinical concerns that include increased cardiovascular risk, HIV wasting, and HIV-associated immune activation (Falutz, Hardy, & Kotler, 2010). A recent study by Dognin and Selwyn (2010) notes a recent trend in the USA in the HAART era of a co-concurrence of HIV and cancer. In addition, the number and type of medications can adversely impact cognitive functioning, especially when numerous medications are used. What is so unique about the older adult with HIV is that in addition to bodily changes resulting from the infection and the medication are the layered aspects of the normal processes of aging.

Researchers studying HIV have merged with others studying gerontology given the similarities between aging and the changes seen in those with HIV and AIDS. Literature across all sciences including nursing is now replete with such research. While evidence is mounting to suggest that HIV infection “compresses the aging process, perhaps accelerating comorbidities and frailty” (Effros et al., 2008, p. 542) and possibly accelerates the aging process (AIDS Alert, 2011; Patel & Crane, 2011), there are two schools of thought about this. Nursing professor Ronald Walent at the University of California challenges this notion, and while agreeing that conditions may look similar to

conditions seen in older non-HIV+ adults, he suggests instead that we concentrate on HIV as a disease process on its own: “though things are happening to HIV populations that generally happen much later in non-HIV populations, it is really due to HIV pathology, and not an accelerated natural process” (in Volansky & Brennan, 2010, p. 1). This tension is reflective of the long standing debate about aging in general, both biologically and ethically, as to whether we view aging as disease or aging as a separate, non disease, natural process (Hayflick, 2004). There are differentiations made in the literature related to “age related diseases” - diseases which the incidence of increase rapidly with aging, for example cardiovascular disease, cancer, arthritis, cataracts, osteoporosis, type 2 diabetes, hypertension, and Alzheimer disease, and “accelerated aging diseases” which are genetic in nature. While HIV fits in neither of these two distinct categories, the shift towards connecting HIV with aging is popular, and there is agreement in the need for better understanding of the pathophysiology of disease in aging adults. Specific to HIV, Schmid et al. (2009) highlight further significance: the older an individual is at time of infection, the faster they progress from HIV to AIDS. The example given is as follows: “There is a life expectancy of more than 13 years in people infected at age 5-14. This declines to 4 years in those infected at age 65 or older” (p. 162). National groups have formed and there now exists an annual National HIV/AIDS and Aging Awareness Day (NHAAAD) on Sept 18. Organizations such as grayingofaids.org have arisen to focus specifically on HIV and aging and portray this shift in demographics and attention. Their mission is as follows: “*The Graying of AIDS* combines portraits and oral histories of both long-term survivors and older adults who contracted HIV later in life with HIV/AIDS information to increase awareness,

sensitivity, and collaboration among care-giving professionals.” Another organization founded in 1995 is the National Association of HIV Over 50 (Scott, 2002).

It is undisputed that the older HIV+ adult does experience health challenges. At the first international conference on aging and HIV in Baltimore in 2010, a myriad of new concerns and research foci were highlighted. These ranged from biological concerns related to drug responses and interactions, cellular functioning, organ function, and immune response over time, to social factors such as quality of life, falls, menopause, and cognitive ability. More specifically, topics studied in regard to aging with HIV range from biological changes to cognitive and neurocognitive implications (Volansky & Brennan, 2010; Vance & Burrage, 2006) and comorbid conditions such as depression and dyslipidemia (Jang, Anderson, & Menten, 2011). In 2001, Goodkin et al. reviewed and found an increase in age-associated risk in older adults with HIV-1 for a number of neuropsychiatric and neurological conditions, including HIV-1 associated cognitive–motor disorder, peripheral neuropathy, progressive multifocal leukoencephalopathy, primary CNS lymphoma, and cerebrovascular accident. This early research suggested a need for early screening and modifications to treatment for the older person aging with HIV. Other areas being studied relate to the psychosocial changes associated with long term medication treatment, and these include: aspects of side effects, quality of life, and factors and barriers to successful aging (Vance & Robinson, 2004; Vance, McGuinness, Musgrove, Orel & Fazeli, 2011; Vance & Brennan, 2011), falls risk (Erlandson, Allshouse, Jankowski, Duong, MaWhinney, Kohrt & Campbell, 2011), and spirituality (Vance, Brennan, Enah, Smith, & Kaur, 2011; Viamonte, Cuevas, Perkins, Vance, & Ball, 2008). A review of the research leads one towards a conception that to live and age

with HIV in North America is now manageable, yet this view is not shared by all. Concerns are raised about a crisis and hidden epidemic which lies ahead for those living long with HIV (Cahill, 2011; Gough & Karapita).

This review of the literature revealed pieces of a complex and unfolding disease puzzle. In North America there has been a decrease in deaths due to AIDS, a decrease in the number of new cases reported, and a stabilizing of new infection rates. This good news is offset by new realities: an increase in the number and age of those living HIV+, as well as the number of individuals who are positive but undiagnosed. To add fuel to the fire, we are told of an increasing infection rate for adults aged 50 and older. The statistic that staggers: by 2015 in the USA it is expected that 50% of those with HIV/AIDS will be 50 years of age or older (Kirk & Goetz, 2009; Patel & Crane, 2011). To add to the complexity of this greying and now chronic disease epidemic are continually emerging findings about adverse changes and challenges to one's bodily health and well-being. The reality exposed in the literature informed and propelled my research into the experience of older adults who live each day with the illness of HIV.

Literature Review: Metaphors of HIV

Metaphors associated with HIV are of importance due to their powerful influence on how an individual tells of and lives their experience of illness. I put forth a view of metaphors as social constructions that have the ability to shape, constrain, expose, liberate, or illuminate how one actually *experiences* the disease itself and their own person. A man living HIV+, John, illustrates this by describing how he began "seeing himself as seen," taking on the stigma and stereotypes embedded in everyday life and language (Mooney, 2005, p. 73). Much has been written about metaphor, being one of

the four master tropes along with metonymy, synecdoche, and irony. This linguistic figure of speech has many layers. On the surface, metaphors make language interesting and are easy to use. I paraphrase from the Stanford Encyclopedia of Philosophy to expound further. A metaphor is understood as a technique of speech used when we talk about two things and we wish to substitute one for the other on the grounds of likeness or resemblance: “two different and disparate subject matters are mingled to rich and unpredictable effect.” One thing is already under discussion and a secondary subject is introduced to enrich the discussion. The two things compared are not alike in most ways but are similar in at least one important way. In this way metaphor suggests, likens, compares, or analogizes one subject to another. This likening is tenuous and of importance within illness experiences, as the most effective metaphors often compare two *unlike* things, and we soon come to speak of and think of the second thing *as if* it was the primary. What is unique is that linkages then made between the two subjects may capture only one aspect of the subject explicitly, while other aspects remain implicit or concealed and the listener must try to make sense or fill in the gaps. Complexity occurs as the ideas embedded in and conveyed through metaphor arise from our world and reflect beliefs and values; they create expectations, influence decisions, and epitomize a powerful way to increase understanding of things and processes (Geary, 2009). While metaphors are powerful in that they are often generative, playful, and can inspire and change the world for the good, they may also hurt, hinder, or mislead when they become too easy or taken for granted such that they blanket the particular and flatten the very idea that was to be conveyed. By stimulating thoughts and uniting two dissimilar things,

metaphors can enter ones' whole body and impact how we perceive the world and ourselves in it, in the present moment and into the next moment of our lives.

Much has been written about the role and influence of metaphor in disease and illness. Sontag's (1977) classic text brought attention to metaphors associated with the "master illnesses" cancer and TB. Her insight into the social constructions of cancer as a disease of the body and TB as a disease of the soul offered a stark portrayal of the power of metaphor to influence thinking and social behaviour in repressive and dislocating ways. She urged caution against thinking of illness metaphorically. Similarly, Lorde (1980) expressed through private journals her sadness and the painful experience of living with breast cancer and feeling the weight of social attitudes enter her being and reduce her sense of self to that of outsider and other. She generated questions and pushed conventional thinking with her critique of breast prostheses as a socially constructed and sanctioned metaphor for silence of women living with illness.

Frank (1995) later highlighted further metaphors used by fellow authors: illness as a gift, illness narratives as a shipwreck (Zaruches), and illness as a narrative wreck (Dworkin, 1993). Hyden and Brockmeier (2008) cite Ann Hawkins (1993) metaphors of battle, journey, rebirth, and healthy-mindedness, emphasizing that each comparison impacts on the illness treatment and trajectory of coping.

More specifically, attention to HIV/AIDS has also grown. In 1988, Sontag wrote *AIDS and its metaphors* to emphasize how illnesses are powerfully influenced by social constructions, initially highlighting the war and military metaphors associated with cancer. She later captured how metaphors of HIV/AIDS are equally laden with fear: AIDS as invasion, as pollution, as contamination and mutation, as punishment, as

retribution, a plague, a death sentence, and “hard death.” She also described how AIDS has been used politically: a metaphor for terrorism and international political evil. This concern is alive today, some twenty-five years later, as seen in the position taken by many countries including Canada to criminalize HIV. As outlined in the CANAC Position Statement on HIV Criminalization (2011), the crime is exposure without disclosure. Severe charges can be laid against people living with HIV/AIDS, such as assault, aggravated assault, sexual assault, aggravated sexual assault, common nuisance, criminal negligence causing bodily harm, murder, and attempted murder. Many believe this political stance raises complex public health and human rights concerns while further fueling stigma by portraying those persons with HIV as violent, criminal, and undesirable members of society. A key concern is that the legislation may undermine prevention efforts and further deter testing, as a positive HIV test is necessary for charges to be laid. A lobby by groups such as the CANAC and the Global Network of People living with HIV (GNP+, 2010) is underway to alter this legislation.

Other metaphors are equally influential and disturbing. In 2007 Hillmer found the metaphor “illness is warfare” used frequently in texts written to describe how the immune system works in HIV/AIDS, and believes this to be a spinoff of Lakoff and Johnson’s (1980) master metaphor “Treating-Illness-is-Fighting-a-War.” Hillmer concurs with Sontag that metaphors, especially those structuring illness in terms of war, are dangerous in that they lead to “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). Drakos (2008) explored HIV/AIDS as a broken narrative and as silence. Lather and Smithies (1997) cite the metaphor of those having

HIV/AIDs as lepers or demons, and Lather (1997) cites HIV/AIDS testing as “the commitment ceremony of the 90’s.” Lather also refers to Linda Singer’s (1993) metaphor of HIV/AIDS as “a world transforming moment.” Lather and Smithies use the metaphor of an angel to present in a popular literary style their findings about 25 American women living with HIV/AIDS. The angel acts as a messenger or bridge and also as a space to breathe in for the reader who is taken on a journey through heart-wrenching stories. Their intent: “to mobilize the familiar image of angels, but then to undercut it, trouble it” (p. 48), and in this way also trouble any easy sense of what living in the world with AIDS means and to force new ways to think about this. A woman living HIV+ for more than twenty years speaks of HIV this way: “the shadow of HIV began to darken my life” (P. Frank, 2011, p. 8). Mooney (2005) has referred to the AIDS discourse itself as an epidemic. My literature search also highlighted two studies that focus on older women as caregivers for persons who are HIV, with findings of facing and fighting stigma (Poindexter & Linsk, 1999; Poindexter, 2002 & 2005). A study by Gosselink and Myllykangas (2007) examined the leisure behaviors of women age 50 and older diagnosed with HIV/AIDS. They found inequalities of health and leisure resources for these women, and yet as the disease progressed each woman showed resilience in overcoming barriers and came to see leisure as a metaphor for the meaning of life. Jones (2002) studied the lived experience of nurses (ages 28-52) who live HIV+ and found a metaphor of a double-edged sword to represent the benefits and disadvantages of taking HIV medications. A year later she studied ten adults ages 35-58 taking HAART, and found the metaphor “a bitter pill to swallow” (Jones, 2003).

There is a small body of literature beginning to emerge related to aging with chronic life threatening illness. Hammond, Teucher, Duggleby, and Thomaset (2012) studied aging and cancer and found the metaphors of older men pointing to a negotiation between the two discourses of decline and progress, respectively. Further research regarding aging and metaphor was done by McCallum (2001) who found two “big” metaphors of aging, the simplistic and overarching depiction of aging as “sinful decay” and the contrasting representation of aging as “romantic.” Another study found metaphors of aging as resilience (Clark, Burbank, Greene, Owens, & Riebe, 2011). In 1991, Kenyon, Birren, and Schroots highlighted metaphors in aging, ranging from frailty and deterioration to a journey, fulfilment, and renewal. In their text the notion of time is reflected in the “clock shop” metaphor of aging, while the notion of mechanics is seen in the “human machine” metaphor. They put forth a call for new metaphors of aging that reflect the complexity in individual lives. This call resonates with renewed concern today for those aging with HIV; just as the reality of living with HIV in the western world has shifted from a deadly epidemic to a treatable chronic infection over a span of 30 years; it is likely that metaphors within stories of life experience have also changed over time.

Literature Review: Stigma, HIV, and Aging

My purview of literature related to aging with HIV and metaphors within HIV also brought to light the harsh reality of stigma. The linkage between HIV and stigma is strong and has been embedded in language over the history of the illness. What we do not yet fully understand is what metaphors arise as more people age with HIV, and how stigma may or may not be present within such metaphors. Another element at play may be aging itself, as ageism is prevalent in our youth oriented western culture that devalues

and distances us from aging and old bodies (Calasanti, 2005). Metaphors of aging as decay (McCallum, 2001) and illness reflect this pervasive view and add another layer of stigma and oppression. Might stigma perceived by a person aging with HIV be unique to HIV or a reflection of aging in general? My research is sensitive to this marrying influence of considering aging and HIV together.

Literature Review: Narratives and Illness

The stories I was interested in were those of persons living with illness, in this instance an adult aging with HIV: their story, their experience, their reality. It is often the case that those suffering with illness desire to reach out and start to talk and tell. Many unequivocally believe that “illness is a call for stories” (Frank, 1995; Sakalys, 2003) and that “bodies and experiences have to be *told into existence*” (Frank, 2009, p. 165). Bulow (2008) expresses that “illness has to be ‘storied’ to ‘exist’” and it must be storied convincingly as the very treatment you receive depends on it (p. 131). Hazel (2007) suggests we cannot function as a people without stories, as they play a part in memory from oral cultures of the past and for us today. Hyden and Brockmeier (2008) describe the study of illness and narrative as having evolved in the past three decades, citing researchers such as Mishler, Bury, Chase, Hyden, and Mattingly.

Physician and anthropologist Arthur Kleinman (1988) is considered one of the first to establish a meaning-centered paradigm with his perspective on “illness narratives.” He suggests illness has meaning and as such, illness narratives have the power to evoke shared experiences and compassion that can in turn teach all of humanity about suffering and death. Illness narratives “give shape” to the everyday experiences of those living with illness. For those living with illness, the stories they tell offer a glimpse

into their experiences of living life in this altered way. Most narrative researchers embrace the assumption that “the story is one if not the fundamental unit that accounts for human experience” (Clandinin, 2007, p. 4). I draw on the phrase “illness narrative” given that it is known and understood in academic and lay literature and offers a starting place to talk about how persons living with illness attempt through language to share their experiences. I use the term loosely with no intent to lock it down or limit the depth it represents, and rely on the term illness more as an adjective to describe the focus on the narrative. I also note that Kleinman uses “illness” to refer to how individuals live with the experience of symptoms and suffering, and “disease” as more biologically focused on a disorder. Frank (2002) uses the terms in a similar way: “illness begins where medicine leaves off” and “illness talk tells of the fear and the frustration of being inside a body that is breaking down” (p. 13). Like Kleinman, Frank sees disease as a medical categorization yet cautions against strict differentiations given that the experience of illness occurs in a diseased body. It is in this descriptive way that I marry the term illness with narrative and use the phrase illness narratives.

Literature Review: What Narratives of Illness Do for Us

Why would one choose to tell of their experience of living with an illness such as HIV? At a most literal level illness narratives are told to health professionals so help can be received, but at a more existential level, telling helps an individual to reconstruct their life story (Bulow, 2008). Researchers agree there is therapeutic value in telling one’s story, more specifically a reduction in stress (Smyth & Pennebaker, 1999) and reduced anxiety and increased coping (Rybarczyk & Bellg, 1997). Holloway and Freshwater (2007) provide an overview of studies in which telling about illness helped to decrease

pain. Riessman (2008) draws on the work of Bamberg and McCabe (1998) to extend functions of narrative as helping to “remember, argue, justify, persuade, engage, entertain, and even mislead an audience” be this an individual or a group aiming to mobilize or foster belonging (p. 8). Holloway and Freshwater (2007a) and Freshwater and Holloway (2010) put forth that vulnerable individuals tell of their experience as a way to legitimize their behaviour and share emotional aspects, all which shape their world and identity. Bury (1982) refers to how illness can change identity as “biographical disruption.” I add that illness narratives also offer a way to release some of the shame that may be part of their reality. Persons with illness are often in a process of deconstructing and reconstructing identity, and may ask if this self facing illness is my “real self” or am I still my old “normal” self. Mishler (2004) and Hazel (2007) also emphasize changing identity and how we create new thoughts and future identity through storytelling. Pennebaker (2000) suggests telling of one’s experience may be cathartic; she found that physical and mental health improved. Wengraf (2001) suggests that telling is a process of “self-preserving self-representation.” This brings to mind the use of stories in our larger world as means to generate understanding, compassion, healing, and redemption. One such example is the post apartheid Truth and Reconciliation Commission in South Africa that aimed to promote individual healing and reconciliation through stories of disclosure. While many believe this approach successful at the individual level, some contest the metaphor of national healing and highlight risks of misinterpretation and misappropriation when stories are taken out of their cultural context (Andrews, 2007; Graybill & Lanegran, 2004).

Charon (2006) and Riessman (2008) emphasize that stories are shared *for a reason*; stories are functional and have purpose. Motivations vary and it may be that we tell to shock, to inspire, to rouse, to upset. Whatever the reason associated with the telling, Ayres and Poirier (2003) write about the need for the narrator to have a sense of voice, and Epston et al. (1992) reference E. Bruner's (1986) belief that one must have confidence in their own authenticity through performing their story. Sakalys (2003) talks of therapeutic aspects of illness narratives: they increase self awareness and help restore personhood, as well as reclaim one's experience from the dominant medical metanarrative; and secondly they help attach persons to others given their invitational pull. In this way stories are connection. This view calls to mind contemporary philosopher and phenomenologist Levinas's perspective that we are called to acknowledge the other, the other coming before "I" in an ethical human response. Van Manen (1990) also speaks of the importance of acknowledging the other; meeting the other as they live life, be it in vulnerability, weakness, or innocence. I extend this to the idea that until someone or something receives our story, actively or passively, it isn't a story. That is, an audience or the notion that the story is "given to" is needed, however envisioned. Examples of passive telling might be telling your story to an unseen audience via a blog, a journal entry, a prayer, a face painted on a basketball, or to a gravestone. Active telling is when a receiver is present and seen.

The breadth of literature on what narratives do for us is collapsed by Frank (2009) into six benefits which seem simplified and yet hold a depth of complexity. These benefits include: stories add *shape and direction* to experiences, and help *restore coherence*; stories "offer *distance* from the immediacy of events, and with this distance

comes a degree of *choice* about the self one wants to be”; stories help with *expressing emotions* and to connect people; stories help one to “regain a sense of *personal agency and responsibility*”; stories help humans perform a moral duty to “*witness* the suffering of others”; and lastly stories help us to live with “the mystery of our bodies” during this time when it feels so much that language beyond the literal is needed (p. 162-167). What is conveyed is that telling one’s experience of illness can positively affect mental, spiritual, and emotional health. Frank (1995) does address choice of individuals within their experience and the stories they tell, emphasizing that choice occurs in a social context that constrains. Stigma would be one such example of constraint. He further emphasizes the role of the social and the self, suggesting that while a person attempts to give voice to their experience, “this voice is embodied in a specific person, but it is equally social, taking its speech from the postmodern time we live in” (p. 18).

While those in narrative research in nursing do not aim for narrative as psychotherapy, they do aim for narrative thinking, listening, and the potential of therapeutic care through illness narratives (Holloway & Freshwater, 2007; Sakalys, 2003). Sakalys draws on the work of J. Bruner (1990), White and Epston (1990), and Shapiro (1993) to describe narrative thinking as a way to think about, organize and frame experience. As differentiated from analytic thinking, narrative thinking emphasizes questions about lived experience, meaning, and expression. She suggests that while both ways of organizing experience are “truthful” one needs to determine the context and decide which form of thinking best serves each situation. Because of the tendency of medical environments to depersonalize and expropriate the illness experience, Sakalys suggests “becoming ill is a call for narrative thinking” (p. 230) and a way to counter this.

Another related benefit is that with narrative knowing, one does not look to find the universal and apply it to a situation, but rather to find the singular and meaningful.

Charon (2006) describes it this way: “narrative knowledge, by looking closely at individual human beings grappling with the conditions of life, attempts to illuminate the universals of the human condition by revealing the particular” (p. 9). It is paying attention to the person and the particular where narrative shines and helps on all levels.

Concern has also been raised that illness narratives are not always without harm, that benefits are also seasoned with trickster aspects (Frank, 2009, who draws on Hyde, 1998 and Radin, 1972). Four significant ways in which the understanding that we desire can be impeded relate to: the form of narrative that imposes the need for an antagonist in the story when there may not be one, or the one chosen may be exaggerated for effect (for example, death being the ultimate antagonist); the danger in choosing a genre for your illness story that others may find unacceptable (for example, a comedic or romantic genre when a drama prevails in illness narratives); the danger that the story can be hijacked or used in coercive ways by others and taken up in rhetoric; and a last danger of taking up stories as the only truth in a way that creates moral insularity (for example, a good death only looks like this). Others have raised additional ways that stories can work against a person. Atkinson and Silverman (1997) refer to a narrative taking on a “confessional mode” in which the teller may reveal more than they intended and thus feel even more vulnerable. Shields (2012, personal conversation) refers to repetitive trauma whereby a narrative is repeated so often it ceases to evolve and catches the teller in its solid web.

Methodology

I draw upon narrative inquiry as my aim is to glean understanding and insight from the stories of personal experience of older adults living with HIV. Key to narrative inquiry is the story, a powerful event for both the teller and the listener. I linger with the terms story and narrative as I wish to account for how these terms are often interpreted and how they are used in my research. I conclude this section with a description of narrative inquiry as the methodology.

Story and Narrative Overview

Narrative researchers have in common a belief that life experience is shared by way of a story or narrative, and most accept that “the story is one if not the fundamental unit that accounts for human experience” (Pinnegar & Daynes, 2007, p. 4). The idea of basic human expression as narrative is seen cross-culturally regardless of ethnicity, language, or culture (Chafe, 1980; Levi-Strauss, 1972). Researchers across many disciplines agree the story provides a frame for life experience; a way to organize and give pattern to life (Epston, White, & Murray, 1992). Riessman (2008), a narrative sociologist, has focused on the social influence upon stories and believes that through analysis we can “see how knowledge is constructed in the everyday world through an ordinary communicative act – storytelling” (p. 14). She also emphasizes that stories are functional, shared for a reason, and have purpose.

Most narrative scholars use the terms story and narrative interchangeably, yet they have distinct origins. The Merriam-Webster Dictionary (2014) defines narrative as “something that is narrated: story, account” or “the representation in art of an event or story.” Narrative is from the Latin *narrare* "to recount" and is related to the adjective

gnarus, "knowing" or "skilled." The term story is more ancient, dating to early 13th century, and is defined as "an account of incidents or events," or as a "fictional narrative shorter than a novel" with attention to intrigue or plot. Story derives from the Latin *storia* and *historia* "history, account, tale, story."

These definitions shed some light but offer no distinct clarity for use of the terms narrative and story within narrative inquiry, a reflection of continuing attempts to define meaning within narrative. Scholars studying narrative agree on the need to begin with a basic definition of narrative and story and yet there is diversity across disciplines. Riessman (2008) summarizes this as follows: social linguistics view narrative as a unit of discreet discourse with a distinction between narrative as a more general form and story as specific; anthropology and social history view narrative broadly and may refer to a full life story; and sociology views narrative as encompassing long sections of captured conversation often over a period of time, with terms narrative and story are often interchanged. Medical sociologist Arthur Frank (1995) uses *story* when "referring to the actual tales people tell" and *narrative* "when discussing the general structural types that comprise various stories" (p. 188). In 2009 Frank elaborated his understanding of narrative as "*a representation of events in which one thing happens in consequence of another*" (p. 162).

Even those who try to hold tight to definitions find that slippage between the terms can happen easily. More recently Frank (2010) shifted his position from believing we can define the terms to suggesting we aim for understanding. He puts forth the idea of story as "*material SEMIOTIC companions*" (p. 42) and distinguishes stories being about the particular and having capacities and elements, and a narrative being more of a

statement. Like Frank, medical sociologist Riessman (2008) originally held firm to a need to differentiate between a narrative and a story but shifted her view over time. In education, Piaget's theory of cognitive development influences how narratives are understood. For example, Piaget's work is drawn on by film and literary critic Seymour Chatman (1980) who emphasizes order and selection as key features of narrative, order being a logical flow or alphabetic progression, and selection referring to the idea that a narrative selects a piece of a greater whole and can never be "complete" but remains always a representation. Hazel (2007) defines narrative as "a *re-presentation* of reality from a particular perspective... reality reconfigured in order to create meaning" (p. 2). He describes expression through narrative as an *imaginative or creative* act that imposes order and design upon experience. He draws on Dijk (1980) who suggests new meaning is created that is "original thought, *invention*" (p. 7). Also from an education perspective, Clandinin and Connelly (1990) suggest narrative encompasses story: "Narrative refers to the making of meaning through personal experience by way of a process of reflection in which storytelling is a key element and in which metaphors and folk knowledge take their place" (p. 245). In psychology, Polkinghorne (1988) defines narrative as "the fundamental scheme for linking individual human actions and events into interrelated aspects of an understandable composite" (p. 13). He offers the singular of *narrative* as the form or process of telling stories, and the plural *narratives* to refer to the more personal and unique content and plots of an individual's stories. Within medicine, Charon (2006) emphasizes narratives, seeing them "as stories that have a teller, a listener, a time course, a plot, and a point" (p. 9). Within nursing, Parker and Wiltshire (2003) and Holloway and Freshwater (2007) view each term as distinct. The differentiation

most often leans toward narrative as the more semiotic and formal and story as more colloquial and ubiquitous. Ayers and Poirier (2003) differentiate by conceiving data gathered as stories, and narrative more in relation to the methods used to explore meaning.

My Early Definition of Story and Narrative

The above overview of how the terms narrative and story can be interpreted reflects the complexity of language and difficulty in defining meaning within the dynamic nature of narrative inquiry at this time. Many established narrative scholars seem to be shying away from earlier specialized language, accepting that no one simple definition is possible and opting to use narrative and story more fluidly. In this inquiry I draw on an emerging view of story and narrative that takes into account aspects of experience, the personal and social, while acknowledging an interplay between telling a story and a loop of influence back to the storyteller.

How I use the term story in this research reflects my current positioning on what I envision as a continuum of ideas as to how one might view what many consider to be foundational turns within narrative inquiry. Pinnegar and Daynes (2007) describe four turns: a turn towards conceptualising the relationship between the story teller and the researcher as relational, a turn towards words and embracing language as data, a turn towards the particular versus the generalizable, and lastly a turn towards acceptance of multiple ways of knowing. My perspective arises from these foundational turns within narrative inquiry, as they relate to my situatedness in the discipline of nursing, to form an expansive and eclectic coming together of many aspects.

A story is a representation of a person's attempt to describe an experience they have had by telling or recounting it. While in this research the story being considered is verbal, my definition of story recognizes that a story can take a variety of alternate artistic forms. A story is metaphoric in that it can only "represent" and act as a shadow, footprint, or glimpse into the original experience, as the nature of original experience is that it can never be fully conveyed to another, given our limitations of language. Even in the best attempt, a story can try to capture only a sliver of the whole of an experience; such is the complexity of experience itself. In this regard, when we ask a person for a story we must be aware that we are asking about only a part of their life. A story is a unique way to provide a frame or a container, that is, a means or tool to help shape or order what was experienced in a certain time and place, and it acts as a way to share what was experienced. A story is also about content, as it serves as an expression of what is told and what a person chooses to give voice to, to share with others. And a story is also about the telling, for example, who it is told to, when, and how, as a story is also told for a variety of reasons to suit whatever purpose the story teller intends. I believe this telling of an experience through story can provide a person with a way to see and know themselves differently. A story holds its power in being able to at least in part convey the experience and possibly generate meaning for the teller of the story and the audience alike; to bring the listener as close or closer to the experience without having experienced it themselves. Power also lies in believing that through stories we can access understanding that may generate compassion for one another and what each of us is experiencing.

Stories also engage and encourage listening, and in this way invite openness and humility. As a representation of experience, stories are complex and lead to questions about the person telling. In my view, the person with an experience that they wish to tell through story, in this instance an experience with illness, is situated in a broader circle of life that encompasses many experiences and factors which continually influence and inform each aspect of their story. The experience one has is personal and can be told as one's truth, but while an experience may seem purely individual, each of us is socialized such that the boundaries of where choice and influence enter become blurry. While some in narrative would argue that a line exists between the personal and social, I am not certain this is so, given how deeply the tentacles of interconnection pierce. We arrive in the world at birth and are instantly a part of and influenced by the greater whole around us, by our situatedness be it gender, culture, geography or a multitude of other factors. My view of experience rings of post modernism in that persons are seen as a relational subject and constituted by experiences as well as by language such as that found within metaphors. An exception to this I believe is rare, yet does happen in unique situations: when we look into the eyes of the other, that moment of human connection, and when we are in an experience so deeply that it is non cognitive and fully embodied.

I take up the perspective that stories are living and breathing (Frank, 2010), and like water, forever changing and ever complex. They mirror life itself in that they magically hold contradictions and irony, clarity and muddiness, truths and secrets, and an abundance of in-betweens. I have come to appreciate stories and narrative inquiry as a coming together of many seemingly paradoxical binaries and tensions, such as told/not told, part/whole, my story/your story, intention/unintentional, risk/no risk, regret/no

regret, choice/no choice, seeing self/seeing other, linear/nonlinear, constructed/deconstructed, and ontological assault/transcendence. Epston (1992) states that stories are indeterminate, ambiguous, uncertain, and inconsistent. And yet stories are one of the best ways we have as human beings to convey and shape our experience.

The term narrative in this research is connected to the term story and follows in relation to analysis. I define a narrative as that object which arises when a researcher, as a type of audience, hears and takes a person's living story and temporarily reifies it as an object to be analyzed and deconstructed in the interest of interpreting meaning. The narrative represents the person's told story which a researcher accesses for a unique purpose, in this instance in the spoken word, and then converted into a typed transcript or narrative.

The view I take in this inquiry of the terms story and narrative has evolved up to this time and no doubt will continue to do so. I trust this and for now accept the terms as laid out here to help guide and provide a frame for this work. They are also congruent with the narrative approach (Riessman, 2008) I am following.

Experience

The idea of illness narratives calls attention to a particular aspect of life experience, and it follows that a person cannot have an illness narrative without having experienced illness. In the human and social sciences it is generally recognized that it is not possible to have direct knowledge of the world; that we know our world through our experience of it. Illness is most often interpreted as the body being vulnerable and under threat. Illness often evokes feelings of uncertainty, betrayal by the body, and powerlessness as one seeks help from a medical system that often dehumanizes, labels,

and silences (Frank, 1995). Phenomenological approaches bring sensitivity and help us go underneath everyday, ordinary lived experience (van Manen, 1990), and stories provide the frame. The interrupting experience of an illness has been sharply language as a rupture of one's life story, as ship wreck (Frank, 1995), and as ontological assault (Sakalys, 2003). Mooney (2005) speaks about illness as being written on the body, about feelings of stigma and feeling not normal. Others extend this and write about the ill body under threat of being colonized (Gadow, 1995; Hoffman, 1992; Langellier, 2001).

Langellier tells of a woman who had her mastectomy scar tattooed over as a way to regain agency over her body. She writes: "The wounded storyteller narrates a story of the body through the body" (p. 146). Holloway and Freshwater (2007) talk in depth of the vulnerability of illness and the difficulty one may experience to even consider telling their story. An illness experience often reminds us of our bodies, this vessel we live in which we most often take for granted. With illness, suddenly the body becomes visible to us and unreliable (Gadow, 1988; Weingarten, 2001), a lived body versus an object body (Gadow, 1980). Donald (1998) reminds us of the language a person draws upon and the use of symbols to tell their story. It has been asserted that even though an individual may believe their story unique, each of us will bring to our story aspects of our culture by way of grand narratives that influence our world view. Gergen and Kaye (1992) are two of many who emphasize the individual and the story they tell as an active co-construction and recursive process between the person telling and the person listening.

The experience of illness is personal, as is the decision to tell or not tell of it. Telling of one's illness experience may not be so easy and is often not straightforward. A person may not have the language or be able to organize the experience. There is a

continuum of ease by the story teller, ranging from those who tell with a sense of rawness to the experience spoken of, in contrast to those who tell in an almost rehearsed or performative way; not from a place of vulnerability but a sense of empowerment and release. Such are the confounding ideas and emotions at play for the individual whom we ask to share what it is like to live with illness. While “to tell” can offer great benefit (Frank, 1995, 2010; Holloway & Freshwater, 2007; Josselson, 2011; Pennebaker, 2000), we cannot lose sight of the real possibility that for many, to tell their story may entail a degree of risk, danger, or regret as the reaction may not render the desired effect. Telling is where an illness narrative begins, in the narrating of and giving voice to experience, which in turn becomes a new experience in itself. I thus address characteristics of narrative, the process of narrating, and what it is that illness narratives can do.

Narrative Inquiry

Narrative inquiry (NI) is one way to interpret stories, as it foregrounds the narrative experience as storied. NI guides and informs without rigidity and prescription, and allows for breathing space and creativity to happen. I turn to the thoughtful narrative methodology of Riessman (2008) to guide this study and provide support to a novice narrative researcher. She acknowledges “realist, postmodern, and constructionist strands” (p. 13) within narrative study. Riessman’s work focuses on how life disruptions such as illness affect identity and how storying is a way to help restore agency for the person facing disruption. She approaches illness narratives as a form of case study. Such exemplars illustrate how knowledge for practice can be produced with careful application of diverse, detailed narrative methods. Riessman’s (1993) narrative inquiry draws on work by Mishler as well as Aristotle, Bakhtin, J. Bruner, Mattingly, and Charon to name

but a few. For structural and poetic features of language, she refers to Labov and Gee. Riessman (2002) favours the “long story”, the “discreet and extended account”, while acknowledging this creates a complex, interpretive challenge in determining beginnings and endings of narratives. She shares Mishler’s view of personal narratives as the stories we tell to ourselves, to each other, and to researchers; the not fixed stories that we continually re-story. She echoes C.W. Mill’s (1959) view of the study of personal narratives as a form of case-centered research: “the approach illuminates the intersection of biography, history, and society” (2002, p. 697). Extending from this is a belief that findings can be theorized from a case, but not across cases. Many studying narrative find clarity in her differentiating narrative inquiry from other qualitative approaches by this generation of coherent stories rather than fractured texts.

The process of interviewing is paramount in Riessman’s narrative inquiry and she admits to pushing boundaries in focusing so particularly on the interaction as a main data source. Like Mishler, she sees the interview as a narrative event that is relational and discursive, and aims to generate detailed accounts. Close examination through a dialogical analysis method helps to reveal social constructions of reality using language as a means to jointly create a reality. Riessman (2000) emphasizes narrative meanings can be ambiguous as they are shaped between the interaction of the interviewer and the context of the story. A dialogical method also attends to the metaphoric performative aspect within the interview. The teller of the story leads the way in a narrative retelling or reconstruction of life experiences. The belief is that how an individual has created and constituted their particular self may be uncovered through an interview that is recorded, transcribed, and analyzed. Power is shared in the interview process, with the teller and

interviewer playing active, influential roles. What the interviewer says and brings to the exchange is not negated. Similarly, the transcription process is considered to be complex, interpretive, and demanding of attention to aspects of language, structure, and culture of both the person interviewed and the researcher. This is a critical aspect as the transcript becomes a linear object; a representation of a complex verbal story. The transcript holds how the storyteller's self is captured or not, and can be technical or associated with gestures that point to a co-constructed "self" or a reflected "self." The attention a researcher pays to transcription is vital but Riessman cautions to resist the temptation to reify the transcript into "holy" (2008, p. 26).

Riessman's analysis of narratives emphasizes description, provisionality, and contingency. She calls for close attention to the sequencing of action, as well as the particular, intention, and language used. Her 1993 guidelines focused on five levels to be considered when writing, telling, and analyzing narratives: attending, telling, transcribing, analyzing, and reading. Believing narratives do not speak for themselves, she conceived a family of three rigorous methods for interpreting data: thematic, structural, and dialogic/performative. The addition of visual analysis was cutting edge in 2003 and remains an essential work in developing how images can be integrated with words to construct a story. Each type of analysis informs in different ways, for example, thematic and structural analysis illuminate the "what and how" of the story, whereas dialogic/performative analysis illuminates the "who, when, and why." Each is made more powerful when complimented with other methods of analysis. Regarding purposes narratives can serve, she discusses several functions: helping to remember the past (time and memory); to argue a position; to persuade, engage, mislead or entertain; and to

mobilize others into action. Each interplays with the social and political, and applies to individuals and groups. The role of the audience is considered a vital, active force in story telling given that identity is constructed and fragile; so easily influenced in this present era. This is where the aspect of performance becomes critical as Riessman believes identity is formed and constructed narratively; it is “crafted and performed” (2002). Also related to identity is the idea of “turningpoints” in stories, “moments when the narrator signifies a radical shift in the expected course of a life” (p. 705).

Riessman (2008) is one of the few in narrative inquiry who is explicit about drawing on Mikhail Bakhtin’s (1895-1975) philosophy of language. Bakhtin (1981) embraced ethical and aesthetic aspects of language, spoke of a sociological poetics (1928/1985), and believed in multiple truths or polyphony. One of his key writings, *The Dialogic Imagination*, highlights the idea that all literary works, all language, and indeed all words are not pure but are embedded with and carry past meanings and future imagined responses. He recognized the fragility of language and saw language as being always inadequate to capture the multiplicity of meanings. Bakhtin also believed language could not be considered in sections; we need to see it in its local orientation. Riessman follows Bakhtin’s lead in emphasizing intention and the idea that each person is an unfinalizable self (i.e. we are never fully realized or revealed). Bakhtin’s ideas about identity bear similarity to those of Levinas who was of the same time; the idea of other-I and that through the other we develop identity.

The idea that stories of living with illness hold meaning and the establishment of a meaning-centered paradigm with respect to illness narratives originates with the work of Kleinman (1988). In this view, the everyday experiences of those living with illness has

meaning and illness narratives “give shape” to and hold meaning that can teach all of humanity about suffering and death. This area of research has evolved significantly over the past three decades with the work of Mishler, Bury, Chase, Hyden, and Mattingly (Hyden & Brockmeier, 2008). Many unequivocally believe that “illness is a call for stories” (Frank, 1995; Sakalys, 2003) and that “bodies and experiences have to be *told into existence*” (Frank, 2009, p. 165). Bulow (2008) expresses that “illness has to be ‘storied’ to ‘exist’” and it must be storied convincingly as the very treatment you receive depends on it (p. 131). I alluded to the vast literature about illness narratives in earlier writings (Candidacy paper, Beuthin, 2012) with emphasis on aspects of the actual experience of illness, characteristics of illness narratives, the storying process itself, and what illness narratives can do for us.

Much has been written about how storytelling generates sense making and meaning (Josselson, 2011; Frank, 2010) and yet exactly how meaning making happens in narrative is not fully understood. Traditionally it is suggested that as life experience happens, we tell of it in the form of a story. Anthropologist Cheryl Mattingly (1998) challenges this, suggesting we are so influenced by our culture and grand stories that guide our lives that it is those stories that happen first, and then our experiences fit into them: “There is no reality without narrative. Because we have stories, we believe we are having experiences; experience is, at best, an enactment of pre-given stories” (p. 33). This view resonates with me in part, as we are born into a culture and immediately influenced by it, be it through language, ideas, beliefs and values. I struggle to make sense of how to hold this notion of being inscribed upon and having experiences that are unique to oneself.

Social Constructionism

One of the philosophical beliefs that underpins and informs my narrative inquiry is social constructionism. More broadly, my theoretical perspective arises from the human sciences and interpretivism. My focus here is on social constructionism and how this view influences what constitutes data and analysis. While construction can be interpreted in many ways, my understanding leans toward the clarity of Crotty (1998) who has drawn on the foundations of Merleau-Ponty, Heidegger, Brentano, Husserl, Adorno, Buck-Moss, and Sartre to illustrate key concepts within this view.

Constructionism is thus defined as

“all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, p. 42, original italics).

Within this view, the subjective and objective are brought together, and it is accepted that actual meaning of objects only emerges once we consciously engage with them. That is, we co-create and co-construct meaning. A key concept emphasized is that of intentionality, that is, being aware of something and consciously reaching towards it in an active and intimate relational way. Within this view of constructionism, it is held that the meaning of an object is contingent upon and emerges only when we interact with it. Furthermore, this interaction requires a researcher to have curiosity and imagination, and to approach an object “in a radical spirit of openness to its potential for new or richer meaning... an invitation to reinterpretation” (Crotty, p. 51). This view of social constructionism builds on the work of Berger and Luckmann (1967) and extends an understanding that “all meaningful reality, precisely as meaningful reality, is socially constructed” (Crotty, p. 55). It is not to say that our reality is not real, but to emphasize

that the social is so interwoven into the personal that is impossible to untangle them.

That is, our culture as a collective has a deep rooted hold on us and influences how we see objects, making the generation of meaning always social.

The connection between social construction and narrative is that any description rendered, such as a story, is not seen as a mirror or a straightforward representation of reality, but a complex representation containing the plural voices of many in our social culture. In this sense there is no true interpretation, but there are pragmatic, liberating, helpful, and rewarding interpretations. To extend this further, it is about the interplay of subject and object, with emphasis on the notion that the object itself has no meaning until an individual interacts with it. In this way it feels personal, as each of us can approach an object with openness and new potential for meaning. This begs the question as to whether there is such a thing as an individual story, to which I would respond yes and no. Yes, something happened to me that I recognize as experience, my experience, and it is personal and very real, but at the same time it is not, as I am situated in a larger influential context and therefore always linked to the broader whole. This view is helpful for entering the stories of adults aging with HIV, as these individuals face great uncertainty and are entering uncharted territory, all within a social context that highly influences how they construct meaning of this new everyday reality. We construct meaning and are constructed; we assimilate, accommodate, and we inscribe while we are likewise being assimilated, accommodated, and inscribed upon. The key aspects of social constructionism overlap and complement Riessman's (2008) approach to narrative inquiry in which she acknowledges a connection and mesh between personal and social stories.

The connection between and congruence of narrative inquiry and social constructionism is strong, as the premise is that the social is interwoven into the personal. From this perspective, a story is not a straightforward representation of reality. While the story is unique and true to the narrator, each story carries the weight of and bears the social influence of one's culture. In this sense, every story holds the threads of and represents a coming together of many diverse voices. This approach is critical to my research as it allows for and honors a focus on the individual and the particular, while taking into account the social influence of metaphors that influence beliefs, behaviours, and identity within storied experiences of living with HIV. Narrative inquiry and social constructionism will foster an in-depth look at life lived by those participants aging with HIV.

It seems important to note that the notion of constructionism is often used interchangeably with constructivism, as both focus on how knowledge is constructed and the interplay with reality. While not wishing to dwell intensively on distinguishing between the two "isms", distinctions have been made and are touched upon here. Within a constructionist view, knowing and reflexivity are seen to occur in a more outward, relational way with a focus on the influence of language and the creating and constructing of meaning that the world inscribes upon the individual (Crotty, 1998). In contrast, within constructivism knowing and reflexivity are seen to lean toward individual, internal cognitive processes and how an individual constructs their world (Gergen & Gergen, 1991).

Secondary Analysis

This study involved a secondary analysis design, meaning that data collected in another study was re-examined to explore dimensions previously unexamined with fresh questions not originally posed (Burns & Grove, 2009). While the use of existing data may shorten the time from research question to answer, the research process remains the same. This may serve to reassure concerns raised that this form of analysis may be “easier” than primary research or bypass the research process. This non-traditional approach is common with graduate students in nursing (Szabo & Strang, 1997) and beyond as it provides a unique opportunity to access existing large data sets and provides opportunities for them to be involved in and mentored in a research program, such as I have been since 2009 and continue to be with the Restorying Research Program at the University of Victoria School of Nursing (Sheilds et al. 2014). The aim of the original research was to explore the experiences of people living with life-threatening illness over-time (cancer, end stage renal disease, or HIV/AIDS). While secondary analysis is recognized as a sound approach, it is critical that the data set be clearly identified and that the research is seen to make a meaningful and distinct contribution to the literature (Aaronson, 1994, in Burns & Grove, p. 272). This holds true, as the Restory study did not address the experience of aging with HIV.

A secondary analysis approach has been well critiqued in the nursing literature, following initial attention beginning in the late 1980’s (McArt & McDougal, 1985). This then novel approach within nursing has since gained acceptance with recognition of advantages already alluded to, and nursing scholars continue to highlight potential beyond the obvious of new knowledge generation; benefits such as efficiency, cost

effectiveness, ability to strengthen collegiality among nurse researchers, and allowing for wider use of data from rare or inaccessible respondents (Hinds, Vogel & Clarke-Steffen, 1997, Sandelowski, 1997; Thorne, 1994, 1998). A further advantage for consideration is that a secondary analysis decreases respondent burden (Szabo & Strang, 1997).

Over time key practical and ethical concerns to be addressed when using a secondary approach have emerged and will be addressed (Clarke & Cossette, 2000; Hinds, Vogel & Clarke-Steffen, 1997; Szabo & Strang, 1997; Thorne, 1994, 1998). First, compatibility of the data with secondary analysis. The most critical factor is that the original study which generated the data be conceptually congruent with the new research (Magee, Lee, Giuliano, & Munro, 2006). I feel confident this is so, as the Restory project was a longitudinal narrative inquiry, drawing on methodology of Riessman (2008) and a constructivist philosophy (Clandinin & Connelly, 2000; Gergen, 2004). Interviews were in-depth and occurred over a 2 ½ year period. My research methodology similarly draws on Riessman's methodology. One difference is that my theoretical understanding evolved over time and is more rooted in social constructionism than constructivism. I do not believe this will create incongruence as both focus on how an individual makes sense of their world. A constructionist view focuses this research on the influence of the social and language as opposed to a more individual and cognitive process of sense making. Secondly, the position of the secondary analyst as a challenge to overcome relates to credibility and transferability of the reanalysis, especially when the researcher was not involved in the original data collection (Thorne, 1994). This is not so in this research, as in my unique role as a doctoral fellow I conducted a majority of the interviews that constitute the data to be analyzed, and was able to consult the primary

researchers. This touches on the thorny questions of where primary analysis stops and secondary analysis starts as well as the related professional issue about degree of overlap between the researchers respective works (Heaton, 1998). A third critical factor within secondary data analysis calls for a full reporting of the original study, with clear descriptions of recruitment, data collection procedures, and methodology. This has occurred. A fourth concern relates to ethics: a call for professional judgement to ensure that the consent given by participants in the original study will not be violated with the reuse of data. All aspects of this secondary analysis were approved by the University of Victoria Human Research Ethics Board. A final consideration with secondary analysis relates to how data will be referred to as well as accessing of data in the future.

Overview of Research Manuscripts

Four manuscripts were written that come together to form a whole in the form of a publication based dissertation that generates understanding and insight into living and aging with HIV. The overarching research question, “What might nurses learn from the stories, specifically metaphors, of older adults living and aging with HIV?” is based in narrative inquiry. Each manuscript focuses on a unique aspect of the inquiry and was written for an identified journal audience. A brief explanation of each follows.

In the first manuscript I focused on the interview experience from the perspective of the researcher, and addressed the question: “What is the experience of being a narrative interviewer in the context of engaging with and co-constructing stories from older adults with HIV?” Through sharing an autobiographical story of interviewing I present issues for consideration and invite readers to reflect upon the researcher’s role. I challenge the objective stance of nursing by considering boundaries and what distance

nurses should have in their relationships. Discussion focuses on how a researcher might come to understand and use six identified tensions within interviewing as catalysts that ignite clarity and help advance narrative interviewing. I came to see the interview as a way of being with another; two people coming together to shape, co-create, and co-construct a story through an intimate exchange. This article has been published in the *International Journal of Qualitative Methods*.

In the second manuscript I addressed the question: “what might metaphors reveal about aging with HIV?” People who are ill often use metaphors unknowingly and without awareness, and while metaphors shape and inform beliefs, hopes, behaviour, and identity, nurses may not listen for, hear, or understand their importance. Five older adults were interviewed on 5 occasions over 3 ½ years about their experiences of aging with HIV. All stories were analyzed for metaphors. Analysis of stories of older adults aging with HIV revealed binary-like metaphors as participants tried to make sense and live in-between held tensions of (un)certainty and hope, of facing death and living in the moment, and of hurt amidst joys of evolving identity. Metaphors revealed complex struggles, language imbued with social influences, and how we are inscribed by the context of our lives. A generated overarching metaphor across this group was shadows and sunshine. This manuscript, co-authored with two of the primary investigators of the original study, is in press with the *Canadian Journal of Nursing Research*.

The question addressed in the third manuscript is: “What are the experiences of living and aging with HIV?” In analyzing the co-constructed stories we found six dynamic storylines that enhance understanding and guide listening: embodiment of the illness, sense making, death and loss, secrets and stigma, identity, and seeking

connection. These storylines revealed how sense making happens in a fluid, shifting way for this group of participants, and how their ability to make sense affected how they are able to live and age better. This co-authored manuscript has been accepted with revisions by Qualitative Health Research.

In the final manuscript I focused on cultivating a narrative sensibility in nursing practice. I explored and critiqued how understanding generated from narrative inquiry and sensitivity can positively impact nursing. I addressed why inviting and hearing patients' stories of their experiences of illness is of importance from both a nursing and a patient perspective, how nurses might attend to understanding through stories, and the challenges and tensions of incorporating narrative into nursing practice as a counter discourse. The mnemonic STORIED was offered to help nurses weave together essential elements of a narrative practice approach. This manuscript has been published in the *Journal of Holistic Nursing*.

Summary

This introductory dissertation chapter set the framework I followed for conducting research focused on what might we learn from the stories and metaphors of older adults living and aging with HIV. A review of statistical data and current understandings of HIV in the western world at this time portrays a new emerging phenomenon of adults who are HIV+ living into older age. A tangled picture with many questions is beginning to emerge across the sciences as the normal process of aging now collides with the impact of the virus and treatment on a person's body over time. It seems somewhat oversimplistic and minimizing, possibly unjust, to reconceptualise the greying of HIV as normal aging or chronic illness and to stop there, given the impact of social factors and

complexity of living and aging with HIV. One cannot turn away from the harsh reality that often accompanies how HIV is experienced. Paying close attention to the stories of adults living this experience and to metaphors within stories will help reveal social influences such as stigma that creep into language and take up residency within stories. Description and elaboration of such storied experiences from a nursing perspective will extend understanding within and beyond nursing about HIV, metaphors, and narrative inquiry. While technologies and medicines facilitate and add miraculous possibility, we cannot forget about the need to listen to the stories of one another, as technology itself cannot take us there. I believe this narrative inquiry will offer possibility and help to balance other more dominant health care discourses. In-depth awareness, understanding, and consideration of the role of storying and metaphors within experiences of illness may help health care professionals be more responsive and supportive. Such awareness is one path to fostering sensitivity and compassion in the nurse patient relationship and across humanity. Imagine a world where individuals who are HIV+ are thought of with compassion, inclusion, and equality, where they are not thought of or made to feel like “other”. Most would agree that within health care we did poorly in many regards in the early days of the epidemic. Here now is a chance for us to do better, a second chance so to speak, by generating understanding that translates into treating those aging with HIV in a respectful and relational way. Those aging with HIV are living a miracle, creating a new path. I want to be part of a new understanding. “When we know better, we do better.”

Chapter 2. Breathing in the Mud: Tensions in Narrative

Interviewing

Beuthin, R. (2014). Breathing in the mud: Tensions in narrative interviewing. *International Journal of Qualitative Methods*, 13, 122-134.

Abstract

This article explores important questions around the often taken for granted approach to interviewing within narrative inquiry. When I applied an interview approach that emphasized the dialogical, performative, and social, tensions were provoked that muddied my assumptions and equilibrium. By sharing my story, I invite readers to reflect upon the researcher's role in interviewing. I address tensions that arose between a) presence and performance, b) equality and power, c) leading and following, d) insider and outsider, e) influence and neutrality, and f) trust and responsibility. I come to describe the craft of co-constructing stories with another as *breathing in the mud* - a dynamic process in which the researcher moves between the tensions of getting stuck in one moment and finding brilliant presence in the next. Discussion focuses on how a researcher might use tensions as catalysts that ignite clarity and advance how narrative interviewing is enacted.

Keywords: interviewing, narrative inquiry, Riessman, metaphor

The Story

The interview is today and I have to prepare. I feel a soft tightness arise in my breathing and gut, a tightness intermingled with butterflies, a heaviness and a lightness at the same time. I am aware of the time all morning, moving slowly. I kneel on my office floor, staring back at the papers that surround me like angel wings. The folder with the interview guide, now dotted with sticky notes that buoy my confidence and remind me of what I don't want to forget. There is the participant file, opened, and I thumb through the consent, the biographical sheet, other loose notes. I feel as if I am beginning to know this man a little bit, on paper. I then turn to the little pile of equipment on the floor, by my bookcase. I test the recorder. The battery light flashes to assure me I have power. I scoop it up, place it in a small green silk bag. I add spare batteries, the microphone attachment, the help booklet. A sigh. I get up off my knees, now stiff. I stand, gather and place my papers and equipment into my tote bag. Check the time. Good. I scribble the address on a sticky note and leave my office. I walk down the hall and stop, check my look in the mirror. Hair okay? Jewelry, maybe too much? My outfit? A nod to myself, it's okay. Finally I set off in my car, feeling a relief to be starting the process.

I find the participant's address, see the house. It is 2:30, I am early as planned. I park on a side street, not directly in view of the house. I turn the car off. Sit. Wait. I pull out my meditation, read it in slow silence. I close my eyes and invite a peace into my center. Time passes. At 3 sharp, I gather my bag and walk up the sidewalk to the house. The yard is neat, a small garden bed that has been tended to. I arrive at the front door, knock, and face the door with anticipation and some angst, a smile in my eyes.

As the door opens, I see the face of a human being, and our eyes meet. A tentative smile. I feel safe in that moment, no radar alarming. I introduce myself. He must also feel it is okay, as he welcomes me in. I offer a handshake. Humility easily covers me as I feel the weight of privilege, of being in this man's home, of being allowed to enter and to ask him of his experience of living with illness. I temper my genuine joy in being here to bear witness with the fact that I am here on a mission with clear deliverables. He asks if it matters where we might sit. I suggest the kitchen table if that is available. I want the intimacy of the chairs, what I imagine will be a comfortable space, with a table to write on, to set the recorder on. We walk through to the kitchen, and my eyes scan everywhere. I try not to be obvious, more subtle glances, and I cannot help but do this; I am hungry for a thousand details. I decline the offer of tea but accept a glass of water. We chat and settle in, linger for a bit. I pull out the recorder and hold it as an alien intruder that must be acknowledged. An awkwardness, the idle chit chat eases for a moment, we set up and test the equipment, review the consent. This is no ordinary conversation with a friend at the kitchen table. I feel a tension that interrupts genuine presence with the reality of knowing every word will be recorded. I become distracted momentarily. My eyes leave his face and shift to the equipment. I test it. Plead with imaginary techno gods that it works okay. I feel a pressure to capture the story, his story, our story, on the machine. The green light is on, it must be okay. What can I do now but trust, refocus, and begin to engage with the person before me.

To engage is easy and it is not. I offer a prompting statement, “can you tell me about.....” And he answers back. I try to listen and not over influence, to not lead. Do I nod? Do I smile? To be genuine, yes, but I am a researcher, so maybe not so much. I am interrupted by a flash thought about others on the research team who will later listen. I want to do well. Should I ask more, listen more, am I getting good material? Did I word that correctly? These thoughts bump about in my head. I am listening and observing, but at the same time am observed. I feel a bit breathless. My mind returns to listening. Looking at the man but also looking away, not wanting to over look or seem too intense. So much to consider and balance. A sense of muddiness. And then this all falls away and I am my unencumbered self, lost in the story, engrossed in the twists and turns, curious and amazed by what I hear. It feels like pure presence. In-between and back and forth, aware of the situation and then lost in it. He says something and I think it is perfect, this will make an excellent quote. I smile. Then suddenly I am aware of the time. Too long, long enough? An hour and a half has flown by. Is he tired? We pause, review, decide we are okay to end. And click off the recorder. It is as if a lightness enters the room. We are more natural, more casual and chat with the freedom of being off the record, just two people with no audience. We laugh, we talk about our everyday lives. I gather my self, my papers, my equipment. We say goodbye, and a hug at the front door feels right. I depart, walking away, sensing the magnitude of the exchange, sensing I am changed but not yet sure how.

I get to my car. I lean back into the seat, shut my eyes. Flooded with thoughts and emotions. I just sit, gather myself, take in the moment. But not for long. I am dying to check the recorder. I turn it on: is the story there? Yes? Yes! Thank you, thank you. The sound is clear. Oh my, relief. Okay, ground myself. I want to reflect on the interview and record this now, in the moment. It is my turn to record my story of hearing a story. And I do. I jot down a few notes to guide me, and then begin to talk into the recorder. It is about a 4 minute reflection. I ramble a bit as I speak and try to use sophisticated language, descriptions that suggest in-depth understanding and insight. I try to be objective as I describe the setting, the emotion, and flow of the interview. I talk too about my reactions to what was said and not said. Then I stop, it is done. Everything back safe and secure in my tote bag. And I drive off, vibrating with energy, still digesting what took place during the interview.

Introduction: Troubled Waters

My intent in pursuing narrative research in a doctoral program was to apply a fulsome methodology that emphasized interviewing and resonated with me as an experienced health care professional. I came upon and embraced Riessman’s (2008) case centered approach, with its emphasis on the dialogical, performative, and social. It seemed straightforward, and I naively believed my clinical experience and ease of conducting thousands of interviews would help smooth my transition to researcher. And

yet as my understanding of the complexity of narrative inquiry evolved and inherent assumptions were illuminated, it became unexpectedly troublesome to co-construct stories with persons living with life threatening illness. Tensions, questions, and angst arose during participant interviews that took me by surprise and sent me on a path of sense making.

This shift in awareness of what I attended to meant that interviewing changed and at times took on a heaviness as innocence was lost, replaced by a new felt seriousness, depth, and responsibility. I accepted the idea that threads of constructionism and performance are part of all stories, yet this clouded my aesthetic notions of mystery and romance with stories. A lens of constructionism led to a peeling back of what I saw and heard on the surface in order to glimpse at and expose influences at play. Tensions now arose where none had existed, for example, what I understood as presence was complicated by an understanding of performance. That such a heartfelt disruption of my way of being in the world, experiencing it, and knowing myself could transpire by taking up a research methodology with an intensity that came to feel like embodiment was not spoken of in the academy or the literature. Was I alone in experiencing tensions that seemed irreconcilable? It seemed natural for me to turn to storying, to voice and seek words to put upon my experience of interviewing. In essence, this storying served as a means to write into the darkness (van Manen, 2002).

By telling a composite story of my interview experience, I aimed to make explicit tensions amplified by my rigorous and passionate taking in of Riessman's (2008) narrative methodology. I did this through exhaustive self reflection, discernment, and analysis of my experiences and pre and post interview notes related to forty-four

interviews of adults living with life threatening illness over a three and a half year period. I present for consideration six inter-related tensions that a researcher may stumble upon: a) presence tempered by performance, b) equality by power, c) leading by following, d) insider by outsider, e) influence by neutrality, and f) trust tempered by responsibility. What follows is an exploration of this breathing in and through a metaphoric muddiness towards a more clear understanding of complexities often hidden within narrative interviewing. The metaphor is intended to evoke. It invites us to re-imagine and generate new insights and possibilities within the interview process; as such it contributes to critical questioning of taken for granted methodological practices within the ever evolving area of narrative research.

The Interview: Background

I begin this exploration of tensions in the interviewing experience with a brief foray into the interview itself, that foundational interaction within narrative research that is used as a means to seek and obtain a study participant's storied experience of a lived event. The interview as method is well established. Interviews are most often recorded in the moment, transcribed verbatim, and converted to a transcript that offers exactness and efficiency to data collection. While this interview approach makes sense for the most part and appeals to human sciences such as nursing (indeed it is not easy to conceive conducting an interview in any other way), the interview story presented here unearths tensions that can surface and yet are invisible within the transcript and more broadly within discussions about interviewing.

Understanding the interview is important as it is a powerful method and a critical component of narrative inquiry. Interviews are the medium through which data are

generated and form the foundation for all that ensues within a research study. The interview has changed over time from anthropological roots to that of hiring research assistants to conduct audio recorded and more recently video recorded interviews. And the interview continues to evolve, from being thought of as a straightforward method of data collection to more of what Gubrium, Holstein, Marvasti and McKinney (2012) describe as a dynamic interactional communicative opportunity. This reframing and questioning of the traditional interview method is in part related to changes in long standing ways of thinking, for example, a moving away from a quantitative-qualitative war to new spaces that welcome a proliferation of paradigms and multiple methods approaches to inquiry (Denzin & Lincoln, 2011; Chase, 2011). As well, the emergence of advancing technologies, beginning with the rise of miniature recording devices in the 1950's, has made it possible to record interviews with ease. In many ways this technique revolutionized qualitative research and became instilled as the standard approach we know today (Kvale, 1996; Riessman, 2008).

The recording of research interviews has become so accepted as to be taken for granted and an often unquestioned practice. We rarely pause to consider what price we pay for this technological gift of being able to transform an audio recording into a concrete data transcript. On the surface, there is a freedom and ease in being able to capture concisely the spoken story. The ability to record frees the researcher to focus on the interaction versus trying to rely on memory or to take copious, distracting notes. I expand on this momentarily but for now return to the interview story to suggest that the privilege afforded by recording stirs tension; the very presence of the device as part of the

interview acts to influence and introduces a performative aspect for the interviewer and participant.

Methodology: Narrative Interviewing

I delve past interviewing as method to its deeper situatedness within narrative inquiry. Here, narrative interviewing is understood as a dynamic approach used to generate stories as a data source, stories that help gain access to a participant's actual lived experience (Duffy, 2007). Within narrative inquiry, it is commonly accepted that lived experience is shared by way of a story or narrative (Sandelowski, 1991), and that this basic human expression is seen cross-culturally regardless of ethnicity, language, or culture (Chafe, 1980; Levi-Strauss, 1972). As a narrative researcher I understand stories as a way to share experiences with others, to give meaning and gain and build understanding, and to influence compassion toward others in our world (Engel, Zarconi, Pethtel & Missimi, 2008). Because we can never access the direct experience of another, we try to get as close as possible and rely on a story teller's retelling of their experience, as I did in interviews of adults living with life threatening illness. While some narrativists use the terms story and narrative with great specificity, most others including Riessman (2008) have adopted the contemporary practice of using the terms interchangeably, as I do for purposes of this discussion. A narrative researcher first comes to an understanding of what is meant by a story, then draws upon philosophical beliefs that underpin narrative inquiry and shape how the interviewing exchange will actually happen. And I suggest it is these assumptions that muddy interview waters.

Applying Riessman's Narrative Approach

"...knowledge is constructed in the everyday world through an ordinary communicative act – storytelling" (Riessman, 2008, p. 14).

My approach to narrative interviewing is informed and inspired by Riessman (2008). To situate research interviewing within a solid methodology adds complexity; it changes the lens with which the researcher sees the world and amplifies everything that transpires in the interview. You are changed. I thus expound on Riessman's "hybrid dialogic performance methodology" that emphasizes "how talk among speakers is interactively (dialogically) produced and performed as narrative" (p. 105). As such, narratives support the performance and construction of a person's identity. Riessman extends aforementioned tenets of qualitative interviewing to understand the narrative interview as a whole event, taking into account the informal pre and post-interview chatter and the formal recorded interview. Her approach is compatible with the use of open ended questioning, audio recording, and transcription of the interview. Face to face interviews are emphasized, as is the establishment of *trust* and *relationship*. The researcher is an *active participant* in the interview, ideally *engaged, genuinely present, and authentic*. The aim is to be *open and subjective*, and to see each story as *contingent* (a linking of ideas or events). The researcher does not interview "to get" the story, but rather enters into and explores the story with the participant such that they *co-construct* it together. It follows that each interview that comes into being is unique, as two people are engaged and responding to one another in the moment.

I expand on two beliefs critical that impact interviewing in the narrative approach of Riessman (2008) and her mentor (Mishler, 1986): *a dialogical process* and *social influences*. A view of the interview as dialogical means that narrative accounts are co-produced and what the interviewer says is as worthy of attention as that of the interviewee. The context is vital and shaped by the back and forth dialogue of two active

participants. The researcher aims to generate a detailed account. A second assumption is that narratives are social acts, a way for us to perform our identity and to use language in certain ways to achieve the telling we desire. The narrative interview is imagined as a discursive, collaborative exchange in which two individuals jointly construct the story and the meaning, and from which a hallmark, detailed account is generated. Within this dialogic and social act, Riessman acknowledges constructionist strands and emphasizes the role of influence from the social world; a belief that the story is “constructed by socially situated individuals from a perspective and for an audience” (2008, p. 23). This is compatible with a view of social constructionism, such as that defined by Crotty (1998). He suggests the meaning of an object, in this instance a story, is contingent upon and emerges only when we interact with it. Furthermore, this interaction requires a researcher to have curiosity and imagination, and to approach an object “in a radical spirit of openness to its potential for new or richer meaning. It is an invitation to reinterpretation” (Crotty, p. 51). Emphasis is on the social, the belief that the social is so interwoven into the personal that it is impossible to untangle them. That is, our culture as a collective has a deep rooted hold on us and influences how we see objects, making the generation of meaning always social. In this way social constructionism is also relativist, as our sense making is just that, a standpoint at a moment in time, an interpretation. The connection between social constructionism and narrative is that any description rendered, such as a story, is not seen as a mirror or a straightforward representation of reality, but a complex representation containing the plural voices of many.

I found that to take up a view of social constructionism within narrative inquiry influences how I perceive the narrative interview, and more critically, how I conduct it.

As a researcher, I do not find a story but become an active participant in a relational interview exchange. The participant and I co-construct stories in a dynamic moment in time. Said another way, an interview generated story is not just *about* an experience that happened to the participant but now becomes a new moment experienced unto itself.

Findings: Tensions Arising in the Lived Interview

I return to my initial story of preparing for and conducting a narrative interview as a way to illustrate how key beliefs that underpin Riessman's (2008) approach influenced me. In the story, I share hesitancy, questioning, and a back and forth uncertainty associated with awareness of these beliefs at play on and in the interview process. At times I somehow manage to find that magical, possibly transcendent third space (Doll, 2003) and place where all constructions fall away and pure presence happens. It is to experience what I will refer to as a Levinas-like moment of human connection with the person you are interviewing, a moment where a connection is felt and we exist in, know our self, and respond to the "other" beyond the physical, more towards the ethical and existential (Levinas, 1966). Writing and reflecting on the experience allowed me to enter deeply and lay bare actions and experience as lived. I could step away from the experience as if a stranger to it and critique the practice of interviewing anew. My story illuminated an undercurrent of tensions within the interview experience, a struggle and discernment of how to be whilst between tensions that took on a vivid energy. Through reflection and close attention, six dynamic and inter-related tensions came to light.

1. Presence Tempered by Performance

Riessman (2008) and others emphasize the importance of presence: emotional attentiveness, engagement, and listening. Remen (1996) speaks of listening generously,

of using silence, and of bearing witness; to be genuine and physically express this by leaning in, maintaining eye contact, nodding, smiling, or using a tone of empathy for example. Following a narrative methodology obligates one to interview with as much transparency, connection, authenticity, and compassion as possible, as the interview in and of itself is also an intervention and participants are often vulnerable. As the interviewer and participant interact and co-construct what evolves, both are changed. There is an ethic at play as well, what Gadow (1990) refers to as a “truth constituted anew” by the personal coming together to two individuals, subjective-subjective (p. 36).

And yet this ideal of presence may slip and become tempered by a desire to perform well. Riessman (2008) suggests all stories are performed and contingent, influenced by audiences hidden and present. As a researcher, the ego whispers to me to do well and contribute to the research team I am part of, who will later listen to the interaction. My presence at times seems to walk a faltering line between authentic genuineness and a metaphoric performance for this hidden audience. The recorder distracts me, alerts and emphasizes my desire for imagined perfection: to do it right, get the good story, and perform in a certain way. I assumed I could be subjective so easily, only to find it is not so. Tension is generated as I pretend the recorder is not there and yet face the reality of attending to its functioning. Pre and post interview, the unrecorded conversation happens in a more natural and less formal way, leading me to question if recording facilitates or flattens the story telling. Does it push us toward a focus on what is said over other expressive aspects such as emotion, the gaze of the eyes, facial expressions, the folding of the hands, and so on? I was surprised at my hidden resentment toward and personification of the recorder as intruder, capturing every word,

dominating, holding me captive to its magic: manipulating presence. It may be the recorder is a mixed blessing: it allows the researcher freedom but also acts to distract and influence what is being co-constructed.

2. Equality Tempered by Power

Riessman's (2008) methodology emphasizes the importance of reciprocity, equalizing power imbalances, and creating equality as much as possible through a sharing in the interview process. The teller and listener play active, influential roles. This ideal can create uncertainty in the moment as the interviewer delicately walks on personal and professional boundaries, whether imagined or actual, and makes in the moment decisions about just how open to be, how much information to share, and the depth of pursuing or not pursuing a curiosity that arises in the story. Do I open that door? There is tension in being there as a researcher to listen and at times wanting to console, offer clinical advice, or suggest advocacy, and discerning what is appropriate and when. How does one minimize the unseen cloak of power we wear that gains us access to the individual and his or her experience; power associated with having education, being a health care professional, in this instance a nurse, and in saying I am affiliated with a university research project. We have privilege and must continually question and examine how it presents itself and influences the interaction, the trust generated and depth revealed, and the story paths that are taken and equally as important not taken. Riessman suggests an interview ideally be extended to include observation, an ongoing relationship, and conversations over time with participants. This is not so easily achieved, and I wonder, for how long, how deep is the relationship and the conversation? Do I say "yes" to the requests for a photo of myself, to a friend request on Facebook, and to the offered gift

box of tea? Do I offer a birthday gift as I genuinely wish to do? Do I call a participant after discovering we have a mutual friend who has died? Do I act on my instinct to give a participant money to buy new clothes? Can one so easily turn off genuine engagement? I think not. My desire to stay in relationship after the interviews are complete is real, but how to do this ethically given the power imbalance? I will hold forever a shadow of “power over” given that I know intimate fragments of their illness experiences as revealed to me in the context of a confidential research exchange.

3. Leading Tempered by Following

A belief in this narrative methodology is that the teller of the story leads the way in a retelling or reconstruction of their lived experience. The interviewer, as an active participant in co-creating what transpires, aims to be dialogical: to follow all threads of the story as it unfolds, to be genuinely curious and to ask, engage, be spontaneous, and to give up control in the interview. This artful way of being requires finesse and a subtlety not so easily achieved. How do I balance spontaneous engagement responses with an intention to not interject such that I revert to a more traditional leading or overly influencing the conversation? This can be tension generating as in-the-moment thought process become laden with interruptive self editing and questioning: am I being too curious, asking too much, or not enough, and how cautious should I be as I do not want to inadvertently do harm by asking something too sensitive? This applies not only to dialogue but also to decisions about place, for example, deciding where to physically be or sit for the interview. Do I lead and suggest a preference such as at the kitchen table, a place where the everyday sharing of illness stories often happens literally and metaphorically (Remen, 1996; Berman, 1991) and which may be a comfortable, familial

place that will add intimacy and generate richer story detail, or do I pull away from any influence and follow their lead?

4. Insider Tempered by Outsider

As a nurse researcher conducting interviews I ponder my situatedness: I am both a knowing insider and a not knowing outsider. I know about chronicity and illness and have a sense of what persons living with illness may experience. I am an outsider in two ways: I do not personally have an illness or direct experience with participants' specific treatments, medications, or local supports, and I accept that I can only ever get close to but never actually know another's direct experience – I always rely on the teller's retelling. This not knowing affords me some naiveté and a genuine openness, concern, and ability to be surprised; it supports my ability to not lead so much as to follow. But do I miss key threads in the interview story that I might have focused on more in the moment if I was more of an insider? And yet knowing too much can create equally delicate moments, as in the instance when an older woman living with HIV tells me she has no health concerns. I know she has a five to eight times greater risk for developing cervical cancer (Robinson, 2013) and in a split second I make a decision of whether to introduce this knowledge or not, weighing the context and my role and the moment we have created together. Dancing inside my head as fast as I can.

5. Influence Tempered by Neutrality

As a narrative researcher I believe in a constituted self and the influence I bring to bear on the interview participant by my physical and social being: my body, race and gender, my education and life experience, and so on; what I represent to the interviewee based on embedded social understandings and how this influences their response. I am

aware of my look, how I act, and what I say. During an interview, I experience fleeting thoughts about the degree of my influence. I wonder how I influence through my smile, my appearance, my gazing upon and looking away. What influence is imparted by how close I sit, or by my touching a participant's arm as a gesture of kindness? And this is all important and profound, as narrative meanings are shaped between the interaction of the interviewer and the context of the story Riessman (2000). We change the person interviewed and ourselves, in ways we do not always understand at the time.

Yet I grapple with trying to influence as little as possible, pulled by a desire to not over-construct or over-shape. And this in-between space at times feels slippery, possibly unattainable within a view of social constructionism. Might my attempts at trying to neutralize influence lead to a lack of authenticity? Does my awareness and analytic deconstruction of influences at play pose a threat to the sacredness of a story being told? I am deeply aware that the story I leave with is very different from what another interviewer may have evoked. The interview exchange and experience are so unique and intimate, an unreplicable reflection of two persons in a moment in time. My awareness and over thinking of the role of social influences is so heightened at times as to feel unhelpful...gets me stuck. I falter in the mire.

6. Trust Tempered by Responsibility

The persons I interviewed volunteered; they wanted to tell their story of living with illness and trusted me as a researcher with this. Riessman (2008) highlights that storytellers want to be engaged, and that stories do important work: narratives are strategic, functional and purposeful, and allowing a meaning-making function to be set in motion. I believe this, that all sorrows and the weight of living with illness can be borne

if we tell them; that we tell stories to live. I hear this expressed by participants and know this to be true in my bones. It is this powerful combination of their trust and personal sharing by a vulnerable person that humbles me as I leave the interview. It swirls about with other emotions, one being undeniable relief that I now have data to work with. At one point I feel a pang of guilt that I may have come out further ahead; that I have “taken” something from the participant. And this might be true if not for the weight of responsibility that rushes in, that call to research work and the responsibility to now do justice with the new story we constructed. This inherent responsibility of a narrative researcher to illuminate meaning through analysis of the interview stirs tension. The participant trusts us to do this, and yet to do it well in light of knowing the depths of all that comes to influence and impact seems daunting to say the least. I concur with Riessman that a narrative does not speak for itself; that any narrative is so embedded with social influences and taken for grantedness that to be used for research purposes it will require close interpretation, continued analysis, and investigation. This knowing lands with a certain heaviness and lays bare so much as to bury any remaining naiveté I may have had about the interview. I come to experience interviewing anew, as a craft, with a criticality I had not known previously. I feel great responsibility and privilege to do this well, to pay full honor to the voice of the storyteller.

Sense Making

Complexity accompanies the narrative researcher and yet I also find the act of the interview to be a time and place of privilege. Narrative interviewing uniquely amplifies and shines a light on the story a person tells about their lived experience. To achieve this, the interviewer is called upon to have an awareness of their presence in relation to power,

leading, being an insider, being non-influential, and establishing a trustworthiness to receive the story. While these ways of being may seem familiar or assumed, they are complex in their own right. To layer upon this an interview practice that emphasizes dialogical, performative, and social constructionist threads (Riessman, 2008) is to add further complexity. An interviewer may feel an opening up and take on a heightened awareness of influences at play that do not simply cozy up but instead stir tensions. My story points to such angst and tensions that portray a messier reality of interviewing. The interviewer may have an initial experience of disruption and being caught in a muddy place between what appear to be linear and opposing dichotomies, for example, the notion of presence tempered with an understanding of performance and other influences. Imagine, I am interviewing Norm who is 55 and has been HIV positive for 13 years. Listening to his story, I have an acute awareness of social factors at play that contribute to his harsh reality of living with stigma and poverty. AND I also physically feel the human loneliness and pain that lie underneath this. I falter at times in interviews, wondering how best to engage, wondering which path to follow with reflections or questions, and what to foreground in the actual dynamic exchange. It is here that a researcher may feel discomfort or uncertainty, and indeed may slip if not fall. To action an in-depth and critical narrative approach may suddenly seem unhelpful to the interview process. I suggest the challenge and art of interviewing is to stand in this muddiness as it arises; to not resist but rather to be still, seek to name the swirl, and let the troubled waters slowly settle.

It takes courage for a researcher conducting narrative interviews to begin a process of sense making and enrichment, to pause and hold within themselves what may

feel like conflicting pulls. And yet I suggest insights and awareness are not only helpful but necessary. For myself, this process involved the naming and unpacking of the origin of tensions experienced. Once named, it was easier to see I was over-emphasizing and indeed embodying the power of the idea of social influences that was so markedly and continually shifting my understanding of presence and power and leading, being an insider, and trusting. Practicing a narrative approach that takes into account social influences makes the notion of co-construction come alive in a powerful and humbling way. I entered into what felt like deep dark waters and confronted existential questions: where does influence end and agency begin, and do we ever have experiences that are truly personal and created? Can an individual ever rise above the myriad of influences that are part of life? Can we change our story? Can an interviewer rise above the context and come to accept a constructionist view as one way to understand the world? Like soil and water combining, the dialogical and constructionism feel muddy at times and I find myself needing air, wanting to add a lightness to the mixture. And I do.

A way to gain clarity may be to not hold the constructionist threads within narrative so tightly such that they distort, disorientate, or dampen spirit and amazement. To keep in mind that social constructionism is a thread running through, not a blanket woven so tightly as to smother mystery. Immersion afforded me a way to mature with these ideas, such that after some time the light began to shift, and I came to arrive at a place of accepting the tensions without judgment or a need to choose. To shift from an “either/ or” place that limits to an “and” thought process that invites abundance. To accept that these tensions cannot be reconciled nor is it desirable that they are; to feel uncertainty and to let it be. To acknowledge any tension as a first step and then at some

point to trust, surrender, and let it fall away, to be genuinely present, in that moment, with the other. And come to envision construction as active, accepting that all is constructed and then setting it aside. And this is no easy feat, to hold a critical awareness of social influences at play and their impact on the life of a person I am interviewing and to not feel the weight of our collective human condition. Yes, a sense of despair threatens to creep in when I consider social influences that are so complex and not easily addressed, feeling somewhat powerless, and knowing in my being that we, the greater we, must and can do better. But I keep this cognitive way of knowing in balance by returning to the equally powerful human connection felt in the moment. To experience this, to have a sense that we are all one, is to feel a deep compassion that renews hope in the spirit. We can rise above social influences, be it the story of Victor Frankl or the extraordinary courage lived every day that I hear in interviews with persons living with life threatening illness. I came to hold this awareness of social influences as important as a means to get underneath and find meaning, while not losing sight of the person who trusted and shared their story.

In light of this discussion, how might we go forward? I began this article sharing how assumptions underpinning a narrative interviewing approach may initially prove to be troublesome. While I questioned at times whether tensions stirred were valuable, I now respond with a resounding “yes”...with temperateness and sensitivity. Such tensions may be vital to narrative researchers as they add complexity and intensity, an amplification to be sure, and also act as catalysts to keep the interview process dynamic. Tensions keep the interviewer alert in that they call us to pause, to continually question and tease apart, to rethink or gain new insight; to possibly generate a new narrative turn.

These tensions call us to keep pushing toward a new synthesis of constructionist influences and creativity within narrative interviewing. Can we re-imagine the interview? Gubrium et al. (2012) call for a transformation to narrative interviewing, suggesting how we currently understand subjectivity of the participant has been oversimplified. They imagine a more interactional sensitivity and artful collaboration between interviewer and participant. Hendry (2007) also suggests a radical deconstructing of the interview, a shifting away from obtaining a recorded representation of the story to seeing the interview as a faith act based on deep listening that extends to hearkening and heeding what is said with humility and faithfulness. Also taking us into the future is Rachel Naomi Remen. Through The Healer's Art course designed for health care professionals, she calls us to listen generously and consider our narrative encounters as an act of service. Gadow (1995) also reminds us about being of service and the importance of intersubjectivity and contingency within narrative as that way through which we "offer one another our experience" (p. 213).

Does this discussion contribute to narrative research? Yes, as more researchers take up aspects of narrative inquiry, we have an opportunity to not take it up blindly but to continually question and improve; to be accountable and to value various ways of knowing. Ultimately, we engage with the person before us to listen to their story of how illness or some event impacts their life. Such an interaction, often occurring through an interview, is a human art form and not a mere set of natural and spontaneous techniques to be applied. It is a way of breathing in narrative wholly that requires attention and intention, to self and other. Whatever the future of how we go about generating a story, this has relevance across all practice domains as we all interact with others and listen to

stories of experience. We can always gain insight into how we listen and hear the other, and how we with others co-constructs our realities. As expressed eloquently by nurse philosopher Gadwo (1995):

“If we believe that patients’ lives depend on us but not ours on them, dualism has triumphed. But if nursing is a world where we live, rather than a service we offer, then they and we together constitute it, inhabit it, each depending upon the other to share local knowledge about where safe passage may be found” (p. 212).

Conclusions

Taking up a narrative interview approach does not happen so easily, as tensions may arise between presence and performance, equality and power, leading and following, being an insider and outsider, influence and neutrality, and the tension between trust and responsibility. I do not suggest these tensions are good or bad, but rather potentialities to be aware of as they act to make the interview experience more alive. Therein lays the beauty, as by attempting to untangle tension in the interview process we may arrive at a new place, one of co-constructing and creating, where we are aware of and name social influences and then feel free to hold them to the side. We may feel more confident as interviewers to slip into the rich in-between place where any sense of pulling dichotomies falls away. We may at times stumble, and when this happens it may be the best way forward is to not resist but instead breathe deeply and let moments of troubled presence awaken us such that we re-imagine the interview process and generate new possibilities.

Chapter 3. Shadows and Sunshine: What Metaphors Reveal about Aging with HIV

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Abstract

Using narrative inquiry, 5 older adults were interviewed on 5 occasions over 3 ½ years about their experiences of aging with HIV. All stories were analyzed for metaphors. Individual metaphors reveal a complex, unique struggle; it is to live in-between tensions of uncertainty and hope, of facing death and living in the moment, and of hurt amidst joys of evolving identity. The tensions are fluid, although time and life experience help 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. These findings suggest that when nurses invite stories of life experience and listen with intention for language used, they build compassion and gain understanding of what support is most needed to honor the personhood of HIV positive older adults.

Keywords: metaphors, HIV, aging, narrative inquiry

Context

Human Immunodeficiency Virus (HIV) and HIV associated disease have now been known for three decades and in that time many advances in care and treatment have occurred. 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+ on older populations is gaining new attention from researchers, public health organizations, and clinicians worldwide. This is in stark contrast to only 10 years ago when such older adults were considered to be an “overlooked” and “forgotten population” within this infection group (Whipple & Scura, 1996). “Older adult” has been defined as age 50 plus by the *Centers for Disease Control and Prevention: AIDS* (Kirk and Goetz, 2009). By 2015 approximately half of adults with HIV in the USA will be 50 years and older (Kirk & Goetz, 2009; Patel & Crane, 2011). The increasing prevalence of persons 50-59 with HIV infection is expected to grow: those with HIV are experiencing longevity, and the number of new HIV infections over the age of 50 is increasing (CDC, 2008). These numbers have led to a shift in conceiving a diagnosis of HIV as imminently life threatening to an emerging conception of HIV as a chronic but manageable disease (Montaner, 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 to age with HIV is not predictable nor without challenges. 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 increased, persons living with HIV/AIDS have increasingly complex

needs as the immune compromise and associated stigma and discrimination may affect emotional and physical health, quality of life, finances, and independence (PHAC, 2007). More specifically, Eisenberger, Jarcho, Lieberman and Naliboff (2006) found that individuals who experienced social rejection reported more social distress and also higher ratings of physical pain. While HAART helps reduce viral load, these medications can produce hypertension, dyslipidemia, and insulin resistance (Heath et al., 2001) and foster cognitive decline (Vance & Burrage, 2006). There is also 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 trend in the USA in the HAART era of co-concurrence of HIV and cancer. Unique for the older adult with HIV is that in addition to bodily changes resulting from the infection and medication are the layered aspects of the normal processes of aging. For this reason, the “Greying of AIDS” (Gough & Karapita, 2011) or the “Greying Epidemic” (Berry, 2009) is a new crisis. The day to day experiences, realities, and challenges of affected individuals remain largely misunderstood or invisible, and for this reason their stories are important. To story is to language and give voice to, and when a person gives voice there is the 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 linguistic figure of speech known as a 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, metaphors are created when “two different and disparate subject matters are mingled to rich and unpredictable effect” (Stanford Encyclopedia of Philosophy). An example is found in Shakespeare’s *Romeo and Juliette* (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 metaphor arise from our world and reflect beliefs and values; they create expectations, influence decisions, and epitomize 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 a sort of symbolic shorthand and a way to *not* say precisely what we mean. The way a metaphor likens or analogizes one subject to another is of importance 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 second thing *as if* it was the primary. For example, we may initially think of disease or a virus as the enemy (Lakoff & Johnson, 1994) and then come to think of and treat a person living with a particular virus in the same way. Caution is required as linkages made between two subjects reveal one aspect of the subject explicitly, while other aspects remain implicit or concealed and the listener must try to make sense or fill in the gaps. Precisely because they are so powerful, metaphors may hurt, hinder, or mislead when taken for granted such that they blanket the particular and flatten the very idea to be conveyed.

Metaphors can also be generative, playful, and inspire change in the world 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 arising 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 into the next moment of our lives. Many authors describe the magic that can happen when two unlike objects are likened. Baldick (1990) emphasizes the new combination of ideas to create more powerful understandings, Geary (2009) talks about the element of “combinatory play,” and Janesick (1994) speaks of how metaphor defamiliarizes the familiar as it “creeps up on you and surprises” (p. 209). Patton (1990) talks about metaphor as 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 pushes current thinking by suggesting 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) emphasize the important role of metaphor across nursing. Malinski (2009) echoes the transformative potential with the sentiment: “change your metaphor of the world, change your worldview” (p. 310).

The intricate relationship between metaphor and illness was exposed in Sontag’s classic *Illness as Metaphor* (1978). She described how metaphors of cancer and TB can

adversely ostracize, objectify, and create an us/them mentality. Her critique was later expanded to metaphors of AIDS (1989) as will be discussed shortly. Yet because language is inherently metaphorical, 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 ensure that representations conveyed do not slip into assumptions of knowing an individual or what it is they are experiencing. For the teller of the narrative, the language used reveals but they also may learn for themselves who they are, even when they may be unsure. We draw on the words of Jan Zwicky (2003) to emphasize 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 academic literature and are seen as influential and disturbing. Sontag (1989) described metaphors of HIV/AIDS as invasion, as pollution, as contamination and mutation, as punishment, as retribution, a plague, a death sentence, and hard death. She described how AIDS has been used politically: a metaphor

for terrorism and international political evil. Her concerns resonate some twenty-five years later, as many countries today are opting for a criminal element within 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 as violent criminals reinforces stigma, fosters a view of persons with HIV as bad, undesirable members of society, and raises complex public health and human rights concerns (CANAC, 2011).

Hillmer (2007) found the metaphor “illness is warfare” used frequently in texts written to describe how the immune system works in HIV/AIDS. Hillmer concurs with Sontag 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 & Smithies (1997) cite a metaphor used for those with HIV/AIDS as lepers or demons. Mooney (2005) referred 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 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 nurses (ages 28-52) who live HIV+ and found a metaphor of a double-edged sword to represent the benefits and disadvantages of taking HIV medications. A year later she studied ten adults ages 35-58 taking HAART, and found the metaphor “a bitter pill to swallow” (Jones, 2003).

Metaphors of HIV, whether harmful or helpful, impact how an individual tells and lives their illness experience. The metaphors alluded to convey how the illness of HIV is influenced and socially constructed by fear and a lack of knowledge. A predominant focus on HIV illness through a lens of warfare emphasizes only the aggressive aspects of the disease and generates fear, while lesser understood aspects remain hidden. Metaphors that instill fear can lead to discriminatory behaviours towards others. Vance, Brennan, Enah, Smith and Kaur (2011) found that adults aging with HIV face adversity and stigma. This population also faces depression (Jang, Anderson, & Mentes, 2011), social withdrawal (Vance & Burrage, 2006), and a need to negotiate secrecy. This is of concern, as findings in a study by Lourdes et al. (2008) suggest that while the prevalence of HIV in older adults is increasing, sexually active older adults with HIV may be engaging in high risk transmission behaviours 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 metaphor. 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), and as frailty and deterioration to a journey, fulfilment, and renewal (Kenyon, Birren, and 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 in the past has revealed an even greater link to stigma for those with HIV. For

adults who are HIV and aging, we do not fully understand what metaphors arise, how stigma may or may not present, or whether stigma is more unique to HIV or a reflection of aging in general.

Aging with HIV is a new area of concern and nurses are being called upon to support and care for greater numbers of positive older adults in this new millennium. As we gain more understanding of the experience as lived, we will be better able to provide meaningful and quality care. This timely research addresses the following questions: how are metaphors of aging with HIV experienced, what do these metaphors reveal, and 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 narratives of individuals who often live at the margins and are not heard, generating insight and understanding into the experience, 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 relates to meaning making, the belief that stories hold meaning (Kleinman, 1988) and that storytelling generates sense making and identity (Riessman). Josselson (2011) refers to stories as “the core meaning-making systems of real people” (p. 33). A second emphasis was on close study of the ‘particular’ within individual stories as a means to illuminate universals in human experience (Riessman; Charon,

2006). As alluded to, the third underpinning concept was social constructionism, the belief that the teller and listener of a story influence one another such that meaning is co-created and co-constructed between them (Crotty, 1998). Stories and the language within are seen as a complex representation containing plural voices of one's social and cultural environment. This powerful interplay between individual meaning making and the social world influences, shapes, and constructs how individuals makes sense of everyday experience. The fourth inter-related 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, raw data from the generated participant stories was then synthesized to capture aspects of the experience in their own words.

Sample: This study involved five Caucasian, urban participants: 3 males and 2 females. Participants were age 50 or older and living HIV+ for at least 10 years. Two of the individuals had been diagnosed with AIDS in the past. At the time of the final interview, participants were age 55 to 62 years (average 58.2 years). Number of years since diagnosis ranged from 13 to 24 years (average 17.6 years). The participants were part of a purposeful convenience sample of 32 adults recruited for a broader study focusing on narratives of life-threatening illness. Each of the five consented to have their data used for secondary analysis and to participate in an additional interview focused on aging. This allowed for a 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 interview approach was used to interview participants five times over a three ½ year period, except one male who chose to be

interviewed three times over the same period. Each face to face interview was conducted primarily by two nurses in research assistant roles who started with the opening question: “tell me about your experience of living with HIV.” They also 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 conversation-like exchange that was relational and discursive, and intended to generate detailed accounts (Riessman, 2008). The first interview focused on building rapport and inviting their story of living with illness in whatever way that unfolded for them. In the second and third interviews we confirmed what was heard previously, asked exploratory questions to understand in further depth, and asked about new developments. The fourth interview offered a chance to reflect on the interviews to date. The final interviews, all conducted by the first author, focused on the experience of living past 50 years of age with HIV. Each interview varied in length from 1 ½ to 3 hours and was audio recorded. The generated narratives were transcribed verbatim to create 23 written transcripts. Immediately following each interview, the interviewer audio recorded spontaneous reflections 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 analysis process by illuminating context and affording our research team a way to reflexively exam our own assumptions.

Analysis: We followed a case-centered approach to narrative inquiry that emphasizes individual agency, particularities, and context (Riessman, 2008). Case is understood as an individual’s narrative that, once transcribed, forms the unit for analysis. This approach

entailed close analysis of each individual's narrative to identify metaphors embedded within stories. Metaphors were not always clearly evident, and as researchers we read closely and repeatedly within the set of transcripts per participant. As primary researcher (lead author) I identified metaphors used by participants in individual interviews, then synthesized them into a short descriptive narrative. All the while I conferred with the other researchers to further validate found metaphors. We returned to the transcripts and field notes repeatedly as a way to continually inform this iterative consolidation process. As a research team we then shifted analysis to the set of transcripts across the whole of the participant group and generated an overarching metaphor of "sunshine and shadows." Analysis involved staying true to Riessman's narrative inquiry by offering a balance between description and interpretation.

Findings

The narratives were rich in metaphors as participants drew upon analogies as a way to express self and describe the reality of their experience across many areas of their life, from diagnosis and treatment to experiences of death and loss, depression, secret keeping, altered identity, and adapting to the life journey itself. We pieced together the metaphors used by each participant into a small representative story as a means to illustrate findings. The dense metaphors within each small story also help illuminate the many aspects of what it is like to age with HIV. Given that metaphors often slip into language undetected, we invite you 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 a connection or impact understanding for you.

Aging with HIV: A candle flame dancing to the music of life. (Nancy, age 58, artist, + 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 back pack 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 only disclose I am positive when I'm in a group or with a witness. To be age 58 with HIV is a lonely place; I am 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, a volunteer, + 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 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 the 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 cakes. (Leonard, age 62, retired, + 18 years)

Diagnosis: two 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 act, of self strength and wisdom, of getting rid of material things. It is to age gracefully, to be privileged, eccentric, to no longer mold 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 book ends 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 roller coaster ride with face into the wind. (Rick, age 56, office worker, + 13 years)

Memories of the 1980's 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, 5 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 am on my 4th cocktail and talk of the 5th 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 veneers, no more secrets; I come out of the HIV closet to everyone. There is 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 neighborhood. I live the lesson that we are all part of one community, part of the mix. For me now, it is 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 am dancing as fast as I can at times, still facing a black well of depression at times, like being on a roller coaster, rocketing around; so many layers to the onion. Post traumatic stress is ever present, yet I am a survivor, I put

one foot in front of the next. 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, a gardener, + 13 years)

My experience of aging with HIV is medications: a double barreled 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 is in 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 is 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 is uncertainty about the future, the future does not exist. I live in the moment, in the present, on a different plane than friends. I am 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 am 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 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 am 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 is not my time. I am older and I am 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 metaphors as a device to help them language the experience of their complicated lives, and to language or give voice to can help one to make sense and gain understanding (Johnson & Lakoff, 1980). Associations made through metaphors were subtle at times and not so subtle other times. Some metaphors held the capacity to support living well, while others remained as stark reminders of associations made through metaphor that can and continue to 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 actually experiences a disease itself and their own person. In this research, metaphors within stories of older adults aging with HIV illuminate how having added time and life experience impact day to day living.

Participants' metaphors reveal the experience of aging with HIV to be one of living in-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 has afforded a shift in the tensions and an evolution over time towards sense

making and reconciliation as they, as older adults, now draw upon rich life experiences and adapt as best they can to living in in-between 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, a back and forth yo-yo between a secret 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 eating tea cakes; a wild roller coaster ride with twists, turns and fear but also joy and feeling the freedom of fresh air upon an unmasked face; and a lab mouse, trapped, going on and off meds, feeling unwell and dizzy and yet not able to find firm ground.

The metaphors reveal that to get older with HIV is to live with struggle in the inescapable shadow of disease. The availability of HAART treatment, extended years, and the move to consider HIV a chronic disease have not erased real and raw hurt, fear, secrets, and the need to gauge truth telling that stigma continues to generate. 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 seen (Mooney, 2005), as tattooed, untouchable, or having the dirty disease and so on. Some have developed coping strategies over time such as taking a mask off, telling all they meet, and being proud to be a face of HIV. Tension lays in living in-between the desire to be free of secrets and live with honesty while living with underlying uncertainty as to one's safety in 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 that is tempered with tension and uncertainty, wanting to take the drugs to live yet knowing they 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. 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 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 sense of community, this being more 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, and 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 researchers, we also engaged 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 the simultaneous holding of tensions within experiences. The representation of shadows raises questions about the role of language in the construction of stigma. Aging survivors of HIV in a western social context feel the cool, dark shadow of what we will name omnipresent 'S' factors: harsh and harmful 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, spiraling, 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 a 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 illustrate that metaphors can help us understand the tenuous experience of another.

Nursing Implications

An awareness of metaphors and how they act in stories has the potential to enhance 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 it, possibly to be humbled and get closer to understanding another's life experience which we can never truly know. The implications of insights and understanding that nurses can glean from listening for and inquiring about metaphors embedded in stories of older adults aging with HIV are far reaching. Understanding of an individual's unique reality invites sensitivity and compassion into one's nursing approach, which in turn supports a tailoring of care and service that is timely, effective, and person centered. Nurses are called to cultivate curiosity and intention and to actively invite stories of 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 for language that helps to reveal; in essence, to bear witness. To ask about a metaphor that arises in conversation and check out interpretations with the individual may uncover further meaning, self understanding, or challenges of aging with HIV such as stigma that metaphors help express. Once communicated, these can then be addressed as appropriate. It is important that nurses take into account the role of stigma given that it may adversely affect health (PHAC, 2007), social ease and ratings of pain (Eisenberger, Jarcho, Lieberman and Naliboff, 2006). The presence of stigma makes aging with HIV

different from aging with other chronic conditions that do not carry the same negative associations. Nurses must also pay attention to metaphors they themselves may be using and be aware of how certain words may serve to silence or adversely influence the person before them. This aesthetic way of knowing that illuminates the art of nursing and perceptual sensibilities (Boykin, Parker, & Schoenhofer, 1994) offers a way into conversations that builds insight and illuminates challenges, beliefs, hopes, fears and sense of identity that may not be easily expressed but are part of living and aging with HIV each day. Informed understanding leads the way for nurses to feel confident and to provide genuine presence and support that encourages 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 in-between a myriad of 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 balance and a reconciled sense of identity and belonging, although this is ever tenuous, variable, and unique for each person. When nurses listen for and understand metaphors embedded in stories, they can more fully support older adults to face shadows and to let in the light.

Chapter 4. Storylines of Aging with HIV: Shifts Toward Sense Making

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Abstract

Aging with HIV is a new phenomenon. It is expected that by 2015, approximately half of adults living with HIV in the United States will be 50 and older. We used narrative inquiry to explore how older adults with HIV story their experience and make sense of aging. Over a 3½ year period, we interviewed five older adults living with HIV for 13 to 24 years. In analyzing the co-constructed stories, we identify six storylines that enhance understanding and guide listening: embodiment of the illness, sense making, death and loss, secrets and stigma, identity, and seeking connection. We theorize that the degree to which one reconciles each storyline influences how well one lives with illness. We share a storied exemplar to illustrate these storylines in one participant's experience of aging with HIV. These findings emphasize how vital is telling one's illness story, as sense making happens in the telling.

Keywords: aging; death and dying; HIV/AIDS; narrative inquiry; social constructionism; stigma; stories

By 2015, approximately half of adults with *human immunodeficiency virus* (HIV) in the United States will be 50 and older (Kirk & Goetz, 2009; Patel & Crane, 2011). Living to an older age with HIV is unprecedented: Three decades ago, HIV was a death sentence. Since the late 1980s, many advances in care and treatment have occurred. The success of highly active antiretroviral therapy (HAART) has altered the course of HIV and enabled affected persons to live longer, to survive to age 50 and beyond. This has led to a shift in conceiving a diagnosis of HIV as imminently life threatening to an emerging conception of HIV as a chronic and manageable disease (Gough & Karapita, 2011). This view is misleading and requires caution. The complex triad of HIV, medications, and aging come together to act on the body in cumulative ways and present new challenges. Extended life expectancy with HIV is a relatively new phenomenon, the implications of which we are only beginning to understand. For this reason, the graying of HIV is an emerging concern. The day-to-day experiences, realities, and challenges of affected individuals remain largely invisible. We believe this deserves attention. Thus, we strive to make known and better understood the voice of those living the complex reality of aging with HIV.

While research into the biological impact of HIV infection on the body is well known (Falutz, 2010; Heath et al., 2001; Kirk & Goetz, 2009), the interrelationships between the virus, aging, and pharmacotherapy and the development of comorbidities are complex and poorly understood. Consequently, this domain is a high priority clinical research area. Most recently, researchers have examined some of the psychosocial changes associated with long-term antiretroviral therapy, including side effects, quality of life, and factors and barriers to successful aging (Vance & Brennan, 2011; Vance,

McGuinness, Musgrove, Orel, & Fazeli, 2011; Vance & Robinson, 2004). Older adults with HIV also face an earlier onset of fall risk factors than non-infected persons (Erlandson et al., 2011), which impacts quality of life. These recent studies indicate that stressors unique to older adults are exacerbated for those aging with HIV. Researchers have also emphasized the importance of early intervention and access to resources and supports that help to overcome barriers to successful aging.

The many changes happening within and on the body are increasingly understood. Researchers have found definitive adverse health impacts including, but not limited to, immune suppression, hypertension, dyslipidemia, and insulin resistance (Heath et al., 2001); cognitive decline (Vance & Burrage, 2006); and cardiovascular events, bone demineralization, and both HIV-associated dementia and non-dementia cognitive dysfunction (Falutz, 2010). While the factors Heath et al. identified are attributed to treatment, others are associated with a combination of treatment, the virus, and aging. Medical narratives that include scientific explanations have provided critical information that has saved lives, yet represent only one way of knowing. What remains largely misunderstood or invisible are the everyday realities and stories of the challenges of aging with HIV.

To further understand the impact of HIV, we used narrative inquiry (Riessman, 2008) and examined the stories of older adults living with HIV and aging in an urban North American context. Narrative inquiry is generally understood as an approach to understanding how people make meaning of their life through the stories they tell. Our purpose in this study was to use narrative inquiry to understand the experience of aging

with HIV and, through elicited stories, to learn more about the confluence of aging, treatment, and living long term with HIV.

Narratologist Arthur Frank (1995) posited that persons with illness seek to reclaim their experience from the dominance of medical narratives. That is, medical knowledge often limits the ways in which an illness experience can be conceptualized and acted on:

Telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe. This voice is embodied in a specific person, but it is equally social, taking its speech from the postmodern times we live in. (p. 18).

Scholars in human sciences (Charon, 2007; Frank, 1995; Gadow, 1995; Josselson, 2011; Riessman, 2008) have emphasized the power of stories as a means to share our experience with others. More specific to illness, Frank (1995) and Sakalys (2003) asserted that illness is a call for stories, and Bulow (2008) suggested that illness must be storied to exist. Arthur Kleinman (1988), considered one of the first to establish a meaning-centered paradigm for "illness narratives," explained that illness has meaning and that illness narratives are holders of meaning that can teach us about suffering and death. For those living with illnesses such as HIV, the stories they tell offer a glimpse into their experiences. This process of telling and being heard facilitate meaning making and the gleaning of understanding. From here, we open doorways to connection and compassion in the world.

As caregivers, the relationship between patient and provider is within the context of telling and listening to stories. Scholars have recognized that having an opportunity to story one's experience of living with a complex disruption such as illness has therapeutic

value and offsets the risk of feeling misunderstood and unrecognizable (Frank, 1995).

The sense making that happens in the telling (Frank, 2010; Josselson, 2011) is critical to that individual and helps him or her to cope (Holloway & Freshwater, 1997; Pennebaker, 2000). The hearing of and intersubjective engagement with stories is critical for those working in health and social services professions, as they generate understanding and insight, evoke compassion and a sense of shared experience, and thus enhance care relations. Evidence clearly shows that in organizations with engaged staff, the patient experience is better: Errors are fewer, and infection and mortality rates are lower (Kings Fund, 2012). Narrative inquiry gives voice to individuals who often live at the margins of society. Such inquiry illuminates social influences, adds to the body of knowledge in this emergent area, and illustrates the powerful potential of storying within health care relations.

Methodology

We framed our narrative inquiry within a social constructionist lens through which “meaning is not discovered but constructed” (Crotty, 1998, p. 42). Within this view, meaning emerges through conscious engagement; meaning is co-created and co-constructed between the teller of the story and the listeners (in this instance, the researchers). Social constructionists emphasize intentionality, contingency, curiosity, and imagination. They view a description, such as story, not as a mirror or a straightforward representation of reality or an internal self, but as a complex representation containing multiple voices representing the social, cultural, and gendered. For this reason, while the participants had very real and personal experiences (individual meaning making that Crotty would distinguish as constructivism), we acknowledged that their experiences are

situated in a larger constellation of narratives and contain many social influences and taken for granted discourses. We recognized a powerful interplay between individual meaning making and the context of the social world that influences, shapes, and constructs how each participant sees and makes sense of their everyday reality. This dynamic view of social constructionism was congruent with theoretical assumptions within narrative inquiry and helped to govern our method, guide our engagement with participants, and influence what constituted data and analysis as we co-constructed stories of aging with HIV.

Specifically, we drew on Riessman's methodological approach (2008). Riessman suggested that researchers story and foreground experience and pay close attention to individual cases with the aim of keeping a story intact. This methodology offers a way "to see how knowledge is constructed in the everyday world through an ordinary communicative act – storytelling" (p. 14). Researchers use detailed personal illness stories or case-centered exemplars to illustrate how knowledge can be generated; as they believe that they can theorize from a case rather than across cases. That is, narrative analysis of a case can evoke understanding and lead to general concepts. We additionally acknowledged core theoretical underpinnings of situatedness, intersubjectivity, and active engagement in the shared construction of narratives and meaning (Josselson, 2011; Riessman, 2008).

Participants

This study involved five Canadians of Anglo-European ancestry living in an urban center: three men and two women. The participants were part of a purposeful convenience sample of 32 adults recruited for a broader study focusing on narratives of

life-threatening illness. Each of the five consented to have their stories used for secondary analysis and agreed to participate in an additional interview focused on aging. While all participants were aged 50 or older and living with HIV for at least 10 years, two had progressed to *acquired immune deficiency syndrome* (AIDS) in the past before responding to treatment and returning to an HIV diagnosis. At time of the final interview, participants were between 55 and 62 years old. The number of years since diagnosis ranged from 13 to 24 years. All aspects of the study were approved by a University Human Research Ethics Board. We have used pseudonyms to protect confidentiality.

Data Collection

We conducted face-to-face individual interviews using a conversational style with semi-structured questions. The process of interviewing was relational, discursive, and aimed at generating detailed accounts (Riessman, 2008). We interviewed participants five times over a 3½ year period, except one man who chose to be interviewed three times over the same period. We audio recorded and transcribed verbatim (netting 23 transcripts) generated narratives of approximately two hours per interview. We recorded and transcribed field notes of interview reflections and impressions after each interview. Re-reading the field notes added depth by keeping research team members grounded to the interview experience, by stirring memories of emotional and poetic aspects, and supporting reflexive examination of our own assumptions and meaning making processes.

Analysis

Our narrative analysis followed a case-centered approach accompanied by analysis across the five cases (Riessman, 2008). We followed a case-centered approach to interpretation

that honors individual agency, particularities, and context. As researchers, we read closely with critical reflexivity and listened for the particular within the depth of each set of transcripts per participant and then across the broader whole. We paid attention to details, context, shifts, and aspects of aging that were most dynamic and poignant for the storyteller. Participants told their stories with heartfelt emotion, tears, and laughter and often in a circular manner, as they talked and simultaneously tried to make sense in the moment of telling. Field notes were an additional resource that informed this iterative consolidation process. Containing elements of description and reflection, they held immediate insights and impressions about the setting and the exchange that otherwise would have been lost or forgotten.

Drawing on Riessman's (2008) methodology, we offer a balance between description and interpretation. The first author identified dynamic aspects of aging with HIV that ran through each participant's story, albeit in different ways. The research team then met to further refine and validate what we came to term "storylines," returning to the transcripts repeatedly to resolve differences in interpretation. Next, the first author crafted the exemplar of Nancy's story through a process of reflection, synthesis of Nancy's transcripts, and creative writing. We chose her story as an exemplar because she has lived with HIV the longest (24 years) and is especially articulate in describing aging with HIV that is reflective of the storylines evident across the five participants.

Findings: Case Exemplar and Storylines of Aging with HIV

We begin with a narrative case exemplar of Nancy's story, followed by knowledge generated through analysis across all participant stories. We present the exemplar for two reasons: to point to and convey the fullness of an experience of aging with HIV and to

interpret and re-present one participant's lengthy story as an exemplar that is short and more easily accessible. In doing so, we follow Riessman's (2008) narrative inquiry and emphasize the particular. Nancy's story, created by the first author by consolidating Nancy's own words, offers insight into how she makes meaning of aging with HIV.

Nancy's Story

When I tell my story, I always go back to the beginning, and the beginning goes back a long time because it's been more than 20 years since I was diagnosed. I had been travelling abroad and when I got back, I wanted to get checked for everything. I don't even remember talking about an HIV test. My doctor phoned and told me I was HIV positive and it was like boom, like you just got hit in the stomach hard. I was just in this total, total fog, and I was sure I was going to die. I caught the bus home and just got into bed because I thought you must die in bed! I had this attitude I was going to die and there was nothing I could do about it and it was so terrible. And I was shocked I didn't die right away. So I was basically in denial for about seven years. Then I became so tired and got so sick I had to quit working. I did go the full tumble to AIDS and was in hospital. They sent me home with a palliative care binder and I was prepared to die.

HIV has put me on a whole different life trajectory. It makes me think of an embroidery I have of a phoenix rising from the ashes. And it's kind of what I see because this disease comes with a huge wall of stigma and has really severe implications, and yet it allows me a commonality with people everywhere. So I can envision myself rising out of the ashes, of having another chance at doing what I want to do. A friend was the first one to help me recognize I was part of the changing story of HIV. And I have been involved in various ways, teaching and telling my story because I do want to influence

and impact change for the better. And it is not always easy. I want to do so much, and it strikes me as urgent to get health care to people for something that is treatable. But at times I feel I'm pushed to the brink and that the world is crumbling. I feel overwhelmed. Part of me feels I need to figure a way around these roadblocks, and another part of me feels depleted and I just want to fall back and rest. I have faced depression, but I have also started recognizing that life is about the yin and yang. You might get smacked in the face in the morning, but then you might have somebody kiss you that night. I know that each struggle doesn't go on forever.

Now, in my late 50s, I am focusing less on my work, taking a step sideways, although that is a challenge. And I'm really working on my own health, my physical health and psychiatric health. I'm dealing with all those things that everyone my age has to think about, but I have to put it into the framework for living with HIV always. What does that mean, and how does that make it any different? I've always looked after my whole self and have been proactive, I mean, it is about taking responsibility for self-care because it's more than just staying alive. And it makes no sense to expect medicine to do it all. There is no magic bullet. I still take meds. I take five a day and one needs to be refrigerated so it's kind of a problem when you are traveling. And I have tried many alternative treatments. It is frustrating at times. You do everything and are not getting better.

Then, there's old stuff that keeps coming up that I need to deal with that I have not. It's easier often not to deal with it, and a lot of things are difficult. I did a collage art recently, and it came out looking like chaos, and I thought that's what I do want to illustrate. There is chaos in all of this too. So for the most part, I have been well and

balanced in my physical body and in my spiritual body, and I often feel more like 30 years old. My CD4 count was the highest it's ever been, 1200! This is right on the high end of normal, so it was just kind of amazing. And I could not believe it! I turned 40, and then I turned 50! I had to celebrate. Anything past 40 to me are bonus years. But lately, my health has imploded. It's not that good. Maybe it's all the stress because I think the psychological and the physical are closely linked. I've got a lot of issues on my mind, thinking about what I'm going to do for money once I am no longer on disability and thinking about retirement. So let's see, I have had blood in my urine, and a sinus infection. And I had some little tests done because I am worried about my memory. And the other is osteopenia. I don't know what's really going on and I am not as good as I was a while ago. And it doesn't feel like it's HIV. Maybe something else. It seems health wise it goes up and down and it's just a fact of life.

The stigma of HIV is still so great, you live with fear that you might pass it on. And having HIV is not like having diabetes, you cannot date, and it now has this criminal element and it is stigma personified. Your identity is changed forever. And the criminalization of non-disclosure of HIV is just making it more stigmatized and less likely that people will get tested. Like I feel really alone, and I want to be in another intimate relationship, to have sexual intimacy, but relationships for me are fraught with concern about disclosure. This issue is huge and I'm scared of it, it adds more fear about entering a new relationship when you already have enough fear when you're my age. It's an ugly problem and I feel humiliation. It has really eroded my self-confidence. I have tried to meet someone and can't. The stigma is always there, the threat of it. It's like always wearing a back pack. I'm never sure when I can take it off and set it down on safe

ground. I want to live my life open and honest, but I cannot trust, there is fear. It stops me from living my life. I can no longer live with innocence. When I meet someone new, I never disclose at a first meeting. I have to gauge if it is safe to tell, and so as a safety I always tell people I am HIV positive in a group so I don't get beaten up by somebody reacting, or I have a witness, so there's safety in who I am and where I am. The stigma creates so much pain.

I am beginning to realize that that is the biggest health thing, self-esteem, because when we have low self-esteem, we are most vulnerable. And this is a sexually transmitted disease or a blood borne infection and the disease gets spread because of uncertainty, because young people are not able to be clear about boundaries. And that is what we need to teach. When I think of what happened in the 1980s and 1990s, all the deaths, I think there was a whole bunch of compassion and awareness that came into being, that it was a real eye opener for the world: There is a group of incredible people here and globally who are totally vulnerable and human beings like the rest of us. This is such an opportunity for compassion. And I don't think we can succeed as a person until we do community work, we are not only what's inside our core but we are our relationships with our communities. And it's that relationship that helps me so much, living with HIV, the community work that I do.

I am aging. Yes. And I live with the threat of HIV all the time, it's always with me. It sits in my body as a tightness, like a tightness when you clench your fist. It's about so much loss, you know, the loss of partners, of innocence, of learning to live with grief. There's an uncertainty about living and there's an uncertainty about dying too. I don't totally trust what the long-term situation will be, we don't know what the effects of

taking these drugs over years is going to be. So I am dancing my dance, my best dance, to the music that is life, and I am trying to relax, but I am not there yet. Joys of aging? Yes, so many, the joy of being alive, of breathing, of every little thing because I do remember being on the brink of death. And to be this age is pretty amazing. HIV positive... that is pretty amazing.

Storylines of Aging with HIV

Findings conveyed through the case exemplar of Nancy's story provide a whole and unique view of living and aging with HIV. Nancy's story also offers a window into the six storylines that we identified across all participant stories. These storylines relate to embodiment, sense making, death and loss, secrets and stigma, identity, and connection. The term "storylines" provides language for recognizing stories that transcend individuals, yet are diverse and socially and contextually shaped. Participants narrated aspects of each storyline, and what was dominant in one interview was often less so in the next. This living and breathing fluidity and evolving nature make it important to take into account just how each storyline is experienced for an individual as he or she ages. Aging with HIV is experienced metaphorically as both sunshine and shadow (Beuthin, Sheilds, & Bruce, 2014), and we kept each storyline open to reflect this capacity to hold both. We found that storylines intersected and converged to create a cumulative impact and shape, thereby revealing the experience of aging with HIV.

Embodiment of Illness. HIV is unlike most other chronic illnesses: The 'cocktail' of HAART drugs and the virus converge with great impact on an aging body. The standard treatment for HIV is a combination of three or more antiretroviral drugs, most often combined in one pill that is commonly referred to as a cocktail, antiretroviral therapy

(ARV), or HAART (U.S. Department of Health and Human Services, 2014). CD4 counts (a measure of the white blood cells that fight infection and decline in number as HIV infection progresses) and viral loads are constant indicators and reminders of internal biology and fragility. Participants spoke graphically of the virus as sitting in their body, living in their blood and in their bone marrow. They recounted stories of the physical lived body as it ages with HIV. Each participant was highly in tune with every change and nuance in his or her body, always discerning if a change in health or the arrival of a symptom was due to aging, advanced illness, or treatment, always wondering if this was the dreaded spiral downward, as if holding a vigil of waiting and not waiting. Awareness was high that as the medical cocktail becomes less effective, options run out. All expressed a vulnerability of feeling like guinea pigs, aware that no other persons have ever lived to age with HIV. Each participant also had or is currently dealing with clinical depression, a dark cloud that has followed him or her into aging, appearing, disappearing, and reappearing many times over. There is a desire to eat well, yet drug side effects, such as nausea, to varying degrees preclude that. All have experienced prejudice by health care providers and now use lessons learned to navigate and maneuver through the health care system to get needs met. One participant struggled to follow his prescribed medication regime, while others accepted compliance as a harsh necessity.

Sense Making of the Journey. The adults we talked with were actively trying to make meaning of life with HIV at this stage in their lives. At diagnosis, they abandoned thoughts of aging. Even now, the passing of years they never anticipated living remains in question, hence the storyline of sense making. Aging added acuity to this, derived from having escaped death for now and survived against all odds. Participants have

accumulated experiences and now draw on knowledge gained. They have had precious time to put toward adapting, building relationships, gathering life wisdom, trying new treatments, testing theories, and developing confidence and inner resilience -- all with varying degrees of insight, sense making, and success. Participants were philosophical and reflective as they spoke of a cautious, half-trusting shift in their own reconceptualizing of HIV from a death sentence to a chronic illness. Stories were peppered with ideas of survivorship, feeling lucky, and of life lessons. They also saw HIV as a blessing or a gift and as a teacher of humanitarianism, social conscience, and volunteerism. While they still experience turmoil and upheaval in relation to what Nancy calls “new and old stuff that keeps coming up,” the sense of drama is less than in the past. They continue their efforts toward reconciling the past, and they appreciate that part of telling their story is sense making. Unlike many older adults in the Western world who yearn to maintain youthfulness, the participants saw aging and life itself as a bonus.

Death and Loss. A significant storyline for older adults living with HIV is the presence of death and loss. Participants recall the AIDS crisis of the 1980s and 1990s and have experienced loss on many levels. They speak of the loss of friends, life partners, jobs, identity, and innocence that have accumulated and culminate in posttraumatic stress. As participants enter older adulthood with HIV, the close proximity of death to daily life looms in varying forms. Any sense of innocence or naiveté about death is gone. All participants have faced death, be it the direct threat to themselves or the loss of friends and others, and all continue to experience loss. For now, they are very aware of the fragile fact that they are still standing, that they are not cured, and that the cocktail they currently take might become ineffective at any time. Each new trauma or challenge

reopens wounds. The cumulative losses experienced by these participants exceed those of most seniors in the general public. All of those interviewed face concerns of limited financial income, which impacts housing options; they quite simply have not been able to work and earn pensions. Unlike many seniors, they never envisioned retirement in the more conventional view of aging adults. They did not make retirement plans, and, even now, having aged and kept death at bay, they feel a lingering uncertainty about longevity, and they make plans for the future tentatively. Aging with HIV is a new phenomenon with compounded losses that pose more challenges to aging than most aging adults face.

Secrets and Stigma. A dominant storyline is that of stigma and the corresponding need to protect oneself by keeping HIV status a secret. This powerful social influence continues to be a threat that permeates, magnifies, and distorts the experience of aging with HIV and differentiates the experience of aging from that of other adults. These older adults carry past experiences of being shamed, humiliated, or marginalized in various ways that remain fresh. Time has not erased or distanced this hurt. Stigmatization continues to occur during day-to-day life interactions. Nancy finds people still withdraw or react with fear and uncertainty when they become aware of her HIV status. Public fear and prejudice rooted in misinformation about HIV fuel discrimination that is real and perceived, and while expressions are somewhat less blatant than in the past, participants continue to experience stigma in subtle and not so subtle gestures. We found that when a participant came to see him or herself portrayed in a negative stereotype, he or she felt the weight of it viscerally and carried it in the body, for example, feeling “dirty” or “a tightness” or like “wearing a mask” or being “untouchable.” In addition, stigma had the power to foster isolation and humiliation. Nancy expressed this in relation to the

criminalization of HIV non-disclosure, which imparts a view of illness as violence. Many countries have opted to criminalize HIV transmission, exposure, or non-disclosure.

In Canada, a person living with HIV may be found guilty of a crime for not disclosing his or her HIV-positive status before engaging in sexual activities that, according to the Canadian courts, could result in a ‘realistic possibility’ of HIV transmission. The crime is exposure without disclosure whether or not HIV transmission actually occurs...The following charges have been laid against PLWH: assault, aggravated assault, sexual assault, aggravated sexual assault, common nuisance, criminal negligence causing bodily harm, murder, and attempted murder (CANAC, 2013).

Portraying persons with HIV as violent, criminal, and undesirable members of society raises complex public health and human rights concerns and reinforces stigma. While Nancy seeks intimacy and connection, the law fuels stigma and fear that impact her ability to meet someone. She feels trapped by the “ugly problem of disclosure” and carries a sense of injustice at a law that adds to her angst, creates a sense of shame, and limits her sexual expression and identity. Aging itself was not seen to add a burden of stigma, but rather was expressed as a time of strengthened self-assuredness. This increase in confidence, in combination with learning gleaned through years of trial and error, now empowered them to enact unique strategies to better cope with stigma. Some participants spoke of “being totally upfront,” of “wearing no masks,” of telling of their HIV status within seconds of meeting someone as a way of disarming and taking pity out, or of disclosing in safe group settings. While shifts have taken place, others still keep secrets.

They have refined the art of how to gauge people and situations, but they remain cautious about fully trusting the reactions of others.

Evolving Identity. A diagnosis of HIV is life altering. One participant explained, “My identity changed forever that day. I can never undo it.” To have now lived with HIV for many years and aged beyond 50 further impacts identity. While participants continued to strongly identify as a person living positively, they experienced a shift toward and layering of other identities. Participants spoke of having a stronger sense of confidence and agency than in earlier years: “I’m the expert now when it comes to HIV.” Assuredness and a sense of being more proactive in dealing with health needs supported shifts in how they see themselves, by varying degrees. Stories revealed evolving shifts in identity from that of victim toward long-time survivor, from outcast toward being a part of smaller or broader communities, and from a masked and closeted way of being in the world toward one of masks off and openness.

While more taken for granted roles in society, such as being a parent, have not been readily available to most participants (only one person had children), the role of older adult is available. Being seen by society as older creates opportunity for newfound identities, such as elder for some and “gay grandpa” for others. The participants perceived these identities to carry respect and acceptance and help “level the playing field” by offering a way of being they can slip into with some ease. The newfound identities also offered a reprieve from stigma or a sense of lessening the stigma-laden reality that has dominated the way they have experienced and been seen in the world. “Society is more respectful toward me as an elder than a HIV positive person. I’m seen as less threatening.” There is a sense of going beyond an identify of having HIV to a

broader reality of “being like other people” in society who are getting old, of belonging and sharing a physical identity in terms of having hair turn grey, losing muscle tone, and facing health challenges. While they accrue this new identity of getting older, that identity neither negates nor trumps the identity as a person living positive that is embodied and imprinted on their knowing of self. Participants spoke of an omnipresent awareness and thinking about HIV that remains as they age: “HIV is with me every day – the pills remind me,” but how it defines them often shifts from being a top priority or obsession to something they spend less time worrying about.

Seeking Connection. Stories of aging with HIV brought to light a storyline about seeking belonging and connection with others through their illness trajectory. Diagnosis for many meant that their original place of belonging was disrupted. Many relocated geographically to seek new identities and safer places to be, leaving behind family and home. Over time, most participants had to re-establish and reconstruct new places of belonging, new families, and new communities or face isolation. As older adults, each participant expressed a desire to have and has sought out meaningful relationships in one form or another, with varying degrees of success. For those who expressed a strong sense of belonging and acceptance, this was in part due to their long-term connections with and active roles in HIV-related work. Here, within this community tied together by disease, they have found respect and a sense of value. As activists, four of the five participants now welcome aging as an opportune time to relinquish this role and pass the torch to others. One participant continues to struggle, has minimal support, and feels isolated. Unlike the other participants, he was the only participant not actively engaged in community work. He sought connection and creatively reached out to others, be it talking

to someone in the grocery line, participating in a research study, or maintaining a strong bond with his animal friend. It is not so much that aging added an urgency to pondering death for these participants, as they are intimate with the prospect of death. Rather, the aspect of aging with this lifelong virus added urgency to seeking and establishing connections because it is only within the safety of trusted relationships that they can let barriers down, be authentic, share their life, and let love in without fear of retribution. While death is closer, the possibility of dying a painful death was at times hinted at but remained, for now, unsayable.

Discussion

Living with HIV shapes one's experiences and perceptions of aging. We are only beginning to understand the interrelationship between aging, HIV, and antiretroviral treatments, all set within a socially constructed story about people with HIV that continues to be infused with stigma. Focusing on the stories of people living with HIV, we illuminated a set of six core storylines that intersect the lives of older HIV positive adults: illness embodied, sense making, death and loss, secrets and stigma, identity, and connection. The exemplar case of Nancy's story provides a full view of the six storylines identified across cases with a particular emphasis on her experiences of stigma. Study participants who were able to gain clarity, temper tensions, shift, reconcile, and evolve within each storyline over time were living better than participants who could not or who seemed stuck, experiencing isolation, frustration, or desolation. The storylines reveal key aspects of the experience and that sense making happens in a fluid, shifting way. Like a typology that is kept open, the storylines can enhance understanding through generating

knowledge (Riessman, 2008) and guide those listening as well as those telling stories (Frank, 2010).

The six storylines offer a way to begin to listen to and make sense of aging with HIV and illustrate how a narrative inquiry can contribute to our learning. Storylines are not meant to be generalized to an entire population in a simplified way, but rather to generate knowledge and prompt us toward theoretical propositions (Riessman, 2008). We theorize that adults aging with HIV for an extended time grapple with these six storylines and suggest that the degree to which one is able to reconcile or negotiate differences between individual experience and cultural stories is directly proportional to how well one copes overall. In her theory of transcendence, Reed (2008) emphasized the importance of storytelling or sharing personal narratives as an antecedent to transcendence and coping in aging, the outcome of which is having a sense of meaning and satisfaction. Also aligning with our research is a newer understanding of the concept of transcendence in aging, one that encompasses a domain of relationship and connection with others (McCarthy & Bockweg, 2013). Pennebaker (2000) found that sharing about one's experience also helps to improve physical and mental health, and Holloway and Freshwater (2007) provided an overview of studies in which such sharing helped to decrease pain. Overall, a growing body of research is pointing to the process of storying as a means of fostering resilience and reconciliation while also meeting a core human need, of feeling acknowledged in one's existence.

Findings of this research add to the existing literature in several ways. First, we give voice to this unique group of pioneering adults who experience aging with HIV over time. Their voice and stories, largely unheard till now, add a broader dimension to an

often dominant medical narrative (Frank, 1995). Second, these stories offer insight into the broader experience of aging with HIV as opposed to one isolated aspect.

Additionally, the set of storylines we identified within stories of accumulated experiences adds to our understanding of aging with HIV as complex and unique from other chronic and life-threatening illnesses. The storylines suggest that the experience is not unidimensional but an interwoven combination of unique storylines about this *and* this *and* that. The storylines reveal tensions, uncertainties, and ‘inbetweenness’ that affects choices made and hopes aspired to.

Last, this research adds to understanding that we need interaction for meaning to happen (Maturana, 2011). While findings from this study do not directly address a link between storying and enhanced health, they are supported by current theorizing that suggests providing persons the opportunity to put language to and to tell of their experiences of facing illness has a potent effect on health and the ability to make sense and cope (Antonovsky, 1987; Pakenham, 2011; Park, 2011). Pakenham (2011) focused on ‘sense making’ as a potent predictor of adjustment in chronic illness and proposed a model of sense making that involves seven processes: “finding new life purpose, awakening to the spiritual, finding cause, revising life values and goals, appreciate social ties as a source of meaning, accepting life as it is, and acknowledging the randomness and/or the incomprehensibility of some events” (p. 264). While all processes were present in the stories of participants aging with HIV to some degree, more research is needed to see how they align with this formal theory of sense making.

Findings of this inquiry also point to practical implications for health care professionals who interact with older adults with HIV. Are there educational resources

developed and available about accelerated aging and the number of critical developments that are only beginning to be understood, such as the long-term impact of antiretroviral medications on the aging body, the confluence of HIV, aging, and medications, and the role of stigmatization specific to older adults with HIV and ways it affects well-being and health, socialization, and isolation? Additional questions arise. For example, how can health care professionals learn more about the importance of seeing the individual before them and not foregrounding the HIV label?

Moreover, gaps exist in our health care services. While specialized care facilities for persons with AIDS exist (Selwyn et al., 2000), older adults with HIV with ongoing care needs are entering mainstream long-term care settings. While we found no formal research, the challenges of integration are being identified in news stories: discrimination based on the virus, reverse age, and often sexuality (Pigg, 2011). How will we prepare staff in residential care settings to create a culture that does not discriminate through care procedures and biased behaviors as this population enters the senior care system for the first time? There is a growing recognition that more training of staff is needed (Houston, 2012). This is significant, as discrimination is recognized as an established social determinant of health (Currie et al., 2012). As more research becomes available about epigenetics and the adverse biological effects of living with discrimination (Wilkinson & Marmot, 2003), we wonder if this might extend to an older adult with HIV. Does not having an opportunity to talk about this illness experience adversely impact well-being, increase pain, and inadvertently cause harm?

Education will be paramount as we move forward and aspire to provide care and have interactions that are respectful and informed. As resources are developed, planning

will be required for effective dissemination. Ideally, this would be augmented by opportunities for conversations around attitudes and often unrecognized biases, conversations that inspire reflection and a sense of connection such that social constructions that are hurtful, harmful, or manipulative might begin to fall away. Health care professionals are in key positions to correct myths and misinformation and to model a relational responsiveness that is effective. Stories like Nancy's do just this, tether us to our humanity through the storied lives we live.

Conclusion

Rendering and making more accessible the experiences of those living and aging with HIV are vital to the wellness of those affected and those supporting them. Stories can serve to reawaken our sensitivity, to move and grab us again, to remind us of why we serve, and to reconnect us to the heart of our health-related work. This is important in times of competing demands and pressures, to be reminded, to pause and hear, really hear for the first time again, the story of the person living every day with this complex virus. Stories inspire us to be relational in our practice. When we are open to this way of being with and learning from one another, we become a way for sense making to happen in the teller and in ourselves, and we respond in ways that feel supportive and non-judgemental, in ways that encourage outdated metanarratives and behaviors infused with fear and stigma to fall away. We create the potential to see the person before us in all his or her strength, glory, and beauty. That is how change happens, through relationships and connections with one another. When preconceptions fall away, we will more clearly see the person before us who is getting older with HIV in his or her full splendor.

Chapter 5. Cultivating Narrative Sensibility in Nursing Practice

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Abstract

Stories hold meaning, and when persons tell of their experiences of living with illness, they are afforded an opportunity to make sense of all that is happening. As nurses we have the privilege of hearing the particular, gaining understanding, and creating a powerful encounter that has healing and health benefits. This is a call for nurses to more intentionally invite and listen to the stories of persons living with illness. The mnemonic STORIED is offered to help nurses weave together essential elements of a narrative practice approach: Subjective, Tell/Listen, Openness, Reflection, Invite/Intention, Engage, and Document. Nurses are the voice of the vulnerable, and to learn to listen to our patients' stories such that what is gleaned contributes to their healing is nothing less than a call to excellent care of the unique person before us.

Keywords: nursing practice, narrative, interpersonal, HIV, nurse-patient relations

This is how the story unfolded... Nancy is an artistic 58 year old woman, miraculously living with HIV for 24 years. A statistic that staggers is that by 2015, approximately half of adults with HIV in the USA will be 50 years and older (Kirk & Goetz, 2009). Nancy belongs to this group. Across five interactions through a research study, we built trust. I posed opened questions about her health and well being. At the 1st meeting she told me what she thought I wanted to hear, mostly her medical story. She described how she had been in denial about her HIV diagnosis and kept it a secret for the first 5 years. And how when her body succumbed to AIDS, she was admitted to hospice to die.

Nurses with years of experience in practice or research know the privilege and profound value of hearing people's stories of living with disease and illness. Although nurses may exclaim "yes, this is what I aspire to," in reality, opportunities to hear patient stories are missed, undervalued, or set aside. Nurses do not always have the intention, support, or understanding of why this is important in their practice or how they might embed it. While most take time to hear patient stories as best as they can, nursing's mastery in this area has diminished over time. In 2002 Cody and Mitchell raised a concern that while other disciplines were turning toward narrative and dialogical methods, nursing seemed to be turning away; that nursing has continued to be primarily represented as biomedical/technical. Other practice disciplines are taking up a narrative approach with intention, and while nursing is catching up, overall we have been slow to do this. As a result, the potential for nurses to use storying to contribute to exceptional patient care is being missed. And this is important at a time when patient groups across

the country are speaking out about their care experiences as less than optimal. It is essential that nurses intentionally embrace narrative knowledge: it generates a way to access understanding by focusing on everyday life experience, and the principles are congruent with and transferable to nursing practice. This article provides information and insights about how a narrative approach provides nurses with a powerful opportunity to enhance care they currently provide and the experience of doing so. Practical ways are offered for nurses to invite and hear patients' stories.

At our 2nd meeting Nancy talked about a recent depression and the lingering regret of listening to a doctor years ago who told her (she now knows incorrectly so) that she could never have children. Her face lit up when describing her active involvement in the community and her amazement at living and aging!

What is a Narrative Approach?

*“All sorrows can be borne if you can put them in a story...tell a story about them.”
(Dinesen, cited in Riessman, 2008, p. 10)*

Simply stated, the aim of a narrative approach is to hear a person's story. It builds on the assumption that it is a basic human expression to share our lived experience by way of a story or narrative (Levi-Strauss, 1972). The story acts as a representation that can bring us closer to the direct experience of another. It is often the case that those suffering with illness desire to reach out and start to talk and tell. Many unequivocally believe that “illness is a call for stories” (Frank, 1995; Sakalys, 2003), and that “bodies and experiences have to be *told into existence*” (Frank, 2009, p. 165).

Four commonly accepted and interconnected concepts that underpin a narrative approach and the power of story are touched on. 1) **Meaning making**: Storytelling

generates sense making and helps us manage and construct our identity (Riessman, 2008). People engage in the process of interpreting themselves through their stories, what Josselson (2011) refers to as “the core meaning-making systems of real people” (p. 33). Stories hold meaning, and to hear a patient’s story is a way to access meaning about the particular (Kleinman, 1988). 2) **The particular**: Stories connect us, helping us to begin with the particular and to then reach beyond to touch and illuminate the universality of human experience. For this reason narrative knowledge is grounded in close study of the particular (Riessman, 2008; Charon, 2006). We see a person in the full context of their experiences; seeing the person first and foremost and the disease secondary. 3) **Lived body**: A narrative focus emphasizes how a person experiences an event as lived in their body, and how we construct our reality and make meaning based on experiences that happen to and through the body. And 4) **Co-construction**: The teller and listener of the story influence one another, such that the story told is co-constructed in that moment. New possibilities and connections emerge when the interaction happens with depth and trust and the receiver of the story is engaged. This is more than applying skills or performing a task, but rather a way of being with. For the teller and for the listener, an engagement becomes a created experience unto itself and has the power to evoke and inspire.

At our 3rd interaction Nancy talked about her world crumbling, about being pushed to the brink. Her emotions were raw as she expressed loneliness and spoke of how new legislation that criminalizes HIV makes her feel shameful. Her story revealed ill health creeping in alongside fatigue, vulnerability.

Relevance of a Narrative Approach

A narrative approach is critical to high quality nursing care. Hearing someone voice the experience of their illness offers us another way of knowing in our current care environments which are increasingly technological, data intensive, and fast paced. While assessment and treatment data give us vital information, such intensity and a sole focus on function and efficiency can easily overshadow and undermine intimacy and connection. Relational interactions that access a person's experience give us data and essential wisdom that augments and balances other dominant discourses. A narrative approach also complements a shift towards patient centered care and patient engagement in primary health care. Benefits to accessing meaning through the stories of those living with illness are increasingly evident. A growing body of research shows an engaged approach positively impacts patient care outcomes and safety (Frampton et. al., 2008; Coulter, 2012). In addition, Coulter cites studies showing a patient centered approach positively impacts a patient's trust of clinicians, their adherence to treatment recommendations, and the quality of their experience. This debunks outdated beliefs that relational care is not expedient and not important; beliefs associated with a view of nurses work as "technologically driven, prescriptive, and outcome oriented" (Jonsdottir, Litchfield, & Pharris, 2004). Benefits to patients are undeniable: they feel visible, heard, supported and validated. Benefits for nurses are equally profound: a feeling of connection makes nursing work meaningful and rewarding, and positively influences workplace retention.

During our 4th encounter I learned more about her frailty. A drop in her CD4 count, concerns about blood in her urine, fear expressed as to whether this is aging or HIV or

an infection. Retirement and money concerns rise to the surface, and she tells me she still feels like a guinea pig even after being HIV positive for 24 years.

Cultivating a Narrative Sensibility

This author joins others who call for system innovation (Gottlieb, 2013) and yet how does one begin to intentionally add narrative elements to their practice? Narrative knowledge and skills can be acquired in a variety of ways. For example, in the Narrative Medicine Program at Columbia University (Charon, 2006), health care professionals are taught fundamental skills such as close reading and reflective writing. Toronto's Mount Sinai Hospital offers The Program in Narrative and Healthcare Humanities. Within nursing curriculums, there is renewed emphasis on narrative pedagogy (Mitchell, Jonas-Simpson, & Cross, 2013). Regardless of the path taken, to cultivate narrative knowing and develop competency requires effort, commitment, and study. The mnemonic **STORIED** is offered to help focus and weave together key elements of a narrative practice: **S**ubjective, **T**ell/Listen, **O**penness, **R**eflection, **I**nvoke/Intention, **E**ngage, and **D**ocument.

Subjective. A narrative approach begins with presence or subjectivity. Nurses are called to be present as thinking and feeling subjects. Subjectivity is about embodied persons with authentic emotions sharing in the experience of an interaction with a patient, subject-to-subject. This contrasts with a traditional view of separateness between the personal and professional of an individual nurse. When nurses themselves feel like objects, there is a tendency to distance, clinically objectify, and treat those in care impersonally. When nurses are present and caring, the interaction is therapeutic and

advocacy is supported (Gadow, 1980). When we enact a subjective approach, we are better able to support and be with the other as they learn to live with inherent challenges of illness.

Tell/Listen. “Telling does not come easy, and neither does listening.” (Frank, 1995, p. xii). Provide the person before you with the safety to tell of their experience. To fully honor and listen to what they choose to tell in that moment, shift the power dynamic such that you do not lead but follow. Listening with intention becomes paramount (Sakalys, 2003; Gaydos, 2005). To build listening of a higher order into your practice, pay attention to how you listen to and follow a patient’s story, how you absorb, interpret, and respond, moving beyond the biomedical for the everyday and essential (Charon, 2006). The simple act of being listened to with respect and kindness is healing of itself, as an outward expression or sharing is different than bearing an experience and reliving it in the aloneness of one’s mind. Listen for language used, as words reveal. Be aware of social influences at play and their power to impact how a person responds to and copes with their situation. Only with close listening and attention to the particular will we hear what is underneath. Listen generously with genuineness and curiosity. To do so is to bear witness to the person’s storied experience and their truth; to not take on their woundedness but to humanly acknowledge their experience in all its pain or glory. We lean in, to listen deeply in an auditory and embodied way (Pelias, 2011). And listen with the heart, from a deep place - listening as a choice to stop speaking and to shift your focus and extend yourself to the other (Pratt & Homan, 2002).

Openness. Narrative nursing requires openness in one’s way of being in the nurse-patient interaction; openness to accepting and enacting foundational concepts of a

narrative approach. As mentioned, interconnected beliefs of a narrative approach focus on meaning making generated by stories, the particular as a way to illuminate the universality of the human condition, experience within the lived body, and the co-construction of a story between the teller and listener.

Reflection. Effective narrative practice has a nurse pause and take a moment of compassionate self-reflection to acknowledge beliefs, values, biases, and other attributes one may bring to an interaction. One must critically discern those that are helpful and those that are not, those which might inadvertently do harm and those that will elevate the interaction with grace. Ask yourself: “Am I able to listen without judgement? Am I able to leave behind beliefs of being right or knowing what is best, and to restrain from the urge to fix?” The intent is to not assume we know another’s experience. Reflection moves us towards intention and engagement.

Invite with Intention. In a narrative approach, a nurse invites stories about the illness experience. You value this way of knowing, create a space, and ask for the story: “what is this like for you,” “help me to understand,” and “tell me more.” And the story told may be long or it may be short, it may be linear or it may be more scattered, it may be emotional or more concrete. This does not matter. What matters is that the person responds to your invitation to share their experience in that moment and in whatever way or depth feels safe. Build on what is already in your practice, intentionally shift from conversational or casual story exchanges, and embed a narrative sensitivity into your care whenever possible.

Engage. And all the while you are an engaged self. Begin with the greatest instrument any of us have, the use of self, and move towards building a connection.

While relational engagement is not new to nursing (Doanne & Varcoe, 2005), it may be new to many. One engages with physical presence and is willing relationally and bodily to enter the shared lived space with another. Physically, you may lean in, maintain eye contact, or offer a gesture. Also engage authentically with verbal responses to help with sense making for the teller of the story: pose a question, ask for elaboration, and reflect back what you heard. Invite silence and let words linger, understanding that to tell and listen takes time and trust. And this, all this, comes together such that you engage with and cultivate compassion and empathy.

Document. Storied exchanges happen but often their value goes unrecognized. Nurses across practice settings are only beginning to consider how to incorporate narrative aspects into the health record as meaningful data that contributes to patient centered quality care. As electronic health records become more advanced and wide spread, the opportunity for innovation is ripe. Another approach aims at increasing clinicians capacity for effective work by encouraging them to write in ordinary language about what they witness their patient experiencing and what they themselves experience as the care giver (Charon, 2006). This is not done in the legal health record but in a “parallel chart” that clinicians then share with colleagues as a way to “recognize more fully what their patients endure and to examine explicitly their own journeys” (p. 156). This act of writing supports care givers to cultivate narrative knowing in their practice.

At our final meeting Nancy shared the deep pain and joy of being age 58 and positive. She revealed a confidence eroded, a longing for intimacy, and her fight for social justice. To age with HIV is to live with grief; it sits in her as tightness. Stigma changes everything; this is not like other chronic conditions. And yet her eyes smile, she is still

here on this earth, and there is also great joy. “I am dancing my dance. My best dance.”

Conclusion

As illustrated by Nancy, what is revealed to a care provider shifts and changes over time. Listening to the storied experiences of someone with illness enables nurses to access understanding and compassion and to embrace different ways of being. Embedding a narrative approach in nursing practice by focusing on STORIED skills honors and expands what nurses currently do, opens further possibilities, and provides a way forward for nursing. Cultivating intention to be present and hear the other is important, as through relational connections we move toward kindness to one another, we become our most humane, and we shine brilliantly.

Chapter Six: Discussion

Over the course of this research journey my aim has been to understand stories of older adults living with HIV, given the emerging reconceptualization of HIV as an illness no longer associated with imminent death but considered chronic. This inquiry was guided by the question: What might nurses learn from the stories, specifically metaphors, of older adults living and aging with HIV? This questioning led me to take into account several interrelated concepts and to consider how stories come into being. In this final chapter I synthesize findings and discuss significance of the inquiry overall. To achieve this I divide the chapter into three parts. I begin Part One with an overview to orientate the reader to foundations of the study: underpinning influences, the thesis, and the four manuscripts which form the body of this dissertation. I also revisit my evolving understanding of seven foundational concepts critical to this inquiry: narrative and story, narrative inquiry, conversation, experience, language, metaphor, and social constructionism. This piece is admittedly lengthy yet is critical as it grounds the research and also this researcher. As well, the discussion informs Part Two which focuses on five significant findings and contributions of this narrative inquiry: new understanding of the experience of aging with HIV, new understanding of relation and conversation in storying illness, new understanding of interplay between the personal and social in storying illness, illumination of tensions in narrative interviewing, and extending the call for new thinking. Lastly, in Part Three, I pull together considerations such as implications for nursing, issues encountered, limitations of inquiry, remaining gaps in literature, and recommendations for future research.

Part One: Overview

Explicating Influences

In this section I locate myself and briefly introduce a variety of thinkers who have influenced, informed, and shaped this inquiry. I apply a scaffolding framework used in research (Crotty, 1998), discussing epistemological, theoretical, and methodological influences. I share this for two reasons: to indicate I am a responsible researcher invested in the process and knowledge generated in this inquiry, and secondly with the intent of engaging, informing, and guiding the reader at the onset of entering this final chapter. I expand on each of these influences in a fulsome and forthcoming discussion of concepts.

Epistemologically, a view of social constructionism (Crotty, 1998; Gergen & Gergen, 1991) influenced how I have come to understand how we experience our world. I drew on Gergen and Gergen's emphasis on the language we bring to an object and a shared system of intelligibility such that knowing and meaning happen through relations. While a full analysis of the concept of self is not undertaken in this dissertation, I draw again on Gergen (2009) for an understanding of self as relational. That is, believing the relations we have in our world come to define who we are and our sense of identity and that reflexivity helps each of us understand our sense of self amidst multiple influences. Shotter (2006) extends this view by emphasizing relational-responsive thinking and understanding that he describes as "withness" (p. 600). I have come to resolve for myself that sociocultural influences are so impactful that Mattingly's (2001) suggestion of stories existing first and informing experience (and not the other way around) no longer startles me. Indeed, I now take up this view with conviction. I also draw on Maturana's (2011) view of language as primary in developing understanding. This coincides with a

shift in my understanding of metaphor as straightforward representation toward ideas proposed by cognitive linguists Lakoff and Johnson (1980): that we think in terms of metaphors and conceptual frames and acknowledge the role of emotions, embodiment, and the subconscious in relation to reasoning. I have also been influenced by Rorty's (1979) view of the unhelpfulness of conceiving the mind as a mirror that holds representation, heeding his call for a shift toward conversations and imagination, new metaphors that shape and influence reason, interpretive meaning, and creative humanism.

Theoretically, this inquiry is situated broadly in the human sciences, described by Dilthey as the study of "persons," or beings who have "consciousness" and that "act purposefully" in and on the world by creating objects of "meaning" that are "expressions" of how human beings exist in the world" (in van Manen, 1990, p. 4). More specifically, this inquiry is situated in interpretivism and a focus on understanding meaning and adding to understanding through interpretation. Philosophically, I have been influenced by several thinkers: Merleau-Ponty (1964) in regard to intentionality of consciousness, primordial perception, and an embodied knowing that involves not just cognition but the whole body and spirit; and Ricoeur's (1975/2003) emphasis on intentionality, desire, and re-presentation. I have been influenced by Jay's (2005) ideas of experience as indefinable and paradoxical, a lived reality that holds the tension of the personal and an inevitable encounter with otherness. The emphasis on ethics as expressed by Levinas (1966) and Gadamer (1995, 1999) was also influential: Levinas' belief in ethics as the first philosophy, the self being possible only in relation to the other, and an emphasis on relationships built on respect and responsibility for the other person; and Gadamer's broad understanding of knowing as happening through relation and aesthetics, through

intersubjectivity, relational narratives, radical contingency, and a dialectic that fosters imagination.

Methodologically these stances align with narrative inquiry in which I situate myself. I am influenced by the writings of Russian philosopher and literary critic Bakhtin (1981) and several who follow his ideas, specifically Mishler (1986) and his students Charon (2006) and Riessman (2008). I draw on two of Bakhtin's concepts of language, the dialogical and heteroglossia. Dialogical refers to a continual dialogue of all words with others; language being embedded with past meanings and future imagined responses, every word going back and forth, influenced by past usage and always bound to context. In this way we are unfinalizable, as are our stories, as our language is formed in an ongoing process. Frank (2005) describes it this way: "Each voice always contains the voice of others" (p. 966). Heteroglossia refers to the notion of meaning being different in every instance given that time, place, and conditions are always different. The primacy of context is emphasized over text. This emphasis on the fragility of and multiplicity within language, its aesthetic and ethical aspects, contingency and polyphony, are also congruent with my narrative approach. I am influenced by Mishler, a medical psychiatrist, who built on these ideas with his emphasis on the dialogical, identity, co construction, and the interview as a narrative event. Charon's ideas about relationship-centered care, a self telling body, and the use of self also influenced and inspired, as did her approach to narrative as a practice for clinicians in health care. Four other present day scholars methodologically were also influential: Remen's (1996) ideas about the use of silence and generous listening, stories as the language of communication, and the concept of service and practice; Frank's (1995) insights into the capacity of

stories; Josselson's (2011) view of stories as core meaning making systems of people; and Hazel's (2007) emphasis on narrative as a creative act that imposes order and design on raw experience, with narrative being memory and meaning. I was also affected by nurses who write about narrative with an emphasis on the aesthetic aspect of knowing, nurses such as Gaydos (2005), Watson (2014), and Mitchell, Jonas-Simpson, and Cross (2013). I used Riessman's narrative methods to pull together many of the preceding ideas in a way that supported the actual generation of co-constructed stories that inform this inquiry: a relational interview, and analysis with a focus on the dialogic, the particular, and cases. I draw on Riessman's understanding of a case to be an individual's narrative that forms the basis for "case-centered" analysis (p. 13). The term can also extend to an identity group, for example, belonging to a group of older adults with HIV.

Thesis Story

I put forth this following thesis or 'small story' to guide myself and introduce early the point of view I advance throughout this final chapter. Much ground has been covered over the course of this inquiry, but before entering that discussion I offer as a prelude this simplified argument of how I have come to pull interrelated and moving pieces of this dynamic work into a whole. Overtime it is as if pieces of a puzzle have slipped and at times fallen into place to create a rich unimagined and yet evolved and evolving picture that will contribute to nursing and narrative knowledge.

Nurses and nursing are concerned with the body. Nursing's paradigm emphasizes health, human beings, the environment, and nursing, and by extension relation and care. We interact with persons who face challenges related to the body (such as aging with HIV), and in this way the two come together (researcher and participant, or nurse and patient/client). We intend and hope for healing to take place, in whatever way or form is significant for each individual. And for this to occur, we need a way to communicate during an interaction. As humans we communicate through our body and language. The language we use is

constructed and constituted within our social and cultural spaces and is what we use to attach and generate meaning of our world and the things in it (that are already there). Our stories and the language we use, such as metaphors, hold, reflect, and reveal how socialized influences impact us and are at play for better or worse, alongside a presence of relational agency and mystery. In our interactions we have conversations as a way to lean into and arrive at meaning, to evoke shared experience, and to help us to live better. And these conversations may be poetic or practical in nature. When the interaction we have with others is relational and has depth and emotion, and when this interaction supports one to put language to experience and share this in the form of a story, then possibilities are created: the possibility to make meaning and generate understanding (understanding linked to interaction and communication), the possibility for healing or wellness, and the possibility for a human connection and compassion towards the other.

Four Manuscripts

Four manuscripts that arose from this narrative inquiry collectively describe research questions, related literature, narrative methodologies, findings, and insights. Attention was paid to metaphors and storylines in participant stories, as well as interviewing and practice aspects of a narrative approach. The contribution of each manuscript has been addressed in preceding chapters.

Revisiting Key Concepts

In this section I review seven key concepts and reflect on how my understanding of each ripened over time and continues to unfold in profound ways. In Chapter One I introduced an early understanding of the concepts of story and narrative, narrative inquiry, metaphor, experience, and social constructionism. Here I add the concepts of language and conversation that emerged as critical to informing this inquiry. A conceptual drawing represents how I have come to synthesize my understanding of each concept into a broader whole (Figure 1).

This section is for me a lived example of writing into the knowing, as it was only through delving into and at times embodying each concept fully that I arrived at

understanding and was able to eventually step back and see interrelated connections as they relate to this inquiry. What I see is that I take up each concept with a *relational perspective* and draw upon scholars who share this view, one that has grown with depth and conviction over the course of my journey and is integral to this inquiry.

1. Narrative and Story

I presented an overview of the literature in the introductory chapter of this dissertation, and expressed my early desire to hold tightly to distinctions between story and narrative. Over time, with continued immersion in diverse views about narrative across disciplines, I have found the terms story and narrative (as well as storying, restorying, storytelling, talk, and conversation) are used but explicit differentiation is not often stated; rather, researchers and writers focus on aspects of language, purpose, process, and experience in relation to stories. However, generalizing across sources, the term story most often relates to *what is told* and *the telling of*, and narratives most often are associated with *analysis*. I now come to find distinctions between story and narrative helpful but not critical. Rather than clear distinctions between narrative and story, what I find more important is the context in which the term is used and the intended audience. As such I have come to use the terms more interchangeably, as do others. Garro and Mattingly (2000) use the terms interchangeably yet acknowledge the value of distinctions, viewing stories more as events recounted and narratives as the discourse that contains stories. As recently as 2010 Frank declared “I make no attempt to define stories” (p. 21) suggesting there is risk in doing so, that there exist too many definitions and great disparity among scholars. He opts instead for a focus on, and understanding of, what stories as living and breathing entities are able to do.

Methodologically, I now assume that stories obtained through a research process are co-constructed (Crotty, 1998; Gergen & Gergen, 1991) between teller, interviewer, and context. This view replaces earlier assumptions of story such as: story as a fixed entity that can fully represent experience, a story as an entity that I might capture, a story as having a firm veracity that I must be authentic to, and a transcribed story as being easily reifiable as opposed to being open to dynamic re-interpretation over time. I favor a view of story as a transformable vehicle used to convey experience as best we can in a given moment for a particular audience, a view that aligns with Riessman (2008), Mishler (1999), and Bruner's (1990) view of narrative as a way of knowing and of telling of our experience (yet never fully). And we remember, all the while, that a person's story about living with illness is one way of knowing one aspect of that person.

While written on this page these insights may appear simplistic, but I experienced these epistemological shifts profoundly. Others using narrative inquiry to explore living with illness share and extend these ideas. For example, Pellico and Chinn (2007) extend Riessman's work on the aesthetic in stories to that of narrative criticism, and Morris (1998) extends the idea of social influences on illness stories to include biocultural forces, citing AIDS as an example of construction between biology and culture that impacts how an individual experiences living with illness. In summary, I now hold the distinction between narrative and story lightly, believing "illness is a call for stories" (Frank, 1995; Sakalys, 2003) and that "illness has to be 'storied' to 'exist'" and storied convincingly as the very treatment one receives depends on it (Bulow, 2008, p. 131).

2. Narrative Inquiry

Narrative inquiry offers a critical way to think about stories from a research perspective. I draw on the work of Riessman (2008) and Mishler (1999) in taking up narrative inquiry as an intersubjective engagement between an active teller and active listener, a relational connection undertaken with another such that an opportunity is provided for the telling of a sensory experience in a way that is dialogical, recursive, and gives rise to a rich, newly co-constructed story. This view of narrative inquiry supports an aim of “seeing how knowledge is constructed in the everyday world through an ordinary communicative act – storytelling” (Riessman, p. 14). Through stories we offer our experience and may find meaning through the act of doing so. As a qualitative methodology, I have used narrative inquiry as a way to hold ideas loosely, softly, letting go, opening up, being okay with being in-between and holding tension. I have paid attention to particulars as a way to illuminate universals of the human condition, and therein lies the beauty of narrative...to recognize that stories are heavily imbued with social, historical, political, and medicalized stories concurrently at play in our experiences. For these reasons narrative inquiry requires close interpretation or analysis, to “interrogate intention and language” (Riessman, p. 11), as so much is contained in stories, so many influences, taken for granted discourses, and values. Throughout this inquiry, I hold a view that stories must be considered in the context in which they are told. A focus on language across the manuscripts was a way to reveal social attitudes as part of the context that informs and shape participant experiences.

3. Conversation

In this inquiry participant stories were generated through an interactive interview process as explored in Chapter Two. Over time I came to consider interviews in relation to the idea of conversation as described by Oakeshott's (1959) in his short essay "the voice of poetry in the conversation of mankind." While humans most often use conversation as a functional means to convey information or make an argument, what Oakeshott refers to as a dominant scientific and practical discourse, I now understand conversation more broadly; conversation as "an unrehearsed intellectual adventure" (Oakeshott p. 11) where talk takes place without focusing on a conclusion but rather as a creative exchange that contributes to learning. This notion of conversation brings to mind sharing stories, as in a storying exchange we use language and have a back and forth conversation with another that helps us make or discover meaning and provide an opportunity to imagine or get close to another's experience. And in this back and forth exchange social influences are present in the language and the context of the exchange. A poetic mode to conversations offers the possibility to engage our imagination, interrupt and soften other discourses, and invite contemplation and delight.

To aspire to such a view of conversation in narrative inquiry poses challenges as narrative inquiry, by its nature, shifts storying away from the poetic into a practical discourse. That is, a narrative interview emphasizes relation yet is designed to yield an outcome, be efficient, and gather information, and does not hold well the tensions of playfulness and seriousness. A conversation would be more provocative, have no doorkeeper, and be more of an "unrehearsed intellectual adventure" (Oakeshott, p. 11). I see this in how I engage with interview questions, how I listen, and in my analysis. In

retrospect the metaphor of shadows and sunshine is more symbolic in language than poetic, in that I aimed to grab attention and hold tension. I extend this idea to nursing research and practice where we are faced with a dual challenge: to listen with an analytic ear and to also listen for the poetic voice of the patient in conversation. Rorty (1979) also aligns conversation with imagination and suggests our current language is no longer sufficient; we need new metaphors that ignite our imagination as a way forward in our world.

4. Experience

In the human and social sciences it is generally recognized that it is not possible to have direct knowledge of the world, that we know our world through our experience of it. I draw on Merleau-Ponty (1964) to understand that as we interact with our world, the body is how one naturally accesses the world and experiences it through perception, with language being in the core of culture. For experience to happen and for it to be storied through language calls for conscious engagement with what is happening, and this links us to the notion of intention as we interact in a world already there. For this reason Merleau-Ponty (1979) favoured perception over epistemology as a starting point for understanding how we make sense of our world.

This brings me to narrative inquiry. Narrative begins with experience, a concept that has compelled philosophers over time and remains elusive (Jay, 2005). Jay describes debates as focusing on a wide variety of contextual aspects of experience (epistemological, religious, aesthetic, historical) and views of experience as lived reality or a linguistic concept (that is, can experience be understood through language). His in-depth study of experience affords insight and suggests no totalizing account of experience

can do it justice. I draw heavily on Jay's view of the idea of experience as ubiquitous and necessarily holding generative paradox and tension, and come to understand experience as a lived reality within cultural constructs, "the only bridge from interior to exterior reality" (p. 264). (This view of experience aligns with a view that narratives mediate the inner world of thoughts and perceptions and the outer world of actions we live in (Bruner, 1990; Garro & Mattingly, 2000). Tension arises in that the idea of experience is to point to that which is usually beyond language, ineffable, or individual and yet we try to share this through language – an intersection between private subjectivity and public language, "to acknowledge that experience is at once deeply personal and yet to a significant extent capable of being shared with others" (Jay, 406). This conceptualization of experience which I draw on is congruent with the constructionist thread of this inquiry. Emphasis is on the idea that experience must be undergone or suffered, that it cannot be acquired vicariously, and that through sharing or recounting it becomes a meaningful narrative available to others. Paradox lies also in the idea that experience is personal, it is your experience and it leaves you altered in some way, and yet it arises only through an encounter, an engagement with otherness. And in this there is an element of intention, a willingness to move outside the self, an aspect of surrender, a turning towards the other, in order to have an experience. I turn to Jay's direct words to emphasize this aspect of intersubjectivity that is pivotal to the findings of this inquiry.

The paradox is evident in another way. However much we construe experience as a personal possession – it is inevitably acquired through an encounter with otherness, whether human or not. That is, an experience, however we define it, cannot simply duplicate the prior reality of the one who undergoes it, leaving him or her precisely as before; something must be altered, something new must happen, to make the term meaningful. Whether a 'fall' from innocent or a gain of new wisdom, an enrichment of life or a bitter lesson in its follies, something worthy of the name 'experience' cannot leave you where you began. (p. 7)

To take thinking forward and encourage an open concept of experience, Jay (2005) refers to Gadamer's expression of the "interminability of all experience" (p. 402), the idea that experience frees and opens us up to new experiences, an unending cycle. Dewey (1938) also understands experience as continual and interactional. I see this relating to Frank's (2008) belief that an experience of event, when told, becomes an experience unto itself:

As storytellers hear themselves tell their stories, they become able to know their own experiences in a new way. They establish an attitude toward an event that becomes the experience of the event. Experience comes to be through the story telling experience. (p. 122)

Anthropologist Cheryl Mattingly (1998) also contends there is a difference or a "distortion" between the lived and the told. And this all leads to discussions of narratives and whether they can represent experience. I arrive at a place of accepting yes, narratives are a way to convey and share our experience, but prefer to use the term re-present as do Hazel (2007) and Sandelowski (1998) to illustrate that one can never fully be the other, stories get us as close as is possible to the experience of another.

The notion of experience is also considered in regard to our socialization, raising a deeper consideration as to the interplay between stories and experience: do stories happen first or experience? While a more traditional view would be to accept we have experiences and tell about them, Mattingly (1998) and Frank (2010) tease this apart to contend we are so influenced by culture and grand stories which guide our lives that it is those stories that happen first and our experiences fit into them. The stories revealed during the course of this inquiry have influenced me such that I have come to take up this conceptualization with conviction. I suggest at birth we enter a culture and in this sense we are born into a story, a story that comes to influence how we experience and make

sense of events. This view is congruent with how I take up social constructionism and reflects the synergy of how we come to language.

5. Language

The preceding section focused on experience, and given that individuals most often communicate experience through voice, I now focus on the concept of language that is critical to this inquiry. I preface this section by pulling together an overview of my initial understanding of language as alluded to in Chapter One, and then share my expanded understanding of the concept of language as primary.

At the outset, I understood language as a holder of meaning that we use to express sensory experience; a way to tell our experience into existence, to be seen, and to know ourselves. We use language to tell a story, and the story becomes the vehicle by which we communicate or share our experience in an attempt to make meaning. I recognized language as heavily imbued with influences from the world around us. I drew on Bakhtin's (1981) concepts of heteroglossia and the dialogical. I was also influenced by Donald's (1998) view that we live in words, that as humans we have the capacity for symbolisation that happens in our brains and in our bodies, and this linking of thoughts and feelings through narratives makes them so powerful. Anderson (1992), who draws on early works of Heidegger, Gadamer, and Gergen, put forth that "the language we use makes us who we are in the moment we use it" (p. 64). In the development of my work I also drew on Gergen and Gergen's (1991) view on the role of language we bring to an object, that language is a shared system of intelligibility such that knowing and meaning happen through relations; bringing forth the idea of a relational view of self. Stories or accounts arise "as an expression of relationships among persons" and it is "within social

interaction that language is generated, sustained, and abandoned” (p. 78). This constructionist view of the socially embedded and collectively generated is further expressed by Gergen and McNamee (1992) who describe language as our shared discourse that supports and limits what we say: “Our constructions of the world and ourselves are limited by our languages, but these limitations must be traced at last to us” (p. 5), in that we create and generate our discourse and can also alter it. I return to the preceding concept of experience understood as being cyclical and find I now see the same applies to this discussion of language; it is not a question of whether language shapes our experience or experience shapes our language, but rather an interdependence and cyclical nature of both influencing each other.

Over time I came to understand the role of language in storying in a profoundly new way. I draw on three key ideas (Maturana, 2011) to augment my earlier thinking: firstly, that language is primary; secondly, we need interaction for meaning to happen; and lastly, we are emotional and rational beings and when emotion appears, our conversation changes. In this view, language is considered a primary medium we use to communicate and founded on certain metaphors which direct and shape our thinking in society (Lakoff & Johnson, 1980). Simply said, we talk about something to make it real and come into existence. This is opposite to earlier thinking that suggested something existed and then we talked about it. For example, we talk about a pen, but until we talk and come to an understanding of what a pen is, we cannot talk about a pen. Through language, described as “a flow of living together” (Maturana), we come to a shared understanding, in this instance of what a pen is. And we need another human being to language with, that is, we need a network of relations and connections. Additionally,

Maturana emphasizes that in our language exchanges, when emotion appears our conversation changes in depth, our desires arise, and this is the beauty of what we do as human beings. In this emerging view, meaning making happens in the telling and with the use of language. In studying mathematics, Thom (2012) draws on the work of Sfard (2000) whose work aligns with Maturana. Sfard too argues for and further develops the claim of the primacy of communication, that we do not start with abstract objects (such as numbers) and then communicate but rather it is the reversal, we communicate and through dialogue abstract objects come into being. Said another way, “conversation occasions meaning making” (Trueit, 2013, oral exchange). Implications of accepting this view in relation to storying of illness experiences in nursing are paramount. When a person has an illness, is possibly scared and facing challenges, it is nurses they trust (Gordon, 2010) and often turn to, to talk, share, and attempt to make sense of what they are experiencing. It seems imperative that in nursing practice we strive to provide or create opportunities for persons to story, that we support individuals to voice their experience and listen (more) attentively. “Language matters, because it can determine how we think and act” (Lakoff & Frisch, 2006).

6. Metaphor

This next section focuses on metaphors and flows from the preceding understanding of language as metaphors are integral to the functioning of all language (Abrams, 1993). I reviewed metaphors specific to HIV in Chapter One and revisit this before sharing my expanded understanding in relation to this inquiry. I had emphasized the possibility and power within metaphors to influence and disrupt ourselves and others in emotional, intellectual, and moral ways. Also, that meaning happens for individuals

when a shift in personal knowing takes place and such a shift is often generated by metaphor. This is significant in relation to stories about living with illness, as stories told and language used to convey them must be convincing as the very treatment one does or does not receive depends on this (Bulow, 2008). I have come to be influenced by, find congruence, and hold interconnections between several perspectives about how metaphor contributes to understanding.

My understanding of metaphor is now more inclusive, shifting from a novice view of straightforward representation to a view beyond representation. A notion of metaphor as representation has been helpful as a base, as a way to begin to understand experience and stories. The idea of one thing representing another enables linguistic transference between the two things, but while comparing can ignite and convey ideas, it can also reduce (Coffey & Atkinson, 1996). In the *Rule of Metaphor*, Ricoeur (1975/2003) prefers “displacement” over the term reduction: “Metaphor constitutes a displacement and an extension of the meaning of words; its explanation is grounded in a theory of substitution” (p. 1). The idea of there being any “truth” seems too narrow for our times where the notion of absolute truths has fallen, and the idea that we can accurately capture the relationship between a representation and an object is challenged (Gergen, 1992). I take up a view of narratives in relation to social constructionism, that any description rendered, such as a story, is not seen as a mirror or a straightforward representation of reality, but a complex representation containing the plural voices of many in our social culture. In this sense there is no true interpretation, but there are pragmatic, liberating, helpful, and rewarding interpretations. I have come to take up the idea of representation cautiously, relating to the previous discussion that we collectively

create and use language to name something but no objects have absolute or pure meanings, or any meaning, it is the meaning we assign as constituted by our language, culture and experience, making representation anything but straightforward. The likening within representation is even more tenuous and of importance in illness experiences, as metaphors often compare two *unlike* things and yet we soon come to speak of and think of the second thing *as if* it was the primary, the danger being that the linkage may capture only one aspect of the subject, leaving the listener of a story trying to make sense and possibly misinterpreting.

I have come to appreciate Rorty's (1979) view that the mind is not a mirror that holds representation. He advocates for a view of metaphor beyond representation, a non-cognitive, experience based view of metaphor and abandonment of the idea of knowledge "as accuracy of representation" or a mental mirroring of our natural world (what he referred to as "the story of the domination of the mind of the West" (p. 13). As discussed in relation to the concept of experience, I lean toward the use of "re-presentation" (Hazel, 2007; Sandelowski, 1998) to reflect a more spacious view, to illustrate that stories get us as close as is possible to the experience of another. Garro and Mattingly (2000) allude to this in reminding us that a story holds a distortion between lived and told, and Frank (2008) too alludes to a separation between the experience and the story, the story telling being an experience in itself that tries to convey that experience. I come to envision the idea of metaphor on a continuum that begins with straightforward representation, moves to re-presentation, and toward conversations and imagination. I heed Rorty's call that this will support new metaphors, interpretive meaning, and will help with intellectual and moral progress.

I am influenced by philosophers Merleau-Ponty (1989) and Rorty (1979) who saw language and conversation as poetic. Others across domains also who hold a view of metaphor as poetic and perception, being attentive to aesthetic, visual, and generative aspects: Gergen (1982), Van Manen (1990), John Kabat-Zinn (1994), Gadow (1995), Zwicky (2003) and Trueit (2005) to name but a few. The idea of reconsidering metaphor from a more ancient aspect of the poetic and creative generates passion and emotion, new thinking, language, and metaphors. In regard to illness, Kleinman (1988) speaks of the necessity to return to a connection with those in our care, to the “heart of healing”, “that aspect of the healer’s art that is most ancient, most powerful, and most existentially rewarding” (p. xiv). I see value in embracing perception through metaphors as a means to convey how we relate to things in our world. Gergen (1982) draws on Heidegger in encouraging us to rely more on “*visual substitution* than conceptual manipulation” (p. 144). I draw on Merleau-Ponty’s (1979) philosophy about “being-in-the-world,” emphasizing the everyday and our situatedness, consciousness as intentional and embodied, the primordialness of perception and prereflection, and the perceiver as body-subject, as this view offers a balance that how we understand cannot be reduced to a cognitive process alone. His perspective evokes a mysterious richness and places humans in and of the natural world, existing with the other in a continuous dialectical interaction.

I hold the ideas of metaphor as re-presentation and poetic/perception and find they are compatible with ideas of cognitive linguists Lakoff and Johnson (1980, 1999) who I also draw on. In this view metaphor is believed to be more than language and words; we think in terms of metaphoric conceptual frames and cognitive maps, with emotion,

embodiment, and the subconscious also playing a role in reasoning. Lakoff and Johnson draw on the work Dewey and Merleau-Ponty to incorporate the idea that reason arises from our perceptions and that through embodiment we make sense of our world, that is, humans are neural beings whose reasoning arises from and is shaped by our sensory system. They put forth that human thought processes are metaphorically structured and we use these structures to make inferences and to manage, remember, and communicate in our world; we categorize objects, events, or entities in memory in a hierarchical way. We conceptualize something in metaphoric thought first and this shows itself in language as secondary. Our thoughts are then inscribed on experience through language. In this view, conceptual mapping and cognitive frames of reference allow us to use metaphors pervasively and most often without awareness. Lakoff and Johnson (1994) also developed cross-domain mapping and classifications of master metaphors, for example “love as a journey” and the “treating-illness-is-fighting-a-war” metaphor. This theory is important in relation to how illness is experienced, as once a frame is set (laid on, chosen, or slipped in) it becomes extremely difficult to change or undo, as if etched in it can permeate how one tells about, lives with, and experiences illness. They acknowledge that this systematic way of comprehending one concept through aspects of another may mean that other aspects will remain hidden, and I share this caution which also arises in a view of representation. I have been influenced by the work of Charon (2006) who also expresses the primacy of metaphorical thinking: “metaphor is how the human brain travels” (p. 119).

The approach to analysis of metaphors in this inquiry was envisioned early and on reflection is more re-presentational than conceptual. Metaphors used by participants

reveal and affirm that metaphors hold social constructions and have power to disrupt, move, evoke, inspire, and generate new ideas. Metaphors shape the illness experiences as narrated and lived for older persons with HIV, with metaphors used as a way to express self and reflect the reality of their experience. Associations made through metaphors were subtle at times and not so subtle other times. Metaphors held the capacity to support living well, and some remained as stark reminders of associations made through metaphor that can and continue to hurt, cause rejection, and foster stigma and discrimination. The depth of stigma that continues to be perpetuated in regards to HIV saddens me. I am reminded of how my awareness was jolted by Sontag's (1990) powerful illustration of how metaphors can hold negative cultural associations that come to adversely prejudice those who are ill. For this reason she denounced the use of metaphors in relation to illness, and while I initially agreed with this view and still heed the caution that metaphors can be unhelpful and dangerous, I see it differently now, that metaphors shape the narrated experience of illness and support sense making and understanding.

7. Social Constructionism

This inquiry has been informed by a view of social constructionism, my understanding of which has evolved over the course of this journey. In this section I build on the foundations of the concept presented in Chapter One: that we experience the world through our bodies (Merleau-Ponty), the world is “always already there” (Heidegger in Crotty, p. 44), only when we consciously engage does it become “a world of meaning” (Crotty, p. 10), and as meaning making beings we “construct” meaning. I have taken up social constructionism as a way to deconstruct, untangle, and make explicit

social influences, a way to lay bare constructions at play, and as a way to think about how humans experience and make sense of being in the world. Social constructionism affords a way to think about stories of living with illness and how this calls attention to underpinning essential concepts that converge: experience, language, meaning, conversation, and metaphor. Pulling together what has been discussed in the preceding section, I see now that social influences that come to us through our relations in the world run like a current through each of these concepts and powerfully impact how illness is experienced.

The congruence of narrative inquiry and social constructionism is strong as they share the premise that the social is interwoven into the personal. While a story told is unique and true to the narrator, each story carries the weight of and bears the social confluence of one's culture. This raises the question and tension as to whether there is such a thing as an individual story, to which I respond "yes and no" seeing this not as an either/or but that we are socialized and have agency in this context. I draw on Gergen's (2009) view of agency as relational, "as an action within relationship" (p. 82). While individuals have experiences that feel personal and very real, at the same time each of us is situated in and always linked to a broader whole of relationships that inform our agency. Every story holds the threads of and represents a coming together of many diverse voices.

Findings in the study further shaped my understanding of social constructionism. The stories of participants aging with HIV revealed adults who face great uncertainty as they enter uncharted territory in a social context that highly influences how they construct meaning of their everyday reality. I think about how the stories reflected experiences of

stigma, a negative attitude that arises and is perpetuated in the social world in which they live. I wonder how an individual may strive to arrive at a place of inner confidence, proud identity, and self love, only to experience socialized discriminatory behaviours of others that continually impose pain. The struggle to not internalize socialized attitudes creates tension, an interplay between the personal and social. Internalizing stigma led to suicide attempts, depression, living with secrets, and feelings of isolation. As individuals we construct meaning and are constructed; we assimilate, accommodate, and we inscribe while we are likewise being assimilated, accommodated, and inscribed upon. These key aspects of social constructionism overlap and compliment Riessman's (2008) aforementioned view as narrative inquiry. She draws on J. Bruner to emphasize how individual constructions mesh within a broader community and culture of life stories. A social constructionist perspective enables the relational view critical to my research. It allows for and honors a focus on the individual and the particular while taking into account social influences within storied experiences of living with HIV.

And so Part One draws to a close. In this section I shone a light on scholars whose ideas influenced me and informed this inquiry. Each key concept drawn on holds views similar to mine in acknowledging and emphasizing the importance and impact of relational interactions and social influences on who we are and how we story experience.

Part Two: Significance of the Study

In this next section I consider the individual manuscripts that form the body of this dissertation as a unique whole, as this affords opportunity to make sense and arrive at emergent insights. Chapters Three and Four focused on the stories of illness and metaphors, as vehicles for meaning generation, and offered a way to begin to understand

the experience of adults I met who live the complex reality of aging with HIV. In Chapter Two and Five the focus was on the storied interview exchange and the context of practice. I identify five contributions to the greater body of literature from this narrative inquiry: 1) new understanding of the experience of aging with HIV (1.a, uncertainty; 1.b, storylines; 1.c, live and age well; 1.d, biocultural), 2) new understanding of relation and conversation in storying illness, 3) new understanding of interplay between personal and social in storying illness, 4) illumination of tensions in the interview exchange, and 5) extending the call for new thinking.

1. New understanding of the experience of aging with HIV.

1.a *Stories of aging with HIV as a journey of twists and turns, permeated with tension, uncertainty, and in-between-ness.* Close study of stories and metaphors used by participants revealed they live with certainty and uncertainty, knowing and not knowing. While little research has been done, Solomon, O'Brien, Wilkins, & Gervais (2014) studied the role of uncertainties in older adults living with HIV and found the episodic nature of the illness led to uncertainty related to current care and future needs and an inability to plan. They suggest a need to focus on positive aging and the identification of supportive interventions that enhance health overall. My research adds to this emerging understanding of uncertainty and extends it by highlighting that for my participants, aging with HIV means to live tenuously in-between dichotomous uncertainties, described as tensions of darkness or light. While there is insight into metaphors of living with HIV for younger populations (Drakos, 2008; Hillmer, 2007; Lather & Smithies, 1997), there is just emerging a small body of literature specific to aging with HIV. Gosselink and Myllykangas (2007), in their study of older women with HIV, found inequalities of

health and leisure resources and yet each woman showed resilience and came to see leisure as a metaphor for the meaning of life. Jones (2002) studied the lived experience of nurses (ages 28-52) who live HIV+ and found a metaphor of a double-edged sword to represent the benefits and disadvantages of taking HIV medications. A year later she studied ten adults ages 35-58 taking HAART, and found the metaphor “a bitter pill to swallow” (Jones, 2003). My research adds to understanding of the experience of aging with HIV through metaphors and further reveals the powerful impact of social influences embedded in language. The metaphor of sunshine and shadows extends current metaphors by emphasizing the dichotomous nature of the experience. This is significant as it informs understanding that tensions exist in and shape the lives and stories of older adults aging with HIV who often hold both aspects of the tension at the same time. A listener with this understanding and awareness can better consider the delicate reality of living in-between. They will have a heightened awareness of and openness to stories as non-linear, an awareness that each story shared of a life lived happens in the same way that life itself is lived, with a dynamic, fluid, living and breathing quality. This will positively impact how we understand, interact with, and support adults living this challenging reality.

1.b *A new way to conceptualize aging with HIV as six storylines.* Analysis and close attention to the particular in each participant’s story generated six storylines that threaded through all stories: embodiment of the illness, sense making, death and loss, secrets and stigma, identity, and seeking connection. The storylines reveal key aspects of the experience and how sense making happens in a fluid, shifting way. Storylines provide for appreciation of this, and like a typology that is kept open, can enhance understanding

and guide those listening to as well as those telling stories (Frank, 2010). As a whole, these dynamic storylines come together as a general concept that can be shared and generate knowledge (Riessman, 2008) and also offer a way to enhance understanding and guide listening. Researchers or clinicians wanting to understand the experience of older adults aging with HIV can draw on this typology. It may also be helpful to those aging with HIV to make sense of their own experience.

No study to date has identified this set of storylines specific to older adults with HIV. There is a small amount of research that identifies aspects of each individual storyline for this population, which findings of this inquiry complement. Regarding embodiment, Kirk and Goetz (2009) describe how medications, aging, and the virus result in a metabolic syndrome that leads to older adults experiencing many bodily symptoms. Regarding death and loss, older adults with HIV face co-morbidities as described at length in Chapter One, and also experience thoughts of loss. Vance, Brennan, Enah, Smith and Kaur (2011) found that adults aging with HIV face adversity and stigma and benefit from religiosity and spirituality. The storyline of secrets and stigma complements and extends research described in the preceding section related to metaphors and confirms testimonials (Scott, 2002). The storyline of identity relates to research about sexual identity and behaviors (Lourdes et al., 2008). The storyline of seeking connection relates to Gosselink and Myllykangas (2007) finding about the positive value of leisure activities. Conversely, research shows that many adults in this population face a co-morbidity of depression (Jang, Anderson, & Mentes, 2011) and social withdrawal (Vance & Burrage, 2006). The storyline of sense making aligns with Reed's (2008) emerging nursing theory of transcendence in which the importance of

storytelling or sharing personal narratives is emphasized as an antecedent to transcendence in aging, the outcome of which is having a sense of meaning and satisfaction. This inquiry also adds to emerging theory development in psychology by researchers such as Antonovsky (1987), Park (2011) and Pakenham (2011) who suggest telling of one's experience has a potent effect on health and is essential to sense making and one's ability to cope. Pakenham (2011) focuses on 'sense-making' as a potent predictor of adjustment in chronic illness and proposes a model of sense-making that involves seven processes: "finding new life purpose, awakening to the spiritual, finding cause, revising life values and goals, appreciate social ties as a source of meaning, accepting life as it is, and acknowledging the randomness and/or the incomprehensibility of some events" (p. 264). While all processes were present in the stories of participants aging with HIV to some degree, more research would be needed to see how they align with this formal theory of sense-making.

1.c Ability to live and age better through sense making. Close study of the storied experiences of participants revealed how their ability to make sense affects how well they are able to live and age with HIV. The benefits of sense-making in relation to a sense of well-being when living with illness have been established in the literature as described in the above preceding storyline of sense making. Ironson and Kremer (2011) found evidence that a variety of coping strategies are effective and that avoidant coping strategies have a detrimental effect for persons of all ages living with HIV. Antoni's (2011) research on stress, coping, and health in HIV/AIDS highlights the need for psychosocial interventions that support optimal physical and mental outcomes. We add to current knowledge about the importance of meaning making through an exploration of

aging and the fluidity of meaning making. The storylines outlined in this study reflect how cultural influences, be they positive or negative, come together with great significance to infiltrate, impact, and shape experience. Social constructions influence how a person sees themselves and the sense they make of their life with HIV. How one is able to grapple with and hold these tensions, to live in-between, relates proportionately to one's ability to make sense and meaning, and to ultimately live and age better or as well as is possible for them. One's ability to derive meaning is proportional to how well one adapts and thrives, or not, in the present moment. This is powerful in and of itself, but also for into the future. Remen (1996) alludes to this aspect of storying that is unrehearsed and takes us into a future, as does Frank (2010) when he talks about improvisation and uncertainty grappled with in the telling and that helps us to make sense. Ricoeur (1984) also holds the idea that people story in the present with a context of the past, and it helps to imagine the 'not yet'. This is significant as we live our lives within social contexts and are socialized whether knowingly or not; the key being to try as best one can to discern, untangle, and identify what influences are at play and whether they support us to stand for what we believe and value. We are influenced, and through relationships in our social world we develop agency such that we can make choices and decisions (Gergen, 2009). In putting forth this idea of reconciliation and ability to live and age better I do not use the concepts of coping or adaptation that align with a psychological perspective, although research in this area is extending understanding of how lives can be lived better.

1.d) *Shift to biocultural.* Stories of participants point to the critical intersection between the biological impact of HIV in the body and cultural factors that impact and transform

the experience of living and aging with HIV. This inquiry contributes to the view that we cannot focus on just the biomedical, but need awareness and inclusion of the role and impact of cultural factors on the experience of aging with HIV. This view aligns with Morris's (1998) examination of how illness is constructed. He calls for "awareness of the elaborate interconnections between biology and culture" (the biocultural) in the hope that only then will we arrive at "a new, transitional, and unfinished understanding of illness" (p. 11). More recently, Davis and Morris (2007) put forth a manifesto calling for an understanding of culture and history in relation to biology. This is significant for those living and aging with HIV as the disease is heavily impacted by social constructions. Stories of participants reveal that to age with HIV is extremely complex due to elements of stigma, the reality of being pioneers, living with uncertainty, and having pain from the past remain ever fresh. Challenges also arise related to the impact of powerful drug regimes and not knowing how an aging body will respond over time. de Vries (2008) reminds us of many age related social factors that also come into play for older adults aging with HIV: a lack of public awareness, preventative campaigns targeted at younger populations, doctors not aware, and older adults who may not be comfortable talking about sex. What is concerning is that while the prevalence of HIV in older adults is increasing, a study by Lourdes et al. (2008) suggests sexually active older adults with HIV may be engaging in high risk transmission behaviours and that perceived stigma is associated with inconsistent condom use. This finding aligns with participant stories in this inquiry, expressions of fear of rejection often leading to withholding or a delay in disclosure of HIV status.

2. New understanding of relation and conversation in storying illness.

This inquiry extends what we understand about the importance of a relational aspect between a listener and the person sharing their experience of living with illness. An assumption of narrative inquiry is that a relationship between the researcher and the researched supports storying to happen (Pinnegar & Daynes, 2007), the premise being that a sense of intersubjectivity and relation or connection evokes trust and fosters the sharing of experience with depth and emotion (Gadow, 1999). Such an approach affords a listener opportunity to get as close as possible to what this experience might be like for the teller constituted within a social context. A rich depth of storying also supports the possibility for the story teller to make sense and meaning, which findings of this inquiry suggest impacts one's ability to live well.

In this inquiry, fairly extensive relations were established with participants through five in-depth interviews over a 3 ½ year period. This fostered trust and the sharing of intense human experiences arising from aging with HIV for many years. Participants expressed gratitude for being genuinely listened to and for the creation of an intentional connection based on respect. Participants also shared how telling their story helped them to make sense in the moment of telling. These findings add to a small but growing body of work about secondary or unintended benefits of in-depth research interviews, expressed by participants as helpful or therapeutic (Lowe & Paul, 2006) and cathartic, self validating, offering a sense of purpose, empowering, and healing (Hutchinson, Wilson, & Wilson, 1994). This finding takes us beyond the notion of intersubjectivity and links to emergent research suggesting the primacy of language and the need for languaging through conversations to take place for meaning to happen (Maturana, 2011).

That is, participants support the notion that people make sense in the dynamic space of telling and that when emotions appear, the conversation changes. This also underscores the importance of establishing relational, trusting connections in qualitative inquiry that support sharing about experiences that take place over time, rather than a single interview. In the clinical context with increasing demands for clinician's time, it becomes more critical that persons living with a complex disease such as HIV are afforded the opportunity to put language to and tell of their experiences.

3. New understanding of interplay between personal and social in storying illness.

To age with HIV is complex. Data in the form of storied experience was alive with tension of an interplay between a participant's experiences that felt and were personal and also held the social values and beliefs of the world in which they live their lives. This interplay suggests that an either/or between personal and social that we often imagine is not helpful and does not fit with the experience of aging with HIV. These binaries can fade away in the space afforded by an understanding of social constructionism. The idea of moving beyond "either/or" toward a view of "both/and" such that we encompass multiple ideas aligns with the work of Sandelowski (2013) and Reimer, Kirkham, and Browne (2006) in the context of nursing. This is significant, as this interplay and dynamic tension of the coming together of personal and social influences impacts experience and supports meaning to happen. This meaning making is ongoing and fluid in that we are constantly having experiences in the context of our world; we story and re-story as individuals and as a society as a whole (Figure 1). Meaning making is conceptualized as happening individually and collectively. It may be that we are in the midst of a more global shift towards what Pink (2006) describes as a

conceptual age and a turn towards an interconnected view of being in the world (Gergen, 2009; Watters, 2010). This inquiry contributes to the notion of interdependent rather than independent realities, and extends understanding by suggesting that to hold the tension between the individual and social can fosters change to happen.

I expand on this understanding in further detail here and note that essences have also been touched on earlier when discussing interrelated concepts. In this narrative inquiry attention was paid to social constructs, cases, and the particular (Riessman, 2008). Revealing the particular was a way to illuminate universals of the human condition. There was an open view that individual stories are just that in one sense, and yet each of us is so inscribed and constituted by our social world that our story also holds broader stories. The power of beliefs constructed in and carried through society were evident in the language found in the stories, both in the metaphors and storylines that pointed to a tension between the social and one's sense of personal experience. Social influences were present in many forms, so interwoven and dominant in their ability to impact and shape a participant's experience in positive or adverse ways that participants often found it difficult to discern what made sense for them. Tensions reflect the conflict and contradictions one may experience between the story they narrate of living with HIV and dominant cultural or medical narratives that hold different or opposing views. This meant sense making was ever tenuous and back and forth, a negotiation and attempt to reconcile differences between individual experience and cultural influences; the impact of the social being experienced by each participant in different and similar ways, and influencing their ability to reconcile tensions, shifting away and back and forth. Participants struggled to distinguish themselves from negative social influences that

fostered stigma and secrets and challenged a sense of identity and embodiment of the disease. Participants often expressed the lived reality as a physical sense of heaviness. More positive social ideas of aging adults such as that of wise elder also impacted this group in varying degrees by fostering shifts in identity, self perception, and a sense of belonging. Further tensions were expressed regarding a shift in public understanding of HIV as a chronic illness, a metanarrative that offers hope yet hides other challenges of aging with HIV.

4. Illuminating tensions in narrative interview.

My focus on interviewing in narrative inquiry as expounded on in Chapter Two brings to the fore tensions between: presence and performance, equality and power, following and leading, being an outsider and an insider, being non-influential and influencing, and the tension between trust and responsibility. The nature of research and interviews creates a performative element for both the researcher and the participant. The tensions are not necessarily good or bad, but may influence the interaction on many levels. While these tensions may add a dynamic nature to the interview that is helpful, I question, as do Hoskins and White (2103), whether they could be reconciled in any way. Exposing them may assist novice researchers and others to prepare such that interview stories generated are rich and meaningful. While the work of Kvale (1996) provides some guidance for novice researchers, my narrative account engaging dialogical narrative interviews contributes through its storytelling, reflexive approach. I also question whether we are at an opportune time to imagine the interview a step beyond Mishler's (1986) conceptualization of the research interview as a narrative event, and expand his philosophical assumption of dialogical processes and the interview as even more

conversational and relational. Hoskins and White support this shift in language, as does Kvale. Through this inquiry I build on Oakeshott's (1959) notion of the conversational and expand research interviews beyond a practical aspect to include a poetic element, challenging ideas of power, purpose, and outcome. I consider ways of thinking about the qualitative interview process that exist within a constructed dynamic of power that impacts and nuances verbal exchanges, and how researchers can become aware of and potentially mitigate these influences.

Chapter Three raises further questions, one being that of professional boundaries that influence the possible depth of a research relationship. Some might argue that in this day and age the idea of such boundaries has fallen away, but I do not find this to be so. As a nurse I am bound by an ethical code and guidelines about relations, the absence of which could place professionals and those they interact with at risk. While necessary, I believe it timely to question the boundaries. For example, attention is begin paid to a continuum of involvement and "boundary crossing" in practice settings (Nursing and Midwifery Board of Australia, 2010). Within a context of subjectivity, I take this further and suggest closer examination of boundaries that influence professionals and human relations. For example, questioning who has set what boundaries, in whose interest, for what reasons, and what role does language used play.

While inquiry and practice roles espouse an ideal of engagement associated with subjectivity, one that I strive for, to what degree can this be most fully enacted? We are subjective, that is we bring our personal selves to our role, but to what degree is this possible given professional and employer related boundaries? We have gained access to the person facing illness by nature of the formal role we bring, the rules of which lie

behind and underneath us. To be subjective is wrought with tensions in nursing: how subjective is our capacity, where are lines if there are any, how easy is it to discern the boundaries if they do exist, and are they becoming more blurred? If I was fully subjective I would act on a post study impulse to continue a relationship with a participant, to stop in and connect with them every now and then. Yet this does not seem appropriate, as intimate stories were shared in a context of a professional relationship. White and Hoskins (2013) explore similar concerns for care practitioners in student researcher roles who conduct narrative interviews, concerns related to perceived risks of fulsome engagement, ontological positioning and depth of subjectivity, degree of “leaning in,” and fear of exploitation, to name a few. They draw on the work of Gergen (2009) and put forth a call for process metaphors that capture the fluidity of the research interview and also guide it: “where the researcher can imagine sitting side by side with participants, where they could explore something together ...and metaphorically hold it in both of their hands, pass it back and forth, turn it, feel it, sense it and make sense of it” (p. 186). Munhall (2007) further invites thoughts about changing the titles of researcher and participant to that of “collaborators,” something that more fully moves us toward the intersubjective we idealize.

5. Extends the call for new thinking.

This inquiry led me to understand many concepts in a broadened way and align my voice with others who call for new thinking and paradigm shifts in the human sciences as we imagine a way forward into the future. That is, to hold concepts more tenderly, with an aim to open up rather than lock in ideas, to allow imagined lines

between to dissolve or fall away, and to be open to an aspect of creativity in our world of constructing influences.

Regarding creativity and spirit, I am inspired by Ricoeur (1975/2003) who expresses a thread of the spiritual in his view of social constructionism, and Crotty (1998) who invites us to reinterpret how we make meaning when we engage in our world. I lean toward a compliment of co-construction and co-creation and arrive at a synergistic place where mystery and creativity arise and flourish within a lived context of cultural influences that imbue us. This view fills me with awe and sustains hope for a future with unknowns and possibilities.

I think about the saying “lean toward the good” and I do. To write about narrative and storying as I do reflects my belief in human kindness and our connection with the other. I see a need for and support those who call for a shift from the egocentric view so engrained in our western world (Watters, 2010) to a more sociocentric, collectivist notion of self and shared realities and influences. This idea is reflected in other cultures, for example the African concept of ubuntu (Venter, 2004) and the west coast Salish “q̓uree nut za”, we are all one (personal conversation Gerry Oleman, 2014). This would shift the idea of story to that of an interdependent reality and open up recognition of contextual layers such that our stories are richer, more fully informed, and not perceived as standing alone. I believe such a view may help make us more, greater than our individual selves, and build tolerance in society. While an I-centric way of being may be difficult to let go of, there is hope. Rifkin (2009) describes our civilization as empathic and suggests we have the need and potential to shift from what he calls an exclusive-autonomous self to an inclusive-relational self, and that narrative is critical to engagement.

The above notion of shared realities leads me to speak of ethics and an understanding of how we are or could aim to be with others in relationship. My views align with those who call for a shift towards more relational view of self (Gergen, 2009), relational-responsive understanding through dialogical exchanges (Shotter, 1997), and relational patient centered care (Engel, Zarconi, Pethtel, & Missimi, 2008; Charon, 2006). This is closely linked with philosophical views that inform my understanding about how we are intersubjectively and primacy of the other in relation to self, or as expressed by Levinas: “The I does not begin with itself in some pure moment of autonomous self-consciousness, but in relation with the other, for whom it remains forever responsible” (in Kearney, 1984, p. 48). A philosopher of our time who was influenced by Levinas, Jean-Luc Marion (2007), writes about love as the ethic that will take us forward. Gadwin (1999) speaks of narratives, ethics and the existential. She posits that through relational narratives ethical knowledge is created, knowledge that is “particular, contextual, and nongeneralizable” (p. 65); that individuals are self-interpreting and through personal narratives offer their own account of the good they seek. This thinking places ethics as foundational and in my opinion aligns with an emergent shift towards blurring imagined lines between ontology and epistemology (Guba & Lincoln, 1994) and an emphasis on relational being.

I add my voice to those in nursing who are also positing that our way forward will involve reconceptualising many concepts and ideas that currently underpin our inquiries and practice. Porter O’Grady and Malloch (2011) suggest we draw on chaos, complexity and quantum theory, and Jean Watson (2003, 2014) asks us to learn caring. Bruce (2002) invites us to question conventional representational binaries such that we consider ways

of listening and being with the other that support mindfulness and abiding in liminal spaces, for example, to shift from listening “for” and “to” toward “listening into.” More specific to narrative inquiry, Mitchell, *Jonas-Simpson and Cross (2013)*, Doll, Fleener, Trueit, and St. Julien (2008), and Trueit (2005) support a view of making meaning through interactions that can act as a bridge toward complexity theory and new ways of thinking. Pellico and Chinn (2007) propose narrative criticism as new theory that brings into play the aesthetic. Gaydos (2005) has also fostered a call for recognition of the aesthetic and co creation within narrative. While from sociology and not nursing, similarly Frank (2010) pushes us toward new thoughts about narrative analysis. With “dialogical narrative analysis” he proposes a shift away from themes to a series of questions that point to how stories inform and give form to human life, questions that focus on what stories do. Beyond nursing, there is a movement towards a notion of third space. From a theological perspective O’Donohue (2004) refers to a third space as spirit. Doll (2003) draws on the work of Serres (1997) to convey third space as spiritual, “a space that honours, utilizes the ineffable, the aesthetic, the creative, the passionate, the awe-inspiring” (p. 2), and he calls us to a more emergent theory of complexity that may open opportunities for more humane relations and create hope in our society. Others write with an emerging focus on radical hospitality (Collins Pratt & Homan, 2002), moral imagination (Lederach, 2005), genuine listening (Remen, 1996), leaning in (Pelias, 2011), lived compassion (Tippett, 2011), and kindness (Webster, 2010). Our interconnectedness is so great as to have us consider whether the teller and listener of a story are really separate?

And so Part Two draws to a close. The five significant findings highlight the powerful impact of three converging phenomena, namely HIV, aging, and HAART in the context of storying experience. In the center of this triad (Figure 2, p. X) is stigma, rearing its head and continuing to impact the lives of older adults with HIV in a drastic way. The findings illustrate why this inquiry is timely and contributes to knowledge in the area of storying in nursing practice.

Part Three: Considerations

Implications for Nursing

The thesis I arrive at through this study is that storying plays a key role in the well being of individuals aging with HIV, and this experience has implications for nurses and how they practice. In this section I address practical care implications, followed by a manifesto in which I promote relational care and a narrative approach in nursing.

Key findings of this inquiry point to several implications for health care providers (HCP) such as nurses who care for older adults aging with HIV. Are there resources developed and available to educate HCPs about accelerated aging and a number of critical developments that are only beginning to be fully understood, such as: the long term impact of antiretroviral medications on the aging body; the confluence of HIV and aging and medications; and the role of stigmatization specific to older adults with HIV and how it affects wellbeing and health, socialization, and isolation? Additional questions arise, such as how can HCPs learn more about the importance of seeing the individual before them and not foregrounding the HIV label? As well, gaps exist in our care. While there are specialized care facilities for persons with AIDS (Selwyn et al., 2000), older adults with HIV who need assistance with ongoing care needs are entering

mainstream long term care settings. While I am surprised to find no formal literature, challenges of integration are being identified in news stories: discrimination based on the virus, reverse age, and often sexuality (Pigg, 2011). How will we prepare staff in residential care settings to create a culture that does not discriminate through care procedures and biased behaviours as this population enters this aspect of our care system for the first time? There is a growing recognition that more training of staff is needed (Houston, 2012). Federal funding helped develop a specialized training program including DVDs through the Re kai Centre (2013) and a rollout plan across Canada is being developed. This is hopeful and important, as participants in this inquiry conveyed that the presence of adverse and impactful social and cultural influences remains real. This is significant as discrimination is recognized as an established social determinant of health associated (Currie, Cameron Wild, Schopflocher, Laing, & Veugelers, 2012). As more research comes available about epigenetics and the adverse biological effects of living with discrimination (Wilkinson, & Marmot, 2003), I wonder if this may extend to an older adult with HIV. Might it be that not having an opportunity to talk about this illness experience may adversely impact well being, increase pain, and inadvertently cause harm? Education will be paramount as we move forward and aspire to provide care that is respectful and informed. As information resources are developed, planning will be required for effective dissemination in nursing and health care settings. Ideally, this would be augmented by opportunities for conversations around attitudes and often unrecognized biases, conversations that inspire reflection and a sense of connection such that social constructions which are hurtful, harmful, or manipulative may begin to fall away.

This inquiry also pointed to the value of storying for those aging with HIV, and this has further implications for research and practice as a tension exists. I have put forth that nurses are in a position to invite stories and create a connection with those living with health concerns. That this exchange happens is critical for reasons alluded to previously, mainly that sense making is supported through talking and telling in interactions that allow for dialogue and depth. When we ask for and hear these stories, when we bear witness without judgement and listen with awareness of laden language and with presence, it is then that further benefits arise. Stories shared afford us a way to make a human connection that may help, heal, and generate compassion to another. The implications of what we learned from older adults storying their experience of living with HIV are significant and generate tension. Questions arise: how can we ensure nurses have the understanding and skill associated with enacting concepts of a narrative approach, and equally important, that they are supported to have time to support those in their care? How can we factor in time for relational or interaction based care? How can leaders in health care optimize opportunities to enhance engagement and support nurses to enact this way of being with individuals given pressures to take up data based discourses and continually “do more with less.” Arguably this is important, especially in this time when the dominant narrative in health care is often production, economy, speed, efficiency, and technology. Concern expressed by Gadow (1980), Gulino (1982), Grossman and Halliday (1992), and Cody and Mitchell (2002) that technology is so advanced we need to focus on relationship continues to be relevant today. Also significant is having nurses take up critical concepts that underpin narrative inquiry, concepts that when actioned elevate who we are and how we value the other before us.

For example, the impact of enacting a subjective – subjective engagement (Gadow, 1980; Watson, 2003; Doanne & Varcoe, 2005) and behaviours that reflect a co-constructionist frame, such as not leading but following the story teller, come together to support storying at its richest. And what is told or allowed or supported to be told directly impacts the teller’s ability to make sense in a more abstract way, and to actually receive or not receive services in a most concrete way. Also significant is new thinking and research that suggests and shows when we imagine something it activates the same part of the brain as if we had actually experienced (Lakoff and Johnson, 1999), that is, the brain registers second hand information the same as first hand perception and experience. In this way, stories are a powerful way to transfer knowledge. This is the power of storying, the craft that is so simple and yet so complex.

I am at times hopeful that current shifts toward patient centered care, patient engagement, and strength based nursing (Gottlieb, Gottlieb, & Shamian, 2012) will offer opportunity and elevate the importance of relational care. An emphasis on knowing through a relational connection in nursing could help minimize and put to rest the illusion of subject-object and self-other dualities, such that the illusion of separateness and the discontent and suffering it fosters would give way to greater compassion towards one another. Undeniably we must go beyond the traditional nursing “how are you” (Cameron, 2004) that prompts short and sweet expected socialized responses, instead engaging with and offering persons facing illness to tell of their experience as they need to. I am reminded how participants revealed deeper truths only after many interview encounters: Nancy is up at night, scared; Rick speaks through tears of the pain of his

father's suicide that took place many years ago; and Norm tells me his doctors don't understand him, that he is lonely and misses intimacy in his life.

And so I arrive at a poetic place and imagine what nursing could be if we were to overcome obstacles and move in this direction, finding a way to advocate for this practice need with clarity and evidence of benefit, steadfast in our valuing of relational, narrative practice. To contribute with our knowledge and skill and understand that it is through our connection, this is a way/our way to access a care connection, to be our best. We accept no compromise; we advocate for and find ways to keep the relational aspect of nursing, to sustain it, to create it where it is lacking. And to image we are not afraid to say we care, I care, we are the other. Nurses can lead a shift toward the use of narratives in practice. Sakalys (2003) reminds us that nursing theorists have long emphasized the importance of subjective experience and the nurse-patient relationship as a vehicle to achieve this. I am excited by emerging ideas such as Watson's Caring Science (2014) that shift us in this new direction and beyond. Yet how: what is the best way to teach nurses, what content, and what and how to document? This is where there remains uncertainty. And yet, imagine the power, beauty, and light, a future where relations and connections in nursing are fully valued and supported and no longer a distant shore.

Issues Encountered

It has been a privilege to undertake this case centered approach and bear witness to the experiences of older adults aging with HIV. It has also been heart breaking and humbling to come to understand the injustices and pain arising from discrimination rooted in human fear and misunderstandings. This inquiry raises a number of issues that call for attention and discernment. I found the lines (if there is such a thing) often blurred

between roles of researcher, advocate, and therapeutic intervener. This was explored fully in Chapter Two related to interviewing. I suggest it is critical that researchers engaged in complex illness stories that touch on life and death have opportunities and supportive spaces to debrief, reflect, and try to make sense. I have been most fortunate in this regard, having a very available research committee open to exploring ethical tangles with and alongside me.

Another issue that percolated was thinking about a person's story as their "truth" and my desire to "do justice" to their story. As alluded to throughout this chapter, I came to let go of this idea, to understand the story as co-constructed, truth as relative, and stories as ever changing.

I was also affected by narrative inquiry itself, this being not so much an issue but a profound reality. I developed a hyper awareness of storying and found myself paying close attention to how I story my own life experiences and the process for others around me. Dare I say I came to embody narrative and many of the intense concepts housed within. This was disruptive at times while also rich, fascinating, and life enhancing, as if to experience life with a new wakefulness. As mentioned previously, to hold any concept rigidly soon failed to offer imagined solid ground. An open attitude to ideas came to be appreciated as a way to literally let air in and to breathe into a sense of mystery about life.

Limitations of the Inquiry

Emphasis on traditional characteristics of validity and reliability, generalizability, and the participant sample (Munhall, 2007) is one way to assess quality of a qualitative inquiry: hearing people's narrative, a focus on the subjective and situated context, seeking understanding and meaning, recognition of multiple truths, and an emphasis on

individual interpretation. These standards were met if not exceeded in this inquiry and help to establish trustworthiness.

I begin by touching on validity and reliability. My view aligns with Munhall's (2007) suggestion that in qualitative research truth is not absolute, that there are many truths. Others agree: "truth is no longer about objectivity, validity or generalization" (Crotty, p. 16). And while I aimed for a coming together of subjectivity and objectivity, there is merit in asking should you believe the findings and is the study trustworthy? The answer is yes, this inquiry had rigor in that it aligned with the narrative turn that the nature of knowledge is variable and has a focus on the particular (Pinnegar & Daynes, 2007). Data analysis was in-depth and involved not only myself but input from advanced narrative researchers on my research committee. Munhall's additional criteria of trustworthiness were also met: research procedures were transparent, participants were fully included in the process and had opportunity to reflect on their story at subsequent interviews, and the narratives evoked emotion. The composite story developed about each participant (see page 1) was not taken back to the participants, given that I viewed this as a story I created, separate from the stories we co-constructed during interviews.

Emphasis on subjectivity and individual interpretation lead to another quality characteristic in narrative research, that of non-generalizability (Munhall, 2007). In this study, no claims of generalizability of findings were made. Findings and insights generated based on stories of five participants are not generalizable in the traditional sense to all older adults with HIV. Should a critique suggest this to be a limitation, I would counter this by drawing attention to Riessman's (2008) explanation of generalizability: that close study of individual cases can lead to unique insights and

general concepts which do generate knowledge. Said another way, it is possible to conceptualize from a case.

Further critique might relate to the sample size of five participants. While this is so, the aim of a case centered inquiry is to engage with a small number of stories in an in-depth way. Small sample size was countered by accessing secondary data related to the five participants that allowed a unique, longitudinal perspective. I recognize that the participant group was also uniquely located, being Caucasian, urban, and living in Canada. Another critique related to the sample might be that the participant group self identified and were motivated by a need or desire to tell their story. Indeed, four participants had shared their story publically in the past in various ways. This raises a curiosity about how stories might be different if one was to interview individuals aging with HIV who do not easily volunteer or publically share their experience. Do they share their story in other ways? What do they find difficult? What would they say? How would storying be different when it is more unrehearsed? I wonder if the stories we often hear are from a strong core of individuals, and what voices are missing?

Future Research

Aging with HIV is a new reality, and in recent years we have come to understand the biological impact of HIV infection on the body. Medical and scientific narratives have provided critical information that has saved lives, and yet this represents only one way of knowing. What remains largely misunderstood or invisible are the everyday realities and challenges of aging with HIV. Understanding is only beginning to emerge on the intersection and impact of HIV, aging, and medications. As discussed previously, side effects of aging with HIV and medications mimic those of aging itself, and

untangling what is happening in and on the body is not easy. Many questions arise. How do current theories of aging or ideas about transcendence apply to this unique subset of aging individuals, and what role does stigma play in this? What unique care will be needed by this group and will it be available as they compete for precious resources by their non-HIV positive aging peers? How can the public and health care providers alike be apprised of this new reality and work toward prevention and support strategies that eliminate discrimination and build compassion? This study highlights the important role of storying, both as a way to learn more about aging with HIV and as a means to engage with and support meaning making for those living with the disease. Through further research we will better understand the stories and what they reveal, thereby continuing to gain insight and advance knowledge in this area.

Another area where understanding is evolving relates to applying narrative concepts in a nursing practice setting. Sakalys (2003) reminds us that the notion of narratives in nursing is long standing, referencing the contribution of nurses such as Cowling (2000), Gadow (1980, 1995, 1999), Newman (1997), Parse (1998), Travelbee (1971), and Watson (1989). Nursing's roots to aesthetic knowing are also well established (Gaydos, 2005; Chinn & Watson, 1994). At the turn of the century, Cody and Mitchell (2002) raised a concern that while other disciplines were turning toward narrative and dialogical methods, nursing seemed to be turning away and continuing to be primarily represented as biomedical/technical. More recently, there has been renewed emphasis on narrative pedagogy in nursing curriculums (Mitchell, Jonas-Simpson, & Cross, 2013) and calls for system transformation that acknowledge narrative (Gottlieb, 2013). There is a need to be better understood how narrative concepts might be

transferrable to practice settings and how they might be taught. This leads to further questions, whether a formally or informally but intentional approach is best, and in educational programs or practice settings. Also critical is a better understanding of how and where insights gleaned from storying might be documented in clinical records in practice settings, in a way that honors the storying and relationship and also contributes to care.

I put forth three recommendations for future research related to the subject matter of this dissertation, and these flow from identified gaps in the literature. Firstly, related to HIV and aging. It is miraculous to consider all that has transpired regarding the evolution of AIDS over thirty years and where we are with talk of a cure being tangible. I suggest an area to be addressed in future nursing research is the knowledge gap related to quality of life issues for those aging with HIV. This would complement biological research that reveals new information about processes happening in the body in relation to aging, living long term with HIV, and the extended use of medication. Ideally, bodies of knowledge, be they social, historical, or biological, would come together to provide a fuller biocultural understanding of the experience (Davis & Morris, 2007). We also need to better understand what happens when individuals such as older adults with HIV are not given the opportunity to story their experience.

A second recommendation is to focus on knowledge translation in nursing about the importance of a relational connection and storying opportunities. Education that helps to move us beyond system wide rhetoric of a narrative approach as being merely “nice” to do, toward an understanding that for persons facing illness and vulnerability storying affords an opportunity to make meaning and affects a person’s potential to live

well. The importance of having leaders in health care understand that conversation and languaging are as vital to providing quality health care as are technological treatments cannot be understated. Imagine if we listened for the heart beat of a story as intently as we listen literally for a heart beat with a stethoscope. To advance acceptance of stories as a way of knowing in *nursing* supports nurses to access the often invisible layer of richness and complexity of human care situations and *nursing* practice. I put forth, as have others, that aesthetic knowing is available to all nurses in all settings. As Gaydos (2005) suggests, this process can be used by any nurse who has an interest in therapeutic use of self as a way to help people better understand their lives.

Lastly, I imagine further research into the role of metaphor in the experience of aging with HIV. While this inquiry focused more on analogous metaphors, what might a focus on more conceptual metaphors (Lakoff & Johnson, 1994) such as “life is a journey” and others possibly related to loss, time, and disease progress also reveal? As well, research could focus on ways that support nurses to listen for and respond to metaphors. Exploration into ways to translate this knowledge into practice would mean metaphors are better understood as a way to generate openings for further engagement, healing, and meaning making.

Conclusion

Alas I arrive at the end and know two things. Narrative as a way of accessing meaning and understanding and generating and evoking compassion shines a light on everything that is vital to nursing, from how we engage in relationship, to what we do and hear and respond to, and how we honor our shared human connection. It is my belief that persons living with illness, nurses, nursing, and our care system as a whole will reap

inherent benefits of health and healing when the act of telling and the act of listening to such stories are more fully understood and supported. Through this research I have come to imagine a narrative nursing sensibility as a metaphor for human connection and caring, relation, and service. Secondly, I know this ending is only a beginning, and this brings me to another metaphor. When I began this journey, I would at times liken my doctoral studies to climbing a mountain, Mount Everest (Chomolungma: *Holy Mother*), but metaphors generate and I soon began to shift my attention away from the physical aspect of such a climb to the spiritual or third pole (third way) aspect of the mountain. I still refer to this metaphor although less tightly. I am near the top, the summit: a holy place to not stand on high and proclaim I have arrived, but rather to walk around the peak in awe, with reverence for the journey itself and to know it is never ending, only a beginning to be in this place. So much lies ahead, waiting to be revealed, and for all this I give thanks.

Figure 1

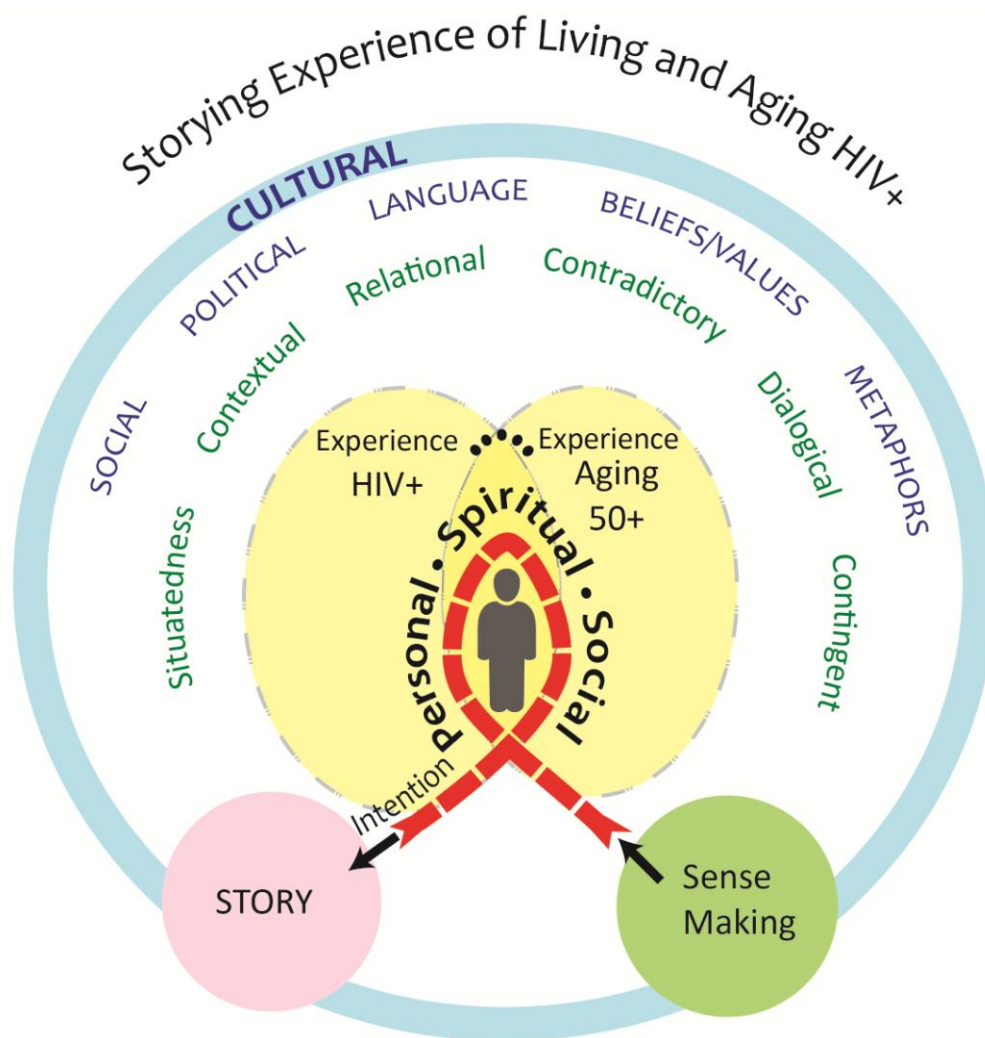
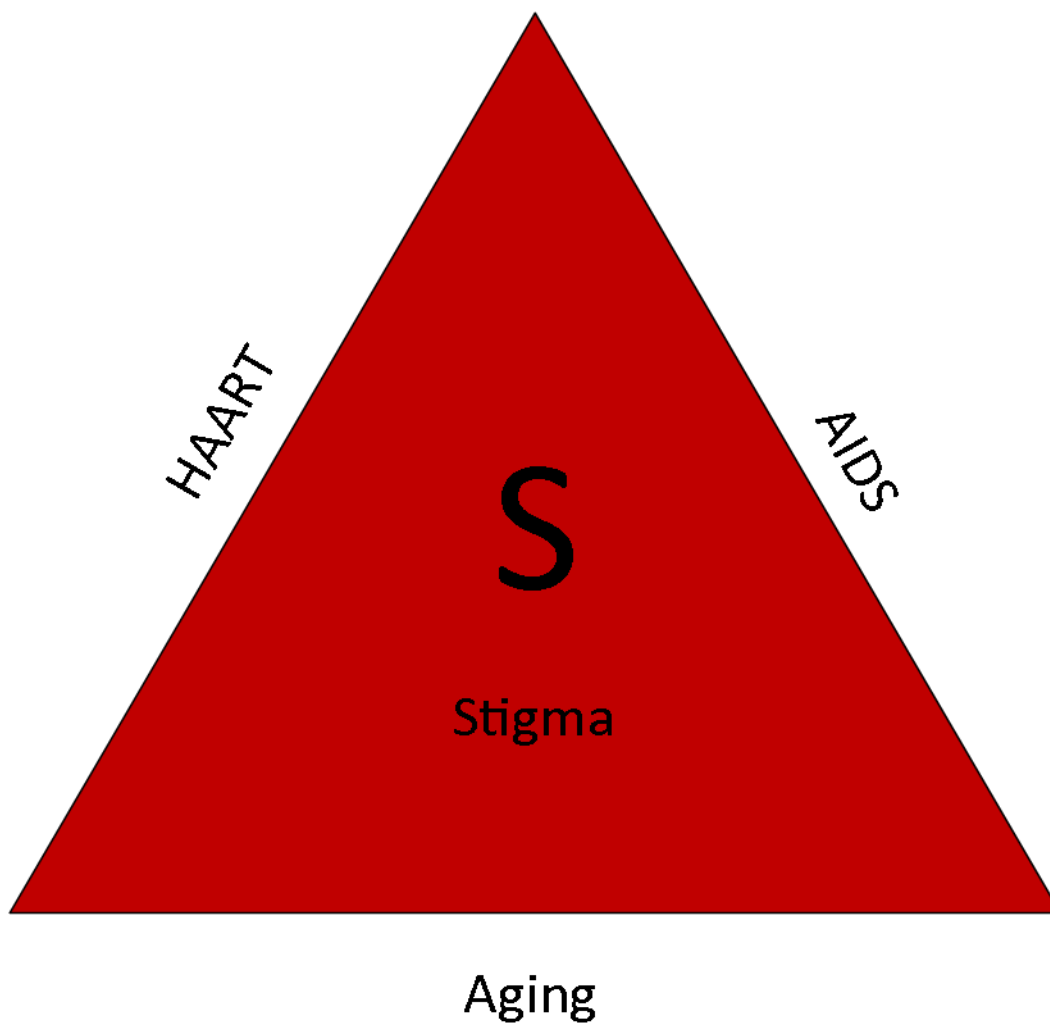


Figure 2



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Appendix A: Ethics Approval

Human Research Ethics Request for Modification of an Approved Protocol

The Request for Modification form is an institutional protocol based on the [Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans](#)

Instructions:

1. Download this Request for Modification and complete it on your computer. Hand written applications will not be accepted.
2. **Submit one (1) original and one (1) copy** of this completed, signed application with all attachments to: Human Research Ethics, Administrative Services Building (ASB), Room B202, University of Victoria, PO Box 1700 STN CSC, Victoria BC V8W 2Y2 Canada. The review period for Modifications is approximately two weeks.
3. If you need assistance, contact the Human Research Ethics Assistant at (250) 472-4545 or ethics@uvic.ca
4. **NOTE: all forms are screened and will be returned to the applicant if incomplete (e.g. missing required attachments, signatures, documents).** Forms may be secured with one staple or clip. **Please do not staple or clip appendices into individual documents**

A. [Principal Investigator](#)

If there is more than one Principal Investigator, provide their name(s) and contact information below in Section B, Other Investigator(s) & Research Team.

Last Name: **Sheilds**

First Name: **Laurene**

Has there been a change in the Principal Investigator? **No**

If yes, provide the name of the previous PI:

Department/Faculty: **School of Nursing**

Email: **lsheilds@uvic.ca**

Phone: **250.721.8051**

Fax: **250.721.6231**

Mailing Address including postal code:

(if left blank, the Certificate will be sent to your department)

Title/Position:

Faculty

Undergraduate

Ph.D. Student

Staff

Master's Student

Post-Doctoral

Students: Provide your Supervisor's:

Name: **Laurene Sheilds**

Email: **lsheilds@uvic.ca**

Department/Faculty: **Nursing**

Phone: **250-721-8051**

Graduate Students: Provide your Graduate Secretary's email address:

B. [Project Information](#)

Original or most recent Protocol Number: **07-258**

Original Project Title: **Re-Stor(y)ing Life within Life-threatening Illness**

Project title if modified: **Re-Stor(y)ing Life within Life-threatening Illness**

Date Recruitment or Data Collection began: **Mar 2008**

Anticipated End Date of Data Collection:

original study June 2011. This new request will extend data collection to September, 2013.

Is this project connected/associated/linked to one that has been recently submitted? Yes No

If yes, provide further information: **Annual Renewal 07-258**

All Current Investigator(s) and Research Team:

(Include all current and new co-investigators, students, employees, volunteers, community organizations.)

Contact Name	Role in Research Project	Institutional Affiliation	Email or Phone
Anita Molzahn	Co-investigator	University of Alberta	anita.molzahn@ualberta.ca
Anne Bruce	Co-investigator	University of Victoria	abruce@uvic.ca
Kelli Stajduhar	Co-investigator	University of Victoria	kis@uvic.ca

For Faculty Only: Any Graduate Student Research Assistants who will use the data to fulfill UVic thesis/ dissertation/ academic requirements: Include all current Graduate Student Research Assistants

Student/Research Assistant	Email or Phone
Kara Schick Makaroff	kara.schickmakaroff@ualberta.ca
Rosanne Beuthin	rbeuthin@uvic.ca
Sheryl Shermak	sshermak@uvic.ca

C. [Agreement and Signatures](#)

Principal Investigator and Student Supervisor affirm that:

- *I have read this modification and it is complete and accurate.*
- *The research will be conducted in accordance with the University of Victoria regulations, policies and procedures governing the ethical conduct of research involving human participants.*
- *The conduct of the modified protocol will not commence until ethics approval has been granted.*
- *The researcher(s) will seek further HREB review if the research protocol is further modified.*
- *Adequate supervision will be provided for students and/or staff.*

Principal Investigator Student's Supervisor

Signature

Laurene Shields

Print Name

Date

Signature

Laurene Shields

Print Name

Date

Departmental Chair, Director or Dean

I affirm that adequate research infrastructure is available for the conduct and completion of this research.

Noreen Frisch
Signature

Print Name

Date

D. [New Project Funding](#)

Have you applied for new funding for this project?
2010 Yes No Year

Has notice of award been received since previous ethics approval?
Year Yes No

Please complete the following:

Source(s) of Project Funding	Project Title used in Funding Application(s)
CIHR	Re-stor(y)ing Life Within Life-threatening Illness
CIHR (not approved for funding)	Re-stor(y)ing Life-threatening Illness over Time

Will this project receive funding from US Funders (e.g. NIH)? Yes No

If yes, provide further information:

Synopsis of Study Progress

1. **Progress**

Please provide a brief description of the progress to date:

PARTICIPANTS: Thirty-two participants took part in four in-depth interviews between April 2008 and April 2011. Study participants included 10 people with cancer, 14 people with ESRD, and 8 people with HIV/AIDS. Participants ranged in age (37-83 years old); gender (17 male, 14 female); location (rural and urban); intensity or invasiveness of treatment; time from diagnosis (1-50 years ago); prognosis (from remission to palliative); treatment effects; and participants' perception of vulnerability and risk. These participants represent a diverse purposive sample supporting a breadth and depth of experiences to ensure rigour and credibility.

DATA ANALYSIS: The research team, including two doctoral student trainees and one research assistant, conducted thematic narrative analysis of interviews using a dialogical and multi-layered approach in order to portray the multitude of voices and tensions permeating participants' narratives and team members' interpretations. Through refinement, patterns and relationships were developed into narrative themes.

FINDINGS TO DATE: With the original study, data collection has been completed. However as agreed in our original consent we will have future contact with our participants to disseminate findings. This modification application requests extension of one aspect of this project to allow for approval of further data collection related to the doctoral work of Rosanne Beuthin.

KNOWLEDGE DISSEMINATION: In order to maximize the utility of our work and to ensure the greatest impact for health care providers our research team has presented at international (*International Institute of Qualitative Methods Conference, Vancouver; American Nephrology Nurses Association, Denver*), national

(*Spirituality and Health: Working Together for Optimal Health, Calgary, AB; Narrative Matters 2010, Fredericton, NB*) and regional conferences (*University of Victoria Nursing Research Conference*). All venues supported opportunities for clinicians, educators, researchers, and students to discuss the project and preliminary findings. Knowledge dissemination includes 3 published manuscripts developed during the proposal development phase and 14 published abstracts from recent conference presentations. Four related manuscripts are under review, two are in press, and multiple papers addressing the study findings are in progress.

2. Adverse Events

a. Have there been any adverse events experienced with this research? An adverse event is any adverse change in well-being or "side-effect" that occurred in a person or community group who participated in the research project.

Yes Possibly No

b. If Yes or Possibly, identify and explain how it was addressed:

c. Did you complete and submit an Adverse Event Report to the Human Research Ethics office?

Yes No

Explain:

3. Modifications

Please outline the details and rationale for the changes along with a brief synopsis of the progress to date. Attach copies of any modified forms, advertisements or questionnaires.

All previously approved appendices must be submitted with modifications **underlined**.

Modification to Recruitment	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No Rationale: Attach copies of revised recruitment scripts, letters, advertisements, invitations etc.
Modification to Participants E.g. pool, group, numbers of, etc.	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Rationale: <u>The proposed project will involve a subgroup of 6 participants (aged 50+ who live with HIV) from the original study, who will be invited to participate in an additional interview. They will be contacted by a member of the research team (not the doctoral student who will be doing the interviews), by the preferred method of contact they have indicated throughout the study (this may be phone, email, or letter).</u> <u>Please see attachment Appendix A with revised invitation guiding script.</u> <u>This fifth interview will support a doctoral research project "Stories of Aging with HIV." A</u>

description of the research project follows:

1a. The research question:

The primary question: What might we learn from the stories, specifically metaphors, of older adults living and aging with HIV? A narrative inquiry case study approach, framed within social constructionist theory, will be used to interpret narratives of older adults (age 50 +) living with HIV for at least 10 years.

1b. The importance and contributions of the research:

The steady evolution of understanding, detection, and treatment of HIV over the past three decades have culminated in this millennium into new hopes and a tangible shift in the once dismal if not downright deadly trajectory of HIV. Today, life expectancy for persons with HIV continues to increase, making aging with HIV a relatively new phenomenon that is only beginning to be fully understood. As the older population of Americans at risk for—or living with—HIV/AIDS grows, the day to day lived experiences, realities, and challenges of their lives remain largely misunderstood or invisible. The unknowns in these successes are the long-term consequences of the disease and the effects of antiretroviral medications on an individual over time as they age.

1c. Background information that will enable the HREB to understand the *context* of the study when reviewing the application.

The disease of HIV has now been known for three decades, and in that time many advances in care and treatment have occurred. The success of antiretroviral treatment has enabled affected persons to live long with HIV and to survive to age 50 and beyond. By 2015 approximately half of adults with HIV in the USA will be 50 and older. This has led to a shift in conceiving a diagnosis of HIV as imminently life threatening to an emerging conception of HIV as a chronic and manageable disease. Yet this new view is misleading and not so easily reconceptualised. Extended life expectancy makes aging with HIV a relatively new phenomenon, the implications of which are only beginning to be fully understood.

	<p><u>The disease may be more manageable with medications, but to live long with HIV is not predictable nor without challenges. For this reason, the graying of HIV is considered a new crisis.</u></p>
Modification to Data Collection Method	<p>X <input type="checkbox"/> Yes <input type="checkbox"/> No Rationale:</p> <p><u>The data collection method will remain the same, however a subgroup of 6 participants (aged 50+ who live with HIV) from the original study will be invited to engage in an additional interview. The interview will be approximately 90 minutes and held at a time and place that is mutually convenient.</u></p>
Modification to Consent	<p>X <input type="checkbox"/> Yes <input type="checkbox"/> No Rationale:</p> <p><u>The consent form will be adapted to add a fifth interview. It will identify that while this interview will extend the original study, it will be specifically used by Rosanne Beuthin for her doctoral studies.</u></p> <p><u>The procedure for receiving consent from participants will remain the same. A copy of the consent form will be given to the participant to read at the beginning of the interview meeting. Each section will be reviewed together. Once the interviewer is satisfied the participant understands the consent, it will be signed and a copy left with the participant for their records. In the instance of a phone interview, the consent form will be reviewed and verbal consent sought.</u></p> <p><u>Please see attachment Appendix C with revised consent form (changes are underlined).</u></p>
Other Modification(s)	<p>X <input type="checkbox"/> Yes <input type="checkbox"/> No Rationale:</p> <p>The interview guide will be modified to reflect the specificity of this aspect of the research question.</p> <p><u>Please see attachment Appendix B.</u></p>

4. Other Information

Please provide any other pertinent information here, or attach the details to this form:

Appendix B

Script to Invite Participation in a Research Study: Stories of Aging with HIV

If I know the participant:

Hi, it's Rosanne calling; you may remember me from the Re-Stor(y)ing Life within Serious Illness study you participated in at UVIC School of Nursing over the past 3 years. I was one on the interviewers for the study...

If I do not know the participant:

Hi, it's Rosanne Beuthin calling. I was part of the Re-Stor(y)ing Life within Serious Illness research team for the study you participated in at UVIC School of Nursing over the past 3 years. My colleague Kara interviewed you...

The reason I am calling is...

Now, as part of my doctoral degree, I am doing a unique follow-up study that focuses specifically on individuals who are over age 50 (and living with HIV). This interview would build on and extend the earlier interviews we have had with you to date.

I am inviting you to participate.

It would involve one interview with me, at a place and time that is convenient to you, and focus on your experiences of aging.

You are by no means obligated to participate.

I can provide you with more information about the study if you wish. For example, you may be interested in:

What the study is about ... What we might learn from the stories, specifically metaphors, of older adults living and aging with HIV.

Why the study is important ... Today, as you know, life expectancy for persons with HIV continues to increase, making aging with HIV a relatively new phenomenon that is only beginning to be fully understood. As this population grows, the day to day lived experiences, realities, and challenges faced remain largely misunderstood or invisible. I believe you could help inform this understanding.

What participation involves ... It would involve one interview with me, at a place and time that is convenient to you, and will focus on your experiences of aging.

Confidentiality ... will be respected in all aspects of the research and you will not be identifiable in any related materials.

What you will get out of the study ...an opportunity to tell your story, to reflect, and to contribute to the understanding in this emerging area.

Thank you for considering this request.

Your participation will be an important contribution and help health care providers to better understand the experience of living with the HIV into older age.

You can let me know now, or think about it and call me at 250-544-0653 or

rbeuthin@uvic.ca

Appendix C

Sample Questions to Guide Interview

Stories of Aging with HIV

Intent: to build rapport and trust; to invite stories and experiences of living and aging with HIV; to tease out language used to describe the experience.

I will do a preamble about age 50 being the demarcation for an “older adult” in the HIV/AIDS literature.

Guiding questions may include:

I am interested in your experience of getting older. Can you tell me what it is like for you to be getting older and past age 50? That is:
 your experiences of aging,
 your expectations,
 the best part, the worst part,
 your hopes, your fears.

Do you feel your age?
 What strategies do you have to help you age and live well?
 To what age do you think you will live to? Why?

How do you believe it is different to be aging with HIV compared to someone who is aging without having the virus?

If you pause and reflect on this marvelous fact that you are here, on this planet, this very moment, what language comes to you instantly that describes what this is like?

Do you ever liken your experience of aging with HIV to something, that is, thinking of your experience in terms of a metaphor.
 For example, saying, “aging with HIV is _____.” (
 Or do you ever liken your experience of aging to something that helps you to imagine the experience in a different way?
 Does anything resonate for you, and if so, has this changed over time?...
 (Note: I am hesitant to give an example of a metaphor as I do not wish to lay a representation on them, but rather hear from them.)

How would you finish this sentence: “Getting older with HIV is _____”
 How would you finish the same sentence if you were talking to a close trusted friend, a stranger, your health care professional...
 Does it change, and if so, why?

Appendix D

CONSENT

You are being invited to participate in a study entitled **Stories of Aging with HIV**

This research is part of a nursing doctorate being undertaken by Rosanne Beuthin.

This research is an extension of the study you participated in called **Re-Stor(y)ing Life within Serious Illness**. It was conducted by Drs. Laurene Sheilds, Anne Bruce, and Kelli Stajduhar who are faculty members of the University of Victoria, School of Nursing, and Dr. Anita Molzahn who is a nursing faculty member at the University of Alberta. I was part of the research team as a doctoral fellow and did a majority of the interviews for the original study.

You may contact me, Rosanne Beuthin, if you have further questions: 250-544-0653 or rbeuthin@uvic.ca

Purpose of this Research

The purpose of this research is to gain an understanding of the experience of aging with HIV. The primary question guiding the study is: What might we learn from the stories, specifically metaphors, of older adults living and aging with HIV? (Please note: in the HIV literature, age 50 is the demarcation for an older adult.)

Importance of this Research

Research of this type is important, as aging with HIV is a new phenomenon that is not well understood. It is hoped this study will contribute to health care professionals' understanding of the complex experiences of people aging with HIV. Understanding can then translate into compassionate and respectful care.

Participant Selection

You are being invited to participate for three reasons:

- you have previously participated in the Re-Stor(y)ing Life within Serious Illness study,
- you have unique experiences of living with HIV, and
- you are over the age of 50.

I am interested in hearing of your experiences of aging with HIV.

You are under no obligation to participate in this follow-up interview and you may withdraw at any time without any explanation or consequence.

What is Involved

If you voluntarily agree to participate in this research, you will be asked some general questions about your age and time of diagnosis, and more specifically about aging.

You will participate in one semi-structured, face-to-face interview consisting of open-ended questions that invite sharing of your experiences. If a face to face interview is not possible, on an individual basis I would ask you to consider an interview by phone.

You may also be asked to comment further on the findings.

Inconvenience

Participation in this research study may cause some inconvenience to you, as time for the interview will be about 1 ½ hours. Every effort will be made to arrange a time and location that is convenient for you.

Risks

There are no known risks associated with your participation in this research. However, reflecting on emotionally sensitive experiences may evoke anxiety, fatigue or emotional distress. If this occurs, adequate time and support will be provided to address any concerns that arise.

Benefits

Potential benefits of your participation may be having the time to reflect and discuss your experience with a researcher who is interested and educated in this field.

Compensation

There is no compensation.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation.

If you withdraw for any reason, you will be asked if you would like to have the interview data remain or be removed from the study. When analysis has already occurred, this may not always be achievable. Where possible however, all reasonable efforts will be made to respect your choice.

Confidentiality and Anonymity

Your confidentiality will be respected. Individual anonymity will be protected by removing all personal identifiers. Numeric codes will be used on all documents. In publications or presentations, personal names will be replaced with fictional names. All data will be kept in a locked metal cabinet in the researcher's office. Any person hired for transcription purposes will sign a confidentiality agreement. Confidentiality will be maintained in any publication and presentation.

Dissemination of Results

It is anticipated that study findings will be published in academic journals and presented at public forums and conferences. Research findings will be shared with participants who would like to receive them. Your name will not appear in any material. Your words may be used.

Disposal of Data

All data will be kept for purposes of secondary analyses for a period of seven years.

Contacts

You may contact Rosanne Beuthin at 250-544-0653 or rbeuthin@uvic.ca

You may verify the ethical approval of this study, or raise any concerns you might have by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4545). In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this research and that you have had the opportunity to have your questions answered by the researcher.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will remain with the researcher.

THANK YOU