# Understanding Hope in HIV Care:

# A Narrative Inquiry into the Experiences of Nurses in Ghana

By

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#### Abstract

In this research, I sought to understand how nurses working in HIV care in Ghana live and work with hope. I tried to make visible how hope enhanced their work over time. Over several months in the summers of 2015 and 2016, I lived alongside five registered nurses as we explored how hope had shaped us. In this dissertation, I consider my narrative beginnings, review hope theories and the nature of hope in nursing practice alongside a narrative conceptualization of hope. My research puzzle was to inquire into what sustains nurses' hope when working with people living with HIV in an acute care setting. I wanted to understand the experiences of nurses in Ghana and the ways that hope is intertwined with their experiences in HIV care. In this study, I invited five nurses from a tertiary hospital to make sense of their experiences of working with hope practices. The five participants—Eva, Lana, Berth, Jude, and Joy—and I attended to their stories to live by [a narrative conception of identity] using the commonplaces of narrative inquiry: temporality, sociality, and place. As we moved from field texts to research texts, we co-composed narrative accounts of their experiences. After looking across their narrative accounts, I identified four resonant narrative threads: becoming a nurse for people living with HIV over time; experiences of practicing with hope, despite hope threats; faith in God from which they gained strength; and learning to live with hope from childhood. By engaging in this inquiry, I learned that hope matters, but that it needs to be nourished. The commonplaces of narrative inquiry inspired an understanding of a narrative conception of hope, and made it visible that hope is an embodied lived experience. Calling on a Deweyan-inspired narrative conception of hope (LeMay, 2014) made it possible to live alongside nurses' experiences of hope. I also learned that in order to sustain my hope I needed to stay wakeful to my hopeful practices.

### Preface

This thesis is an original work by Gideon L. Puplampu. The project received research ethics approval from the Noguchi Memorial Institute for Medical Research-IRB (Ghana) and University of Alberta Research Ethics Board, Project Name "Understanding Hope in HIV Care: A Narrative Inquiry into the Experiences of Nurses in Ghana", No. 044/14-15(IRB, Ghana), 2015-2016, and No. Pro00052132 (University of Alberta, Canada), 2015-2016.

# Dedication

To my God, my Creator, my King, and my Redeemer, Jesus Christ, who has given me life and health to come thus far in my life journey, to Him I dedicate this dissertation. To Him be the Glory.

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# **Table of Contents**

Chapter One: Narrative Beginnings	1
Tension-Filled Moment	
Looking Backwards in my Life	5
Unpacking the Tension	8
Hope for Me	10
My Research Puzzle	11
Chapter Two: Conversation with the Literature	12
Definition of Hope	12
Theories of Hope	13
Snyder's Hope Theory.	13
Relevance of Snyder's Hope Theory to my study.	15
Farran, Herth, and Popovich's model of hope.	15
An experiential process	16
A spiritual or transcendent process.	17
A rational thought process.	17
A relational process.	19
Nature of Hope in the Context of Nursing	20
Cognitive dimension.	
Goal attainment dimension.	
Hope and Meaning	
Hope and its Relevance to Nursing Practice	24
Hope and HIV Conceptualized	26
Hope Conceptualization in the Ghanaian Culture	
Hope Conceptualization in Narrative Inquiry	28
Chapter Three: Research Methodology: Turning to Narrative Inquiry	30
What is Narrative Inquiry?	
Philosophical Assumptions of Narrative Inquiry	33
Why Narrative Inquiry?	
Narrative Inquiry Process	
The relationship between the researcher and participant	
Narrative accounts	
Narrative beginnings	39
Beginning My Research Study	
Revisiting the orientation to study experiences of hope.	
Ghana in the Context of HIV and AIDS	
Research Setting	
Composing the Field: Recruitment of Participants	
Living in the Field	
Quality Criteria in Narrative Research	
Negotiation of relationships and being in the midst.	
Moving from field to composing field texts.	46

Moving from field texts to interim, and research texts	47
Ethics	48
Relational Ethics	49
Towards Analysis	50
Final Thoughts	50
Chapter Four: Narrative Accounts: Eva, Lana, Berth, Joy, and Jude	52
Eva's Narrative Account	
Early beginnings: Moving from one region to another	
Education and training.	
Connection with her family.	63
Precursor toward Eva's career choice	
Eva's experiences of hope	67
Role models of hope.	68
Availability of medication.	69
Each patient's context	71
PLWHs' family support	72
PLWHs' compliance.	73
PLWH's avoidance of feelings of anger towards HIV.	75
Toward the motivations of hope.	
Negative babies	76
Institutions	76
Hope in a continuum	77
Her hope influences others' hope	78
Living with hope when working with those who are stigmatized.	79
Career vulnerability and non-transfer.	80
Vitality of hope.	81
Solidifying hope	82
Places of hope threats	82
Fear of infection	
Lana's Narrative Account	84
Opening the conversation with Lana.	
Lana's initial occupation and her education.	85
Early places in Lana's life	89
Secondary education and change of career.	
Lana's travel towards her goal	
Connections with extended and nuclear family.	
The story of the boy.	
Transfer to Fevers Unit.	
Lessons from the Fevers Unit.	
Resembling a family.	
Hope arrives incomplete.	
Hopeful experiences	
Lana's challenges to her hope	102

PLWH behaviour concerning sexual transmission.	102
Hopeful moments	103
Hope connections	104
Hope nourishment	105
Hope threats.	106
Returning to anxiety and importance of hope	106
What is care to Lana?	107
Experiencing stigma in HIV care	110
Lana's experiences of hope and God.	110
Berth's Narrative Account	
Maiden name	114
Birth place	115
Hospital as a birth place	115
General education.	115
Nursing training placements.	116
Midwifery training.	118
Health services administration placements.	119
The story at accident centre.	120
Marriage and family	122
Berth's hopeful journey and HIV nursing	124
Hope and education	127
In times of hope loss.	128
Equipment lack as a hope sucker.	131
Revisiting hope threats	132
Hope for one another	134
Hope-filled beginnings	135
Replenishing hope	136
Hope as an important element in Berth's work.	138
Joy's Narrative Account	
Early education and hope	144
Marriage and children	146
The nursing journey.	
Faith inspires hope.	150
Interventions and compliance.	
Shortage of ARVs.	152
Family support	153
Influential factors of hope	156
Ethical values and feelings of shame.	158
A hopeful day	
Impacts of hope	
Hope threats and personal faith	
Jude's Narrative Account	
Meeting with Jude	163

Early beginnings alongside Jude	
Beginnings of Jude's career.	
Thinking about college days.	
Nursing education.	
Hopeful elements.	
Threats to hope	
Connecting to earlier times.	
Involvement of family	
Stigma	
Roots of hope.	
Thinking with hope	
Christian hope and work.	
Chapter Five: Narrative Threads Across Participants' Stories to Live by	
Thread 1: Becoming a Nurse Working With PLWH Over Time	
Thread 2: Experiences of Practicing With Hope Despite Hope Threats	
Hope threats.	
Thread 3: Faith in God from which They Gained Strength	
Thread 4: Learning to Live With Hope From Childhood	
Discussion: Gathering Threads	
Temporality	
Sociality.	
Place.	
Chapter Six: Summary, Justifications, and Implications	
Personal, Practical, and Social Justifications of Study	
Personal justification	
Practical justification.	
Social justification.	
Implications for Practice	
Theoretical Contributions	
Future Research Possibilities	
Conclusion	

### List of Abbreviations

- AIDS Acquired Immune Deficiency Syndrome
- ART Antiretroviral treatment
- ARVs Antiretroviral drugs
- BECE Basic Education Certificate Examination
- CD4+ count measure of the number of CD4 cells (or T-helper cells)
- CEE Common Entrance Examination
- EN Enrolled Nurse
- GCE General Certificate of Examination
- HIV Human Immunodeficiency Virus
- IPMC Integrated Program Management Consultant
- IPPD Integrated Personnel and Payroll Database
- IPS Institute of Professional studies
- ISTAR Institute for Stuttering Treatment and Research
- NHIS National Health Insurance Scheme
- NTC Nurses Training College
- **OPD** Out-Patient Department
- PLWH People living with HIV
- SRN State Registered Nurse
- UPS University of Professional Studies

#### **Chapter One: Narrative Beginnings**

The genesis of this dissertation was my master's thesis where I found myself wondering about the factors that attracted and retained nurses working in HIV and AIDS care (Puplampu, Olson, Ogilvie, & Mayan, 2014). I sought to understand why nurses chose to work with people living with HIV (PLWH) amidst the stigma and discrimination that PLWH and HIV care providers' experience. Considering the emotional, physical, and psychological demands of HIV care, I wondered what factors had informed Canadian nurses' choices to work with PLWH as a career focus/specialization. I found that the retaining factors were related to the discovery of antiretroviral drugs (ARVs) that gave hope to nurses and PLWHs. Subsequently, I found myself puzzling over orientations towards hope and how nurses in HIV and AIDS care could work with hope in their professional practice settings. I found myself engaged in conversations about the literature of hope with my supervisor which led to my enrolment in a hope course entitled *Hope and Helping Relationship*. These actions helped deepen my understanding of hope by offering me new insights.

As I continued to contemplate nurses' experiences of hope in HIV and AIDS care settings, I felt tensions between my hope-focused self and how others storied me. I had always storied myself as a hopeful person but never thought about how I enacted and engaged hope in my nursing practice. I engaged these memories to make sense of the tensions I felt between the stories I appeared to be living and those of hope practices. I believe hope is a critical element in HIV nursing care because hope can help people feel, think, and act in positive ways. In my doctoral research I explored the research puzzle of: What are the experiences of hope among Ghanaian nurses working with PLWHs in acute care settings?

## **Tension-Filled Moment**

When I started work as a nurse in Ghana, I was filled with hope to succeed and an eagerness to continue my learning. My travels took me to different places in the hospitals and clinics such as the surgical care unit, medical unit, allied care unit (orthopaedic and genitourinary care units), and the emergency room, as well as community placements. I often engaged in the caring process and with the patients on different units. I still remember a day in November of 1998 when I arrived at the Fevers Unit which was part of the medical care unit. The Fevers Unit had a ward for PLWH. It was in this place that I experienced what filled me with the tension I sought to unpack for my doctoral research. The exploration of this narrative beginning allowed me to look backwards to earlier times, places, and relationships (Clandinin, 2013).

The ward for PLWH was silent at first sight and the quiet stood out. Nurses entered and exited the wards when they had a care duty to perform, such as giving medication, assisting with patient hygiene, or taking specimens. Occasionally relatives who came to visit walked the long hallway with saddened facial expressions and slumped bodies. PLWH spent almost all day in their single beds, as they were too weak to engage in any activity. The silence of the ward could also be experienced around the rooms and the surroundings by looking at the old paint on the walls, the empty beds, and the plain floors. The small cubicles with small windows for ventilation were shared by two residents. Every room opened into the hallway. The gloomy nature of the physical environment seemed depressing for PLWH and probably for their care providers. Death, too, was always present. Looking backwards, it was the first time that I became aware of the level at which HIV generated negative feelings in the healthcare staff towards PLWH. Three decades after the first diagnosis of HIV, the attitudes had become a fixed

story, a story that was told again and again (Squire, 2008).

One story that stood out in my memory centred around Kojo<sup>1</sup> who was a PLWH during my initial days on the HIV ward. Kojo had just been diagnosed with HIV and, after a health assessment interview with the primary nurse in the consulting room, he returned to the ward with a despondent-looking face. I had met Kojo earlier and I welcomed the opportunity to talk to him again. Kojo was very direct and his concern focused on a possible cure for HIV. He appeared hopeless and terrified at the same time. I could hardly imagine what questions he might have on his mind. Perhaps he had questions such as: can I reclaim healthful longevity? How will I tell others? What will change in my life? What threatens my hope? After explaining HIV and AIDS to him and assuring him of his role in recovery, he posed the question to me "So am I going to die?" I recall my struggle to answer the question. My feelings, thoughts, and behavior at that point revealed discouragement and despair. As much as I had wished to be hopeful, it was not visible anywhere in my demeanor. I used to believe that hopeful nurses were resourceful, and could see many ways to solve a problem. I thought that there was a hopeful, spontaneous side to my personality to support me in such situations. However, I experienced tension in that moment. Kojo's question had offered me an opportunity to be hopeful. It was frustrating to find myself with the same worries as Kojo and little hope to call forth.

I later became Kojo's primary nurse and answered some of his questions straightforwardly, without even a thought of fostering hope or despair. I wondered how my responses made Kojo feel. Is it really possible that my responses in this situation revealed despair, and that empathy eluded me in practice? I wondered if nursing actually made me less

<sup>&</sup>lt;sup>1</sup> All names are pseudonyms.

empathetic. I feel that my tension in this situation certainly confirmed these suspicions. The loss of capacity to see alternatives for responding to such a challenging question illustrated my discomfort, if not hopelessness in this situation. I did little to explore Kojo's fears or concerns. I also did not explore my own feelings. I did not know how to respond. It was an opportunity missed forever. Although reflecting upon this account continued to fill me with tension, I could see that I could have done more than "just offer a prayer" in response to Kojo's question. I could have explored Kojo's hope threats and encourage him to explore his own hopeful strategies. I could not discuss his HIV status or my tension in being caught up in his despair with his family. I had to consciously filter what I told them. I found it difficult to be open and honest with Kojo's family as they had not visited him; they had only made phone calls. Writing about this experience made my thoughts more concrete and in that way I became more vulnerable. I felt tense in talking about the situation, most likely due to a tendency to avoid revisiting past difficulties and challenges, even though I knew I could learn from them.

I also realized that I had new and complex questions such as: what was my experience of hope? What nursing actions influence hope? How does hope impact a terrifying diagnosis such as HIV? What threatens my hope? What had been my experiences with hope in my own life? If I had responded in a way and manner that had demonstrated hope, would Kojo's questions have been different? The memory of his demeanor, his way of asking this deeply philosophical, yet pragmatic question about mortality remained with me. While my initial response might have been without hope, I soon realised that all I had to offer to undo Kojo's despair was to request we pray together. He agreed. After the prayer he said, "I am not going to die!" As I looked back on this, I wondered what I understood his question about dying to be. When I thought about my

work with Kojo I wondered how I understood, and also practiced, hope. What did hope mean to me? Even though, with time, Kojo became very ill and eventually died, I wondered if my response of praying together to his question provided him with a feeling of hope, and also assisted me, as a nurse, to experience hope.

Over time, I also began to wonder how other nurses lived with, and experienced, hope in their daily practice with PLWH. How did they sustain their hopes? How did they make hope visible? Recounting this experience with Kojo I was reminded of the importance of hope. Understanding nurses' experience of hope and HIV in relation to PLWH, as well as experiences that threatened hope among nurses who cared for PLWH, was important in the advancement of nursing interventions.

#### Looking Backwards in my Life

Looking back on my life, I longed to retell part of my narrative beginnings<sup>2</sup> from the midst of a student nurse landscape, and explore the stories I carried from this time as I moved into my professional landscapes. In February 1995, along with other students, I began training as a nurse. On the first day of nursing school, the principal, along with other tutors, met and welcomed us at the college's largest classroom. The principal talked about, among other things, the college's rules and regulations, including the expectations. One of the expectations was to obtain a passing grade in all examinations, both theoretical and clinical. I hoped and trusted that I would pass all my examinations and graduate on time. For the Grace of God I did pass.

The high academic standards created a tension that permeated my thoughts, feelings, and behaviour by motivating me to commit to my studies. In spite of limited teaching and learning

<sup>&</sup>lt;sup>2</sup> Narrative beginnings are those experiences that position a researcher in a study.

resources, such as textbooks and laboratory equipment, by dint of hard work, favour from God, and support from family and friends, I graduated from nursing college at the end of the mandatory 3 years. Although the concept of hope was not common, or taught in academic circles, graduating from nursing college was a hope experienced.

The nursing instructors and student friends both created places in my life that contributed, in one way or another, to my experience of hope and who I was becoming. The instructors' objectives were goal-focused. They wanted to see students succeeding academically and, therefore, they organized classes during out-of-school hours to augment regular hours. Essential support systems such as kitchen services (student meals), hostel accommodation, and transport for clinical placements were put in place to minimize delays and distractions. The rules were strictly observed and no student could escape consequences, ever, when the rules were broken.

The other story I carried into my nursing training was about my stuttering. I recall that my level of speech dysfluency often troubled me. When I became older my dysfluency was a daily barrier to me expressing myself effectively and, to my embarrassment, people asked me to repeat the things I said. Eventually I started to carefully select words to avoid any that were difficult to pronounce, and I too often chose not to speak up. Being quiet is an easy habit to adopt, and being considered shy is easier than having to explain what you are trying to say when others don't understand you. I began to intentionally avoid conversations and many social gatherings or meetings in order to reduce my speech-related anxiety. I became aware of the social rejection related to my dysfluency and began to wonder what I could do to control my speech. I tried many things including voice training, relaxation exercises, and diaphragmatic breathing, all to no avail. I was almost driven to despair. But there were times when I gained an unexplainable fluency when I engaged in teaching and learning activities. This "Grace or Gift" of intermittent fluency contributed to my continuity in nursing and teaching as educator.

However, before graduate school, I finally located the Institute of Stuttering and Research (ISTAR) in Edmonton, Canada. I commenced therapy in December 2006 with high expectations and hopes that the dysfluency would be cured. I had the 3 weeks of intensive therapy with several treatment follow ups without a lasting fluency. While I had improved greatly, I still had lingering moments where I caught myself filtering what I chose to say. I still found that I needed to consciously make an effort to speak my mind around others. Having this experience growing up made me more understanding of others with difficulties regardless of whether they were health related or otherwise. Through my experiences I perhaps gained patience and compassion to help people as a nurse.

I wondered how this hope had become visible in my work as a nurse. Hope had become the drive that propelled me towards my dreams. Rooted in my belief in Christ, hope was a way of life for me. I lived hope in several ways: daily practices such as prayers, as well as attending to goals such as graduate school, and the creation of helping relationships through volunteer work. Over time I learned to practise my hope through prayer, self-talk, and worship. As I grew in this spiritual process, I focussed on my goals for the future. To achieve these goals, I drew on several resources such as social, collegial, family, academic, as well as financial supports, as I also continued to practice my fluency skills.

Choosing a helping profession, such as nursing, had provided contexts, as well as opportunities, to foster this hope in my clients, particularly those who lived with HIV. Hope was shown through a caring relationship. My experience of sharing hope with my clients resonates

with Sobsey (2001) who asserted that we survive as a human race by the support we give to each other, as a family and as a community.

## **Unpacking the Tension**

While recounting my own challenges, I still think about Kojo and the importance of his question of dying to my work with hope in HIV care within the Ghanaian setting. This thought opened up several thoughts, particularly the thought to serve God through humanity. Hence, I saw my nursing practice as a ministry. This experience challenged my understanding of nursing relationships established during my college training and with PLWH in particular. I wonder: How are nursing students prepared to meet the emotional needs of HIV positive patients as well as their emotional response to them?

I wondered about my nervous tension when I first began to work with PLWH. I had not considered myself unprepared for HIV care at the time. Over the years, I became more troubled with attitudes towards caring for PLWH, which increased my curiosity to understand the experiences and caring capacity of nurses choosing to work with PLWH. My expectation was that everyone would accept PLWH as human beings, instead of stigmatizing and discriminating against them. What I observed and what I felt filled me with tensions, as the discrimination and stigmatization were visible. This tension revealed what I experienced. How did my hope mitigate these tensions? I felt grateful for the opportunity to have worked with HIV in my early career as well as during my nursing training as the exposure offered me the opportunity to turn towards hope. I recall when our tutor brought a PLWH to class who told us about her story of becoming HIV positive. Her husband had died of AIDS and she was later diagnosed with HIV. I wondered what my hope was for her. I wondered if I saw hopelessness or hope in her situation. These early encounters uncovered my inadequacy for clinical experiences. In the clinical setting, I found HIV nursing challenging as it was not easy to sustain my hope. I was not only losing trust in the way and manner colleagues related to PLWH, but also in my own practice. These were challenging experiences for me; it was often my faith that renewed my hope.

This tension between hope and hopelessness, and how to maintain hope in my care practices, led me to wonder about the ethics of nursing practice among nurses providing care to PLWH. In an observation involving two nurses conversing about a patient, one nurse said to another nurse "let him die, he has given it [HIV] to many people". This comment made me wonder if it might seem right and/or natural to some people to allow PLWH to die for these kinds of reasons. For me, to practice with hope means caring, and the nurse's comment makes me think of my own attitude towards PLWH. If nurses in HIV care are to foster hope in their practice (Tutton, Seers, & Langstaff, 2009) then it is essential that the philosophical foundations of hope, nursing, and caring are dutifully observed.

Nurses intertwine their caring activities with hope by way of assuring and reassuring. In other words, the attitudes of health care providers can determine how much hope or hopelessness is fostered in PLWH in a clinical setting. I still think about the nurse's value-laden statement and how it spoke not only to the complex ethical issues and challenges of what hope might mean, but also to the social and institutional narratives that shape nursing practice. The words distressed me and, for some time, I remained shocked and avoided conversations around patients' morality. As I considered my colleagues' attitudes towards PLWH, I began to think more deeply about our commitment to care as nurses. I saw much hopelessness around me and it caused me still more tensions. I began to ask myself: How did I live hope? How did I live courage? And, what

### threatened my hope?

### Hope for Me

The first time I became so attentive to *hope* was when I became a Christian, learning about heaven's bliss and happiness, a place devoid of suffering and pain. In the Holy Scriptures I learned about how God uses people and circumstances to inspire and give hope to others. However, the Bible also shows that people are fallible and circumstances are constantly changing. The hope that abides in God is everlasting. The second time I found hope meaningful was when I thought about my stuttering and the embarrassment it caused me. My stuttering almost always plunged me into hopelessness. I could not find my hope. After the intensive therapy at ISTAR, I was constantly drawn to the hope that I could communicate effectively and complete my sentences with clarity. This hope increased my confidence and gave me a different view of who I was and was becoming. I still worked on my fluency skills every day.

Turning to the study of hope as a student researcher introduced me to a course titled: Hope and Helping Relationships taught by Professor D. Larsen at the University of Alberta. As part of the class activities I joined the Hope Foundation's monthly meetings at Hope House. I personally came to know it as the home of hope researchers. It was a source of hope information and a hub where I met with other students and researchers interested in hope. The house was filled with a hope library and hope symbols.

Hope played an important role in my life, particularly in my Christian life and as a researcher and a person who stuttered. My symbol of hope was the visible house sparrow because they live close to humans. Their constant presence outside our doors made them easy to overlook, and their tendency to displace native birds from nest boxes caused some people to

dislike them. But house sparrows, with their capacity to live so closely with us, were just recipients of our own achievement. For me, a sparrow carried a promise of God's providence and of hope-everlasting. As the sparrow lived without planting or harvesting yet fed daily, hoping aided me to complete my sentences as well as support others every day. My stories might not have happy endings but hope always made me see myself as a victor and not a victim.

# **My Research Puzzle**

In this narrative inquiry, alongside participants, I explored the following research puzzle:

What are the experiences of hope among nurses in Ghana in the context of HIV? How do nurses work with hope in HIV settings in Ghana? What sustains their hope? How does work alongside PLWHs shape nurses' experiences of hope?

#### **Chapter Two: Conversation with the Literature**

As I moved away from the tensions called forth by working in HIV care and wondered about nurses' experience of working with hope-focused practices, I addressed the need for a theoretical framework to support the foundation of my hope understanding. I also acknowledged the need to be familiar with other theoretical considerations to ensure more complex learning. Given that the tensions I felt related to hope and HIV care in Ghana, I examined the definition of hope, hope theories, and hope in nurses' contexts and in the contexts of HIV. I also explored threats to hope; the importance of a relationship to effective caring, cross-cultural experiences of nursing and hope; and hope in HIV and AIDS care. Finally, I examined how Ghanaian nurses working with hope in HIV and AIDS care experienced hope, as well as I examined Connelly and Clandinin's (1999) notion of how stories to live by could influence what I began to understand as a narrative conceptualization of hope.

## **Definition of Hope**

As a result of the contemporary increase in problems affecting the mind and body, the concept of hope has received tremendous attention. Hope is a positive inspirational and mental attribute that is theoretically necessary to generate and sustain action toward goal attainment. (Arnau, Martinez, Niño de Guzmán, Herth, & Yoshiyuki Konishi, 2010). Undeniably, hope is vital for goal attainment. Hope offers an individual a reason to initiate an action. Although hope is basically connected with an initiation of action toward goal attainment, other authors have uncovered other human experiences associated with hope. For example, hope has been found to be "a process of anticipation that involves the interaction of thinking, acting, feeling, and relating, and is directed toward a future fulfillment that is personally meaningful" (Stephenson,

1991, p. 1459). With these words, Stephenson makes an attempt to concisely summarize the parts of human experience affected by hope. Hope is thus essential to human life and wellbeing possibly because of its attractive positive force. From Stephenson's definition, hope can be categorized based on a number of characteristics or complexities. Other theorists (Larsen, Stege, & Flesaker, 2013) define hope as composed of attributes of temporal, cognitive, affective, behavioural, spiritual, interpersonal, and goal-oriented aspects. Jevne and Miller (1999) describe hope as "looking forward with both confidence and unsureness to something good" (p. 10). Hope can be seen as appealing differently to different authors and disciplines. Hope, as a central construct for nursing, has been analyzed, defined, and studied by nurse researchers.

# **Theories of Hope**

Hope theories are generally classified as uni-dimensional or multi-dimensional, depending on the level of complexity (Larsen et al., 2013).

**Snyder's Hope Theory.** The most renowned among the uni-dimensional hope theorists is Snyder and colleagues' Hope Theory (Snyder, 1994; Snyder, Irving, & Anderson, 1991; Snyder, Rand, & Sigmon, 2002). According to Snyder and colleagues (1991, p. 287) "Hope is a positive motivational state that is based on an interactively derived sense of successful (a) agency and (b) pathways." The agency is goal-directed energy and the pathways involve planning to meet goals. This uni-dimensional hope theory can be subdivided into goals, pathways thinking, agency thinking, and barriers.

Goals, according to hope theory, may be whatever a person desires to achieve, become, experience, create, or do. As such a goal can be a lifelong pursuit. Goals have been found to be associated with all human action, and they form the central cognitive component of Snyder's hope theory. Human behaviors are also guided by the goals seen as mental targets that have significant value to us. For humans to attain their goals there must be a combination of *a will* and a way. Goal attainment is linked with positive emotions (Snyder, Sympson, Ybasco, Borders, Babyak, & Higgins, 1996), and negative emotions are linked with goal blockages (Diener, 1984). This assertion is not always the case as persons with high hopes respond differently to barriers and do not see the barriers as blocks but rather as challenges to overcome (Snyder, 2000). In this way, high-hope individuals develop alternative but specific strategies or plausible routes towards a goal (pathways thinking), especially when the goals are important. The detail and confidence with which we formulate these routes is important for our overall hope. Several detailed pathways to one goal would increase the likelihood of achieving it. Meanwhile, agency thoughts use our chosen and developed pathways to reach our goals. In other words, agency thinking helps us initiate and sustain the motivation for using those strategies or routes. Self-referential thoughts, which relate to our energy to maintain focus on our goal pursuit, is important, especially if one encounters barriers to the goals. Snyder and colleagues (1991) developed hope tools or scales to measure levels of hope as well as agency and pathway thoughts to help predict outcomes of hope.

In spite of the theory's strengths such as its straight forwardness, comprehensiveness, and support for the hope scales regarding validity and reliability, it has been criticized as being overly cognitive with a heavy reliance on data obtained from undergraduate students to establish these scales (Chang & Banks, 2007; Cheavens & Gum, 2000). Another criticism is that on the Snyder's Hope Scale, 3 out of the 4 agency items measure confidence or optimism, and not hope (Carver & Scheier, 2002).

Relevance of Snyder's Hope Theory to my study. My wonder is about the experiences of hope among nurses in the context of HIV and AIDS care. Nursing work is full of uncertainties as outcomes are often foreseen as possibilities and not as probabilities. Patients' outcomes are constantly changing and so are goals. Goals set by nurses and administrators may enhance nursing actions and create a context for patient care. Using goals may also boost the hope of nurses, thus making Snyder's Hope Theory more amenable to the caring process. The theory can also be utilized as a process or outcome measure for the experiences of nurses working with hope in the clinical setting or educational contexts.

**Farran, Herth, and Popovich's model of hope.** The multi-dimensional models of hope connect hope to various human experiences that are frequently recognized as attributes of hope. These attributes comprise temporality, thinking, acting, feeling, relating, transcendent, future-oriented, and goal-oriented aspects (Farran, Herth, & Popovich, 1995; Stephenson, 1991). Among the multi-dimensional hope theories, the work of Farran, Herth, and Popovich (1995) is key because their theory is rooted in nursing and has the dimensions that provide the contexts for nurses and their experiences with hope. The authors describe hope as a way of feeling, thinking, and behaving. Hope functions to drive the person onward when times are difficult. When hope is associated with a sense of resilience, the thought is that nothing bad will occur or, even if bad things do occur, there are other ways out of the situation, and is described as a way of thinking. Hope becomes a way of behaving when one actively seeks applicable alternatives to a situation. Hope is also a way of relating to oneself and the world. The theory has four central attributes of hope:

*An experiential process.* Farran and colleagues (1995) assert that the experiential attribute of hope is linked to change at four levels: physical, psychological, social, and spiritual (Missinne, 1984). Physical changes occur at cellular or systemic level. The psychological level involves a response to difficult situations such as diagnosis and what it means for one's life. The social level accounts for how others respond to the afflictions. The spiritual deals with the questions of why and why me?

Subsequently, hope is associated with adversity, sense of trial, captivity or suffering, and pain, and hope is almost always experienced in the face of difficult times such as times of illness, loss, social pain, and disability. According to Farran and colleagues (1995), individuals confronted by such afflictions recognize their own incapacity to escape the circumstances or predict the outcome of the circumstance; however, they continue to hope despite the unpredictable outcomes. The key factor expressed by the authors is that such individuals learn to discover hope in their sufferings. How do nurses in HIV and AIDS care experience hope; how do they overcome stigma, burnout, compassion fatigue, and foster healthy wellbeing in their work environments?

Understanding how nurses experience these related difficulties and how they work with and experience hope, can offer healthcare providers awareness in designing appropriate interventions for themselves. As we learn what inspires hope in difficult situations during the caring process, nurses are more likely to gain more support from each other and other healthcare providers to help improve their wellbeing. In spite of the assumption that childhood experiences can be a source of hope for later life challenges, it is not well established in the nursing literature (Larsen, 2009). Another dimension is the spiritual process.

A spiritual or transcendent process. This dimension of hope links to a faith in oneself, in others, and to spirituality. It engages the ability to find one's soul and rise above difficult circumstances that are associated with the spiritual or transcendent attribute of hope. This kind of hope can be experienced through an active prayer life, or it can be experienced through nature. Farran and colleagues (1995) emphasize that this hope is linked with power above the individual. The individual's expectations are fluid but moving in context. The individual is not able to see or understand the full outcome of a situation, neither can others, and the experience is open to possibilities that can contribute to the interest of the individual. Activities such as prayer, meditation, and attending spiritual meetings are but a few ways of expressing spirituality. This dimension of the theory contributes to the conceptualization of hope, but it is difficult to objectively measure. The dimension makes no reference to how healthcare providers experience spiritual hope during the caring process, though it is known that support from religious faith can influence the care process (Averill & Sundararajan, 2005). Considering the evidence that HIV and AIDS nursing is associated with fear of the unknown about the progression of the illness and time of death, there is value in an argument to put one's hope in a power above where individuals lack capability to control affairs. However, how nurses who work with hope experience the transcendence of hope is not fully explored. I agree with Brumbach (1994) who asserts that belief in God gives nurses hope in their practice. Another dimension is a rational thought process.

*A rational thought process.* This dimension is related to the process of thinking and often described as the mind of hope. It is subdivided into goals, resources, active process, control, and time. The goal describes a realistic process in which what is hoped for and desired subjectively

is combined with what is objectively possible (Moltmann, 1975). It answers the question: what are you hoping for? Thus the goal part of the rational thought process deals with an objectively possible outcome of an expectation. In this attribute, goals are flexible and realistic. It implies that whatever the outcome of the goals, they are accepted as "reasonable" or "realistic". Much health literature tends to assert "reasonable" hope but does not really address these challenging issues of whose hope is reasonable.

The resources vary from the physical, emotional, or social energy and the transcendence that support one's attainment of hope. It answers the question: What supports this hope? The resources deal with the factors that support hope. In healthcare, such factors will include the policies that guide practice, the administrative procedures, and the healthcare provider's own sources of motivation. For nurses and patients, hopeful resources can include family, friends, income, and level of education. In this study, nurses' resources of hope include patients, colleagues, friends, material resources, and families.

The active process aspect reflects the steps taken towards attaining goals or dealing with situations (Pruyser, 1968). It responds to the question: How committed are you to hope? The individual plays an active role in achieving goals. For example, a patient who hopes to improve his/her quality of life is more likely to adhere to the treatment regimens. Activities such as monitoring vital signs, regular assessments, and implementing interventions are a few indications of active involvement in achieving healthy living goals. How do nurses who work with hope maintain this active process during the caring process to sustain their hope?

The control aspect of rational hope aids the individual to feel secure and more hopeful (Fromm, 1968; Marcel, 1962), as the individual is seen to be in charge of his/her destiny (Farran

et al., 1995). Hope is associated with being in control. Healthcare providers can be hopeful when they are able to keep up with a reasonable workload and work within amenable policies and friendly healthcare settings that promote their wellbeing and fortitude. Farran and colleagues (1995) argue that the loss of control results in feelings of hopelessness. Understanding how nurses in HIV and AIDS care settings experience control of the caring process can help improve the supportive systems for healthcare providers.

The time facet places the process of hope in a time frame (Farran, Wilkin, & Popovich, 2009) giving a sense of one's past, present, and future (Marcel, 1962; Stotland, 1969). It responds to the question: Are there past pleasurable experiences? Thus rational hope is also a learning process grounded in time. The authors reiterate the argument that hope involves experiencing life challenges such as the pain of failure, losses, disappointments, and illness (Farran et al., 1995). Such experiences of hope across time can offer a context for considering change and innovation in policies and procedures that shape the caring process of healthcare in the future. Another dimension is a relational process.

*A relational process.* Hope through relationships is a kind of hope that occurs between persons. An example might be someone who carries hope for you when you are unable to carry it yourself. Relational hope is postulated as an entity that is fostered by others. Farran and colleagues (1995) explain that human behaviors such as being there and positive statements will influence another's hope. Hope-generating positive experiences from childhood can impact one's ability to overcome hopelessness or difficulties. Thus Erikson's (1982) assertion that hope is a developmental process is confirmed. As a developmental process hope is linked with the temporal spaces of past, present, and the future. However, the question of whether or not

relational childhood experiences can influence professional activities such as the caring process in nursing is a gap of knowledge in the literature.

It is acknowledged how important relationships in clinical settings are and that they have prompted positive experiences such as coping with difficult times (Farran et al., 1995). However, these relationships usually affect patients and occur within family circles, between friends, congregational members, and other patients. I wonder about healthcare providers. How does the relationship between patient and healthcare provider impart a health care provider's hope?

The two major types of hope complement each other. Farran, Herth, and Popovich's theory of hope has attributes that were based on extensive analysis of data on hope from philosophy, theology, nursing, medicine, psychology, and sociology (Herth, 2000). It therefore has a wide application to health-related situations.

## Nature of Hope in the Context of Nursing

Everyone I tell about my research says to me: "that is an interesting study." It makes me wonder if they are genuinely curious or responding with disbelief or disappointment. When I explain further that I believe hope-focused practices are important in every nursing situation, individuals often seem to have some idea about what I mean. This does not surprise me, given that hope and nursing are interconnected in key ways. By this I mean that the idea that nursing care can give hope, and that hope can invigorate nursing, is commonly understood. Hope has been conceptualized in nursing as important to the caring process and that nurses have the potential to foster or hold hope for others (Tutton et al., 2009). In what follows I will attempt to examine hope from different dimensions.

**Cognitive dimension.** Expectations were often described as realistic and unrealistic which may arise from a view of hope as a cognitive decision making process in which making and achieving goals was of paramount importance. It was often assumed that hope had to be realistic in order to be defined as hope (Bays, 2001; Benzein & Saveman, 1998; Herth, 1993; Morse & Doberneck, 1995; Morse & Penrod, 1999). Snyder (1995) supported this model of hope defining hope as "the cognitive energy and pathways for goals" (p. 355). In this dimension, energy is required to move toward goals and there must be clear pathways to achieve goals in order to experience a high level of hope. If these are not present, it is suggested that low levels of hope will be experienced. Managing people's hope is often difficult in complex clinical situations. Begley and Blackwood (2000) provide case studies where they suggest knowing the truth may, for some people, undermine hopefulness and reduce opportunities for enjoying life. Unrealistic hopes are evident in human life, such as instant healing or a belief that one can escape from prison, yet arguably, these hopes may sustain positive emotions. In cancer patients, hope for a cure exists even when patients are dying (Sharp, 1994). This reflects a general hopefulness that something good will happen that is not happening at the moment (Halpin, 2001). Eliott and Olver (2002)'s sample of oncology patients suggest that hope is always beneficial and enables them to endure difficult situations. They propose that professional constructions of hope are unhelpful. For example, health professionals discuss hope generally in terms of cure and less of other outcomes. Thus patients' hope is more likely to depend on what the health professionals say about the treatment of the illness. Hope for oncology patients has many different meanings and exploring the relevance of these, at a specific time and in particular situations, may be more beneficial. This could suggest that professional constructions of realistic and unrealistic goals need to be considered within the context of lay constructions of hope within an illness experience. Such skill or expertise when applied in HIV and AIDS care settings can help surmount challenges such as the disclosure of the true nature of a patient's health status. How nurses in HIV care settings work with hope to overcome such difficulties is another gap in the literature. In a study with peer counselling providers by Harris and Larsen (2007), it was found that peer counsellors do foster PLWH's hope. However, studies related to HIV nurses' hope is lacking. In this study it was confirmed that peer group counsellors (Models of Hope) promoted and supported hope not only in their peers but affected the nurses as well.

**Goal attainment dimension.** In areas of recovery rehabilitation and health promotion, the significance of hope can be realistic as a goal-orientated phenomenon. Morse and Doberneck (1995) suggest that

Hope is a response to a threat that results in the setting of a desired goal; the awareness of the cost of not achieving the goal; the planning to make the goal a reality; the assessment selection, and use of all internal and external resources and supports that will assist in achieving the goal; and the re-evaluation and revision of the plan while enduring,

working and striving to reach the desired goal. (p. 284)

In the context of health, the threat of illness/injury creates hope for recovery and identification of actions that are required to achieve goals.

Turner (2005) identifies hope as a driving force linked to choices. Hope, in this way, is focused on believing that people make choices that will lead to fulfilment; that they will have the energy and focus to make choices; and that they will be able to meet chosen goals. To be connected to other people and prepared to work at making good choices are essential components of hope. In other areas of practice, where goals may not be so important or different from other times in their life, such as patients who are dying or those who are older, a wider approach to hope may be required. If hope is only linked to goals, being able to achieve them may be restricted.

Bunston, Mings, Mackie, and Jones (1995) argue that older people have a "declining sense of hopefulness as a person sees a past that out distances the future" (p. 85). Herth and Cutcliffe (2002) suggest that definitions of hope that focus on achievement, success, and control are not so useful when associated with losses in old age, although healthy older adults have different views from those whose health is declining. The meaning of hope for this group would therefore need to be generated from the older people themselves within the contexts in which they live. Whether this notion that definitions of hope are personal and contextual will hold for health care providers in HIV care is yet to be explored. However, understanding hope from the perspective of those who matter within the contexts of their work can offer a strong guidance for practice.

### Hope and Meaning

Herth (1990) states that hope is having a sense of meaning or purpose in life. Attainable aims are identified by people in relation to hopes for themselves and for their families but these are more about the experience of life and death than finding pathways to goals. Elliott and Olver (2007) support this by identifying the use of the verb "hoping" in conversations with dying patients. Their research shows that the use of the word "hoping" was fundamental to conveying the elements that gave dying patients' lives meaning. Conversely, hope as a noun tended to be linked to bio medically derived evidence in relation to their illness. From conversations with dying patients, Sharp (1994) found that hope was focused on maintaining patients' present diseased state; that medical and nursing staff would 'be there' and care for them; that their families would continue to grow and develop; and a wish that they would have a future with them. Hope was therefore a fundamental concept for people who were dying (Sharp, 1994). The focus of hope for these patients was on the experience of living and dying rather than goal attainment. But what is the focus of hope for the nurse in the HIV and AIDS setting? Do they experience hope similarly? Do social aspects such as stigma and discrimination impact a nurse's 'sense of hope? If so how? Which of these experiences are covert or overt? What threatens a nurse's hope?

Within the nursing literature, hope as a concept is generally viewed within a positive light; it is dynamic (i.e., a process with degree and focus of hope changing over time) in nature and orientated towards the future. Thus hope tends to be placed within an injury/illness and recovery trajectory. It is often portrayed as a psychological process that enables individuals to *rise*. I believe that hope underpins, informs, and holds a variety of caring purposes and outcomes together in unique ways. Like the weather, it changes through the seasons in and across caring landscapes. It is difficult to see and/or describe because hoping, in itself is elusive and unique (Dufault & Martocchio, 1985; Farran et al., 1995).

## Hope and its Relevance to Nursing Practice

Hope as an essential concept for nursing has been studied by nurse researchers. Hope is a process that unfolds in various ways across one's life. The nursing literature suggests that nurses are an important source of hope to the less hopeful and the helpless (Cutcliffe & Gant, 2001; Herth, 1990, 1996; Moore, 2005; Stephenson, 1991) due to their constant interaction with

patients who are suffering. However, how exactly nurses work with hope in their practice remains unclear. Currently, hope activities appear to be embedded within the nursing care process and are difficult to describe. Cutcliffe and Gant (2001), based on conversations with five qualified nurses who worked with people living with dementia, identify hope-facilitating strategies as part of everyday practice. Hope was facilitated through the humanistic principles on which care was based, how they used knowledge in practice, their interpersonal relationships, and how health care professionals managed the care environment and organised care. The study was based on the assumption that hope was something that can be given to people rather than facilitating the individuals' ability to hope: an issue that requires exploration in future research.

Herth (1996), from her study of hope in homeless people, suggests that nurses can work to support homeless peoples' hope through creating a nurturing environment, listening to their stories, supporting individuals' sense of self, and focusing on positive realistic goals. If nurses take on the role of facilitating hope in others then it suggests that they require skills in this area. In Moore's (2005) opinion it was important that nursing staff have a high level of self-awareness and have hope in themselves in order to inspire hope in others. Health care providers who use hope-enhancing skills have inbuilt support systems for accomplishing their work but do acknowledge the emotional costs. This was supported in Freshwater and Robertson (2002) who identify being with patients who experience despair as very challenging, because the patient's despair can resonate with the nurse's own feelings. It is possible that HIV and AIDS settings can mimic the challenges faced in palliative care. This would suggest that working with HIV and AIDS patients will require deepened emotional work and mechanisms to support care. There was, therefore, some evidence to suggest nurses have a role in this area but what that role is and
how it is manifested in practice remains unclear and requires further exploration. The authors suggest that nurses have a role in relation to hope (Freshwater & Robertson, 2002). However at present the role is diffuse, generic, and embedded within interpersonal relationships. It may be helpful to explore further what nurses do in practice and examine the emotional consequences of undertaking this role in care settings and how hope may play a role.

#### Hope and HIV Conceptualized

In the context of healthcare hope can be a formidable support for both patients and health care providers. In the nursing literature hope has positively touched the lives of many terminally ill patients such as cancer patients, very ill patients, and mentally ill persons (Herth, 1990). Hope has been conceptualized as a process of thinking, acting, feeling, and relating to the future that is meaningful to the person (Stephenson, 1991). The interaction of these basic states can impart health. Hence, hope can affect wellbeing and thus determines not only health outcomes but also overall quality of life (Snyder, 2000). Farran and colleagues (1995), before the arrival of anti-retroviral therapy (ART), found that persons with a diagnosis of AIDS have significantly lower levels of hope than persons with other terminal diagnoses. I do not find this surprising since the social retribution associated with an AIDS diagnosis is phenomenal and has a negative impact on the patients. This social retribution of HIV and AIDS is perpetuated by all cultures in the world, particularly cultures influenced by Judaeo-Christian and Muslim religions. Such cultural attitudes can impact hope (Li & Larsen, 2012).

But today, 2 decades after Farran and colleagues research studies in the pre-ART era, it is expected that the scales might be balanced. The researchers also found that the caregivers of terminally ill patients do not indicate loss of hope as patients' conditions deteriorate; however,

caregivers of persons with HIV infection were less hopeful than caregivers with other terminal illnesses. The idea that healthcare providers experience hopelessness when providing care to HIV patients is a knowledge gap in the literature that needs be addressed. The authors of the above studies used qualitative methods in focusing on hopelessness and the studies were largely conducted by non HIV and AIDS care providers. In addition, hope and hopelessness are not always opposites, as less hopelessness may not mean more hope. A person may be in a hopelessness situation like cancer, but they can still be hopeful. The use of a qualitative methodology, such as narrative inquiry, can add another dimension to the research in this important area of nursing and care practices.

Other researchers propose that hope is the ability to envision a future in which we wish to participate (Jevne, 2005). PLWH see the future with uncertainty as they know that their condition has no cure and this uncertainty can affect their thoughts and behaviors as well as their relationships with healthcare providers. I wonder, how do PLWH hopes impact nurses' hope? How does hope impact their wellbeing or quality of life?

### Hope Conceptualization in the Ghanaian Culture

Hope is known to be useful in human lives and is also present in all cultures. However Li and Larsen (2012) argue that different traditions of religion influence hope conceptions. In the context of health care hope can be a formidable support for both patients and health care providers. In the Ghanaian culture, I see hope as constantly emanating from God or a power above. Both positive and negative feelings are based on the interaction between dependence and belief in God.

# Hope Conceptualization in Narrative Inquiry

According to Clandinin and Connelly (2000), narrative inquiry stems from the epistemological standpoint taken by Dewey's (1938) pragmatic philosophy. Dewey (1981) conceptualizes "experience as a changing stream that is characterized by continuous interaction of human thought with our personal, social, and material environment" (Clandinin & Rosiek, 2007, p. 39). Connelly and Clandinin (2006) further state that to use "narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study" (p. 375).

To consider Dewey's (1938) notion of experience as that which grows from past personal and social encounters, broadens understandings of experience. The individual's experience as postulated by Dewey (1938), as both personal and social, provides the philosophical underpinnings of narrative inquiry as well as grounding for the consideration of the three dimensional narrative inquiry space of place, temporality, and sociality (Clandinin & Connelly, 2000). Clandinin and Rosiek (2007) argue that "framed within this view of experience, the focus of narrative inquiry is not only on individual's experience but also on the social, cultural and institutional narratives within which individuals' experiences are constituted, shaped and enacted" (p. 50).

Considering the importance of stories in human history and their use in narrative inquiry research, understanding healthcare providers' experiences of hope can help improve support for the care giving process. Hope, as indicated by Farran and colleagues (1995), has an attribute of experiential process that an individual goes through during a difficult time. Stories are known to exemplify hopeful situations and stories can sustain hope in health care providers. Choosing to narratively inquire into nurses' experiences in HIV and AIDS care will allow me to understand

how nurses work with hope, and also offer the opportunity to hear the difficulties that are part of their stories of hope.

As a narrative inquirer, I connect to my hoping self (Larsen & Larsen, 2004) by documenting and sharing stories about my experiences alongside HIV care nurses who will share their experiences of hope. LeMay (2014) asserts that we need to understand hope in relation to experiences. For LeMay, "[t]he Deweyan-inspired narrative conception of hope is grounded in a commitment to the relational, ontologically and epistemologically" (p. 29); this extends to the educative element that one experience has on the next. Conceptualizing hope narratively will help me appreciate the experiences of my participants and how their hope making in HIV and AIDS care impacts their lives and shapes subsequent experiences for them.

#### **Chapter Three: Research Methodology: Turning to Narrative Inquiry**

My research puzzle evolved as I attended to experiences of hope in the literature and in the hope classes and meetings<sup>3</sup>. I chose narrative inquiry as my methodology to help me make sense of how nurses in HIV and AIDS care constructed and reconstructed their stories to live by (Connelly & Clandinin, 1999) in relation to hope. As an approach, narrative inquiry is a collaborative way to inquire into participants' experiences in the three-dimensional spaces of temporality, sociality, and place (Clandinin & Connelly, 2000). Temporality refers to past, present, and future dimensions; sociality draws attention to the personal and social dimension; and place attends to the locations where experiences occur. Following the Deweyan narrative inspired conception of hope (LeMay, 2014), my study was conceptualized within a framework of narrative inquiry as I sought to understand Ghanaian nurses' experiences of working with hope in an HIV and AIDS acute care setting.

## What is Narrative Inquiry?

According to Clandinin and Connelly (2006) narrative inquiry is a way of understanding experience. It is collaboration between researcher and participants over time, in a place or series of places, and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in the same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of experience that made up people's lives, both individual and social. (p. 20) Describing narrative inquiry, Clandinin (2013) asserts that narrative inquiry is an "approach to the study of human lives conceived as a way of honouring lived experience as a source of

<sup>&</sup>lt;sup>3</sup> The meetings about hope practices happen once in a month.

important knowledge and understanding (p. 11). Thus narrative inquiry can take on a practical approach where lives are studied in order to understand experience. This way of studying experiences brings the inquirer and the participant together to co-compose a path of retelling their stories in a way that is unique from other qualitative methodologies (Clandinin & Connelly, 2000). For example, the core of narrative inquiry is to study storied experiences of persons situated within cultural, social, and institutional narratives and write narratives reflecting those experiences (Clandinin, 2005). Hence, I see narrative inquiry as a collaborative way of inquiring into, representing, and understanding experiences of hope for nurses providing HIV and AIDS care.

Individuals' experience, as postulated by Dewey (1938), provides the philosophical underpinnings of narrative inquiry as well as grounding of the three dimensional narrative inquiry space of place, temporality, and sociality (Clandinin & Connelly, 2000). Narrative inquirers explore individuals' lived and told stories. Stories tell us about people's obligations to others, and stories create obligations for participants and researchers. Obligations to care for stories are expressed by Lopez (1990) in the following way:

If stories come to you, care for them. And learn to give them away where they are needed. Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memory. This is how people care for themselves. (p. 48)

Thinking about truth goes back to Plato's days when there was an increased search for a universal truth over meaning. Bruner (1986) called this emerging phenomenon a paradigmatic mode of thought versus a narrative mode of thought. He argues "each [mode] provides distinct ways of ordering experience, of constructing of reality" (p. 11). Narrative knowing is

characterized by stories that gain credence through their likeness (because they are meaningful). The narrative mode is concerned with the particulars of experience which chronicle events over time. According to Bruner, the proper venue of the narrative mode is within the subjective world of meaning.

The paradigmatic mode of thought has created a worldview and a language of its own, a language that has become indispensable for describing what Bateson (1972) has called the world of the "non-living" (p. 163). However, in the 1980s and early 1990s the voices of narrative researchers have become ever louder. For example, O'Connor (1998) reported the attention that various researchers from different disciplines (philosophy and linguistics) have added to the phenomenon in the 19<sup>th</sup> and early 20<sup>th</sup> centuries. This era heralded the move from modernism to postmodernism where principles and rigid practices were no longer the norm but more attention was being paid to human experience and other ways of knowing.

Recounting the historical background of narrative inquiry, Pinnegar and Daynes (2007) assert that although there is a history of narrative work and narrative research, researchers began to take interest in understanding experience narratively in the late 1980s and early 1990s. It was at such time that researchers like Connelly and Clandinin (1990), specifically, began to advance a research methodology named narrative inquiry. Over the years, narrative inquirers have developed significant terms (touchstones) and distinctions that have become more obvious and well recognized (Clandinin & Caine, 2013). Narrative inquiry is now a well-established methodology and phenomenon (Clandinin, 2007) that continues to be different from other qualitative methodologies.

Narrative inquiry methodology is used as means of understanding the experiences of

participants, consequently Connelly and Clandinin (2006) assert that "story is a portal through which a person enters the world and by which his or her experience of the world is interpreted and made personally meaningful" (p. 47). As an account of past events in one's life, a story speaks of experiences. Dewey's notion of experience, as a growing from past personal and social encounters through interaction and continuity, is the grounding view of experience that is used in narrative inquiry. There are experiences that are difficult to represent or any other way but they too are part of human lives, such as feelings, imaginations, and expectations.

## **Philosophical Assumptions of Narrative Inquiry**

Dewey's theory of experience (1938) is most often cited as the philosophical underpinning of narrative inquiry (Clandinin & Connelly, 2000). Dewey's two criteria of experience, interaction and continuity, enacted in situations, offers the grounding for the attention paid to the narrative conception of experience. According to him, experience is both personal and social, thus individuals can be understood in relation to their social contexts. An individual difference is unique but also understood as connected to other individuals in the context of communities. Furthermore, Dewey postulates that experiences can sprout out of other experiences as the present connects to the past and the future in continuum. Dewey's notion of experience and continuity are key in my thinking about nurses' hope in the context of HIV and AIDS care. I will move back and forth between the personal and the social, at the same time thinking about the past, present, and the future.

There are many key authors from a variety of disciplines that have influenced the philosophical ideas of narrative inquiry. Among these are Bruner (1986) (psychology) who distinguished between paradigmatic and narrative knowing. Carr (1986) (philosophy) wrote

about the narrative structure and coherence of lives implying a narrative always follows linear, chronological ways, from a beginning to an end. Bateson (1989, 1984) (anthropology) also drew attention to continuity and improvisation as a response to the uncertainties in life contexts, making experience and stories essential for living. Coles (1989) (medicine/psychiatry), who applied using narrative in life and teaching practice, indicated the important role of narrative in medicine.

Clandinin and Rosiek (2007) argue:

Framed within this view of experience, the focus of narrative inquiry is not only on individual's experience but also on the social, cultural, and institutional narratives within which individuals' experiences are constituted, shaped, expressed, and enacted. Narrative inquirers study the individual's experience in the world, an experience that is storied both in the living and telling and that can be studied by listening, observing, living alongside one another, and writing and interpreting texts. (pp. 42–43)

From this ontological and epistemological position, narrative inquiry is a way of understanding and inquiring into experience that is situated in relationships and community and tied to notions of expertise and knowing in relational, participatory ways. Clandinin (2007), while acknowledging that researchers agree that narrative inquiry is the "study of stories or narratives or description of series of events" (p. 4), emphasises the assumption that story is the basic unit that gives explanation to human experience.

Thus, narrative inquiry becomes a methodological approach where lives are studied in order to understand experience. Clandinin (2013) makes allusions to people's storied lives when she asserts "people shape their daily lives by stories . . . they interpret their past in terms of these

stories" (p. 13).

Narrative inquirers such as Caine and Estefan (2011) remind us that stories are important because they sustain and remind people that lives are lived, told, retold, and relived in storied ways. Stories are what people know, how people know, and stories are how people live. For the Ghanaian context in particular, stories are the primary medium of passing on knowledge. I remember when growing up in the countryside, every evening all the children were gathered around the hearth and listened attentively to the stories from our Elders. Many of the stories told by Ghanaians are moral stories of a popular character called "Ananse" meaning spider, who always escapes consequences. Such stories made me think, feel, and act in ways that were relational and helped me build my identity of who I was and was becoming as Ghanaian.

People have used stories to provide accounts of their experiences in life. Studies from the past (Carr, 1986) also indicate that people relied on storytelling to provide explanations for basic questions in their lives. People used stories to describe their cultures, and storytelling in different cultures earned credibility because of the meaningfulness it provided. Stories make lives meaningful within cultures. Doan and Parry (1994) argue that it is the quality of meaningfulness, rather than factual truthfulness that gives the story credibility.

Over the years, significant terms (touchstones) and distinctions have become more obvious and well recognized as guiding what counts in narrative inquiry. This distinction makes narrative inquiry a well-established view both as a "way of understanding an experience [phenomenon] as a narrative construction and as a way to understand how we might study experience [methodology]" (Clandinin, 2013, p. 47). Narrative inquiry focuses on experience and Clandinin and Connelly (2004) observe that, "Humans are storytelling organisms who, individually and collectively, lead storied lives, and the study of narrative is the study of the ways humans experience the world" (p. 44). According to Clandinin and Caine (2013), narrative inquiry is characterised by an ontological view where the inquirer is concerned with inquisitiveness; he or she wishes to find out about the way people are living and that which constitutes their experiences. By studying and understanding experiences narratively, researchers and participants form relationships over time in unique places and different contexts. Within these relationships, research participants tell and live their stories that speak of, and to, their experiences.

# Why Narrative Inquiry?

After my master's degree, I found myself engaged with a narrative inquirer as I began to work with a new supervisor for my PhD program. As we engaged in discussion around my master's thesis research findings, I began to wonder how the use of stories could re-frame the HIV and AIDS situation in Ghana. This wondering became more grounded after I enrolled in a narrative inquiry course which inspired me explore the stories I lived by and, in turn, intentionally connected to my hoping self (Larsen & Larsen, 2004). I was curious about the stories of nurses' hope and how they made hope visible in their work. Narrative inquiry allowed me to focus my research puzzle on experience, particularly who I was in the stories I lived and told, that is, my stories to live by. Narrative inquiry is culturally appropriate to the Ghanaian context and to my life context. Finally, narrative inquiry enabled me to participate in, and describe the ways of telling and retelling the stories of experiences of hope of nurses who worked in HIV and AIDS care in clinical settings.

Further, narratives constructed in a spatio-temporal context assisted in meaning-making.

In particular, referring to narratives in organizational studies, Boyce (1995) posits that narratives constitute symbolic forms through which groups and members of organizations can construct meaning. Narratives also provide individuals with a means to express and shape their identities, beliefs, and hopes. A narrative approach can thus be useful for studying the experiences of hope among nurses within structured institutional settings.

As narrative inquiry is a relational methodology, it assisted me to enter into relationships with nurses providing HIV and AIDS care to understand their cultural orientation, as well as their stories about stigmatization and the role of hope and faith in their practice. This way of engaging offered me a position and identity to define who I was and who I would become in relation to the phenomenon of the research, to the participants, and in relation to the literature. Thus my personal involvement and investment and my awareness of my position as a researcher throughout the research shaped and deepened my puzzle (Clandinin & Caine, 2013).

Utilizing narrative inquiry generates rich and unique insights. These insights have various aspects which influence the relationship between individuals and society. It helped me to understand what brought me to my puzzle, thus offering me a sense of what stories I am living and telling in the research relationship, and helped keep me attentive to the experiences of research participants (Clandinin, 2013) by way of living and staying awake to how nurses practice with hope in an HIV and AIDS care setting. I remember the early years of my life when an elderly cousin who occasionally visited from another town told us bedtime stories. I took particular enjoyment in recounting those stories to my younger relatives when our cousin was not around. Later, my interest in narrative inquiry methodology developed when I discovered how and why we make meaning in our lives, during a course on narrative inquiry as part of my

ongoing graduate studies. This experience was deeply relevant to the development of my personal philosophy and it provided a background for thinking about narrative inquiry as a way to understand the experiences of hope. I know that narrative inquiry is fundamentally more than telling of stories. I believe that narrative is a way humans create and recreate their realities and themselves. Over the course of my research, Clandinin and Caine (2013) helped me to understand the processes for using narrative inquiry through writing narrative beginnings as well as preparation for engaging with participants during the co-composition of narrative accounts, and looking across accounts in this current studies.

# **Narrative Inquiry Process**

Narrative inquiry requires ongoing negotiation and collaboration between the researcher and participants. The researcher listens and responds to each participant's stories and also engages in a living alongside the participants (Clandinin & Connelly, 2000). There are three major areas that the researcher must present in a clear manner: the relationship between the researcher and the participant, the development of narrative accounts in both oral and written forms, and the inquiry approaches engaged in the study.

The relationship between the researcher and participant. The significance of the relationship between researcher and participants has remained an area of interest to many scholars (Caine, 2010). Both the researcher and the participant must create a sense of comfort during the process. Narrative inquiry takes a nonjudgmental approach and establishes a sense of equality between the researcher and the participants to ensure that narrative inquiry avoids potential challenges [such as patriarchal roles] (Poirier & Ayres, 1997).

**Narrative accounts.** The narrative should be a purposeful and ideological way of gaining insights into participants' lives. Thus, it goes beyond reproducing participants' stories as narratives and must be meaningful and useful to its readers. The researcher should provide accounts of his or her narrative research processes. In other words, he or she must provide a detailed account of his/her story alongside stories of participants. The interaction between the researcher and the participant is a fundamental area that needs clear illustration. There are inherent challenges such as interpretation of accounts that the use of a narrative inquiry can bring to a research process. Thus, researchers must provide the best ways of handling such challenges during the study and be willing to negotiate this with participants.

Developing a narrative account is a foundational process that the researcher must explore in order to organize the participant's experiences so that they can be shared and negotiated. The researcher has some obligation to interpret the collected information as part of the analysis (Clandinin & Caine, 2013). However, both researcher and participant may recognize that interpretation of the narrative may not end with his or her work. Research texts may attract criticism within the process of negotiation and open new avenues for further interpretation. These final texts thus lay the beginning for new wonders, new inquiries, and new possible relationships.

**Narrative beginnings.** Narrative beginnings are starting points for narrative inquirers in their research. It is where a narrative inquiry begins. Narrative beginnings reach far back to previous experiences, even into pre-reflective landscapes of the research puzzle (Clandinin, 2103). The position taken by the researcher is very significant in narrative research as the researcher, along with a participant, is a part of research. In narrative inquiry, a researcher is not

a participant-observer of a research participant's practice. Close interactions, the creation of a relationship between a researcher and a participant affect both of them and often instigate very important changes in them. The process of those changes is also recorded, interpreted, and narrated in research texts such as finished papers and in this dissertation. Clandinin and Connelly (2000) state "enhancing personal and social growth is one of the purposes of narrative inquiry" (p. 85). Thus, narrative inquiry can change lives.

## **Beginning My Research Study**

Revisiting the orientation to study experiences of hope. As a Ghanaian by birth, I spent the greater part of my life in Ghana before moving to Canada where I continued my nursing education and scholarship. During my working days in Ghana, the tension I felt working with PLWH is consistent with the experiences documented in the literature. My interest in HIV care and, in particular, working with hope in HIV was ignited by what I witnessed during my clinical practice as a nurse in relationship to Kojo. He was diagnosed with HIV the morning he was brought to the unit where I worked and he was very ill. The nurses talked about him and one nurse said that he gave the infection to many women and deserved to die. The nurses' attitude was aligned with the problematic beliefs and the irreverent attitudes of the general Ghanaian society. I found myself distressed and less hopeful as I offered care in this time and place, and did not think about working with hope with this population. Based on these observations my personal conclusion is that care for individuals with HIV or AIDS poses a serious challenge to some nurses in Ghana. In my undergraduate research project in nursing at the University of Ghana on coping strategies used by individuals with HIV/AIDS, I felt the tension and the hopelessness toward individuals with HIV and AIDS. The tension is centered on

my inability to respond to the actions and statements from the nurses. My lack of courage and advocacy skills to speak up for Kojo filled me with hopelessness and disappointment. I reflectively wonder about nurses' hope toward this population. How do nurses experience hope in their work? Could the inclusion of specific content about HIV and AIDS in undergraduate nursing curricula help to foster hope in nurses toward PLWH? I strongly believed that by talking to Ghanaian nurses who cared for HIV clients I could gain some insights into their experiences of working with hope. In the long term, this information may help me find ways to encourage more nurses to respectfully and humanely work with individuals who are HIV positive and to sustain and create a favourable nurse-patient environment as well as engage in this work with hope.

#### Ghana in the Context of HIV and AIDS

In the Ghana AIDS Commission's National HIV and AIDS Strategic Plan document (2016) it was stated that 274,562 persons were living with HIV by the end of 2015. There were 12,635 new infections and 10,958 AIDS deaths. HIV testing increased from 21% for women and 14% for men in 2008 to 43% and 20% for women and men in 2014 respectively. At the end of 2015, 2,335 testing sites had been set up nationwide. Annual AIDS deaths amongst children were estimated at 1,423. By the end of 2015, 89,113 people were on anti-retroviral treatment and 7,813 of eligible pregnant women received ARVs to prevent mother to child transmission. The HIV prevention interventions were expanded significantly to cover more Ghanaians including key populations such as sex workers and their clients, men who have sex with men, and prisoners. More than 34,000 female sex workers and 17,000 men who have sex with men were reached with HIV prevention services throughout the country. These alarming figures call

for hope and courage in order to continue caring for PLWH and understanding how the experience of working with hope can invigorate the caring process.

Globally, in the year 2015, PLWH were estimated at 36.7 million and approximately 1.1 million died from HIV related causes (USAID, 2016). Providing care for PLWH is described as exhausting and associated with burnout (Bennett, Kelleher, & Ross, 1994; Puplampu, Olson, Ogilvie, & Mayan, 2014).

Nurses who provide care for PLWH also have concerns about their well-being and health, the complexity of their role, and the HIV care related stigma (Mill et al., 2013). These concerns can contribute to the stress and challenges of providing meaningful care. Although antiretroviral therapy provides benefits to PLWH, the well-being of the nurse is fundamental to providing effective care.

# **Research Setting**

I have experienced the nursing landscapes with nurses who worked in HIV and AIDS care in my career in Ghana. The clinical setting for my research was in Ghana at the Korle-Bu Teaching hospital where I received my training and worked as an RN. The Korle-Bu setting had nurses who had long careers in providing HIV and AIDS care. The Korle Bu Teaching Hospital started operation on October 9, 1923, and grew from an initial 200 bed capacity to 2,000 beds, as reported by the hospital's official site (http://kbth.gov.gh/). In 2016 it was the third largest hospital in Africa and the leading national referral centre in Ghana. It is located in the southern region of Ghana.

The Korle-Bu Hospital was established as a General Hospital to attend to the health needs of the Ghanaian people under Sir Gordon Guggisberg's administration, the then Governor of the Gold Coast. In 2016, according to the hospital official site (http://www.kbth.gov.gh/2/aboutus.html), the hospital had 17 clinical and diagnostic Departments/Units. It had an average daily attendance of 1,500 patients and about 250 patient admissions. Clinical and diagnostic departments of the hospital included Medicine, Child Health, Obstetrics and Gynaecology, Pathology, Laboratories, Radiology, Anaesthesia, Surgery, Polyclinic, Accident Centre, and the Surgical/Medical Emergency. The Fevers Unit was under the Medicine Department and catered to all patients with infectious diseases, including PLWH. The unit ran a weekly HIV outpatient department clinic. The Hospital also provided sophisticated and scientific investigative procedures and specialisation in various fields.

## **Composing the Field: Recruitment of Participants**

All participants for this study were selected by seeking volunteers from within the HIV unit at Korle-Bu Teaching Hospital after getting clearance from the Noguchi Memorial Institute for Medical Research. I also secured clearance from the University of Alberta and an institutional clearance from the Korle-Bu Teaching Hospital. I then approached the Director of the HIV unit (Fevers Unit) and asked to talk with nurses to inform them of this study. The Director was kind enough to introduce me to several nurses at the unit. Following interaction with the nurses, I invited five nurses who had at least 5 years of experience in HIV care. They were all interested and willing to participate. I subsequently met each of them individually at the work place or at home as agreed upon to have a conversation. I observed that meeting my participants at the work place was comfortable for them and helped me get to know them better. Over time we cultivated relationships marked by friendship and trust between us.

### Living in the Field

In this study I met with nurses who worked in HIV care long enough to grasp the events and stories of PLWH. I spent time negotiating my relationships, relational engagement, responsibilities, my purposes, and transitions with the participants (Clandinin & Connelly, 2000). I lived alongside the participants as we talked about their experiences of hope. I documented in detail the interaction between the nurses and myself after the conversations. I focused on the participants' stories of working with hope, which was the central focus of this research. After my initial conversations, I returned to Canada to write narrative accounts. In the following summer (summer of 2016), I returned to Ghana to share and negotiate these accounts prior to writing about resonant threads.

### **Quality Criteria in Narrative Research**

Drawing on Clandinin and Caine's (2013) work around touchstones, quality in narrative inquiry is about a commitment to methodology and relationships. The methodological commitments involve comprehensive reading, writing, and continuous engagement with participants and other scholars (e.g., response communities) to help follow the complex process of co-composing interim and final research texts. Clandinin and Caine (2013) describe qualitative touchstones that are used as qualitative characteristics in order to determine the quality of the research. One touchstone underscored the negotiation of relationship.

**Negotiation of relationships and being in the midst.** Entering the inquiry field opens with negotiations of relationships, the research puzzle, and continues through the inquiry including an interpretation of events that normally arise when researcher and participant have different ways of interpreting similar events. My participants and I collaboratively shared

experiences and showed appreciation of experiences even where sometimes we were positioned differently. In view of this, the participants and I engaged in ongoing negotiations and were able to attend to challenges, disagreements, and tried to work through these challenges together. The negotiation of tensions was made visible in the relational qualities. At the same time, I always kept the reader in mind, particularly as final research texts were written. As a narrative researcher, I sought to understand the world view of participants by situating myself within their lived and told stories for an intensive period of 14 months. Geertz (1995) writes: "You don't exactly penetrate another culture, as the masculinist image would have it. You put yourself in its ways and it bodies forth and enmeshes you" (p. 44). For this to happen, according to Clandinin and Connelly (2000), the researcher needs "to be there long enough and to be a sensitive reader of and questioner of situations in an effort to grasp the huge number of events and stories, the many twisting and turning narrative threads" (p. 77). To begin to understand how HIV care nurses practise with hope, I negotiated relationships with the nurse participants by introducing myself and my wonders about hope practices of nurses in HIV care contexts. As an insider to the Ghanaian nursing landscape, I was accustomed to the hospital culture and was able to appreciate my participants' experiences. This familiarity helped me maintain flexibility and openness as the inquiry developed (Clandinin & Connelly, 2000).

This initial negotiation of entry was later followed by many other negotiations within the relationships with participants. These included negotiating my exit from the relationships I formed with participants (Clandinin & Caine, 2013).

Being aware of the power imbalance between myself and the participants, I proceeded through conversations that were relatively unstructured, allowing me to leave room for

participants to tell their stories in relation to the research puzzle and within the three dimensional space of place, temporality, and sociality (Clandinin & Connelly, 2000). From these spaces, each story told and lived was understood within larger cultural, social, familial, and institutional narratives. Relational engagement was a significant mark of my inquiry, as it helped in the understanding and the social importance of experience. As required of a narrative researcher, I gave key consideration to who my participants were and were becoming in the research (Caine, Estefan, & Clandinin, 2013).

Narrative inquirers endeavour to understand and describe participants' experiences narratively. In doing this, I paid close attention to the conversations and lived in collaborative ways in which I "co-compose and negotiate the living, reliving, telling, and retelling of the stories" together with participants (Caine & Clandinin, 2013, p. 169). Co-composing the stories, I entered into research relationships in the midst of my life and the lives of participants. Research relationships begin in the midst of researchers' lives being lived out within institutional narratives such as graduate studies, nursing, or teaching. Participants are also in the midst attending to the temporal, and relating to the socio-cultural narratives. The narrative inquiry began before the day I met my participants. My life and their lives will continue after the inquiry.

**Moving from field to composing field texts.** Clandinin and Caine (2013) describe another touchstone as moving from field to field texts. There are different kinds of field texts such as field notes, conversations, researcher to participant letters, participants' letters, memory boxes, and documents (Clandinin & Connelly, 2000). My field texts included field notes, transcripts of conversation, and photographs where available. After inviting five nurses to engage in this research, I engaged in ongoing conversations with them. These conversations took place during their breaks at work or on off-work days at home. I gave priority to having the meetings at the convenience of the participants. Guiding questions (See Appendix C) were initially used to guide the conversations and to help elicit in-depth, diverse, and biographical details (Wengraf, 2001). As I wished to blend into the environment rather than be perceived as an ever-present recorder, I only scribbled a few notes on a stenographer's pad while in conversations. Occasionally, when a moment seemed essential to my inquiry, I scribbled detailed notes then and there. At the end of the day I wrote field notes in which I conveyed the rich details I observed. These field notes, with description from my observations and experiences, proved key to my inquiry.

I audio recorded, in addition to handwritten notes, all conversations or reflections on what the nurses' experiences of hope were and how they worked with hope. I also kept a personal journal for recording daily important events. These records provided a reflective balance (Clandinin & Connelly, 2000) for my field texts.

**Moving from field texts to interim, and research texts.** Moving from field texts to interim and research texts is another touchstone. I co-composed five narrative accounts of the nurses' experiences of hope. In so doing, I relationally attended to participants' stories to live by (Connelly & Clandinin, 1999) with particular attention to the commonplaces of temporality, sociality, and place (Clandinin & Connelly, 2000; Connelly & Clandinin, 2006). We co-composed narrative accounts as interim texts of participants' experiences.

In narrative inquiry, interim texts are negotiated with participants. In composing my final research text, I continued to attend to the three dimensional space of temporality, sociality, and

place (Clandinin & Connelly, 2000). As a process of creating interim texts, participants and I met to discuss their and our stories and experiences of hope for meaning before moving to the final research texts. Findings were discussed in the light of the three dimensional narrative inquiry spaces, as well as relevant literature.

# Ethics

It is a norm in research to ensure no harm is done to participants, including emotional, psychological, or physical harm. Measures considered in this study included reassurance of participants' confidentiality in the narrative accounts and in the final research texts, in addition to those they interacted with in relation to this study. In order to secure an institutional approval for the study, the proposal document was submitted to the Health Research Ethics Board at the University of Alberta and the Noguchi Memorial Institute for Medical Research (NMIMR) at the University of Ghana.

Permission was sought from participants by means of written consent through which I outlined their rights and obtained permission to use an audio recorder during our conversations. I also explained the purpose of the study, the composition of field texts, and the nature of the participation. I made participants aware that in qualitative studies researchers use quotes from the conversations to justify their analysis and that these quotes are sometimes used in presentations and publications. The identity of the individuals who provided the quotes would be kept private. The participants were informed that they would not receive any remuneration for participating in the study. I ensured they were fully aware that they could withdraw from the study at any time. I knew it was my responsibility to ensure participants' trust. That being said, there were moments when I had to check in with my participants and advisors to ensure that I was doing everything possible to maintain the participants' anonymity given that their administrators were aware of our ongoing sense making on and off the nursing landscapes.

# **Relational Ethics**

Ethical care is required when attending to stories in narrative inquiry as stories are doorways by which narrative researchers enter participants' experiences of the world (Connelly & Clandinin, 2006). I considered carefully the moments when I was filled with tension during the conversations as participants shared stories about their level of patient care in the Fevers unit. I slowed down in my research and conversations to find ways to address my feelings of uneasiness.

I continuously encouraged a relational space (Bergum & Dossetor, 2005) in my interactions with participants. Bergum and Dossetor define a relational space as having an acceptance between two parties such that the space "does not negate the others' beliefs and knowledge" (p. 87). In a relational space attention is paid to developing mutual and open respect and trustworthiness by exploring and acknowledging the vulnerabilities, uncertainties, and ambiguous nature of each person's ongoing experiences. I achieved this relational space by being open with participants in our conversations as they shared diverse experiences as well as by recognizing "that people live in a specific historical and social context as thinking, feeling, full-bodied and passionate human beings, in other words through embodied expressions" (p. 137). Bergum and Dossetor also stress how important it is to work alongside participants in a relational space as if they are about to sign the consent form at every moment. To this end, I checked with participants periodically to ensure their ongoing consent. I was always given the nod to continue the conversations until we mutually exited the study.

### **Towards Analysis**

As narrative inquirers move from field text to interim research texts and then final research texts, the value of meaning and social significance becomes paramount. Aware that in narrative inquiry "the initial focus is often vague and ill-defined" (Foster, 1996, p. 19), I sought to be responsive and flexible to the ideas and issues which emerged during the course of conversations. Later, as my focus sharpened and narrowed, I was more selective in what I recorded in detail. I was also mindful of Polanyi's (1958) recognition that tacit knowledge based on our personal experience of the world is crucial to interpreting field text and making new discoveries.

I was aware of the relational ethics as a most important part of narrative inquiry and how the ways I represented participants' stories in the narrative accounts can expose their personal stories (Clandinin, 2013). For this reason I focused on the resonant threads of participants' narrative accounts. By focusing purposefully on the threads I followed the forms that threaded over time and place across the participants' narratives. Then I laid the accounts representationally alongside one another to search for resonances, or echoes that resounded across the five narrative accounts.

#### **Final Thoughts**

A narrative inquiry methodology, with a focus on experiences of hope among nurses in HIV and AIDS care, was described. I detailed my narrative beginnings, in addition to how I explored experiences of hope among nurses working with PLWH in Ghana. A conception of hope, HIV and AIDS, and narrative inquiry were also described. As I conclude this study, I am reminded that it has been 2 years since my engagement with the participants. In the following chapter I include the narrative accounts of the participants.

#### Chapter Four: Narrative Accounts: Eva, Lana, Berth, Joy, and Jude

Following ethical clearance by the University of Alberta in Canada, and the Nugouchi Memorial Institute of Medical Research at the University of Ghana in Ghana, and an institutional approval from the Korle-Bu Teaching Hospital administration in Ghana, I approached the Deputy Director of Nursing Services in charge of the Fevers Unit of the Korle-Bu Teaching Hospital. The Fevers Unit used to be called the Infectious Disease Unit. This is where I had proposed to recruit participants. I still remember entering through the main gate of the hospital and eventually finding my way to the Fevers Unit. I was greeted with the familiar scent and sight of a hospital, as well as the dread that seems to accompany the Fevers Unit. I felt a cold chill running down my spine. I felt scared to return. I remembered my experience with Kojo. My stomach felt hot, my legs felt feeble. I was sweating. The familiar smells of chlorine and iodoformized agents used for cleaning the hospital were ever present; it was as if I had only left the unit yesterday, or perhaps just hours ago.

The Fevers Unit of the Korle-Bu Teaching Hospital was often accompanied with a sense of hopelessness because most patients who were admitted in the 1980s had AIDS related and/or other infectious conditions that often resulted in their deaths. Consequently, many Ghanaians have associated the Fevers Unit with a place-of-no-return; a mindset that spoke to the fact that in-patients had a slim chance of returning to their homes once they had been admitted. It was this kind of fear which I had come to know through my work as a student on the Unit that welcomed me when I entered through the gates in my position as a researcher. I reminisced about my clinical rotation days at the Unit. The thought of the Fevers Unit wearied me and filled me with sorrow. I remembered how the patients laid in their beds in their cubicles, mostly they were positioned supine or lateral watching the ceiling or facing the wall or the door. They could not interact very much with staff or others as they were feeble and drowsy, and often carried only little flesh on their bodies. The location of their ribs and collarbones were not hidden from sight. I saw their eyes full of misery as tears flowed down their cheeks. These images bred the stigma and increased the distance of contact for them from both relatives and nurses.

However, that was 18 years ago. Why should I still carry that memory of dread? I remembered my new mission in my role as a researcher. I wanted to understand nurses' experiences of hope that they lived on the Fevers Unit. I pulled myself together and walked towards the building. Upon arrival at the door, I entered with some confidence and some hesitation. I walked through the corridor towards the Deputy Director of Nursing Services' office. Here again, I smelled the disinfectants and listened to the noise of footsteps as I walked. It was a quiet day as there was no intake of new patients that day.

In the Deputy Director of Nursing Services' office I exchanged greetings and introduced myself. I explained my intended research. The Deputy Director at the Fevers Unit received me warmly as I handed over my clearance letter to her. She discovered the letter was not directly addressed to her, which it should have been. I went back to the Korle-Bu administration to have the letter corrected. When I returned to her office she readily accepted my research proposal and introduced me to the staff working on the Fevers Unit and to a number of nurses who qualified to participate in the study. I had talked to her about my inclusion criteria and she introduced me to potential participants.

The Fevers Unit is located in a brick building, much like other buildings in the hospital. The clean floors were covered with terrazzo. The Fevers Unit is shaped like the letter 'H'. The two posts represent the south and north wings, and the connection represents the offices and changing room. The south wing has admissions beds and the north wing has consulting/counselling rooms. Each of the wings and the connection has an aisle. The aisles serve as waiting areas for patients and families. The nurses' station is located in the south wing aisle. The walls are painted yellow and doors and windows green. Some of the louvered shutters are broken in the north wing. My general impression was that the unit needed renovation and repair. In one of my conversations with Deputy Director (Research Conversation June 23, 2015) I got to know that the resource allocation to the unit was not adequate to help manage the unit. According to the Deputy Director they need help to maintain the place. She said:

I think we need help because our patients don't generate anything so we need donors and philanthropists to support us, maybe the renovation of the physical structure and the care of the patients. So if we can get people to help us or donate or even renovate the place for us. (June 30, 2015)

A community philanthropic agent is supporting the first phase of the renovations of the unit. According to the Director the current painting was sponsored by one of the philanthropists.

And when I came here I had a lot of challenges here in terms of infrastructure, renovation, and those things. But by God's Grace and the help of other philanthropists we are on course because we had some people to come do part of the renovation for us. (July 14, 2015)

I wondered about the days when the hospital had a decent structure. At the time of this research it needed maintenance as its structures were getting old and were fading. I engaged with five participants throughout my fieldwork. What follows in this chapter are five narrative accounts. The accounts tell of the experiences of each of the participants. There is one narrative account for each participant. Generally each narrative account begins with a description of the recruitment of participants, early beginnings, and formal education and nursing training before writing about the participants' experiences of hope.

### **Eva's Narrative Account**

I met Eva at her office at the Fevers Unit during the introductory escort by the Director. When I was introduced to Eva, I felt excited because she was a potential participant; I hoped she would take part in the study. I felt enthused and eager about my study. I sensed in my spirit the readiness to begin my research conversations. I had not met Eva before. I noted the experience as follows:

Meeting Eva, it was ordinary. Strangely, I was not overwhelmed with a flood of dreadful emotions, but rather, a sense of disbelief. Just having felt dreadful at the exit/entry gate when entering the unit, I tried to absorb the reality of the recruitment process. Wow, I am now a narrative researcher. I must be daydreaming from the jet lag. I am becoming a different person.

Eva's office was located close to the main entrance of the building. She shared the office with a secretary and a nursing colleague. There was a window to the west and a door opening into the aisle leading to the main exit. There was furniture and little space. Eva stood and walked towards us, meeting us at the door. Standing and walking to greet a visitor is a usual courtesy exhibited by all nurses in Ghana when they see their superiors. It is a sign of respect and acknowledgement of authority. Standing at Eva's office door, the Director introduced me to her

and her office mate and colleague, Lana, who also became a participant. Eva was in her neat white and sparkling nursing uniform with her green belt indicating her rank as a principal nursing officer. She was full of smiles and her eyes stared into mine as if measuring the density of my eyes. Our meeting brightened my spirits. I was delighted to see such a welcome, but I was anxious and struggled with what to say. While still standing, the Director offered me the opportunity to say a bit more about my research. Following a deep but silent breath I began to paraphrase the information sheet.

I am here to investigate how nurses work with hope in HIV and AIDS nursing. This study will focus on identifying strategies that have shaped nurses' hope work with individuals who have HIV/AIDS. I believe that because you are actively involved in providing care for PLWH, you are suited to speak about how you work with hope and what threatens your hope in this area. (June 9, 2015)

I explained my research to Eva and my interest in nurses' experiences of working with PLWH and invited her to participate. She enthusiastically accepted and I gave her the information sheet and consent forms. We mutually agreed to start our first conversation the following Tuesday. I went home excited and happy to know that I would be working alongside Eva. I could not wait to start my conversations with her. The weekend passed slowly but finally Tuesday came and I went back to the unit.

My first conversation with Eva (Tuesday, June 16, 2015) was at the unit in one of the counselling rooms. Eva led me to the room. On entering I sat on the chair farthest from the door. The position allowed me to see who entered from the opposite entrance. I took a minute to look round. "The room felt stuffy and the air has an undertone of bleach. The walls are white

and are faded. The posters on the walls are cheap benign prints of informative scenes" (Field notes, June 16, 2015). I felt the room was dull and had little natural light. The chairs were arranged such that Eva sat squarely in front of me with her back to the door. There was a desk between us. Eva's disposition was bright and she smiled. She looked relaxed, displayed an open posture, and made direct eye contact. Eva showed confidence in her practice and work as a nurse; she was sitting upright and appeared confident.

I was still feeling anxious but not as intense as during our first meeting. I tried to be relaxed too but I also felt a lot of pressure as I felt I was expected to ask good questions. I was full of delight about starting my data gathering and beginning the composition of a relationship with the first participant. At the same time I was trembling inside, a feeling that always comes when I meet new people.

I wondered what Eva was feeling. Did she have doubts about her participation in the study, about the relevance of the study's focus, or how the results would be used? I wondered if she anticipated certain questions. Eva seemed positive about the study and at this time voiced no doubts at all regarding our interactions and possible ways the study might unfold. I went over the information sheet and the consent form, which Eva had already signed. I asked if she had any questions. She responded "No." The following narrative account suggests my interpretation along Eva's story as we make meaning of how to practice with hope in the HIV nursing context.

**Early beginnings: Moving from one region to another.** Eva grew up in Accra but she was born in the Brong-Ahafo Region. Her early memories of life were from when she was in Accra.

I'm a Brong. I was born . . . in the [southern] Region . . . in a [small] town . . . . Even

though I was born in the [southern] Region I was bred here [in Accra]. So I started my primary education at Cambridge Preparatory School.

Eva is a Brong, which means she is from a tribal ethnic group in Southern Ghana that comes from the Brong Ahafo Region. Brongs are part of a larger tribe called the Akans, the largest ethnic group in Ghana, but she grew up in Accra. Her response helped me to relax as I heard Accra for I thought we might share some common experiences. As I listened to Eva's early life experiences of attending school in a neighbourhood community, I was reminded of my school days in Accra. I tried to recall how I experienced school in those early years. I remember not liking school very much until later in junior high where I became more comfortable and confident in speaking fluent English and taking on leadership roles such as a class prefect.

Accra is a well-developed city with many neighbourhood communities. We both grew up in Accra among the Gas (another ethnic group). I wondered what it was like for Eva to leave friends and loved ones behind at such a young age. I wondered how this move shaped Eva's childhood experiences. Did she feel a sense of loss? In our July 28, 2016 conversation during the sharing of her account, Eva did not report any anxieties about her relocation to Accra.

As I wondered about Eva's early childhood experiences, I realised that I had no memories of my own relocation to Accra, when I was just 2 years old. I had no memories of the transition but I believe that the most significant persons at that stage of my life were my parents and siblings. As long as they were in reach, everything seemed all right. My parents and siblings shaped the contexts in which I composed my life.

Accra is different from what it was when I was growing up. Growing upm the neighbourhoods were safe. Kids played soccer behind the houses and on the roads that barely

existed. There was no electricity for light at night. The kerosene lamp or lantern was the light used at night. Everyone expected the rules and every adult was a parent when it came to discipline. Occasionally, I witnessed other children fighting to entertain adults, particularly in the crowded places. I also remember occasionally people became drunk and aggressive. Otherwise there was quietness and tranquillity.

Education and training. In the year that Eva was born Ghana had already gained independence from British rule and education was becoming a standard for everyone. Every family, particularly along the coast where education began, was participating. The town where Eva grew up was a coastal town. Eva started schooling at a private preparatory school "I started my primary education at Cambridge Preparatory School. . . . I walked to school even though my Dad had a car because the school was closer to the house and I always went to school late." I am also called to my memories of commuting to school just like any other child until I completed high school. Eva also talked about her experiences in Accra. In our July 28, 2016 conversation, Eva said a bit more about her primary education: "It is interesting that I made so many friends though I consider myself not that friendly. We played 'ampe' [a game mostly played by girls] and all that." Referring to her secondary school friends Eva expressed she was still connected with those friends with whom she decided to do nursing. According to Eva she got along well with her schoolmates and still connected with some of them. She said:

When you chat to them [friends] they will . . . encourage me . . . They are also happy I'm here, I'm working as a nurse, you have a colleague working as a nurse, when you have any problem you phone me for help or something. So it's all part of the encouragements working as a nurse. So it's also giving me hope to work as a nurse or as an HIV

caregiver.

This gift of friendliness was part of Eva's narrative. I observed her outgoing attitude with her colleagues at the unit. This was evident as I was present around the Unit and saw her interactions with colleagues. I always engaged with her and her colleagues in her office before we proceeded to the counseling room for our conversations.

Eva's stories to live by, a narrative concept for identity (Connelly & Clandinin 1999), reminded me of making friends at primary school. I played soccer with my schoolmates but was not very intimate in my social connections at the primary school level. I remember my experiences of struggle with primary school. I was petrified of the morning mental-arithmetic exercise. I often felt scared because one error on the morning mental exercise attracted one stroke of the cane. I do not remember making close friends. I made close friends when I started junior high; it was only then that I became confident with my peers.

Eva started her primary education in Accra at Cambridge Preparatory School. I wondered about her challenges in primary education. Following primary education, Eva challenged the Common Entrance Examination (CEE) and moved on to secondary education where she studied for 5 years. In Ghana, before the education reforms in the mid-1980s, there was the traditional 6 years of primary education, 4 years of middle schooling, and a 7-year secondary education (5 years of preparation toward the Ordinary [O] Level Certificate and 2 years of Advanced [A] Level training before entering degree awarding institutions. The average age of a first-year university student in Ghana for middle school leavers was often about 25. Students at the middle-school level took either the Middle School Leaving Certificate Examination and terminated their studies or, at any time from seventh to tenth grade, they wrote the Common Entrance Examination which admitted them to secondary or technical schools. Those with Middle School Leaving Certificates could enter into the job market or take up apprenticeships or enter into professional institutions like teacher training and nursing training. Students with Middle School Leaving Certificates were awarded a Certificate B or enrolled nurses' (EN) certificate at the end of their study in a training college. Graduates who were awarded a Certificate A from a teacher training college or State Registered Nurses Certificate from nurses' training college had to hold O /A Level certificates from secondary schools. Many students who attended preparatory schools (predominantly privately owned) like Eva were children of affluent or educated parents.

I attended middle school because that was the standard for the general population. I completed my Middle School Leaving Certificate, challenged the Common Entrance Examination, passed, and went on to secondary school to do 5 years O level and 2 years A level before entering post-secondary educational settings. Unlike Eva, I spent 4 years at middle school education. However, like her, I read science. This means that we both read physics, chemistry, and biology and additional maths in addition to the core English and math subjects. In Ghana being a science student comes with some level of pride as many people find science challenging because it requires additional mathematics and time to practise in the laboratory. The opportunities for science students appeared unlimited as they had options to switch to other programs or courses while other students could not.

Eva had several opportunities for a future career as a science student, but she chose to do nursing. Eva's decision to enter nursing as a career might be traced to her final year of secondary school when she read science that prepared her to enter into nursing. Her interest in
nursing was located in secondary school experiences where she and her friends decided to become nurses. One of her friends brought up the idea. In Ghana, nursing is a career where there is readily available employment after graduation. However for Eva, no one influenced her, she said. "I liked nursing, nobody influenced me. The five of us, because we read science, [we] decided to do nursing, so I don't think . . . nobody influenced us." I noticed her self-motivation and wondered if her five friends were also self-motivated. Later in our sixth conversation (July 28, 2016) she said of her friends: "The five of us decided to do nursing . . . three had it, two did not . . . one is now a teacher, another one works at Piccadilly . . . one is in Canada."

Many young women in Ghana decide on their own what professions they want and are not pushed or coerced by others. Eva was one of them. Although, she mentioned in our second (June 23, 2015) conversation that her natural desire to help people contributed to her choice of nursing, she also spoke of support from her parents, particularly her father. She said: "My father took me to the NTC [nursing training college] for the interview." This showed support and approval to Eva from her father. Eva's father was a laboratory technologist who worked in the same hospital but was now retired.

While in nursing training, Eva talked about her nursing tutors as inspiring her success. Eva said of her tutors:

Our tutors, sometimes I look at some of them as young as they were, when they were teaching us. I hope one day, I would become like them, so that made me learn harder . . . they are like models or mentors. Very young but standing in front of these people teaching, I said, "why can't I also be like this lady" and it's through learning she learned hard. So I was hopeful that one day I would be . . . I also learned harder and became

what I am today.

In spite of the fact that her decision to become a nurse was supported by family, in our second conversation (June 23, 2015) Eva spoke of her own intuition and decision to become a nurse. She said, "Nobody influenced me." I remember in most selection interviews in which I participated, a majority of candidates said they were influenced by a relative or close personality to make the decision. Eva did not see the influence as coming from her grandparents or her relatives or a nurse.

I wondered what it was like for Eva in the nurses' training college. What did nursing mean to Eva before, during, and after her training as a nurse? In our sixth conversation (July, 28, 2016), Eva stated that nursing, to her, meant: "to take care of the sick." Eva expressed that nursing changed her in many ways. She now described herself as loving but she used to be condescending. It was through the study of pathology and the experience of seeing humans die that she became humbled. She said, "Seeing how people were dying changed my perception about life." Eva's nursing training created a new person in her.

**Connection with her family.** While Eva was working at the Fevers Unit, she was connected to her family.

It is my family, they are very supportive, my husband, the only thing is that you have to be careful. You have to do this; you have to do that. You know, caring for these people with HIV you have to be very careful so that you don't also get infected. At times he says that he wants the best for me.

Eva's connection to her family was a source of hope. She talked about her husband's support for her work with an added caution that her husband wanted her to be careful so she did not get infected. Her husband, she said, "desired the best" for her.

A network of family, which includes her husband and three children, marked Eva's life. She spoke affectionately about her husband who supported her and encouraged her to keep her work at the Fevers Unit. "Like my husband said, 'you're better off working at the Fevers' . . . I was surprised when he said that . . . because you know the type of cases that we deal with." Eva was amazed by her husband's words as the population she worked with was highly stigmatized and discriminated against. I saw her husband's words as evidence of her commitment and honesty, as well as assurance of support. His words showed understanding and a respect for the population that Eva worked with. Eva talked about her three children:

The first one attended school at [this] High School. And then after completing he went to a Training Centre. He did it for 1½ years . . . He didn't complete . . . Well it's supposed to be 2 years and he went for 1½ years and I don't know, he didn't write the final exams. So we had another admission at [a different school] where he completed with a certificate. He's now working at the Ministries . . . That's the first one. And the second one also went to high school, he completed 2 years ago. He's at the university . . . , level 200. The third one just completed his high school. He's awaiting his results.

All of Eva's children had attended at least a secondary school. I saw the confidence with which Eva talked about her family. Her eyes were bright and her voice steady when she talked about her family.

As I listened to Eva, I was called to memories of nurses working in an HIV unit who were anxious about their relatives or spouses getting infected with HIV. This was during the initial days of the illness when we were still learning about the disease. I hoped that people might have grown to accept that it was OK for their spouse to work at the Fevers Unit, as it was OK to work on the general ward. Yet, the reality was that the fear still lingered on. Eva added during the sixth conversation (July 28, 2016) that her children had no concerns about her work setting: "My children are OK with where I work. They helped me with the chores at home."

**Precursor toward Eva's career choice.** Eva worked as a principal nursing officer; she was an in-charge nurse as her green belt indicated. Her decision to become a nurse stemmed from her interest in people:

I was interested in people, I like ... you know ... people. And when somebody falls sick I really feel for the person. I remember one day ... you know ... my mother is a seamstress and sometime ago she had this needle prick ... That's a needle ... the sewing needle. She had a prick ... The needle went direct into her nail and into the skin. I had to remove it, remove it, people were scared, everybody was scared, but I was feeling for her and I had that courage to remove it. I have that ... I don't know .... I have that talent to care for people, so maybe that's one also that contributed in coming [in]to nursing. (June 23, 2015)

During my interactions with her, I saw that she enjoyed conversations and liked talking to people. Her interest in people's well-being linked to her story of the act that saved her mother from pain. She treated her mother with sympathy but at the same time she was full of courage. Her decision to become a nurse was based on her interest in people, especially the sick. She also demonstrated sympathy in caring for them. I believe that Eva's parents' support for her career choice contributed to her success.

In her career, Eva practiced nursing in different clinical areas in the Korle-Bu Teaching

Hospital, the same hospital where she was trained.

From Nurses Training College I started . . . and completed. And then from there I was posted to the Ear, Nose, and Throat department. So ENT ward [B] to be precise and I worked there for 4 years and I had the admission to go to midwifery. After midwifery I was posted to the Fevers Unit and ever since I haven't gone anywhere.

She began nursing in the ENT (Ear, Nose, and Throat) Department at Korle-Bu Hospital. After a number of years she went on to specialize in midwifery. I wondered about her motivation for specializing in midwifery. In Ghana in the 1980s, midwifery was the main specialization for nurses as it provided opportunity for promotion and placements. I wondered if these were the reasons why Eva went into midwifery. After she completed her midwifery specialization, she was posted to the Fevers Unit and had not returned to practice midwifery.

During my research period, Eva was posted to the maternity department. She told me about her mixed feelings, as she was leaving old colleagues and, at the same time, she shared her excitement about learning new things at the new posting. I wondered how she experienced the move from general nursing to midwifery to HIV nursing and back to midwifery.

The policy in Ghana before 2008 was that all NTC graduates were hired by the government and posted to places of need with the exception of those in a few specialty areas like midwifery or perioperative units. It was expected that after midwifery Eva should be posted to the Maternity or Obstetrics unit. Surprisingly, she was placed in the Fevers Unit, formerly known as the Isolation Unit, where communicable diseases were treated. The name of the Isolation Unit had to be changed to the Fevers Unit because the name was scaring people who visited the centre. I wondered why the unit was not called the Infectious Disease Unit. I wondered how Eva responded in relation to her feelings. How did she deal with HIV at the time when there were no drugs for HIV? How does she feel now? Eva described her extended stay at the Fevers Unit as follows:

Nobody has changed me even . . . if you want to transfer to another department. They will say no! You have been here for so long a time. I want change, to have other experiences . . . authority will say that you have been here, 'aah' [meaning long time], why don't you stay . . . I don't have any choice. Yes. Ever since . . . I was posted here, I've not been changed.

I wondered how Eva felt about staying on the unit for such a long time. The Fevers Unit was an acute infectious unit for patients with diagnoses of communicable diseases. Patients who were admitted to this unit were most often in critical conditions and needed total or partial care including administration of IV fluids, bed baths, feeding, grooming, and frequent monitoring of vital signs. The unit also ran outpatient clinics on specific days within the week for follow up care and review for treatment. I saw suffering and ecstasy in Eva's words as she said:

Nobody has changed me even . . . if you want transfer to go to another department. They

will say no! ... I want a change, but I don't have a choice.

In our July 28, 2016 conversation Eva told me that she had finally been transferred. I visited with Eva that day at her new work location at the Maternity Block outpatient department.

**Eva's experiences of hope.** As Eva and I conversed, I began to see her experiences of hope shaped by the following plotlines: the role models of hope, the availability of medication, and the state of each patient's condition. Other features that shaped her experiences of hope were good nutrition, family support, and good personal hygiene.

*Role models of hope.* Eva spoke of some patients as the role models of hope [as they are popularly called]. These are PLWH who have become heroic survivors of HIV infection and became role models for other newly infected PLWH. They were bold enough to disclose their status to others without shame or fear. They openly participated in seminars, workshops, and support in counselling sessions. Their bravery to combat the HIV stigma earned them the title Role Models of Hope. Eva said of them:

The models of hope. They are on the medications . . . They are like ambassadors, they talk to others and they take part in the clinic, especially counselling. They talk to other new cases about the conditions. They use themselves as examples, 'ooh look at me I have this condition. But now look at me. I am doing very well so you can do well.' So there is hope. And when they talk because they are also part of them, the clients listen to them. That makes you hopeful as an HIV care nurse.

Eva's view of the role models, HIV positive patients who were doing well on medications, because they complied with treatment regimens and follow up care, shaped her experience of hope. PLWH lived in the community but were engaged in regular clinical activities, HIV counselling, and also served as role models to newly infected patients. The role models were involved in clinical activities and they were part of the clinic team as they provided one-on-one individual support and group psychosocial support. Role models of hope also worked in the community and provided community outreach to locate those lost to care, engage or re-engage clients into care, and market HIV services. The resilience and determination shown by these role models in their own lives positively shaped Eva's experiences of hope and the way she practiced hope. She said after a long pause, "What makes me hopeful . . . is about the [role] models of hope . . . We started . . . , I think 1986, and up to now they are doing very well. So I think there is hope, there is hope."

It was inspiring that, for Eva, these peer role models of hope sustained her hope. I am reminded about the fortitude of the role models of hope as evidence of a milestone thought to be impossible. The diagnosis has become a hopeful experience. I can only imagine how, on a daily basis, these role models of hope influence Eva's hope and practice, feelings and thoughts. As Eva continued to tell stories of what made her hopeful in HIV nursing care, I was called to memories towards hope in my own life as a PhD student. What kept me going during difficult times? Considering the struggle of my experience with this dissertation research, I remembered the words "I can do all things through Christ" (Philippians 4:13 New King James Version) and "Those who walk with God always reach their destination" (Henry Ford).

*Availability of medication.* Eva also talked about the availability of medication. Medication availability as a means of treatment was a challenging experience in developing countries such as Ghana. A "cash and carry" system of procuring medication in Ghana, introduced in 1990, co-existed with the National Health Insurance Scheme (NHIS) to help address the problem. Under the former system, the health needs of an individual were only attended to after initial payment for the service was made with exception of emergencies. There were cases where patients had been brought into the hospital due to emergencies, and they were required to pay money at every point of service delivery. Eva spoke of one such case:

I remember one patient I don't want to mention his name. Very ill on! ... He came in at ... HIV stage 4, very ill, critically ill, on drip (IV infusion), he could not eat, and we

have to pass an NG tube and all that. But because of the moral support of the sister, who was buying all the expensive medications: this sulphurdiazine, so many people cannot afford it, but the sister was doing very well buying all the drugs and the prescribed or the requested labs. She was doing everything. In fact, the support was there and we were also doing our best: feeding, and giving all the medications through the NG tube. And this man [the patient] came back to life.

The NHIS was introduced in 2003 to largely replace the "cash and carry" system. Where the NHIS does not cover a service, a service fee is charged up front and paid for by the service user. Antiretroviral drugs are covered, but the related opportunistic infections or symptoms of HIV are treated with paid (out-of-pocket) medications. For example, antibiotics, IV fluids, and antidiarrheal mediations are paid out-of-pocket. Thinking about Eva's hope as connected to the availability of medications, I was awakened to how she commended the client's sister. She said: "the sister was doing very well buying all the drugs and the prescribed or the requested labs. She was doing everything." Eva reminded me of how committed this relative remained to her brother. It is how hope is lived. The client's sister was able to provide the needed financial and medical support for the patient who was critically ill with HIV Stage 4. It was how Eva's hope was sustained when families were able to afford their prescriptions and the patients responded to treatment. The support for the patient was connected with Eva's hope.

Fortunately, the current NHIS covered all necessary HIV medications and there was an available medication supply for all patients. The more readily available the medications, the higher the possibility of recovery and the stronger will be Eva's hope. As I wondered about Eva's hope narrative, I was reminded that most Ghanaians faced difficulties in relation to buying prescriptions as a result of poverty. As most of them didn't have savings, it was always difficult to purchase mediations for HIV patients. Even though the NHIS covered all necessary HIV medications there still was a need for adequate food and coverage for other basic health needs. Eva experienced hope when patients and their families were supported, especially in relation to the expense of prescriptions. Eva spoke further about the support the sister had for her brother.

And this man came back to life. And now when you see him, he is gone back doing his work. There is hope 'paaa'. There is hope. So there is hope . . . If relatives are supportive there is hope. Usually it is the neglected ones that don't do well. But when they get the support, there is hope.

The impact of poverty on health has long been documented. Poverty deprives people of the power to afford necessities and many health needs are compromised, as they do not get diagnosed or treated. As Eva referred to those patients who do not do well as the "neglected ones", I was reminded of the relationship between poverty and HIV. As an immune disease, people living with HIV need good nutrition and medications as well as social support to boost their immunity. Without these supports and the consequential boosts, the individual is exposed to opportunistic infections or early death. It was Eva's words that reminded me of the need to sustain hope in difficult times when support is not coming forth as expected. I am called towards memories of PLWH who live with poverty and are united in strength; they fight for their survival. This community of hope, as I call them, is supportive in the face of daunting poverty.

*Each patient's context.* As we continued the conversations, I learned of Eva's experiences of hope when there was early reporting of HIV status, which varied with the condition in which the patient arrived at the hospital. Eva spoke of her experiences this way:

The thing is to report early. Ghana [they] don't report early at all! Hmm . . . usually stage 3, or 4, these are late stages. When [they] report at that stage there is little that the [healthcare providers] can do. Some of them [patients and families] will say . . . as for

this condition the only treatment is abstinence, because they don't report on time, hmm! Eva's experiences of hope were influenced when there was late reporting. I shared her distress, because when patients came late during their disease process, accessing treatment was difficult it too shaped my practice of hopefulness. Because of the conditions of people with later stage HIV, it is necessary to invest more resources into the care of patients. Consequently, patients who are at the later stages and are critically ill often need additional attention, which, at times, involves life support equipment. Such critical care experiences shaped Eva's experiences of hope, particularly where relatives were actively involved in buying medications. Eva expressed her hope through her commitment to providing the care needed. I wondered if Eva expressed that same commitment or energy to patients and relatives who could not afford prescriptions. Relational or family support defined much of Eva's hope.

*PLWHs' family support.* Eva's hope was experienced through the care she offered to patients. In the rendering of care Eva offered hope to the patient but strengthened her own hope when the patient's family also supported the patient. Thus Eva's experiences of hope and hopeful outcomes were, in some measure, dependent on the supportive attitude of relatives. She said: "If relatives are supportive, there is hope." The usually neglected patients, whose relatives did not visit, failed to buy their prescriptions, refused to perform body hygiene, or denied family love, discouraged Eva's hope, as the patients frequently deteriorated and eventually died. Eva's hope was sustained when she experienced a patient with family support. I was called towards

memories of Kojo who had little family support. I do not remember how I responded to that but I lost hope somehow. For Eva, a relative's "moral support . . . buying all the expensive medications, this sulphurdiazine . . . doing very well buying all the drugs and the prescribed or the requested labs" brought hope to Eva as well as to the patient and family. In the story Eva said that when there was family support the healthcare team also gave their best service. In the story told earlier, she said:

In fact the support was there, and we were also doing our best: feeding, giving all the medications through NG tube. And this man came back to life. And now when you see him, he is gone back doing his work. There is hope. There is hope.

Eva said that when patients have family support, nurses also give their best service for the process of healing to occur.

*PLWHs' compliance.* Eva's body language and speech emphatically expressed that she experienced hope in HIV nursing when she worked with patients who were devoted to taking medications, willing to follow medical advice, and were able to honour follow up care appointments. Eva described how she talked to patients about what they needed to do and her language expressed how firm she could be:

You must come for review . . . when you listen to what your doctors and your counsellors say, you will do well. Hmm! Eat a balanced diet . . . good personal hygiene, when you have any signs [symptoms] you quickly report to the hospital, so many things. When you listen to what your counsellor says you will do well.

I wondered how Eva's experiences with patients' compliance dictated what and how she communicated with the patients to inspire mutual hope, to help diminish worry, guilt, and blame.

Perhaps her steadfastness in dealing with compliance was a means to ward off the stigma. While I worked with PLWH I realized that many HIV patients in Ghana felt guilty and shameful for their infection. HIV and AIDS are still issues in our communities. Eva responded to my question about how organisations or activities influence her hope in the following way:

They are also supporting them [PLWH]. They are not shunning the Retro cases [PLWH]. They are also giving their moral support. So, there is hope which means everybody is also supporting, they are also supporting. They are not neglecting them. They are not neglecting them. They are thinking about them.

Eva's situation reminded me of my own experiences with nursing HIV patients. I used acceptance and open-ended questions and tried as much as possible to be more reflective than critical. How did therapeutic communication shape Eva's experiences of hope? How did reflection shape her professional and personal life? Eva shared that when patients were well and were not depressed by their infection, the nurses did not fear losing them.

I wondered about how Eva experienced hope with patients who could not survive the infection, patients like Kojo. I was called towards the memory of my shock when Kojo died. What could make me feel this way? Did Kojo die peacefully? Had I offered him the best care? Thinking with these questions revealed my humanity. Relationships developed through care can sometimes create spaces of risk and hopelessness. It is clear that my best practices did not develop during feelings of hopelessness. While I faced my humanity with shock, Eva worked against her feeling of hopelessness by speaking words of encouragement to the patients and to herself. She said:

As you grow you know the word hope . . . with hope everything works for you. You

should always be hopeful. I will say maybe I heard the word hope from NTC. If you have positive mind and you have hope it will work out for you. You should always have hope . . . you have a positive mind of the condition and you will do well.

Eva's ability to encourage patients to experience hope by way of thinking positively can be an indispensable tool for the transformation of patients' lives. Words matter. I also wondered about how hope suckers such as depression and noncompliance in her patients affected Eva's experiences of hope. As I continued to travel alongside Eva and felt the importance of offering hope to patients, I was reminded that giving hope to others is part of the necessary steps to sustain my own hope.

*PLWH's avoidance of feelings of anger towards HIV.* I continued to learn about how Eva thought PLWH should respond to their illness.

You don't have to think so much . . . hmm! "Where did I get this condition? Who gave me this condition? It is not necessary." So, I mean this is just like any other condition what do we call it . . . diabetes, hypertension, and all that. Your [patients] take the medicine . . . for so many years . . . so far as you live. So, this one too, when you are on the antiretroviral drug hmm! You take it 'aaah' [endless] until thy kingdom come [far into the future].

Eva's caution about avoiding attitudes of anger or blame towards the infection is a precursor of hope for patients. Her focus on treatment was more important than blame. The treatment may take extended time but it will yield results. The expression "until thy kingdom come" indicates a length of time which is far into the future.

Toward the motivations of hope. There are several entities that influenced Eva's hope.

Eva and I discussed two things: negative babies (babies born to a mother who is HIV positive, but the baby has a negative HIV status) and institutional practices that gave Eva hope.

*Negative babies.* Eva experienced hope when women living with HIV give birth to babies who test negative for HIV. Eva talked about the models of hope who were having babies who were not born HIV positive. When responding to my questions about what entities influenced her hope:

It's models of hope. They are doing very well since 1986. They are doing very well . . . They are all working. You won't think they have the virus and they are producing these negative babies. They're doing well, so there is hope.

*Institutions.* Some institutions also influenced hope in Eva's life as she said, "then it will be churches, organisations just last week there were here . . .. They came to pray for them. They gave their love and then gave items to them." Institutions such as churches and charity organisations also influenced Eva's hope. The church members of one of those churches came to pray for patients and were giving their affection, presence, and donations. In Ghana, churches are very active in donating to hospitals and clinics, as they believe it is their duty towards the sick as required in the Holy Scriptures (Matthew 25:36). Such religious support confirmed and shaped Eva's experiences of hope in caring for PLWH. Charity organizations identified with the suffering that resulted from the stigmatized illness and showed their moral support for the less fortunate in society. Eva's hope was elevated by the actions taken by these organizations in supporting and not neglecting PLWH. Hope was a vital element in religion, especially Christianity and Christian hope in shaping Eva's life. It is my common observation that some believers of the Christian faith had discriminated against PLWH and this might have bred

feelings of hopelessness in Eva, but now one Christian organization was strengthening her hope.

**Hope in a continuum.** There were days when Eva felt more hopeful and days when she felt less hopeful. Her less hopeful days were associated with times when new patients that were admitted to hospital failed to thrive, and when several new patients died.

On the wards (units) . . . there are some days, there is certain group [of admissions]. Sometimes you get about 18 patients and then a few will be discharged home, the rest will all die. When you look at our admissions and discharges book. Most of the people that come . . . no relatives are coming. . ... Because of the support they are having most of them they will be discharged home. But a certain group too nobody comes, no medication. So, there are certain times that I feel hopeful.

Eva's hopeful experiences were on days when new admissions were supported by family, something that was noticeable because many visitors crowded the wards at visiting hours. Eva's experience was also shaped by the cultural beliefs of Ghanaians that human beings must experience illness before they pass, so when someone is suffering from a serious illness such as HIV, families with good financial standing readily throw their weight behind the patient to give them the best care before the inevitable happens. Experiences of hope for Eva live in the spaces between support and medications and neglect and deprivation. Describing her days when she experienced hope, Eva stated that:

The support, when you get the support, the moral support and everything . . . you will do well . . . by God's grace you do well. For me that is the hope. You have the hope that this patient . . . the patient's relatives are visiting, buying medication, doing labs, and all that. For me that is the hope. And by the grace of God the patient will do well.

She described days when she experienced less hope as:

Nobody comes . . . no visitors . . . nurses and doctors sometimes buy the medication for them but it will not be that much, sometimes the psychological effects [of no visitors] can affect the patients. They just pass on; in such days, there is no hope.

**Her hope influences others' hope.** How Eva experienced hope on a continuum impacted others, including patients. Talking to others, Eva said:

I think it is like what we are doing now. It is education. You talk to people about your experiences, what you are doing. How they are doing, like when you do this or that . . . so you do well. That is the impact, everything about HIV this voluntary counselling when you come early, when you report early to the clinic you do well.

Other ways such as counselling and her bodily expressions showed Eva's hope as she showed an erect posture with a smile and relaxed facial expression. She was certain that an accessible and welcoming attitude invited patients, relatives, and other nurses to discuss their problems with her. Such an attitude was a hope experience for Eva and was reflected in a more therapeutic relationship.

Eva expressed confidently that being kind opened a space for a therapeutic relationship, as patients were able to come forward to share their problems.

As a nurse . . . you should be approachable because . . . you should always show smiling faces. Otherwise when you go to the ward if they have challenges they cannot even tell you. This nurse . . . When I am coming to ask something, I don't even know how to ask. If I ask her she will just 'throw me off' [ignore me]. You see, so you must be nice so they come out with their problems. Usually when they see the doctors they don't usually

ask them anything . . . even when the doctors go to the ward and ask them "do have any problem, how are you"? They would respond: "I am ok". But the nurse who is nice or jovial, they would ask . . . Aunty Nurse yesterday I could not sleep at all . . . then the nurse will tell the doctor. So, it always nice to be approachable.

Eva observed that patients found it challenging to approach doctors but could talk very easily to nurses. Eva became awake to how she experienced hope during an experience in nursing school when she was trained to think positively about whatever she planned to do. The smart, young tutors who taught her were hopeful inspirations to Eva. She felt strongly about being like them, as they had become her mentors. This desire to be like them provided her with motivation for studying hard to pass her examinations to qualify as a nurse. In describing what sustained her hope, Eva stated that God sustained her hope: "Maybe God sustains my hope. When you are aspired and you ask God. . ... You hope to be this or that and you ask God, it comes to pass." Seeing her patients doing well also sustained her hope.

Eva talked about her nature as a nurse and a person, a cheerful nurse, very open and jovial, because she observed that when on duty everybody liked her, including patients' relatives and patients. Eva wondered if she inherited her soft nature from her father. "Maybe that's my nature; my father was like that . . . Everybody likes him. Very jovial. So maybe I don't know whether it's hereditary." I observed that Eva had a more extroverted personality and had an attractive persona, including a big infectious smile. You cannot fail to return her smile. Eva's smile made me smile too. Eva's warm attitude was hopeful and had the potential to impact others positively.

Living with hope when working with those who are stigmatized. Despite support from

her family, Eva also echoed the associated stigma resulting from caring for people living with HIV and AIDS. She narrated a story about a colleague, a medical doctor. They met at the staff residence in the Korle-Bu hospital and they started a conversation. During the conversation the doctor got to know that Eva worked at the Fevers Unit. Eva said,

After chatting for some time, he asked "where are you now"? . . . "No, I asked that question first, so where are you now"? He said, "Oh I'm at Ridge Hospital". He goes "where are you" and I said, "Fevers Unit". When he heard Fevers Unit, he jumped into his car and then he sped off. It was a very bad experience; I was like hey because of the HIV that I mentioned.

This is one experience that Eva narrated about her nursing career in HIV and AIDS care. Eva expressed surprise but not discouragement at the medical doctor's behaviour. According to Eva, she had experienced stigmatization from her mother in-law, friends, and even colleagues. Recounting the nurses' stigmatized actions, she said, "Nurses also have been doing that, when they see you coming the way they will look at you as if you are PLWH." Eva stated she didn't really feel bad about working with the HIV and AIDS population. She said,

I think I'm better off... like my husband, my husband said you're better off working at the Fevers... because you know the type of cases that [you are dealing with]. So, it's better to work, even to work at the Fevers Unit and even I come to work I bring [in] my best, I put my best to care for my patients, I don't really feel bad working at the unit.

**Career vulnerability and non-transfer.** When working with PLWH, care providers can be vulnerable to burnout and compassion fatigue. Asked why she kept working in HIV nursing for a long time despite the stigmatization, Eva responded:

Nobody has changed me even . . . if you want transfer to go to another department. They will say no! You have been here for so long a time I want change to have other experiences authority will say that you have here . . . 'Aah' why don't you stay?

I wondered if there were deeper reasons for this wish to change the environment Eva had worked in for many years. Could these reasons include underlying emotional, spiritual, and behavioral conditions? Was there a deep disconnection to what it meant to live joyfully, authentically, and meaningfully with a career in an HIV setting?

The Korle-Bu Teaching Hospital authorities had always found it challenging to transfer nurses to the Fevers Unit as nurses refused transfers to the unit for reasons such as losing valuable years of experience accrued from their current units or departments. It was evident that many nurses did not feel comfortable working with PLWH, even though there were medications that reduced the viral load and therefore risk of infection. In our 6<sup>th</sup> conversation (July 28, 2016) I learned that Eva's request to be transfer was honoured. I wondered how Eva felt about this transfer and how it affected her hope in care and outlook in general. It was during my second round of fieldwork, when we negotiated the narrative accounts, that Eva was transferred to the Maternity Unit of the Korle-Bu hospital.

**Vitality of hope.** Eva believed hope was critical in HIV nursing and believed she was always hopeful about her patients, no matter the situation. She believed that nurses needed hope to do their best. As she said,

As for HIV care you must be always hopeful. No matter how the situation is. Like nurses, we are always hopeful you do your best so hope is very important . . . aspire for the best. Whatever you say it will sometimes come to pass so you should always be hopeful . . . you do your best.

Eva was aware of her hope and how hopeful words impacted her patients. Did her life experiences with PLWH give her such powerful insights? She talked about how infection with HIV did not always mean that patients were at the end of their lives. She pointed out that with counselling and compliance to medical advice, PLWH could do well and that there would be hope that they may live for some years.

**Solidifying hope.** Eva's training and understanding in HIV interventions strengthened her confidence and hope in HIV care. While Eva had no formal training in HIV care, she had on-the-job training through workshops, conferences, and counselling sessions that added to her skills to provide care to the PHA. She said,

We've had lots of workshops, counselling . . . Oh lots and lots, but the longest was 2 months. We went . . . and we lodged there 2 months on HIV and AIDS and counselling, we had a lot of workshops.

As we continued to converse, I learned more about what threatened Eva's experiences of hope.

**Places of hope threats.** Responding to places in her life that threatened her hope, Eva said:

Fevers Unit, where we are now . . . you see people coming to us very ill . . . very ill. There is no hope. So, I think that the threatening . . . this patient there is no hope is coming to die. We feel very bad when we see such cases.

This feeling was not unusual as many Ghanaians associated the Fevers Unit with death and therefore fear. The cries heard from the unit because of the loss of loved ones became almost routine as well as a conditioned universal threat or fear. Families and individuals living with HIV were also affected by this fear within, and about, the Fevers Unit. Describing how the unit threatened her hope Eva said families sometimes carried PLWH on stretchers to the centre as they were very ill and that this threatens her hope. "Most of them come in very ill. As for that one 'die' [particularly one] we have to confess . . . [He may not survive]."

Using a stretcher to transport patients is synonymous with a poor prognosis as both relatives and health care providers could easily predict the outcome of such cases. Patients who were brought in on stretchers were always very seriously ill and most of them died soon after being admitted. In some cases, Eva observed how patients carried on the stretchers had their necks hanging and were drooping as well as gasping:

They will just be talking so depressing . . . we get up and see the patient and say something to the patient very bad, the head drop to the back . . . those cases some of them gasping, and all that very bad cases . . . we feel very terrible, bad if this patient had come earlier it wouldn't have gotten to this stage. When we see very ill patients we feel bad.

*Fear of infection.* I found it difficult to listen to Eva about what threatened her experiences of hope in her work with patients who have HIV.

Fear . . . fear of the unknown. Working here . . . hmm! One might think she will also be infected with the virus, nursing HIV and AIDS patients. Yes, because we know the type of conditions that we are dealing with . . . You might take all the necessary precautions . .

. Still you might be infected, that is the fear. We have so many cases like that. Fear of the unknown that in the future . . . I might also be infected with the virus.

Eva expressed her fear of the unknown as she was not immune to HIV and she might also get infected one day. Asked if the HIV context undermined her hope in life, she said:

Oh no I don't think so . . . We are doing our best. Ooh no! Not at all. We are doing what we can, usually when you fear nursing them rather . . . so you have to feel free and nurse them . . . do what you are supposed to do and God will help you laugh . . . go through everything.

Eva was confident that when she set herself to do her best, God would take care of all other things. She was certain that doing her best with courage provided freedom from fear.

## Lana's Narrative Account

I first met Lana in her office. It was during the time the Director of the Fevers Unit was taking me around the unit and introducing me to potential participants on my first day on the premises. My initial impressions were that Lana was dark in complexion, of average height, and calm demeanor. We exchanged greetings and I felt welcomed by her soft but confident ways of speaking. I felt happy to meet a potential participant. When I completed my introductory tour, I returned to talk with Lana. She agreed to participate in this study. I read the information sheet with her, and I left her with a copy plus the consent form. I informed her that I would be at the unit every Tuesday and Thursday as those were the off-clinic days for all the nursing staff. I also suggested we could meet at another place at her convenience. Lana chose to meet on Tuesdays at the Fevers Unit. Consequently, I returned every Tuesday to meet with Lana.

**Opening the conversation with Lana.** It was on Tuesday, June 16, 2015 at 11:25 a.m. that we had our first research conversation. It was at the Fevers Unit. I arrived quite confident to begin the conversations. As convention demanded, I went and said good morning to the Director before I met participants. I exchanged greetings with Lana and asked about any questions regarding the information sheet and the consent form I gave her the previous week.

Lana had read them all and had signed the consent form. I went over the information sheet and the consent form with her, and she confirmed her acceptance to participate in the study. After I had collected the original consent form, we moved to one of the counselling rooms for quietness as her office was shared with other colleagues. On entering the room, I took a casual look around and saw the health-related posters on the wall as I had already met here with Eva. A close look at the windows that faced a spacious backyard of the unit lit my eyes with a bright sunlight stream that entered into the room. It was the rainy season and it was cold, so the warm air inside the meeting room and the warm sunshine coming from the outside made a comfortable combination. I wondered what Lana was thinking in relation to her decision to participate in the research.

Lana was in her white nursing uniform with her green belt. I sat in the same chair as I had for the meeting with Eva. Lana was as calm as she was confident in her posture. She always made direct eye contact and had a relaxed facial expression. While I felt excited about learning about her experiences of hope in a setting so often considered infectious and hopeless, I was not certain just how the conversations would go. "Good morning," I greeted her again. "Good morning," she responded. Greetings are critical in the Ghanaian context as these open a conversation and set a caring attitude and respect towards one another. I repeated my question, "any questions about the information letter and the consent form?" She responded in the negative and we began our conversation about her experiences of hope in working with PLWH. During the course of our conversations many plotlines emerged.

Lana's initial occupation and her education. Lana started her career as a dressmaker following vocational training. She did not make the choice of becoming a dressmaker. Her

mother and Pastor imposed that decision on her. She said:

When I completed [school] . . . I had wanted to go to secondary school, but my problem is my father disowned me, so I was in the care of my grandmother. She was taking care of me. So, I had wanted to go to secondary school, but my mother was a twin . . . one boy and one girl. My grandmother took the boy [uncle] to school, leaving my mother. So, my mother didn't . . . have any idea on education. So, she has been saying that she doesn't want all her . . . female children to go to school. But my grandmother took me to school, [and] when I completed I wanted to go to secondary school and she [my mother] was not in favour with my grandmother. So, I also . . . I become annoyed, so I decided to stay at home. So, in the course of staying at home, she herself saw that most of my mates are continuing their education. So, she consulted our Pastor and so I was at home when the Pastor came with some other friends and they told me they're coming to open a vocational school. So, if I'm interested I can go to vocational school. In fact, I wasn't in favour, but there was no choice, so I went to vocational school for 3 years. So, from there I came home and then practiced the sewing.

Lana came to know during her childhood that many women do not pursue secondary education, but are forced into trades such as dressmaking. Lana experienced this compulsory treatment in her career path as a dressmaker, a vocation she did not want to enter. Her hope was to continue her education to a secondary level so she could enrol in nursing at a college, but there was a barrier to access secondary education as her mother refused to support her proposal on furthering her education. I wondered why her mother did not want her female children to go to school. Lana's account was that her grandmother was her guardian. It is clear to me that I had not experienced Lana's journey or traveled on her landscape, so I could only imagine the pain and the frustration that Lana went through as she waited at home for her fate. I wondered what made her give up her hope for secondary education. Why did she accept her mother's decision to go to vocational school? The sewing vocation was a diversion to her dream of becoming a nurse following secondary education.

Sadly enough, her sewing was not lucrative as her customers refused to pay for their clothes.

People used to sew . . . People used to sew, but they don't come to collect their items, because of the money. I was then . . . a slender person, so I saw that they were taking me for granted.

Lana was unhappy with her customers who were not paying for her services. She thought her slender appearance was a disadvantage. Thinking about dressmaking, the women of her age usually learned dressing making and/or nursing if their education was advanced enough to offer the opportunity. Lana was denied the opportunity of secondary education that would have helped her to achieve her life dream. I wondered how this experience affected Lana's hope.

Lana's mother changed her career destination by asking her to become a seamstress. This was a gender narrative being perpetuated. There were brief moments when I wondered why Lana did not stand her ground. I also thought about her neighbourhood narrative; where one is born matters in relation to making a career. Lana was born and raised in the coastal region of Ghana. In this part of Ghana, from my experiences and observations, women focussed their careers on fish mongering as the men were mostly fishermen. Today, the landscape has been altered and many more careers such as trade and commerce are possible. As a fishing community, it can be expected that cash flow among the residents would be periodic as fishing was seasonal.

It was clear in our conversations that education at that time was not as accessible as today. At the time of this research, the region where Lana grew up had many excellent secondary schools and two public universities. Young women became more educationally privileged and education became much more gender neutral and accessible to women.

Although Lana could not participate in secondary formal education during the early part of her life, her dream to become a nurse was not abandoned. Lana's story, like many other Ghanaian women who were denied formal education, reflected the contexts of her age. I remember how Brock and Cammish (1997) described reasons for these policies and denials as geographical, sociocultural, health, economic, religious, legal, and political/administrative. They described:

A major deterrent to female take up and follow through of educational opportunities (even when these are available) is a near universal fundamental cultural bias for males. The widespread operation of patriarchal systems of social organisation; of customary early marriage; of the incidence of first pregnancy (in and out of marriage); of heavier domestic and subsistence duties of females (especially in rural areas); a generally lower regard for the value of female life, all combine though differentially in each case, to adversely affect the participation of girls and women in formal education. Together with the fundamental socio-cultural bias for males, the economic factor, especially regarding grinding poverty and hunger, is probably the most influential in adversely affecting female participation in education, especially in rural areas. (p. 9)

Lana's experience with these contexts plus the absence of her father and lack of opportunity for secondary education as a woman were stories that challenged her hope. However, a transition from one career to another is worth celebrating. As we navigated Lana's life journey, we turned to her early years of life.

**Early places in Lana's life.** Lana was born in the city. The city was predominantly rocky and was generally undulating with steep slopes. There were valleys of many brooks amongst the hills. This place was one of the tourist attractions in Ghana. Childhood experiences with fishing or selling fish or trapping crabs usually abound. The city also had several sites affirming the memory of the stories of the slave trade. When Lana's father left, she and her mother had to move in with her grandmother [her Guardian]. It too meant that they had to move to a different town.

I was born in [this city] and my grandfather was then in [this city too]. So we were all in [the same place], but he was retired some years back . . . I think 1965. So we all moved to [somewhere else] and we have been there till that date. My mother married there and my grandmother, we were all together. Unfortunately, my mother died about 2 years ago and I have eight siblings with . . . some twins, so we are eight and I'm the firstborn. In her early life, Lana was living with her grandparents in the same city where she was born. Her mother was also living in the same household. Her father had divorced her mother and he

did not support Lana's mother or Lana financially. The grandmother who was Lana's guardian moved from one place because her husband retired and they relocated. Lana's mother also came along, where she remarried and had more children.

The city where Lana moved was similar to that of the other place, as both were fishing

ports. I wondered what her experiences were growing up here. I remembered young girls my age when I was growing up sold retail items or provisions to support their family's income. Lana's early life focused more on family context and primary education. As a first-born child of eight siblings Lana also tended to her siblings. The expectation of a role model and sometimes taking parental responsibilities were also some of Lana's early experiences.

Secondary education and change of career. Lana started school after her grandparents moved.

I started school in the year [we moved] . . . When I completed this, I wish . . . I had wanted to go to secondary school, but my problem is my father disowned me, so I was in the care of my grandmother, she was taking care of me.

Lana's experience of her absent father affected her opportunity to have secondary education. It was the blessing of her grandmother that saw her through primary education. However, Lana's great desire was to have secondary education, as this would allow her to take up professional nursing as a state registered nurse. This was her dream and she pursued it with every breath. Lana's stepfather was a nurse and I wondered if that inspired her early dream of nursing.

Lana's quest for education demonstrated her belief that higher education offered the opportunity and skills for a better job or higher income. However, as she was hard-pressed, Lana accepted to go to vocational school to learn dress making after staying home for a while. It is amazing how Lana sustained her hope of becoming a nurse. I saw Lana nurturing her hope, holding it very close to her. I wondered how Lana continued to sustain her dream of secondary education while in vocational school. Lana's experience of vocational education reminded me of my teacher training. While I was in teacher training college I was hoping to get admission into

nursing training college. It happened. I left in my second year to start nursing training.

Lana's desire to have a professional education to improve her life resonated with my own experience. Lana changed her career from dress making to an enrolled [practical] nurse. She got admission into a Training School to train as an enrolled nurse (EN). Lana's stepfather, who was a nurse, introduced Lana to the principal who guided her to write an aptitude test. She passed and was admitted into the nursing training program. She said:

And my mother married a male nurse . . . So, I told him I want to change my career to nursing. And he agreed, so he helped me to write . . . the application letter . . . Fortunately one of his mates was also a principal in one of the nursing schools, so he told him and he said I should write an aptitude test, if I pass he will take me. So, I wrote the aptitude test and lo and behold I passed. So, I went to Oda training school and completed . . . I completed in 1979 and I worked till 1981 [when] I left there.

Lana achieved her dream, a hopeful experience. Following training Lana requested a transfer from Oda to Winneba because she did not like the neighbourhood. "Honestly I didn't like the way some youngsters live . . . I didn't like their behaviour, so I decided to move out. So, I went to our head office to request a transfer." On returning, Lana continued to work as an enrolled nurse at the District Hospital.

However, Lana really wanted to have a secondary education. After many years of work as an enrolled (practical) nurse with only a primary school education, she registered in the General Certificate Examination [GCE] Ordinary level [O' level] class. Lana was able to enrol in her secondary education with the help of her siblings. After passing the O' level exam she was admitted into the state registered nurse training program at Cape Coast. Her sewing career continued even after nursing training and while working as a qualified nurse. During our conversations, I wondered about how her experiences as a seamstress shaped her experiences of working with PLWH.

Lana's travel towards her goal. As I reflected on Lana's determination to become a nurse, I was reminded of my experiences to complete my graduate program. Lana shared her impediments to achieving her dream, including the difficulties of generating an adequate income. I acknowledged the difficulty in combining full-time studies and work and wondered how she was able to combine the two. I too wondered about her family support and her hope.

First, I was an enrolled nurse and all my siblings they passed through secondary school up to university. When they saw that I didn't have a secondary education they became teachers in my life. They sat me up, taught me and I [challenged] the Ordinary level [examinations] and passed.

Lana's desire for secondary education helped her to be continuously motivated towards her lifelong learning goal. She received encouragement from others while in psychiatric nursing training, as a mental health component of nursing when she was at a training school. She said:

And the nurses were encouraging us to . . . write Ordinary levels, so we can further our education. So, it was ringing in my mind, so when I came to Winneba and . . . they were having classes there, I joined and then [challenged the Ordinary level examination], I passed and then I applied for nursing training college in Cape Coast [for the state registered nurse (SRN) program].

The training for ENs includes a mental health component. Through the support and help of siblings and other nurses Lana gained admission into NTC where she graduated with an SRN

certificate. As I think about Lana's determination, I remember her track record of success and the hope she had experienced at the various places. I am called towards memories of Cape Coast NTC. I taught several years in a Training College and I am familiar with the breeze that blows over the classroom as the school location was close to the ocean. I remember there was quietness of the town and the historic sites. Lana acknowledged that her siblings contributed to her success in her Ordinary level examination.

My younger brothers and sisters . . . they encouraged me to write O-level [secondary school certificate exam], because they are all [O-level holders] . . . They've written their O-level, except me. So, one was an English teacher to me. They shared among them [to teach me]. So, after attending my classes, when I come, they will also go over with me what we did [in class]. So, I passed and then I went to Cape Coast [Nurses' Training College].

Lana wondered if her siblings would have rewarded her the way they did if she had not supported them. She said, "So I hope that if I did not take good care of them, they would not in turn do to me what they did for me".

**Connections with extended and nuclear family.** Lana was connected to her siblings, grandparents, and mother. She said little about her father who had disowned her. Lana grew up with many siblings and played a vital role in supporting the family financially.

my stepfather, he also got married to another woman, in addition to my mum, so in fact the children were many, so he couldn't cater for her [my mother's] children, plus his attention was on the other woman. So, I used my meagre salary to cater for all my brothers and sisters. Lana's family connections with siblings were strong. She related well to her siblings to create an opportunity for supporting her during her upgrade to secondary education. Lana also shared how her grandmother and mother apologized to her when they realised they did not support her wish to attend secondary education earlier. Lana's mother later came to plead for forgiveness because of her decision. She said:

But when I was writing the O-levels, my mother then asked my grandmother to join her to beg me because she was saying she doesn't want the children to go to secondary school, but all of them had secondary background, with the exception of me. So, she begged me that I should forgive her.

Lana responded with understanding to her mother. In her words:

I said oh it's nothing, but I learned also how to sew in vocational school. So, when I entered nursing and even when I was a student at [at the NTC], I was sewing, so it also benefitted me in a way.

I found it hopeful that Lana forgave her mother. It was amazing that Lana showed such tolerance towards her mother. Lana described that this really increased the quality of their relationship before her mother passed away.

Lana then had a nuclear family of five with three children who were adults. She started her own family after she completed her enrolled nursing program and returned to Winneba. In 1981 Lana moved to Winneba where she married and had a child before furthering her education.

Concerning her children, she said: "They are here [Ghana]. Only one [second born] is in the USA. She is married. She is doctor of optometry . . . the first girl read management and

education, and the third boy did general engineering. They are both looking for jobs."

The story of the boy. Lana worked in many places, including hospitals at various communities, and the national hospital in Accra. During our conversations Lana recounted one of her early nursing stories.

When I was in Winneba . . . I was at the OPD and a driver brought a patient. And the moment he came he said, "Aunty Nurse I have brought a patient." "Where is the patient?" The patient was not in the car. So where was the patient, but there was blood around the car . . . Where was the patient? He said, "The patient is in my boot, he's in my boot." When we opened the boot there's about an 11-year [old] boy in the car boot with lacerations all over the body and I think he has a head injury. . . So, he says, "Where is the trolley? Bring the trolley so we can put him on it and take him to the mortuary." And I said "No." I felt the pulse and the patient wasn't dead. So there and then I called . . . In those days there were no telephones, but fortunately one of the doctors came around, so I reported and there and then I arranged for a police officer to take the driver to police station. So, he was detained for some days . . . We took the boy to a ward [admitted and treated] and he's there [alive]. So, the hospital gave me Best Nurse award.

When I listened to Lana I could hear her strong sense of professional responsibility towards patients, which reflected Lana's initial determination for her career in nursing. Her passion for nursing showed up in her tenacity. Lana responded to the driver's panic with calmness, and was also firm with her actions. Listening carefully to Lana, I wondered if there is a connection between responsibility and hope for her.

Transfer to Fevers Unit. Lana told a story of her experience when she arrived at the

Korle-Bu Fevers Unit.

The first time I was transferred here [Korle-Bu Teaching Hospital] . . . , when I came I was given a letter to come to the Fevers Unit. I was afraid. I became worried. So I cried 'aaah' [unceasingly] until one nurse came to meet me at the gate [entrance/exit] and asked why I was crying . . . I explained that I was transferred to this place, but I am afraid, and she said: "Ooh don't be afraid!" She took me here [Fevers Unit]; she brought me here.

Lana was an experienced nurse who had worked for many years at different places and was now being transferred to Korle-Bu Teaching Hospital as her husband was transferred to Accra. The populations that Lana had worked with were different from the patients at the Fevers Unit. Her fear was related to the characteristics of the population, that is, the label of HIV positive population. The fear in many cases came from beliefs about contagion which are so paralyzing that potential nurses do not want to work at the unit.

After working for a while on the Fevers Unit, Lana was no longer fearful of the Fevers Unit. She began to feel more secure. Lana did not regret that she accepted work at the Fevers Unit because she improved her understanding of the universal precautions.

But when I came [to the Fevers Unit] I saw that most nurses . . . don't want to work here on the Fevers Unit. So I sat down and had a second thought that this . . . place is a safer place . . . to work even though so many do not know that. I saw that this place is a better place to work than the other areas. Because you know the actual disease you are nursing here. You know the kinds of things you should use to protect yourself. But in other wards [units] you won't get it like that. You do all sorts of things before you find out that this patient is an HIV patient. So I like working here.

At the time of my research she felt delighted to have worked so many years at the Unit following her initial experience of unceasingly crying. The fear that Lana faced in the initial stages of working with PLWH faded out over time. Thinking about Lana's fear, I remembered being posted to the Fevers Unit as a student and then as an instructor who was to follow up with students. I do not remember crying, but I too was fearful of the Fevers Unit. I also experienced anxiety about the Fevers Unit, and this fear was part of my hope threats.

*Lessons from the Fevers Unit*. As time went by, Lana recognised the Fevers Unit as a safer place to work than other areas, as the population characteristics of the unit are well known. Lana knew how to protect herself. I wondered if this exposure had changed her hope practices or had reduced her anxiety and fear. In my field notes, I commented about how the transfer affected her emotions and how that might have affected her morale. I wondered what impact the nurse who brought her from the gate to the unit had on her revival and change of attitude towards the patients on the Fevers Unit. I wondered if the helping nurse who consoled and accompanied her to the Fevers Unit was a source of hope for Lana. I wondered what lessons Lana might learn from the helping nurse's behaviour. I cannot remember how many helping opportunities had crossed my way but some of those helping behaviours had paid back by way of satisfaction and joy. Lana's "Good Samaritan" [helper] positively impacted her future outcome as she worked at the unit until her retirement. In our last conversation (August 11, 2016) Lana had retired from the unit.

**Resembling a family.** People may affect our hope in many ways, sometimes these ways are positive, and at other times they are negative. Lana talked about the Fevers Unit team as a
family as they extended their hand to one another when needed. She said:

In working here my colleagues, nurses, and doctors, we all work hand in hand. So if in case something happens to one of us and you call one doctor or colleague they will immediately come to your aid and then help you . . . working as a team and a good one too. At times, we can work as a team, but you can see some differences, but here we are more like a family.

She further illustrated with an example when asked to describe the "family" team. Lana narrated a story about how she got help from a medical officer colleague who was a team member.

If let's say you are sick . . . my daughter was sick. One morning we woke up and found some changes in her. I called him [one of our doctors]. He was not around during the day. However, he came at night and attended to my daughter, and he gave her the necessary treatment . . . we were all surprised. Also, the following day he wrote a lab request . . . to do some labs investigations. I was highly impressed.

Lana was awestruck as the physician's kind gesture offered her hope. As she reflected on her arrival at the unit with almost no hope, at the time of her interview she said she would not transfer, even if they asked her to.

I said when I was coming here I was afraid, now I am no more afraid. Even if I am asked to go to other wards I will not go. I prefer to stay here because I like the way we nurses care for our patients here.

Unfortunately, when I returned to negotiate the narrative accounts, Lana had retired and was no longer working as a nurse on the Fevers Unit.

Hope arrives incomplete. Lana also spoke about the necessity to improve and expand

the care rendered at the Fevers Unit as the only unit in Ghana that specialized in HIV and AIDS. Lana identified a lack of resources at the unit and spoke about efforts made to address it.

There is room for improvement here. In Ghana, this is the only ward for HIV [specialized] patients. So the facility has to be expanded. We lack so many facilities in this unit. We have to approach benevolent societies to come to our aid. We have been doing it, but some people listen to us, others don't. Me for example, my bank manager, I narrated the story here to my bank manager, and he came down to help us. He bought

Lana talked about the Hope Society where her bank manager was a member. As of this writing I have yet to learn more about this society but the name implies it is a benevolent organization that helps individuals and institutions with specific needs or concerns. Lana identified such supports as a communicable hope, as their kindness attracted others who were also encouraged to donate to the unit. Hitherto, Lana spoke of the level of physical deterioration at the unit as no matter what the benevolent societies contributed there was still room to do more. Hope arrived incomplete.

fridges, microwaves, and paid for the repair of some doors and windows for us.

Some benevolent societies have been coming [to support the Unit] before I came to the unit . . . They [the authorities] have to build a new building for this one to be renovated.

That is the main problem . . . even now all the roofs are leaking.

Lana was advocating for a new site for the unit so that the old one could be renovated. She said it was about time that the unit got a decent building. I wondered how Lana's hope was affected by the poor structural conditions of the unit and how this impacted her nursing practices. Lana responded as follows: "I can say I become a bit confused sometimes. I am tired of working here. I am working with hope." While Lana experienced poor conditions, during my visits I noticed that some renovation work was taking place. Lana thought the Fevers Unit needed renovation or a new building to meet the needs of the population as time had moved on and the population had increased. Regrettably, the expansion and upgrade of the facility had been slow. Lana's hope of working at the Fevers Unit was being threatened as shown in her statement: "I am tired of working here."

**Hopeful experiences.** In our first conversation, I asked Lana to tell me a story of what made her hopeful in working with PLWH. She cleared her throat and recounted:

OK at first . . . we weren't having hope because there were no drugs but these days we have drugs for HIV/AIDS patients, even though the drugs are not drugs which would cure them but just drugs which suppress the disease and thus it can prolong the patient's

life so that the patient may live for longer years if he/she takes good care of him/herself. In her early career Lana did not experience hope due to lack of effective medications. As time went by antiretroviral medications became available and had a positive impact in sustaining the lives of PLWH. Lana then became hopeful as she recognised the connection between patients' longevity and compliance (with the treatment regimen along with healthy life choices). Lana saw that medications provided hope. During our conversations, I wondered if Lana's experiences of hope were dependent on access to medications for the patients.

Hope was also evident when Lana reflected on her experiences at the Fever's Unit. I can say I thank God that He has sustained my hope. He has given me hope to be able to work here for the time I was posted here up to today. When everybody is sick, it takes another person to nurse [him\her]. In nursing, we didn't come to nurse only a group of patients, but every patient and every nurse is responsible for taking care of every patient whether HIV or whatever.

Lana saw herself as caring for every sick person and not imposing judgements as a way to sustain her hope. I wondered if her firm belief in God contributed to her hopeful practices. I also wondered if her early experiences of discrimination as a woman whose culture denied her education contributed to her hopeful practices. I shared Lana's views about caring for everyone, yet HIV stigma and discrimination stood in the way of showing that caring attitude towards everyone. This discrimination impeded the legal rights of PLWH, especially where those rights become critical to the survival of PLWH.

We had a workshop at some place and we complained and they are saying they (patients) have legal [privileges] . . . So we raised the point that whenever a couple is coming to marry, they should make [it] a point . . . to test for HIV before they get married. But when we raised that topic, the organizers said they also have a legal right, and they can

do whatever they want to do so. [It] is not proper to test a couple before they get married. Lana's beliefs that people should be tested for HIV before marriage, while reflective of larger social and cultural narratives, were in contradiction to people's legal rights. I wondered how much the inability to force people to disclose their HIV status to their sexual partners, for example, impacted Lana's hope. I remembered earlier Lana's initial fear of working at the HIV Unit showed her attitude towards PLWs at that time: she wanted to protect herself as she was fearful of contagion, but she also wanted to protect society from the spread of HIV. This view of testing and disclosing might be important to Lana as it challenged her hope as a HIV nurse if not carried out by PLWH. Lana's challenges to her hope. Lana's hope was often challenged by things that seemed to be at variant with her principles or perceptions. Throughout our conversations I noted several plotlines that challenged her hope.

*PLWH behaviour concerning sexual transmission.* The main route of HIV transmission in Ghana is through unprotected sexual intercourse. This understanding informed Lana's view of testing for one's HIV status before engaging in sexual relations. She was worried about PLWH who knew their HIV status and were on medication but did not ask their new partners to go for testing or to come to the clinic for the same before marriage. She said this behaviour threatened her hope.

What threatens my hope is basically the way the patients behave . . . we tell them when they want to marry, when they approach any female or male they should bring the person to the clinic so that we counsel them and then test them, whether the person they going to marry he/she is OK or negative . . . But they won't do that. They will go ahead and impregnate the other partner who is negative. We've talking about it and they are doing

While testing was not mandatory by law, Lana felt that PLWH should bring their partners to the clinic for testing. She felt so strongly about this that she raised her concern at a workshop. As she told me her concern, I asked if the lack of legislation to compel individuals to have the testing done threatened her hope. She responded, "Yeah, we keep on talking to them, and we are hoping most of them would adhere to what we say."

it. By doing so, they keep on spreading the disease. So this is my worry.

Lana often talked to PLWH about the importance of disclosure. This was within her

scope of practice. I also used to encourage people to do the testing but I could say little about their responsibility to their potential partners. I feared they might lose their partners or be rejected by friends as the stigma associated with HIV and AIDS was significant.

**Hopeful moments.** Every moment in Lana's life as an HIV nurse impacted her hope and defined what she was comfortable with and what she was not. Lana talked about some hopeful days

Our talking is not done in vain. Some of them would do what we say and when we see that we are all happy and I have hope. We are hoping that most of them would change their lives.

One of Lana's key activities as a nurse was to provide health education. On the Fevers Unit Lana talked to her patients about the management of their HIV, including prevention and follow up care. The prospect of her health talks depended on the compliance and collaboration with patients. Lana was happy when there was a measurable change in the lives of her patients.

Looking back on my student days at the Fevers Unit I recall that nurses most often shaped the environment in which patients functioned, as a word or an attitude can do a lot to affect hope in patients. Patients hardly reject health providers' counsel during their stay in acute care. Occasionally issues related to medication refusal due to side effects or previous bad experiences with the same medication might arise. Lana wanted her patients to listen and comply, as such actions supported her hope. Lana dwelled on compliance. I wondered about Lana's childhood experiences and reconnected with her conversations about women education and the beliefs associated with it. How was her hope linked to larger social narratives that shaped people's lives? What of her hope for getting an education and that of her children? I wondered what sustains her hope outside of her care practice site.

**Hope connections.** Lana talked about different ways in which hope was connected to other events. She related to behaviors that sucked her hope, sometimes called hope suckers (LeMay, et al., 2014).

Some of the patients they know that they are positive and they would go and do what is dangerous. Like the person who knows that he is positive, he would go and marry somebody who is negative. And he/she would not tell the one what he/she is going through. So when I see things like that, it brings my hope down. It seems the talking we are talking, we are talking in vain.

Lana's hope also connected to others at the work place. She applied her knowledge in counseling and diagnostic skills to minister hope to people around her. She said:

Since I started working here some nurses would have cases, suspected cases, and they would bring the relatives [cases] for counseling and the little experience I have here, I would be able to counsel them. And then a laboratory test would be made, and if the person is positive, mostly the cases are positive. So that makes me glad to say that most of the nurses or other colleagues have hope or interest in me.

I wondered how knowledge inspired Lana's hope. Did Lana know that knowledge impacted hope? Did she know how her hope impacted knowledge? I remember when HIV was newly discovered and not much was known, there seemed to be no hope, but with time hope increased as more was revealed about the virus. Lana freely shared her knowledge and skills, which she linked to hope.

Lana had many connections to hope. She told how she first learned of hope: "I could not

get a life so easy. However, I was hoping that I would become what I am today. I have seen that my hope has worked. [Laughing]".

Hope nourishment. I asked Lana "what sustained your hope that one day you would become what you are today?" Lana related her success in achieving hope for her family particularly her grandmother and siblings who reciprocated her gesture and helped her fulfill her aspiration. Her words reminded me of the role my family played in my physical and professional development. Lana drew attention to her grandmother and her siblings as sustaining her hope. While she was well connected to her children and her husband, she did not say much about other aspects of her family. Lana was a mother and a wife, and those connections gave her hope in her life. However, Lana's husband did not initially support her transfer to the Fevers Unit. She said:

Hmm because it has not been easy.... Even when I came here my husband was against my coming here (laughing) but now he does not complain anymore. He has seen that I come to work every day and I did not take any complaints to the house.

Asked what made her husband not initially supportive, Lana said: "Maybe at first he does not have hope that there will be a cure [recovery] because he thinks whenever a needle pricks a nurse that is the end of it. Now I have taken the time to explain everything to him, and he knows how to go about it."

Another part that was significant in Lana's life was her belief that one day medication to cure HIV infection will be found. She said:

I am hoping that one-day curable drugs would come for the patients to be free from this situation. When we started nursing HIV patients here, the patients were told not to have

babies because all the babies may be positive, most of them may be positive. However, now other interventions are in, that they can have children and most of the children are negative. So this boosts my hope: that one-day drugs would come that would eradicate HIV in our society.

Her love for her work told me how hopeful she was about a cure for PLWH and their quality of life. Many of Lana's hopes were goal oriented and some had been achieved. One hope remained: she hoped for a cure for HIV. This expectation is one that everyone hopes for.

**Hope threats.** Lana spoke about work-related conflicts from colleagues. Lana expressed the notion that nurses "eat their young", by which she meant that nurses bullied each other, and that nurses who only recently graduated were often not well supported. For Lana it was important that nurses support each other.

We are individuals so . . . we cannot get everything on [a] silver platter. One day or the other you may offend or do something which may offend . . . [the] other colleague and there may be small quarrels . . . but at the end [of the day] we can come together and solve it.

Lana drew attention to the inevitability of conflict. She noted it was important to come together to solve conflict. Consequently the need for nurses to know how to handle conflict when it surfaced was critical. It may have been that most of the disagreements in nursing were not comprehensively resolved and may have remained threats to the hopes of those involved.

**Returning to anxiety and importance of hope.** Lana had a needle prick many years back before HIV was made known in Ghana. In those days Lana did not think about hope for a cure.

I had needle prick somewhere, it happened to me years back . . . there was no HIV . . . maybe there was but it wasn't rampant like this [current situation] . . . , when I came here [to the Fevers Unit] I had the opportunity to check on my HIV status: that brought hope to me, as I was negative . . . [Laughing].

Lana was happy because she tested negative for HIV. Lana acknowledged the importance of hope in her work. She spoke of hope as follows:

Hope is important because if you are doing something and you do not have hope it will not end up well, so whatever I am doing I have hope that it will be well . . . If you take hope out of your life you cannot work here. We have to try and [have hope] [Laughing].
Hope was in living. Lana echoed the importance of hope in working at the Fevers Unit. Lana could not work at the unit without hope. I believed her. Her cheerful demeanor not only promoted hope but also promoted healing to patients and sustained a welcoming environment to work in. Lana puts it this way when asked to describe how significant hope is within the Fevers Unit. "If you take hope out of your life you cannot work here."

What is care to Lana? Caring, as related to HIV in the eyes of Lana, was about supporting, counseling, and providing non-judgemental care to patients. Lana talked about care for a sick person.

Care is when . . . caring for someone with . . . sickness, so care for . . . somebody's . . . in the morning when we come to wards . . . in-patients, in the morning we normally do our morning devotion. After morning devotion we read our reports and they [nurses] share a room . . . at times six patients or seven patients to one nurse, or two nurses, so those who are not able to bath, we bath them. We feed them, we do their bed . . . and then thereafter

we give them medications, and in our leisure times we converse with them a lot, to know their problems. Social problems at home . . . they talk a lot about stigmatisation, they are not accepted in their various homes.

The meaning of care for Lana included personal care for patients and interaction with them. Such activities promoted and fostered hope in patients and also represented hope experience for Lana. She reported that for the unit to promote positive experience for families, they implemented family involvement in the care of the patient.

For Lana, care involved activities of religious observance (e.g., morning devotion), report reading, bathing patients, and counseling. It also included conversations with patients and finding solutions to their health problems; patients on the Fevers Unit were receiving holistic care. Lana's nursing care embraced the patient's physiological, emotional, and spiritual needs. The morning devotion was meant to encourage patients to use the scriptures and hope messages. Lana described the situation when she first joined the team.

So when I came here, for instance, for the first time [previously], the nurses and doctors here, they don't allow ..., they don't allow relatives to come in contact with the patients, because they were saying they didn't know the particular organism or so, so most of the relatives will come on the Saturday, back of the ... window to ask the patients about their health, but later they [the nurses and doctors here] saw that what they were doing was bad, so they allowed the relatives in. When they come they only come and stand there and ask them how are you, and then whatever they brought, they will put it down and go, but gradually we saw that it's better to work hand-in-hand with them, and so we introduce some of the bath. We encourage them and then we made them to assist us, so

that when they [patients] get back to the community . . . they will be accepted by their relatives easily, and that has worked for us.

Lana was involved in implementing the process for reintegrating patients into society, particularly to foster their acceptance by their families. Lana experienced hope by showing active interest in the lives of patients. Lana's hope was also connected with her caring attitude.

It's good to care for your patient because if the patient is not having good care . . . the patient will die, or he may be depressed, and so care . . . is good, because . . . it's good to take good care of our patients, and continue to talk to their relatives. Also to take good care of them at home when they are discharged, and we also do follow-ups, there are various home visits by the public health nurses.

Lack of counselling will affect the care of our patients. If you continue to counsel relatives . . . counsel our patients and their relatives, we can see that they will know that there is hope for the patients, but if you don't counsel them, that will bring about stigmatisation, so we always continue to talk with their relatives, in order to accept their patients at home.

I wondered how Lana saw her activities of caring and counseling as it was very easy to shift focus to task-oriented care as the system demanded, rather than to human caring. Lana was a senior nurse who had advanced knowledge in nursing. Lana's caring approach within the HIV landscape was solidified in her tolerance and non-judgemental approach with a deeper understanding of the context of poverty and power. Her feelings, thoughts, and desires for patients to belong and be accepted were components of her caring. **Experiencing stigma in HIV care.** According to Lana "Some of them [patients], they talk a lot about stigmatisation, they are not accepted, in their various homes." The stigma not only affects the patients but also Lana. She reported of her neighbour who asked her ""when are you requesting for a transfer from the Fevers Unit?" Lana encountered the stigma in the residence where she lives as a colleague and a neighbor asked her about changing her place of work. Everyone knows the HIV stigma is ubiquitous but when the discrimination comes from a colleague it has a high impact. Lana was assertive as she responded to the staff member in a transparent manner: "Go and inform the Korle-Bu hospital authorities to transfer me." Lana found hope in using her voice to defend and stand tall, not only for her integrity but also for the dignity of those affected by HIV.

Lana's experiences of hope and God. Lana, like the rest of the participants, also talked about her faith in God. In my field notes, I wrote nursing, in particular, had a historical association with the Christian faith. Care through faith was received through respect, touch, gazes, expressions, and a welcoming attitude towards patients. Lana expressed how she sustained her hope through her belief in the creator, God. She said: "Oh! I can say I thank God that He has sustained my hope. He has given me hope to be able to work here for [the] time I was posted here up to today."

## **Berth's Narrative Account**

Berth was the first person I met during my arrival to the Fevers Unit of the Korle-Bu Teaching Hospital. Berth was part of the leadership team at the Fevers Unit. "Come in," she said. I greeted "Good Morning" as I entered the office. After we exchanged greetings she said "Have a seat, what can I do for you?" I introduced myself as a doctoral student from the University of Alberta and a fellow Ghanaian. I also told Berth that I was once a student in the unit and also a tutor. Berth warmly received me, which she expressed through a smile on her face. She was full of energy. As I took my seat, I was thinking about my journey of being a nurse tutor and now student researcher. My thoughts were interrupted by a knock at the door. Berth kept the office door closed to minimize noise and distractions. A nurse entered after Berth signaled me to open the door. They spoke briefly. Berth did not want me to excuse myself, even though I insisted. In the end I conceded and stayed; perhaps I felt more uncomfortable than she did as I did not want to intrude on potentially private matters. After the staff left, she put a "Break" sign at the door. I removed my backpack from my shoulder and placed it beside me. I sat on the chair closest to the door. I felt welcomed, but anxious. I took a deep but silent breath and said "I have a clearance letter from Korle-Bu Administration for my proposed research." Berth and I went through my clearance document to ensure I had the permission to carry out my study at the unit. She was satisfied with the verification of my documents. She offered to take me around the premises to meet with potential participants.

As we left her office, I was thinking, "What an opportunity to meet potential participants for my study!" We move from office to office. It was Berth who introduced me to Eva and Lana. Berth left me at the nurses' station so she could continue her work in the office. When I had finished with my recruitment discussions with the nurses at the station, I went back to Berth's office and said thank you and bid her goodbye. She too decided to participate after I explained that participants would have their own schedule. I offered her the appropriate forms. We scheduled to meet the following Tuesday to begin our conversations. I also remember that Berth's assistance of introducing me facilitated the recruitment of three participants on the same day. I went home thinking about becoming a narrative inquirer and the journey that would be ahead of me.

As I lingered with thoughts of being a novice researcher, there was nothing more that I wanted than to hear hopeful stories that were connected to places, contexts, and told over time. I was called towards memories of Berth's office. Her office looked out over a corridor and it was open the morning when I arrived on the unit. The office was well lit, with a plush sofa for lounging. Berth's office was adjacent to Eva and Lana's offices. The sunlight entered from the only window. The window overlooked the parking lot and allowed Berth to see when people were passing through the entry and exit gate. Berth's office was decorated with pictures including pictures of Florence Nightingale and some religious pictures of Jesus Christ carrying a lamb. Berth inherited those pictures from her predecessor. "These pictures were here when I took over the Unit" she said. The chairs and the desk in the office were very close to each other, leaving only a close passage between them.

I continued to wonder during the week about the pictures I had seen on the wall. Florence Nightingale's picture reminded me of the history of nursing and allowed me to travel back in time to think about how far nursing has come. I also remember there were wall hangings in my office in the college where I was an instructor a long time ago—in those times, the wall hangings were words of hope and encouragement. I began to see hope representations as I thought about the pictures. I wondered if they did signify hope for Berth. A significant part of my hope in life is rooted in the belief in God, and I practice Christian rituals such as prayers and communion. Shifting my thoughts away from the religious picture, I lingered with the thoughts of Florence Nightingale's work and the hope she would often express in relation to her patients. For a moment, I thought about the connections between Nightingale and the nurses in Ghana. I wondered which photos or paintings would represent Ghanaian nurses. In these early times of meeting Berth my mind sometimes wandered. At one point I recollected the memories I held of the Fevers Unit, which served as an infectious disease unit. The Fevers Unit was located in the southwest wing of the Korle-Bu Teaching Hospital and had a rectangular compound with an entrance and exit at the west end. The exit and entry gate had a security officer, as do most of the gates in the Hospital. Up until the day I met Berth I somehow had forgotten about the security officer. My mind shifted again and returned to my engagement with Berth.

The week had passed by very slowly from when I saw Berth last. However, I found myself back at Berth's office to begin the conversations. I said, as I entered her office, "Good afternoon! Today is Tuesday, June 16, 2015." Berth was sitting in the chair, engaged with paperwork. She wore her white uniform, which she matched with a mauve [an appropriate color for her title] belt. Berth was smiling and appeared very energetic. She responded, "Good afternoon, how are you?" The happy tone of her voice was congruent with her smile. I said "fine." With an enthusiasm about our upcoming research conversation, I asked: "Do you have any concerns about the information sheet and consent form (which she had filled out and signed) I gave you the first day of our meeting?" She responded "No! I have no concerns, provided the stigmatization of the patients is not at stake." I was struck by Berth's concern about the stigmatizing of the patients and wondered what she had experienced in the past. I explained that our conversation would focus only on the two of us and no particular patients would be identified during our discussions. I assured Berth that our conversations would remain confidential as they were meant to understand how nurses experienced and practiced hope and that they were less about patients' experiences. Yet, I wondered why Berth made the comments that touched straightaway on the risk of stigmatizing patients. Why did the patients' protection matter in Berth's life? Did nursing ethics play a role here for Berth? The thought about patients' protection lingered with me while we proceeded with the conversation for the day.

Maiden name. As we talked, sitting in Berth's office at the Fevers Unit, I followed up with a question "tell me more about yourself." She said: "My maiden name was [different]. I was born on the 10th of February . . . at Korle-Bu Teaching Hospital . . . I'm married to my husband [ . . .]." I listened carefully to Berth as she talked about her life journey. Berth started with her maiden name. She also called forth memories of her birth place, her marriage, and her education. Berth went by the name of her husband and she no longer bore her family name. I remembered how my family name had shaped my thoughts about who I was and who I become. I wondered if Berth would have felt differently, for example, if she had not taken on her husband's name. I recalled memories of the value that her parents placed on her as young woman: sending her to a private school, secretarial school, and then post-secondary nurses and midwifery training school. Her family name maybe carried some of these experiences.

At the same time, when Berth mentioned her married name there was pride. "I'm married to my husband . . . who is now . . . an Assistant Commissioners of Prisons." She said it with such a confidence and joy. "I am married . . . and my husband has been very supportive . . . Very, very supportive. Yes very, very . . . He encouraged me to upgrade myself . . . He's very, very supportive." As I listened to Berth, I reflected on memories of my first name Gideon.

Gideon is a Christian name which I took during my baptism later in life. Both our first and last names can shape us into our characters and personalities.

**Birth place.** When Berth introduced herself to me, she also identified her place of birth and talked about her parents. Berth paused when she talked about her family; perhaps she was thinking about her parents. When she mentioned her place of birth, I remembered Korle-Bu Hospital which served the entire country of, and within, the West Africa Sub-region. It was costly to attend the hospital as it was considered very efficient in its medical care delivery. I wondered why Berth's parents chose to deliver her there. The Hospital was one of the competent places to receive obstetrical care because it had almost all the experts on hand, should an emergency arise. In mentioning Korle-Bu Hospital it too called forth my knowing that only affluent people, who had the means to pay for the higher user fees than other locations in the country, could receive care there. I wondered if Berth considered her birth place as a privilege.

**Hospital as a birth place.** Thinking about the Korle-Bu Hospital I was called towards memories of cash and carry and the purchasing power of the parents. The ability to pay for Berth's delivery at Korle-Bu Hospital also showed the hope Berth's parents had in her. I wondered what hopes and dreams they had for her. Did they imagine that one day she would become a director of nursing? What was the feeling for Berth to trace her beginnings through the very hospital where she was born, trained, and worked in a leadership position? I wondered if she ever thought of rising to take up her place in the Korle-Bu Hospital as a director and an administrator.

**General education.** I remember what my mother told me about women's education in the 1930s in Ghana. According to her, women married, kept the house, and took care of the

children and cooked for their husbands. Only the men went to school. However, in the 1960s women's education in Ghana became a status. Women were encouraged and supported by the Ghanaian government and many well-meaning citizens of Ghana to pursue their education. Berth was born in an era when education was becoming more gender neutral and supportive of women. Berth had the opportunity and the ability to attend school. Reflecting back on her education she recounted, "I started my primary education ... at [a] Preparatory School and continued my secondary school at [a] Girls Secondary School." The Preparatory School was a private school and Berth's parents sent her there. I was called towards memories of private schools. They usually had efficient teachers and more facilities to support teaching and learning. Students who graduated from private school had a greater chance of entering post-secondary institutions. Berth was successful at the common entrance examination and proceeded to secondary school at a Girls Secondary school which was a government school. Berth completed secondary education in 1982. She stated, "I completed in 1982 and came into nursing in 1987."

Secondary education for women during the 1960s was considered a milestone. After secondary school Berth enrolled in a secretarial program for 4 years. Berth pointed out that her initial plan was to become a secretary, so she started secretarial training school. "I attended secretarial school 4 years before coming into nursing training at the Korle-Bu Nurses Training College." Thinking about the stories she had shared with me, I appreciated Berth's daring attitude towards entering nursing training. What a significant accomplishment and a hopeful trail.

**Nursing training placements.** Clinical placements or internships are an essential component of nurses' training experience. Often this time of training is also a time of much

reflection. Most often the internship marks the entry into the real world of working as a nurse perhaps it is a time of transition. I lingered with the thoughts of Berth's choice to enter the nursing profession.

In fact, it was the dress and the appearances of nurses that attracted me into nursing. Apart from the fact that I have the passion . . . When I see people who are sick in fact, I have the compassion for nursing those people, but it was the appearance. I came to the hospital one day, and I saw a nurse who was neatly dressed . . . a green nurse with the apron and cap. So when I saw the nurse, I said as for this one . . . I will, by all means, be a nurse. So, in fact, it was that . . . apart from the passion for caring for patients, it was the appearance of the nurses that attracted me into nursing, yeah!

Over time Berth gradually came to develop a strong passion and compassion for the sick. I wondered why Berth chose the Korle-Bu Nurses Training College to begin her lifelong profession and learning. I lingered with the thought for a while. What might have motivated her to come to this place? What seemed most important to Berth was the completion of her nursing education. "I completed successfully as a staff nurse . . . , and I did my rotation." In the course of internship Berth worked at many departments in the Korle-Bu Teaching Hospital and in the Accra West District. This arrangement was part of the training program at the Korle-Bu Nurses' Training College. I recalled memories of my own clinical placements and my supervisor directing my assignments. The supervisor was a preceptor and a mentor as well as an instructor or a nurse clinician. The preceptor role could be a complex one. Berth recalled memories of her placements.

When I was still in school it was part of the program to go around the region (district), so

I worked at [the following district hospitals]: I worked at Accra Psychiatric Hospital, I worked at Ankaful Hospital, I worked at Ridge Hospital, I worked at 37 Military Hospital

... But when I was doing my rotation [following nursing training], I went around the

whole hospital; I worked at surgical unit, I worked at maternity unit and emergency. Berth also recalled places of work while working as a staff nurse within the Korle-Bu Teaching Hospital.

At Korle Bu I have worked at various units. I started on the medical unit and I was posted to the Fevers Unit, because Fevers is under medical then later I went to accident centre [unit]. So I worked at the accident and emergency unit for some time, then I was posted to administration, then administration I came back to emergency . . . back to the Fevers Unit.

I lingered with Berth's various placements for a while; she had such varied experiences. I was called towards memories of places I found particularly hopeful in my life while being a nursing student at the Korle-Bu Nurses' Training College. I remembered the doctors' rounds at the Korle Bu Accident Centre Unit and the early morning nurses' reports as if they happened yesterday. I remembered my first day of rotation in the hospital. It was exciting but I was filled with anxiety about how to succeed. Every place had its own memories of hope.

Berth's experience of nursing training illustrated a lot of self-discipline as participating in these numerous placements can be daunting and stressful. I, too, remembered I had to discover a method to remind myself that I had a goal to achieve.

**Midwifery training.** Following the qualification as a staff nurse, Berth went back to school to train as a midwife. "After my internship [following nurses raining college] I went for

my midwifery education that was a 1-year program at that time . . . at Korle Bu Midwifery Training College. I completed this in 1992." As an insider of nursing in Ghana, I knew that additional training in midwifery offered many opportunities for fast vertical progression in a nursing career. Some of the opportunities included independent practice and shorter periods of promotion in the ranks, and a sense of personal accomplishment.

In addition, midwifery training was in high demand for female nurses in Ghana. I wondered what Berth's midwifery school experiences were. I made eye contact with Berth, wanting to hear more. I wrote down: "Midwifery training" to remind myself. I was called towards memories of the Korle-Bu Midwifery Training School premises. I remembered the buildings; I wondered how things were now. I tried to imagine Berth among her friends, sitting in the classroom or working at the hospital during her clinical placement. I was quiet. I listened as Berth continued her narration. "I worked at the maternity unit when I was doing my midwifery, I went to the maternity labour ward, and I went to the gynaecological ward." These places remind me of different hopes. Looking back on those days, I remember my wonder about newborns. I recalled the cry of them. I recalled also the memory of midwives yelling "push, push" and saw them cutting umbilical cords. I was carried back in time. I recalled memories of midwives, obstetricians, and other healthcare providers moving to and fro in the Labour Unit. Graduating from midwifery school was a milestone. Berth confidently puts it "I completed in 1992!" Following midwifery training, Berth was placed at the Accident Centre for many years before she went back to school to take a health services administration course.

Health services administration placements. Berth had a dream. "I wanted to switch to administration, so I went to university to read health services administration course." Berth did

this after she had worked for 17 years at the hospital. There was a component of placement to her training; she was to do clinical placement. I remember what she said:

I worked [internship] at Ga South [Municipal Hospital (AKAWE)], that was after my health services administration course in Legon [University of Ghana]. I was posted there to do part of my internship there. So I was there, I was with the administrator. And . . . in my internship too I had the privilege to work with all the support services units. So I worked at maintenance, I worked at a kitchen, I went to the mortuary, I went to all . . . I worked with all the directorates—finance, human resource, IPPD, I worked in all of those areas . . . so I had the opportunity to work with all the directorates.

Berth had vast experience in her internship. Internships can be very stressful and also very challenging. Some of the challenges with placements included bullying from some preceptors. Fortunately, Berth and I did not experience direct bullying. Berth worked at different places at the Korle-Bu hospital during the nursing course and completed all her placements. Berth's work experiences at the Korle-Bu Teaching Hospital allowed her to rise through the ranks to become the Deputy Director of Nursing Services. Thinking about Berth's accomplishments, made me think that her life was one of success and hope. Berth remembered particular stories and shared them freely with me.

The story at accident centre. The longest place that Berth worked in the Korle-Bu Teaching Hospital was the Accident Centre. I asked Berth if she had a story to illustrate her hope.

When I was at the Accident Centre, I was on duty, and they brought a young boy with an amputated leg [It was on a Sunday afternoon]. I learned the boy . . . went to church with

the mother and when they were [returning home from the church] they had to board a vehicle. [As] they were trying to board a vehicle, the mother entered the vehicle first and she thought the boy was following, not knowing one of the legs was down close to the tire and the other leg was inside the vehicle. So the vehicle runs over [the foot on the ground] and the leg [severed from the body]. The vehicle amputated the whole leg; it was in a camp boot [foot wear]. So those who brought the boy, brought the boy alive with the leg in the boot, amputated, it was detached from the body. So I was on duty .... in fact, after the doctor has seen it, the doctor said, there's nothing that we can do about the leg. So I treated the leg as we treat dead bodies. So I labeled this leg, and I had some formaldehyde, and I put it inside, labeled and everything, and I called the mortuary people to come for the leg. So I was ... off [day off] when the DDNS called me that I should come. So when I came, she said there was an incident case . . . the leg was amputated, and they can't find the leg, and the father called from outside [abroad] that they should bring the leg with the boy outside. So she wanted to find out whether I threw the leg away, I said no I didn't throw the leg away, I did last offices (rites) for the leg, I did everything, labeled it, so the leg is at the mortuary. The way the Sister thanked me, they even called me to the administration, they were very . . . appreciative, because the father was ready to sue the hospital because of that. So I think that is a funny experience or something that I'll never forget in my nursing career.

Berth was guided by her ethical responsibility. Berth valued the detached leg and preserved it as a full body. The respect with which Berth treated the amputated leg was commendable. I wondered if Berth realized her ingenuity and discernment. I was called towards memories of last rites of the dead—washed or cleaned and preserved. Berth honored the leg thus illustrating hope for the boy. I lingered on this act by Berth. I traveled alongside with her. I hung onto Berth's story of attending to the leg as a hopeful thread that had become visible in her life. This powerful story reminded me that there was hope for what might seem hopeless.

**Marriage and family.** Most life stories are not linear, although sometimes I expect them to be. Berth began to share more of her personal history. She told me that after her midwifery practice, she got married and had children. I could see so many places in Berth's life where she had a path, and marriage was one of them. When she talked about nursing, she always spoke with a clear tone and vigor, but when touching upon her marriage she spoke with passion.

I'm married, I have three children. One boy and two girls, they've been very supportive. The first boy is at university level 300 and the second one is a girl, she's in level 200, she is at a school in Legon. The first boy is at the UPS [University of Professional Studies] yeah . . . The former IPS [Institute of Professional Studies], he is there. And the last one is a girl, she is writing the BECE [basic education certificate examination], she will be going to the secondary school this year hopefully. They've been very supportive . . . In fact when I was even going for the interview [position for deputy director], my boy was the one who typed most of the things for me. Yeah the PowerPoint and all those things, he really helped me. Because at that time he was doing an attachment [internship] at the accident centre, and he had the chance to do most of the things and they've been very supportive. Yes very, very . . . He encouraged me to upgrade myself . . . He's very, very supportive.

There was another pause. I looked at the time as we had agreed to have a conversation for an

hour. I looked at the smile on Berth's face. I always would tell her when our time was up. Berth was easy to listen to. I thought about Berth's story of marriage and family. One of the things I know about marriage is the importance of building a relationship and learning how to share. Over time Berth had built a relationship with her family and the family began to work as team. All hands were on deck when Berth was preparing for the interview following the application for the position of a director.

I could see that Berth's context of hope and possibilities included her family. She described her family as supportive. I wondered how this kind of unwavering support affected her career and life in general. I lingered with the thought of how marriage can affect our lives— Berth always made me think about so many things. I too had been changed by marriage. Marriage changed me in many ways: I grew more generous than I used to be, more tolerant, sympathetic, empathetic, more interested in, and sensitive to other people's problems and needs. I learned lessons of patience and serenity. I was refined and solidified in my humanity but not as confident as before. I grew more cooperative, communal, and less authoritative.

Berth's children, one boy and two girls, were students. Berth confidently demonstrated how supportive her family had been to her. I wondered if this care was also a deep reflection on her nursing career and work. As Berth spoke about her family, I heard her speak of a team of individuals bound together by affection and harmony towards a life journey. I wondered what sustained this affection and what threatened it. I was called to pay attention to her contributions as an educated woman in society. I remembered the importance her parents placed on her when they sent her to a private preparatory school. Berth's family support made visible her work and hope. Our time was up. Berth had to go. I thanked her and said goodbye. We agreed to continue the conversation the following Tuesday.

**Berth's hopeful journey and HIV nursing.** I was back at Berth's office. Having learned some things about Berth, it was much easier to navigate her practices on the HIV landscape. Asked about what made her hopeful in HIV nursing, Berth intensely responded:

I am hopeful because there is treatment, we have treatment if the patients take their treatment . . . though is not curable . . . it prolongs their lives . . . And because we are educating the patients and they know how to live positively.

Berth's response echoed the importance of the availability of treatment which gave direct hope to the lives affected and to her. Treatment availability could not exaggerate Berth's concern. I noted it in her speech. I could hear the change in her tone. I heard her deep breath, saw tightening of her facial muscles. She spoke with seriousness.

I recalled anxiously thinking in the early days of the HIV epidemic that infected patients needed to pray for God's miracle. Clearly things have changed and I was delighted to be reminded that there was accessible treatment to prolong lives. Berth became much more hopeful with treatment discovery. Berth's hopefulness was also sustained as she saw medications prolong the lives of PLWH. Listening to Berth made me think about the longevity and quality of life for PLWH. I started to look for hope in situations where nurses could perform without much anxiety and despondency, where they had the confidence to continue in the face of a poor prognosis and treatment failures.

Another context of hope for Berth was the Models of Hope. She spoke about the Models of Hope as they used their lives as a source of encouragement to other HIV-positive patients. "They use their lives as an example though they are people living with HIV, they take good care of their lives [and] is a way of encouragement to our clients." The Models of Hope were a great source of encouragement for other PLWH to live hopeful lives. Berth reported that the Models of Hope took their medications, listened to counseling, and attended follow-up care.

[There are] Models of Hope here who use their lives as a source of encouragement to our clients. They use their lives as an example though they are people living with HIV but the way they take care of their lives- follow up care, medication, and counseling.

I had many questions about the Models of Hope: How did they deal with the emotional stress related to their diagnosis? How did they come to normalize their HIV status? How did they deal with the stigma? How can HIV be normalized to help reduce the stigma and therefore promote free living? I too wondered how differently each Model of Hope impacted the nurses at the Fevers Unit. Models of Hope came into contact with the nurses and their colleagues at weekly meetings. Some of them came from far away. They formed a community of hope and support. As Berth's hope motivators rose, her hope was also threatened by the upsurge of the infection rate.

Yes, the speed at which HIV is increasing is overwhelming, and some of them don't abide by education. Some of them go around having unprotected sex with other people and some of them do not live positive lives despite the education and some do not report to the clinic; they do not want us to know they are infected patients, so that makes [it] more threatening.

Berth lamented about the negative attitude of some PLWH who would not take precautions when engaging in sexual activities or inform their sexual partners about their HIV status. This threatened Berth's hope and it filled her with anxiety as some patients failed to listen to counseling. I recalled that in some of my early work, I went around the community with an AIDS volunteer team, campaigning against unprotected sex and explaining the major roots of infection. Yet I was not surprised that the infection was on the rise, as the Ghanaian culture had ingrained in people conspiracy theories about who carried the virus and the modes of transmission. As well, many people could not accept that carriers of the virus were not identifiable by their physical appearance. Berth's sympathy for her patients was affected by understanding their story and the grand narrative of HIV and AIDS. The belief that HIV had become a chronic disease was the patient's construction of reality. People could fully live their lives before the inevitable came. I wondered what type of education was needed to increase compliance to all aspects of treatment. How did Berth handle such threats? Berth often thought about the reasons for people to be non-compliant and she reasoned:

Some do not have people to support them financially so after taking the medication they fall [i.e. feel drowsy] . . . some of them do not take their drugs because they feel they don't have enough diet [food].

Berth acknowledged the challenges that PLWH faced but found that addressing the connection between poverty and HIV was beyond the nursing mandate. In my proposal, I wondered how nurses in Ghana experienced hope amidst poverty and limited resources. Poverty caused noncompliance and threatened hope, but according to Berth poverty was not the only factor that mattered. Disclosure of statuses by PLWH who were in relationships was another area of challenge. Berth explained:

Some infected people don't even tell their partners because of stigmatization. They feel threatened to tell their relations, and in the end, they end up infecting the relations. For

instance, if the husband is positive and refuses to tell the wife, he will more likely infect the wife as well as the relatives who are taking care of him. They don't want to break the news to the families . . . because of stigmatization.

Stigmatization was a threat to Berth's hope and it had been a key reason for negative behaviours shown in PLWH. I wondered if and how hope in HIV care could mitigate the impact of stigma. Berth asserted that to reduce the stigma, education was necessary. She declared: "That is why we are educating them, and the Models of Hope also are [doing their part]." She continued, "So I think stigmatization is going down because of the education that we are giving them. We counsel them." Stigma had always been part of HIV, and in spite of extensive educational activities targeting the stigma, it appeared the attitudes were not always positive or changing rapidly.

I lingered with the thoughts about stigma and wondered about how much culture affected the degree and the kind of stigma. I was called towards memories of seeing poverty as a major part of many PLWH's life. There is no doubt poverty adds to the burden to afford proper nutrition and medication. Poverty makes people more vulnerable to the effects of the illness as they are not able to provide for basic necessities of life. The more severe the symptoms or signs are, the greater the vulnerability to stigma. Hope can be a positive force however and understanding Berth's hope threats is important.

**Hope and education.** In this segment Berth recounted behaviours, attitudes, and activities that negatively affected her hope. Berth's hope was nested in the lives and activities of the PLWH. She recounted an incident she witnessed in the waiting room of the Fevers Unit.

Normally we have a waiting room [where patients are health-educated] when they

[patients] come for review in the clinic. When I see the nurses giving education and the responses, some of the questions that some of the patients throw at them, I think we are getting somewhere because I see that some of them understand it better, some even come out and tell the other colleagues . . . what positive living is. So I think I am more hopeful because the education . . . the education is going far.

Berth narrated that in earlier times, education was not impacting the attitudes of the public as expected, but with the passage of time the culture was changing and education had helped with the change. Hence the past, present, and future held different hopes for Berth. Health education is helping patients understand their condition. It helps PLWH gain knowledge and builds on it to increase their understanding. I believe the health education method, where nurses work *with* PLWH, is more practical to PLWH as it takes into account their experiences. Teaching as a top down didactical method appears unfavourable to PLWH as nurses hurriedly tell patients what to do. However, both Berth and I recognised that it may take more than health education or teaching to change behavior. By trying to live alongside PLWH, Berth was impressed by their demonstration of understanding of HIV concepts and prevention. Berth saw the efforts being made by PLWH about living their lives in hopeful ways. Meanwhile, Berth also talked about places where she felt a sense of losing hope.

In times of hope loss. Turning back to the personal history, Berth adored her family, liked her job, and had the privilege of being well educated. These places were hopeful in Berth's life. In the context of PLWH, Berth's hope was variable. Our conversation explored aspects of hope including the quality of hope. In the conversations with Berth I was reminded of hope in places, situations, and across time. Our conversations came to focus on the characteristics of PLWH that signified, at times, the loss of hope for Berth. On one occasion, as I listened to Berth, made eye contact, and saw her facial muscles tightening, she raised her voice suddenly as if choking on words, trying to tell me about her gloomy days. Then Berth became silent. A drop of a pin could be heard. I noticed the temperature was cold, but the room was stuffy. The windows allowed in fresh air but not enough. Berth broke the silence in a low tone voice:

The days that I am not hopeful are the days that you see defaulters being held to the place [clinic] in wheelchairs, sometimes in very devastating conditions. Sometimes I see them in a taxi. In fact, if I see them like that I lose hope.

I felt compassionate as I tried to imagine the scene Berth was describing. When Berth recounted PLWH who returned to clinic very ill, hope was gone. It played out in her body language. Her energy was diminishing. As I reflected silently on what Berth was saying, I felt my back hurt, my legs numb, and my throat dry. I felt tired. Narrative conversations can be demanding. My hope was sucked. I was living alongside in the relational space with Berth.

Berth was an experienced nurse and she had many insights to share with me. The quality of health of a PLWH was relative to Berth's hope. However, I did not know Berth would show me her hope loss. Berth's hope was comparative to the sea tide when PLWH were discharged home. I wondered about her joy when these patients returned home, reunited with their families, friends, and the community. I remembered Berth's narrative on the condition of the patient on their arrival, I could tell from her tone of voice how this had affected her hope. It was a depressed tone. I wondered in times of hope lost what brought hope to Berth.

I remembered the time when I worked at the Accident and Emergency Departments of the Korle-Bu Teaching Hospital and had observed a correlation between prognosis and baseline data. Through Berth's stories, I could see similarities between the HIV patient and emergency room patients. Every one of them needed sustaining hope as each most often arrived in a critical condition. There were factors that determined a good prognosis. The level of damage to organs and the capacity of the private reserve are key determinants of a good prognosis. HIV patients with CD4+counts of 200 or less are likely to deteriorate fast. HIV infection can be a depressing diagnosis. Berth's hope loss in such situations filled me with memories of my own losses of hope. In my field notes, I commented that hope was a variable thing. It could be compared to a continuum—moving back and forth. Berth recounted a situation of her loss of hope.

Recently there was a patient [admitted] here . . . I was here on Saturday, I was not supposed to come, but seeing the patient I really [desire] the patient will get well, but when I came back on Monday they said we've lost the patient. So in fact . . . my hope was lost.

My memory of hope loss in this way was during my nursing training. A patient in the surgical unit, diagnosed with bleeding problems, became very close to me in our patient-nurse relational space. The patient later passed on. I imagined how Berth felt about the experience. Berth lost hope. Although hope is lost in times of such experiences as death, it was not completely diminished. Berth continued:

Because I had hope, and even the children, anytime they come round I encourage them that their mother would be OK. So I was able to help the children. So when I came, and the patient was dead . . . I didn't lose my hope because I still had hope in God, so I just said OK may [be] the will of the living God.

The context of God was very important to Berth's hope inspiration and a place that shaped her in

profound ways. Perhaps it was her interactions with patients that drew her closer to the practical living of hope. Perhaps hope, like a breath, is silent until provoked. Berth touched on living the Christian life as a hopeful life.

The Bible even says when you are sad you should . . . pray, when you are happy you should sing praises. So sometimes I ask myself why? But who am I to question God . . . in any way, my hope is somehow affected.

The Christian life teaches living true to oneself. I remember a quote from John F. Kennedy "As we express our gratitude, we must never forget that the highest appreciation is not to utter words, but to live by them." Living hope is living by our words. Berth sometimes witnessed deaths that bring back her sad feelings. I thought of her statement "who am I to question God?" Berth indicated there were times when her hope fluctuated:

As for hope, I keep it, though sometimes it goes down . . . Patients affect my hope. We have a patient who was brought by the sister, and the patient was here for 2 weeks, nobody was visiting the patient . . . The day the patient died was the day the sister came.

So some of these things affect our hope in caring for the patients.

I fell silent as I listened to Berth and I wondered how words would carry me in our understanding of the experience of hope, yet I could not stop to ask, I could not stop to listen. Berth then shifted from the context of hope lost through patient's physical characteristics to material resources.

**Equipment lack as a hope sucker.** Often I heard about the lack of equipment in the hospitals in Ghana. For instance, I heard unit managers presenting on the shortage of their supplies during conferences, they always pointed out that inadequate supplies were some of their

challenges in their work. To go through this feeling cultivated less hope for Berth.

Sometimes you don't even have the things to use . . . like diapers and so forth. The hospital does not supply diapers. So they are supposed to buy them. And you know our patients with diarrhea and those things. If the patient doesn't have the things to make the care . . . I don't know how to put it. It makes the care difficult; it makes it difficult.

Of course, if I am caring for patients without the appropriate equipment, it will be difficult. Berth had practised for many years and knew about the impact a lack of equipment had on the quality of care. This thought took me back to those early days as a newly qualified staff nurse when patients brought in their own boxes of disposable gloves. Understanding this feeling and the experience of scarce resources was important. Berth too related to the lack of equipment undermining her hope. I wondered how Berth's experience with a lack of essential equipment shaped her ability to improvise in her practice. I remembered being told by one instructor to learn how to improvise. Yet improvising never seemed to solve the primary problem. I do not know what a hopeful nurse does in these circumstances. How did Berth sustain confidence and how did she sustain her hope practices? I do not remember if Berth talked about if she could work without hope and still feel safe. I listened to Berth in her office, learning about life in her office. I listened to Berth. I found myself alongside Berth as we travelled to hopeful places in her life, but we also wondered about Berth's hope threats.

**Revisiting hope threats.** I returned to Berth's office for our third conversation. Berth kept on talking as I kept on prompting and asking for clarification and detail. I was wondering and living alongside Berth. I recalled memories of her hope threats, reminding me of what she had said before.

I told you that as for my hope there is nothing taking it away ... but, I think ... negligence especially when relatives neglect the patient. Though my hope is low, my hope in getting the patient properly cared for is high. ... I told you that our policy is patient centered so if you come to work and the supplies are not there. The things that you are supposed to use for the patients are not there. It makes the work difficult; it makes the work difficult. Somebody is having diarrhea, and the person doesn't have diapers. You know the right thing to do. You have the hope that if this stuff were to be there, it would have prolonged the life of the patient but these things are not there, and especially when the patient is conscious, the patient will be thinking about all these things, and it can affect the patient negatively. And I also mentioned drugs. If you take drugs without food, it will affect you.

Berth's way of talking with such seriousness told me how important the problem was to her. At the core of every field of human endeavor are ideals. Those can be full resource support in an organization such as in Berth's case. However this ideal was not met in this instance. Berth reminded me of the lack of support for HIV care. The impact of a lack of resources on Berth's hope and patients' recovery could be significant. I paid attention to Berth's story. I felt lost. I wondered about her roles and challenges faced with budgeting and fund allocation. Poverty had always been significant.

Berth's style of advocating for both patients and nurses was a way to open the closet for the Ghanaian public to see the actual state of the Fevers Unit. I wondered if the authorities would hear Berth's voice and do something about the situation. I remembered my working days at the unit with the same hope threats that Berth experienced. The authorities would always say
we do not have enough. In the midst of inadequate supply of resources, Berth's hope suffered.

Hope for one another. I returned to Berth's office. I was learning about Berth's hope and myself. I thought, "Have I asked good questions in our conversations?" Berth, as usual, welcomed me warmly with the usual "how are you?" She asked, "Where are we?" Without a thought and a breath, I said, "hope experiences with people in your life." I asked Berth to tell me more about how her hope affected others in her life. Berth became more awake to how she intentionally offered her hope to others as she said: "I encouraged them [colleagues], I talked to them. And I make sure that the things they need for the work to take care of the patients are being given out." Berth became more attentive to the needs of her colleagues as a unit head, particularly towards those who she supervised and acknowledged how she ensured the equipment they needed to work with were provided. As a director and an administrator she had some authority. She was in a position that offered her power to influence hope in more practical ways as well as giving hope to her community of nurses. I remember Berth verbalizing her hopeful actions:

And once a while we motivate them, words of encouragement, or meet their needs because it is not easy taking care of HIV patients, knowing the sort of patients that you are offering care. So, sometimes I tried to allay, alleviate that anxiety that fears from them.

Hearing about encouraging her staff reminded me of students. I too encouraged my students. I listened to Berth; she straightened up in her chair. I became more and more attentive and wanted to hear more of how she too supplied resources to her staff. They needed it for their work. I wondered how Berth's hope was crushed by the experience of inadequate supplies to her staff. I

looked at her face. She was intense. I do not remember how she filled me with hope. Asked how she motivated her staff she said:

Oh! We have a lot of motivations, even encouraging somebody is a sort of motivation . . . being with them, talking to them is a kind of motivation . . . is not only finance . . . encouraging them even providing the things that they need to work [with]. You know, our patients are not allowed to pay anything. So generating funds [through tips] here is very difficult. So getting money . . . sometimes I come out from my pocket to [help] and

if somebody needs something [I] give it to them. I think it is a sort of motivation to them. I wanted to hear more about Berth's hopeful fostering experiences. Berth began in the midst of her hope. I remember her words: "It is a motivation to me." The motivation of her staff was, in fact, Berth's experience of hope. As a practice that was hopeful I wondered about the out-ofpocket kind of motivational acts. I could be judging, but my fear was how to sustain it. We moved on. Asked about when she first heard of hope, I teased out the plotline below.

**Hope-filled beginnings.** Berth, like many Ghanaians, grew up as a Christian. Christian nurses are greatly influenced by the Judeo-Christian perspective of hope. She said that in her early years of hope, she learned from the Bible. I remembered what she said about her hope beginnings:

I learned about hope in the Bible [in the book of] 1st Corinthian 11 . . . it says love, hope, and faith, and the greatest is love. So I learned of hope from the Bible . . . Hope is the substance of things not seen . . . evidence of things . . . not seen. Though I haven't seen it, I have the belief.

Berth as a Christian lived faith and hope simultaneously, and I do not remember Berth

differentiating between faith and hope. I wondered what the two meant to her. The Bible is a Christian Scripture that represents hope—one day the Messiah will come and end all pain and sin including all forms of suffering. I, too, shared Berth's core beliefs that all suffering will end and will be replaced by bliss and everlasting life. Berth lived with the biblical hope in her practice.

We have a waiting room there when they come we meet them; we talk to them, give them words of encouragement. We use the Bible; we have pastors here who preach to them every morning, and we encourage them with motivational words.

Berth's early life contact with the Bible seemed to have blossomed into love for the practice of its tenets. I wondered how Berth felt about patients who might not accept this. Was she frustrated? I read and listen to words of hope from the Holy Scriptures to gain strength, but for others this might not be the case. Berth also grew up in a Christian home full of hope that was evidenced by the place her mother was sent to deliver her. I also became more hopeful when I was baptized. The time when I became a Christian, it still is something that defines me today. The Christian life was the beginning of my hopeful awareness and the reliving and retelling of my stories of hope. I became a dreamer in my life; it connected with myself and taught me from within. God made me so. The place of beginning of Berth's hopefulness was the Bible. I travelled back to the moment she told me the Bible was where she learned about hope. I understand the Bible can be a source of renewal when hope is needed.

**Replenishing hope.** As I lingered with Berth's hope-filled beginnings, I pondered how the plotline of "replenishing hope" was connected to Berth's Christian faith. Thinking about my experiences and what felt very much like the "gas tank", I remembered what I always did to refill the tank. Berth, too, experienced hope deflation. Berth described the way her hope was sustained:

The grace of God . . . So it is the grace and favor of God that helps me maintain that hope. I have hope in God I trust in Him, and I know that He will carry our patients through. So I always tell them to rely on God sometimes I even tell there's nothing like HIV in the Bible so they should put their trust in God and confess the word of God for God created this world by the word of His mouth. So whatever you confess you get it. So I have been encouraging them with these motivational words.

As I made sense of Berth's hope refill and nourishment I also heard that HIV was not in the Bible. I remembered about pestilences in the Bible and I believed that HIV might fit into that description. I felt there was a connection between Berth's early hopeful experiences with the Bible and her nursing practices as I heard words like "confess the word of God." I sensed as a Christian, Berth shared in the faith and hope in desperate situations. For example, where patients arrived in the hospital almost dying, Berth's only hope was to wait upon God for a miracle. Berth was filled with hope with the word of God and this hope could unlock doors in the times of need and trouble. Hope in God impacted Berth's practice of nursing. Could it be one of the antidotes to life's stress or motivation to continue in the face of adversity and discouragement?

As we co-composed Berth's account I wanted to know more about places of hope in her life. I was interested in events or physical locations that connected to hope in Berth's life. One of the places of hope for Berth was her belief in God. She said: "Yea! I told you I have God; the Bible says that if you have God, you have everything" (Matthew, 19:26). What a powerful statement as it made visible Berth's foundation of hope! Berth continued:

As I said, hope is the evidence of things not seen, when you have hope in nursing a

patient, you are hoping that the patient will get well . . . There is a policy in Korle-Bu hospital that [the] care is patient-centered, so all our attention is geared towards the patient so when you care for the patient, you should have hope that at the end of treatment that the patient is going to get healed. The patient will be OK, the patient is not going to die. So that is the hope that I have.

Listening to Berth credit the Bible or Christianity epitomized a place of hope. It was the place from where Berth received inspiration to practice her nursing activities. Her hope, inspired by the Bible and for that matter God, directed her daily routine and decisions. Berth's response made me think about the connection I was making between hope and context. Hope did not always connect to physical places in our lives. It also connected to experiences, beliefs, and even policies. Hope then became an indispensable element in Berth's life.

Hope as an important element in Berth's work. As I thought about how Berth used hope in her life and to support her patients, I remembered my experiences with nursing work 17 years ago as I moved from clinician to instructor. My first day of reporting at the college I was filled with anxiety and fear. I do not remember if I had any hope. However, the Principal's warm reception gave me hope and I stayed in that college for 4 years. Yet, I cannot tell how hope supported me, but it did. Berth emphasised the importance of hope in her work:

You can't take hope out of HIV nursing care because any time you are doing something or implement something you should . . . you have to get the result. So I apply something because I want to achieve results so without hope you can't achieve result, you just can't implement it without producing the results.

As I reflected on the importance of hope in Berth's life and how her hopes were resonant

with mine, I was called to memories of hope in HIV nursing work. I wondered how Berth's hope had supported her in ways that had sustained her energy, enhanced her commitment, and inspired her to find the sense of satisfaction in her being and her work. Berth lamented that "you can't take hope out of HIV nursing." In other words Berth could not work without having hope in what she was doing. Hope was essential in Berth's work. I remember in the Fever Unit lives were seen departing in many painful ways. And without hope, I could not imagine how Berth's energy would be sustained.

Hope yielded desired results in Berth's work. As I lingered with Berth's hope thoughts, I remembered Kojo. I was carried back to how I called for hope during the time to sustain my courage and optimism. Courage was a feeling to continue in spite of the current situation. Berth's story reminded me of HIV nurses and families who were at risk without hope. Like courage, optimism was that constant feeling and thought of positive force towards life. Berth supported that idea that hope was imperative in nursing care.

As for HIV care you have to be always hopeful. No matter how the situation is. Like nurses we are always hopeful you do your best so hope is very important . . . aspire for the best. Whatever you say it will sometimes, it comes to pass, so you should always be hopeful . . . you do your best.

Hope at the workplace for many nurses meant connecting hope with patients. The patients' experiences with hope were different from the nurses. For Berth, it is significant to add that the nursing mandate included either supporting life to recovery or peaceful death. She also showed that the nurses had tremendous hope power that was connected to patients' hope. The greater the hope of the nurses the greater the chance that the patients' hope would be sustained. In the

situation of pain, the nurse's touch can mean a lot to the sufferer. The loss of hope that results from patients' behavior and scarce resources creates room for improvising and generating other ways to support nurses' hope. Berth reminded me that the nurse who speaks with hope speaks with power.

At the same time Berth's words reminded me of the stigma. Perhaps if nurses were always hopeful, they would speak against discriminative behaviours. Hope always connected me with my best behaviours. I agreed with Berth that hope empowers what we say, when we say it with hope. In writing Berth's account, I wondered and traveled to many places in my thoughts and memories.

## Joy's Narrative Account

I met Joy on my third visit to the Fevers Unit but I already knew about her as a potential participant. The Director of the unit had told me about her during my first visit and I had left an information letter for her. It was a pleasure to finally meet Joy who had an appearance of freshness and vigour. She too was both mature and pleasant. I arrived in the morning at the unit, while the day already grew warmer as the sun rose higher. I was glad to be enjoying the warm environment in Accra. The location of the Fevers Unit in the south of the historic Korle-Bu Teaching Hospital impacted my positive experience in a significant way. The usual generous reception at the Director's office and the beautiful day set me in a good frame of mind as I met Joy.

As I waited in the counselling room for Joy, I knew she was running up with the morning exchange shift report. Joy worked the night shift. I heard a knock at the door and said, "Come in." As she entered, she said, "Good morning sir." As she took her chair, I welcomed her by

saying, "Hello Joy." I continued by saying, "I heard about you last time I was here and left an information letter for you to read. Do you have any questions?" She responded, "The question I want to ask is, you talked about confidentiality [in the information sheet]. Are there going to be video tapes of me?" "No," I responded, "only voice recording will be done." Once I confirmed that I would not be videotaping her, she agreed to participate in the research. In a clear voice I expressed my gratitude: "Thank you for your acceptance to participate in my research." I went over the consent form with her to ensure nothing was left out. We agreed on everything including the understanding of the uncertainty of our research journey and that we would continuously negotiate the focus of our conversations. I turned on the recorder and said, "Today is the 18th of June 2015, the time is 9:00 a.m."

I had already met other participants in this room so I was comfortable and confident in the environment, which was helpful. I wanted to explore Joy's life and was anxious to hear about her experiences of hope. It was as if I jumped in with both feet, rather than focusing on a slower start. I asked her to tell me about her hope experiences in her life and work. Joy appeared confident as she sat upright with her head held high. I noticed her dark complexion and her smart uniform. After a brief silence, Joy started to talk.

I came here [Fevers Unit] in 2012. Formally [previously], I was at the [Korle-Bu] Polyclinic so getting to 5 years. I can say formally when there was no ARVs [antiretroviral drugs] we were losing most of our patients and then I will say there was no hope but now with the introduction of the HIV drugs that is, anti-retroviral therapy our patients can live, depending on their adherence to the medication and then also being on a good diet by taking care of their nutrition and then adhering to what we tell them. Joy was transferred to the Fevers Unit from the Korle Polyclinic and had been at the unit for almost 5 years now. As I reflected on what Joy said about ARVs, a feeling of hope suddenly punched me in the chest. I should be thinking about lives saved through the ARVs when patients complied. Joy knew that compliance to medication promoted recovery. When PLWH refused to comply with medication, her hope was crushed. She also spoke in similar ways about the hope she felt when patients took care of their nutrition and follow-up care. However, Joy recognised that some patients failed to do these things, and she felt the need to remind them to take their treatment regime. She explained the benefit of compliance with ARVs regime.

The reason why I am saying that is we have patients who before we put them on the medication we have to do . . . counselling. We want the patient to be compliant but at times we have difficult patients. When they go home they don't take their medication but with the experience I have had here, with patients who take their medication, I have never seen them on admission. We have patients who were diagnosed in early 2000s that the medications were started with them, since I came I have never seen them on admission before. And then when you see them it doesn't show on them. So I think with the introduction of the ARVs there is hope. We also feel happy because formally we have to do everything for the patients when they become so weak. We have to do bed bath, everything we have to do for the patient but now because of the ARVs most of them are able to come out of their rooms and do things on their own except those who don't come to us early. Normally some of them come in the third and fourth stages.

Joy was knowledgeable in the connection between non-compliance and prognosis of HIV infection. Her knowledge in this regard wakened her to the importance of educating PLWH

about critical interventions such as medication compliance. Joy also expressed her efforts towards educating PLWH on personal hygiene.

Joy continued to express her hopeful experiences. What I appreciated most was the cordiality with Joy. At another point, she emphasised nutrition for PLWH as a hopeful experience.

Yes, apart from taking the medication we educate the patient on the nutrition that is a balanced diet because if you take your medication and you do not eat well still you will be losing weight there you know. When [we] talk of a balanced diet it comprises of a lot of components that are carbohydrate, vitamin, minerals and all those things. And a body needs that every day so the patient who is already immune compromised, so the patient shouldn't lack these things so we tell them to eat well and take their medication and they also have to maintain good personal hygiene and environmental cleanness. The reason why we tell them is that because they are already immune compromised and we don't want them to pick up other infections like typhoid, cholera, those that come from food and improper hygiene.

Joy recognized the importance of nutrition in the life of an immune-compromised PLWH. She experienced hope when PLWH followed dietary instructions. I remembered the food served from the hospital kitchen; it was the same kind for every in-patient. It was always warm. The staff who served the food were friendly. The rhetoric around HIV nutrition was also about affordability as many PLWH were poor and had difficulty maintaining adequate nutrition. While looking at Joy's experiences, I also noted resonant experiences shared by other participants. I learned how hope was connected to interventions such as ARVs and nutrition. We had a long

day as Joy had to go home and rest since she had worked the night before. We said goodbye.

**Early education and hope.** Joy's early life experiences such as her general education influenced her pre-nursing training. Joy's preparation commenced with basic education that included primary and secondary education.

I started my nursery, primary and junior high school [in Accra]. And then after completing junior high school I proceeded . . . for my senior secondary school education. There I read science, I did physics, chemistry and biology. After sitting for the senior high examination, I came out with flying colours [I applied for nursing and] I came to the [school] at Korle Bu. I went for a 3-year course.

Joy experienced schooling in private education settings from nursery school to junior secondary school levels before she moved into a government school. In my view I saw this as her parents' expression of hope for their daughter to have a quality education. These early schooling experiences resulted in her admission into nursing training to become a senior registered nurse. Although Joy, at a very young age, faced challenges when her father left the family, she was able to continue her education into nursing training.

I remember when I was a kid our father left us. We were four and then we were lucky my mother was working at the bank but for her to be alone was difficult. But God being so good I secured a scholarship to senior secondary school. But during senior secondary school I faced a lot of challenges. There was a time I was involved in a road traffic accident. I didn't sustain a lot of injuries [following the accident] but had frequent nightmares. Anytime I slept I was shouting in my sleep. I was having nightmares. I was very scared to go for my results . . . because I was afraid that something like that [accident] will happen to me, so my sister went for my results. Even during my final exams on that day I was very sick. That was a few weeks after I had the accident. But I was feeling very weak, that day was unlucky for me I was having abdominal discomfort. I was passing loose stools. I was in the exam but would go and come back . . . and God being so good I passed my exams and I came into [nurse training].

Joy gave credit to God for sustaining her by helping her win a scholarship, surviving the traffic accident, and passing her exams. She graduated from nursing training. Joy explained that

When I completed senior secondary school I wanted to go and do medicine but my mother said she couldn't afford it. So I had to go to nursing training as students have half scholarships, called allowances. So that one will help you, but I don't regret being a nurse too. It has helped me a lot. If you are hopeful or you have faith you can go to the height that you can be.

Joy said that she was "a Christian and I am a Presbyterian. And they say without hope you can't please God." Joy disliked being discouraged and did not want people to tell her that things were not possible.

So I don't want people who when you want to do something they tell you it can't be possible. I want people who would say it would be possible. Because that's what God likes. He wants you to believe in Him because if you don't believe in Him how can He trust you.

My experience with the Christian faith are similar to Joy's. I shared the scriptures with others as well as prayed with them. I wondered how Joy used others' faith to promote her practices. When Joy expressed her hope she was very confident and calm. **Marriage and children.** When I met Joy the second time, she spoke of her initial place of work and told stories about her life. I learned she was a wife and a mother of five children. She recounted a story of her first pregnancy.

After a few months of my marriage I got pregnant. I gave birth to my first child. But after that first child it was difficult for me to conceive again. When I went to the hospital they told me that there was nothing wrong with me. My husband too was told that there was nothing wrong with him. So I said OK then I will wait upon the Lord His time is the best, I got pregnant again, I had a miscarriage, I went on admission I passed through that and another one came lucky for it was twins. And so I was happy, so years passed but what I thought was that after the twins it will be the same I was not careful with my ... so by the time I realised I was pregnant again. The children were not even 1½ years when I was pregnant again. So I had to go for family planning. I told God to stop because now I am OK with the children. So I have seen what God can do it if you trust in Him. He can do it and I am hoping He will take me higher in my nursing field. May be give me a position in my nursing field and blessing to others later in life.

Joy continued to live with her family. She spoke of her family in this way.

The first born is 11 years, he's a boy. And then the second, they are twins . . . boy and a girl, they are 5 years plus, and then the third . . . and then the third is also a boy, he is 3 years plus. And then the last is a girl . . . she's 1 year 4 months.

Joy had a large family and was happy with them, particularly with how they related to her at family times.

My kids, do you know what I love about them? Like when they get 1 year they don't want me to put food in their mouths, they want me to serve them. I don't always because . . . there are other siblings on the dining table. So the 1 year 4 months when she sees that I'm sharing the food, then she will start wriggling in the chair and then she be saying],

"Ma, ma, ma". I'm happy, so they also make me happy.

Joy interacted happily with her children at meal times. I am called to memories of my childhood when we gathered around the small dining table. Each child was given a piece of fish placed in a bowl at the corner of the dining table. Several hands went into the bowl at the same time, occasionally collisions occurred. The food might not be enough to fill every belly but everyone was happy. There would be another meal. I was filled with longing as I reflected on the scene Joy described. As Joy talked about her family and her experiences of having children, it was clear that she believed strongly in God and that God helped and guided her.

The nursing journey. At another point in our conversation Joy further described her nursing journey. Joy wanted to go to a medical school but her mother could not afford the fees, so Joy opted for nursing school. I remembered that this medical school rhetoric was common among nursing students. I wondered how Joy worked through her desire to be in medical school. Joy attended the Korle-Bu Nurses' Training College and successfully completed her training within 3 years, the minimum duration.

But after completion of Nurses Training College at Korle Bu, we went for a top up course at the University of Ghana. The Nurses Training, it was from 2000 to 2003 . . . from there we did a top up course at the University of Ghana . . . to get a diploma certificate. So currently I'm a diploma holder—after the University of Ghana, the top up, I applied for employment at Korle Bu Teaching Hospital where I was then employed, after going through the necessary requirements and then the interview. When I was employed I started work at Korle Bu Polyclinic. I worked there for 7 years; that was from 2004 to 2012 July, when I was reposted to Fevers Unit, where I'm currently working.

Joy told her story of finishing nursing school through nursing college as a story of unspoken determination and hope. I wondered if it was the accomplishment that filled her with hope or the opportunity to save lives. Starting her nursing career in a place where all kinds of patients were treated, including PLWH, provided Joy an opportunity to experience hope in different ways.

At the Polyclinic we nursed all kinds of cases, when they [patients] come [for assessment] they [are] referred according to the specialty, if it's a gynae[cological] case we refer to gynae, if it's a medical case we refer to medical, if it's this place [where we sitting now-Fevers], it was referred to Fevers Unit. But when I was there I didn't know that they always come too late or maybe I will say I thought when you get HIV that is the end of you.

At the Korle-Bu Polyclinic patients were treated for general illnesses and then referred to specialized clinics such as the Fevers Unit. Joy's working experience at the Fevers Unit deepened her understanding of hope for patients who were given an HIV and/or AIDS diagnosis.

But what I want to say is if you are not here, if you are not working in this Unit [Fevers] and then you are working in a different department, they ask you, "do you have hope for HIV patients?" You will say no.

Joy believed many nurses had no idea what hope for PLWH might mean. I remembered

our earlier conversations. Joy's experiences of working on the Fevers Unit offered a broader view of HIV management and recovery. Because poverty was very conspicuous, Joy experienced a loss of her hope with the lack of power of affordability of essential treatment.

I remember when I was in the Polyclinic when I was recent, like first employed, like when you come in. At times when you nurse patients who . . . don't have money, yet you are being compelled to help them. I remember [sickle cell disease patients]. They used to come on admissions very often. So there was this [person with sickle cell disease], I didn't even know her but . . . she came with severe anemia and they have to transfuse her. The mother didn't have money [for the blood] so I told the doctor that we didn't have enough for me to—at that time the doctor was at the clinic, the doctor was very good, so the doctor added up and then I went to pay at the blood bank. And the girl who was transfused, they got better. So later the mom saw me in their area, she didn't know I was staying in the same area. She came with the family and thanked me and I told her "all thanks belong to God".

Joy showed a generous behaviour when she organized the money for the transfusion. She made efforts to secure the blood for the transfusion. Hearing Joy tell of this experience strengthened my hope. Poverty still upset Joy, as it limited access to life saving products, such as blood. This made Joy more susceptible to hope loss. Providentially, the physician helped by paying out-of-pocket and thus contributed to Joy's hope.

The Korle-Bu Polyclinic was a place filled with many stories of hope. As well, it was a primary health care facility that admitted and transferred or referred patients beyond their management to other facilities including to the Korle-Bu Teaching Hospital. Working with the Polyclinic after the completion of her nursing training provided Joy with a different hope experience than the Fevers Unit. Joy believed that the responses to the question of hope would be different for different work settings.

I don't think most nurses are going to do well in answering this question [hope experiences] because when you come here [Fevers Unit] and then you nurse and then you see how the ARVs are doing in their [PLWH] lives, you know that there is hope for them, with the introduction of the ARVs.

Working at the Fevers Unit helped Joy to understand more about her experiences of hope. In the Polyclinic, her experiences working with PLWH impacted her hope negatively, but in the Fevers Unit Joy said she experienced hope because she saw the positive progression of patients through the help of ARVs. Considering Joy's transition from the Polyclinic to the Fevers Unit, I saw that she began to experience a restoration of her hope.

**Faith inspires hope.** Joy experienced inspirational hope from her Christian faith. Faith dictated how Joy should live her life. She put it this way:

When I came to nurses' training college, I was also part of the Nurses Christian Fellowship. During that time I was their secretary. So I've applied hope or I've been with Christ—like Christ in you is the hope of glory. So I trust and I apply. So everything that I do, I don't leave hope, I don't put my faith away.

Joy shared a belief in God and made visible how that experience was part of her ordinary and everyday practice. I was called to memories of hope in my Christian faith. It was a struggle for me to think without logical reasoning, yet neither life nor hope was always equated to logic. In her nursing training, Joy was the secretary of the Scripture Union where students who shared the Christian faith came together to study the scripture and to pray. Joy referred to God as her hope in situations perceived by others as very difficult or hopeless. The Christian religion had shaped a strong relationship between Joy's values and her nursing work. Joy knew that the Christian religion had been seen as detrimental to HIV prevention, as the use of condoms was denied. This narrative was very significant as the foundation of condom rejection among Christians was based on ethical values, yet condoms could prevent the most common route of HIV infection in Ghana. Joy and I did not engage in further conversations about this topic, but it was something that I continued to think with. Our conversations returned to her nursing work.

**Interventions and compliance.** One of the parameters of hopeful experiences for Joy was her connection of hope with compliances to medications by PLWH. Joy had much to say about the attitudes of PLWH towards medication adherence or when there was a shortage of ARVs. Joy spoke of her experiences when patients did not adhere to antiretroviral medications:

When that happens, we, the workers here, become very sad . . . when the patient misses one medication even for a few days it affects them . . . what will threaten my hope is when there is a shortage of antiretroviral [medications].

With the onset of antiretroviral medications, Joy also noted:

We also feel happy because formerly we had to do everything for the patients when they became so weak. We have to do bed bath, everything we have to do for the patient but now because of the ARVs [medications] most of them are able to come out of their rooms and do things on their own, except those who don't come to us early.

The availability of medications and PLWH's compliance supported Joy's hope. Hope was a positive force and it was called forth and reinforced in times of a patient's well-being. Joy

experienced a significant loss of hope when PLWHs were dying from their illness. During our conversation, I wondered if Joy was aware of her own hope, or if she became aware of the significance of this when she was confronted by sadness or discouragement.

Joy also pointed out that health education was an important aspect of her practice, which was also linked to hope. I was struck by this source of hope. I know that one of my happy moments in life is teaching. Joy told about her hope:

Yes, apart from taking the medication we educate the patient on the nutrition - that is a balanced diet, because if you take your medication and you do not eat well you will still be losing weight, there you know that when we talk of a balance diet it comprises a lot of components that is carbohydrate, vitamin, minerals and those and all things a body needs. . . . the patient is already immune compromised so the patient shouldn't lack these things so we tell them to eat well and take their medication and they also have to maintain good personal hygiene and environmental cleanness. The reason why we tell them is that because they are already immune compromised and we don't want them to pick other infections like typhoid, cholera those comes from food and improper hygiene.

While health education and compliance to medication were significant elements in Joy's practice, she also recognised larger structural barriers.

**Shortage of ARVs.** I understood that the anxiety around ARV shortages confounded treatment choices and impacted Joy's hope. While HIV medication and family support were necessities for the survival of PLWH, they were also connected to Joy's hope. Joy expressed her emotion about medication shortages and their significant impact on patient recovery.

I... say with the shortage of the ARV [medications]... There should not be a shortage.

There should always be adequate supply of the ARV [medications] . . . And most at times what threatens my hope is when I nurse a patient, and I know my patient is recovering and then all of sudden the patient dies. Some of us when we lose some of our patients we

At the time of this research, the administration of ARV medications in HIV care was the most effective treatment in reducing the viral load and promoting CD4+ counts in the acute stages of the disease. It was most concerning when the medication was not accessible to patients, either because of a shortage of supplies or because of cost. As Joy pointed out, it was particularly difficult when patients were doing well and deteriorated only because of a lack of access to medications. Joy's response to such an experience led to less hope for the patient and deflated her hope.

become very sad because we know the patient is doing very well, and then [dies].

**Family support.** Family support was critical to the well-being of PLWH. Family members were needed to provide many aspects of support. At the same time, Joy was anxious about the risk that spouses and family members of PLWH could also become infected.

We also work at the counselling side, when the patient is being referred here for the first time, normally when the patient is married we have to ask for the other partner. And some of them are not willing to open up. So what worries me is the other partner. The [positive] person will give it willingly to the other one without him/her knowing anything about it. And some too, they cooperate with us and they will tell us that they will bring the partner for us to screen. And then we have to go ahead and do it for the children. The level of complexity in dealing with the families of PLWH was daunting.

There have been instances that when the couples come, . . . we have one to be positive

and the other one negative, but with that one I am looking at the future [when one dies], . .. who is going to care for children, usually you don't have reliable family members to look after the children, if there are children there. And at times too you have children who are positive. The problem we have is if the parents leave them, the family members ... don't give their best to them, because we have instances that we admitted adolescents with the disease and ... when the parents are dead you can see from the relations that

they are not willing to take responsibility so I don't know what they do for the children. When and where family support was available to PLWH it strengthened Joy's hope. But the family sometimes failed to provide support when it was most needed. This was particularly complex when children were involved. Joy narrated a story to show how a lack of family upset her hope.

You can imagine yourself being in the shoes of that patient. I think 2 weeks ago we admitted a child. She came with the father. When she came with the father ... [the father] did not allow the one who was making the referral to write the child was HIV positive. They wrote only chicken pox that was the one that was obvious. So later when we looked at the child we saw that comparing her age she should be older than the way she was looking. So we screened and when we screened she was positive. And the father said I told them not to write it. So we said that it is OK. We found it. ... We waited for the father, the father didn't turn up. He sent someone to come and tell us that he is feeling dizzy. He didn't turn up. So we went ahead and then we nurse ... we started seeing the girl ... she was on admission. The next day I was on morning shift when I came. I was there when the father sent a certain lady with a big bag that these are

the child's belongings. So we told the lady we wanted to see the father. So we asked one of our staff to go with her. So it took them about one hour. They were not coming back so I think the lady wants to run away but the worker was so fast that she grabbed her and she asked one of the security men to bring her. So they brought the lady. We called the man, the man didn't come. When the child came she could not open the eyes but when we started the medication she opened her eyes and the rash was going down. So the doctor said she doesn't want to admit a child that has no relations. She is getting better, she is not on any IV medication. So we can take the child home. So the lady should take her home. She said she is the step mother. So we even told her that we taking her to the police station and we threatened her if anything happens to the child she will be held responsible. So we discharged and they came for [review] on Monday, the discharge was on Saturday. But I don't know what will happen at home.

Thinking about the statement that the "child that has no relations", within the context of HIV meant also understanding the institutional context of family support, as well as the economic and sociopolitical context of many families. Joy pointed out that the father was hiding, probably because of shame, poverty, and discrimination associated with HIV. Even though Joy understood the larger social context, the father's attitude was still very negligent. This encounter and worry for the child impacted Joy's hope and created anxiety around her as she wondered what would happen to the child. Through the process of admission it was visible that the child's family was not caring enough, and was possibly impacted by issues of shame and poverty. As Joy was talking, I was thinking just how quickly stigma can rip family structures to pieces and leave individuals who are infected to stand alone. Listening to Joy tell this story, I felt this

experience to be very disheartening and hope sucking. As I was thinking about the story, I too wondered how Joy responded to such difficult situations. What supported Joy's hope? What kept her moving on with her work?

**Influential factors of hope.** According to Joy her spouse was comfortable with her working with PLWH. This spousal affirmation of support strengthened Joy's hope. Joy also identified that no one at her work place threatened her hope.

I will say personally my husband doesn't have a problem with me working here [Fevers Unit]. As for the work place I don't have anyone who threatens my hope. What I don't like is when I received a patient . . . I will give the patient to other colleagues to do the counselling because of the relationship [as] the patient won't open up.

In some cases, Joy received patients who were known to her in the community. When that happened she referred the patients to colleagues, as those patients found it more difficult to open up to people they knew. Joy found it distressing to engage with patients she knew from the community who found it hard to open up to her. This conversation made me wonder, how do patients come to trust Joy to the extent that they share some of their private stories? Joy described her challenge in such circumstances.

Some [patients] too, there will be resistance on my side [pertaining to counselling]. I will be doing my work but is not everything that I will be looking at because patients have [not] opened up the facts about the condition, everything. So there have been instances where you know someone who comes and because the person knows you, after the first visit the person will not come again because the person knows you. But if they will not come back again because of my presence we have other centres that I can direct the person to go or the person may not be comfortable seeing you at the clinic because you are staying in the same area with the person.

Joy expressed how difficult it was for her to counsel someone with HIV that she knew personally. She felt uneasy about the relationship. Perhaps this feeling of uneasiness was deeply impacted by the feeling of shame associated with HIV. Many PLWH prefer to keep their stories private. In my experience they avoid everyone knowing their statuses including community members who happen to be healthcare providers. Joy illustrated how nurses built capacity to respond to such situations: "Like for our work, we have been trained that you are not supposed to disclose someone's diagnosis to a third party so we don't do it."

Joy's remark was important, as many times community members who wanted to know about others' health conditions came to ask the nurse. At times this put nurses in difficult positions, with competing professional and personal loyalties.

Even someone from the neighbourhood will come and ask you. I know you work at this place and I heard that this person has this and that, so when they come and ask you, you also have to be tactful. You don't have to disclose. . . . But as I keep on nursing them I have gained experience and even if I have a nearest relation who has it I will do my possible best to help without breaching confidentiality.

Joy illustrated the difficulty in disclosing the HIV status of others through the use of a metaphor. She said a surgeon would not operate on his own child but would step aside for another surgeon to operate in order to avoid an emotional reaction. Joy compared this to her experience reassigning PLWH who she personally knows to others. In such instances Joy preferred a colleague do the pre-counselling disclosure. I wondered if this difficult conversation of disclosure had to do with stigma or just discomfort. I wondered how Joy experienced hope as she carried out her ethical responsibilities and care practices.

Ethical values and feelings of shame. Talking about building relationships with patients who were known to Joy reflected a stressful experience for Joy. I remember the difficulty I faced with disclosure to Kojo's family about his diagnosis. Often shame prevents newly diagnosed PLWH from seeking early treatment until their conditions force them to come. Joy shared with me her experience with some people who reported their status late and how complex the repercussions around disclosure were.

Normally when they come, they are ambulant as they are not critically ill, they [the patients] walk in. You will ask [the patient] is this the first time you have been diagnosed? Some of them they did the HIV test years back and they were in denial so they went home, put the referral somewhere. So they have been in the house and they realised that they are still getting sick very often. And so they decided to come. So the reason why we ask is we want to know the stage that the person is . . . then you ask the person for sex partners. Some of them, they won't open up but we need [those answers] because we want to help everybody. You want me to help you so I also want to help the one that will come with you . . . We want to help everybody. So some of them with their spouses some of them will say I will never bring my wife or my husband because I don't know what will happen in the house. I don't want any divorce . . . Maybe when she tells the other partner when we do the test and the other person is negative they go and divorce but we tell them that is not the best solution.

In talking about the kind of patients who report to the Fevers Unit, Joy described those who were

ambulant. She used a simple assessment tool to find out what was happening in the lives and families of PLWH. The next level of questions opened into admissions into the hospital so as to have baseline data and some insight into the patient's history. This exploration strengthened Joy's hope if responses were favourably and few or no hospital admissions had occurred that indicated complications from being HIV positive. Further to the history was sexual partners, an area PLWH very often feel uncomfortable to disclose. Joy strongly believed that the sexual partner also deserved care. Joy talked about how her hope was impacted if PLWH refused to disclose their partners. The repercussion of disclosure of HIV illness made it even difficult for Joy to maintain hope.

A hopeful day. One day, several months into our conversations, I returned to the Fevers Unit. The day was a non-clinic day. Joy was working in the morning and so we met in the afternoon. We had a follow up conversation to something we talked about on our first day. In trying to write about Joy's experiences of hope, Joy gave me an example of one of her hopeful days.

When I am at the outpatient department . . . when I pick the folder I will look at the first visit, when I look at them, normally if the patient was diagnosed in 2000 or may be 2001, while I am looking through the folder I will ask, have you been admitted before? If the person says no, then I will feel very happy because when I see such patients they are

ready to comply, they are ready to live with the disease, like they are not depressed. Joy saw the baseline report of the PLWH as a significant piece of PLWH health state. She used the number of times PLWH had been admitted since their initial diagnosis as a signal of compliance. Joy saw PLWH who had zero admissions as having overcome the denial and that they were moving on with their lives, which gaive Joy hope. Another hopeful characteristic of the PLWH who are rarely or never admitted after their diagnosis, was their coping mechanism with the illness, as they were not depressed. Joy also made sense of hope through counselling PLWH. She used the counselling strategy as a way of fostering hope. She continued,

But you see certain patients, we've always been doing counselling with them, they will say this sickness that I have got, there is no hope for me. I will say because of the ARV [medications] most of our patients they have hope now. They are living a normal life. When you come on clinic day and you see the number of patients that come it doesn't show on them. And then normally on the wards most of our patients we nurse them and they get better and they go home. We also feel very happy. However when we lose them we get very sad.

Joy pointed out that the PLWH who got discouraged from their illness were counselled and reminded that medications were available and were working effectively. This counselling, coupled with the nursing care made the patients better. In these moments Joy's hope was high. At other times the only hope for Joy was her sense of a strong community of caring nurses who worked with PLWH who were dying, patients who often arrived late to the Fevers Unit and their condition could not warrant recovery.

Well at times we know that the mortality rate here is very high and the mortality rate depends on the stage the patients come in [with] . . . we have patients who don't come to us early . . . some are being referred from other hospitals. They come in an unconscious stage, some of them come critically ill. They are already in the fourth stage, so when they come we are not able to do that much to help them so we lose them that is when I

get very sad.

Joy knew that the late arrival to the Fevers Unit was an indication of a problem. In the Ghanaian sociological context of illness, every illness was assumed to have causal effect from a spiritual dimension if recovery was slower than expected. Hence, many patients would first consult with spiritual leaders before coming to the medical centre. In such cases, some PLWH might have lost significant time to access western medical care, and it might be too late to provide treatment that would save their lives. Joy's hope was challenged when patients failed to report early or when they did not adhere to follow up care. However, in the face of alternative treatments or traditional medicine, I wondered if all PLWH would accept conventional treatment as the first choice, in the way Joy did. Joy's thinking might show that she was assuming that western medicine was the golden standard of care. In my thinking, western hegemony of illness intervention had shaped how Joy experienced hope. I remembered reading Foucault (1973) and his view about the medical system. The hospital was portrayed as a place where all cures reside, saving bodies, not souls. The clergies who used faith and hope were discredited. Hence hope was placed in doctors and nurses who mainly dealt with the physical impact of an illness. I felt the complexity of late reporting. It looked from the surface as an attitude of patients but after a closer look, I believe poverty and stigma in addition to the intrapersonal beliefs all played a part.

**Impacts of hope.** Joy saw herself as instilling hope in PLWH, particularly as she saw them recovering. At the same time Joy experienced hope too. Joy described how hope impacted her at work:

Normally when you are the first person [nurse] that meets a referred patient and you are very nice, anytime the patient comes back to the clinic the patient wants to see you. So you tell the patient that my colleagues here are also as good as me. But what I can say is that all of us are very good. We don't shun our patients so they feel free to come to us. Normally when they come for the first time, when you see them, you feel very scared but as time goes on and you keep on working and nursing you see them recovering. You get some hope and then you also start feeling happy.

Joy recognised how critical the first contact with patients was and she saw this as a place where a trusting relationship was established. It was in those beginnings that Joy also already began to story hope. I think it was particularly important that Joy drew a connection between hope and happiness. Later on in our conversations, Joy talked about how her initial fear of working at the Fevers Unit was gone.

First, when I came here, I said, this place, I can't work for long, but now I don't want to go out of this place. I can work even if they retain me here until I go on pension . . . I will be a source of happiness to a lot of people.

Hope threats and personal faith. Joy was a staunch Christian and believed that experiences of hope threats in her life and work depended on how one assessed the situation. For Joy it was significant how one reacted to the challenges one encountered in life.

Like what happens to someone and he will be depressed for days. He will not eat. It will happen to someone, and though it will be worrying the person, the person will go on normally in normal life thinking that there is hope. God is there for them. So it depends on our attitude, how we approach the problems when they come.

Joy pointed out that hope threats might not be the same for everyone. Over time, I could see that for Joy, her intrapersonal hope was so strong that hope threats could not make her hopeless. Joy

shared the notion that hope was important in life and work, as hope supported life and gave vigour to it. Joy described her view on hope as,

I would say in life hope is very important. I will say that if you don't have hope you can't go on in life. It is true you have to have hope. You have to trust that what I am doing is going to get well with me. When you do that you can move on and God too will help you.

Having hope within the context of HIV for Joy meant having hope for life. Joy's experience with hope drew attention to the living of hope in working with PLWH. She identified times when she felt hopeful because a patient recovered. She automatically developed hopeful feelings when patients recovered. At the same time Joy became part of the hope that shaped the recovery of PLWH.

## Jude's Narrative Account

**Meeting with Jude.** In narrative inquiry, the early efforts in inviting participants to join a study opens the door to narrative conversations. It is often here that researchers first meet with potential participants and begin to share experiences. I met Jude on my first visit, June 9, 2015 at the Fevers Unit of the Korle-Bu Teaching Hospital. I was briefly introduced to her by the person in charge of the unit. I explained my research and invited her to participate. She kindly agreed. I was so impressed by Jude, who appeared very smart and elegant in her white uniform with matching white canvas shoes. I was so looking forward to further research conversations with her.

The following week, I arrived at the unit. It was in the morning and the sun was rising. I got to the unit earlier than the first time in order to relax and to settle before the conversation

began. In the now-familiar meeting room, I sat to wait for Jude, as she was not yet finished her shift. In about an hour's time there was a knock at the door and Jude entered. I welcomed her with "Hello Jude, nice to see you again, how are you?" I felt an immediate partnership with Jude and a beginning sense that we shared a common interest in HIV nursing. This was not surprising as Jude remembered me, as I had been her anatomy instructor—it seemed many years ago now. She responded to my greetings and took a seat facing me.

**Early beginnings alongside Jude.** In talking about her early beginnings, Jude named her birth place and where she grew up and had her primary education. Jude's recollection of her town of birth and its significance to her preparation for life was an important part of her story.

I'm Jude . . . I'm from . . . the Volta Region. I was born on Thursday, October 17, [and] I'll be 30 this year. I had my primary, junior and secondary education in the Volta Region. [I went to different schools]. Now my tertiary [education] was Korle Bu Nurses Training College and I'm working in Korle Bu now. And currently, I am a senior staff nurse of the Fevers Unit. (June 16, 2015).

Listening to Jude's school journey, I could see several milestones of her development, but the key among them was her education. I wondered what school was like for Jude in the Volta Region. I had always found the region so serene and beautiful. The rolling hills and valleys, rocky outcrops overlooking Lake Volta, and lagoons, rivers and waterfalls made for one of the most attractive areas of Ghana. I had the opportunity to visit the region months after my first meeting with Jude, when I was back in Ghana for follow up conversations with participants. I enjoyed the peaceful and calm environment. It was so different from Accra where I was schooled. Accra was bustling and noisy, especially in my neighbourhood with traffic

congestions all over. Seeing the Volta River, I remembered the lagoon fishing I did with friends and family and felt nostalgic. As I listened to Jude tell of her early years in the Volta Region, I wondered about the means by which she got to school, what kind of friends she had, and how they impacted her hope. Jude seemed to have had an uninterrupted schooling experience as a result of a stable environment and constant parental guidance. Jude's general educational background from the Volta Region prepared her well for her nursing education. I remembered my working days with the Nurses' Training College. Applicants had three choices of schools, and they might get the first choice or nothing at all as there were always more applicants than vacancies. Following graduation they had to serve in the region where they were trained. Therefore Jude started her career at the Korle-Bu Teaching Hospital in the region of training.

**Beginnings of Jude's career.** I wondered about Jude's education from primary to nursing college, so I asked her to tell me more about how her primary and secondary schooling prepared her to enter into nursing.

[Growing up] I happened to stay close to a hospital and my mom had a very big retail shop, so the nurses, almost all the staff of the hospital, came around to shop. So from even there . . . I had in mind that I would work in the hospital, but I was thinking of doing pharmacy.

While Jude dreamed of working in the hospital, she dreamed of being a pharmacist. I asked why nursing was not part of her dream.

I saw a man with a very big wound. So I asked who took care of that wound and a friend told me the nurses did. So I got discouraged and said no! I'm not doing nursing, because the wound was so scary at that moment. So I changed my mind about nursing, I can't do such a wound dressing; you know I couldn't just imagine myself dealing with such a wound.

Jude kept thinking about her original goal to work in the hospital as a pharmacist. Following many second thoughts she finally found her place.

So along the way I've changed my mind from studying pharmacy to nursing. And I also realized along the way I've changed my mind again, but the thing was that nursing was the best. But I was also thinking about the employment aspect too and I realized that yeah, I have interest in nursing, when I complete I'll not suffer looking for a job because there is so much unemployment around from my experiences from my cousins, family and friends. So I said no, the nursing will be the best. And now after senior secondary school, I was so sick, very sick and when I went to the hospital the care given to me by the nurses and, I realized that no, I need to do the same to people. So I just love nursing. I applied, I was picked and I'm in nursing and it's worth it.

It took a while for Jude to settle on the choice of nursing as a career. After Jude was hospitalized, she thought of giving back to society what she had received. Her experience of an illness at a young age was a powerful one. This experience sealed her decision to become a nurse. Jude's positive experience of being healed nurtured her hope and confirmed her decision to study nursing. As she said, "I think when growing up . . . I was sick and . . . a time came I wasn't so sure, I lost hope but with the medical care and the nursing care that I went through I got better."

In senior high school where the foundation of professional choices are made, Jude made a choice that favoured her decision to take nursing later in life. She read science, an opportunity

that led to her return to nursing and consequently to become an HIV nurse. Jude pursued her instinctual feelings and was grateful for the decision.

But I knew that when I go to secondary school I'll do science because I want to work in the hospital and I want to go and study pharmacy. So all my choices it was science, science, science, we've got three choices of my stream. So I did science.

According to Jude, her own experiences of being sick and healed by the medical and nursing care she received helped her become an empathetic nurse. One good turn deserves another. Jude made a decision to give back to society.

And when I also started working as nurse I always put those patients in my shoes when I also felt sick like them. So I give hope to myself as a nurse that the result will be good and I use that hope to encourage my clients, or my patients and at the end of the day the patient recovers and goes home.

**Thinking about college days.** During our conversations, Jude shared a number of her experiences during her college nursing training program.

Yeah, there was one patient when the patient was brought in, I was a student by then, so I concluded that this patient might not make it, but upon second thought I realised that it could be possible [to recover]. So we were all hoping that this patient will get better. It took quite a long time but eventually this patient was OK and the patient was discharged. ... so I realised hope is good, hope is positive. And moreover in my work I realised that you shouldn't give up hope or when you see a patient you shouldn't just conclude [that they will not recover], but if you have hope, the hope will encourage you to make it, or [help to] achieve the patient's full recovery.

Jude's resolve to stay hopeful for this patient's recovery, in spite of what might appear to be impossible, was important. This moment significantly shaped Jude's understanding of hope and the importance of it. Jude also talked about faith and what sustained her hope on a daily basis.

Yeah, OK number one, as a Christian I pray and I have hope and faith, everything. Moreover, too what gives me hope is you care for the patient, the patient gets better. It encourages you when you meet another patient with or without the same status. You know that with hope this patient will get better.

Jude had experienced hope in relation to recovery. From that experience she grew to have more hope for other patients' recovery. And this hope was been sustained by her belief in God.

**Nursing education.** As I travelled alongside Jude as she shared her experiences with me, I also remembered some of my nurse educators and preceptors who constituted a powerful force in my nurse training. I knew they could terminate a student's training by turning in a serious error or reporting a negative attitude or behaviour. I could not remember how many of us during my student days had trouble with expressing how we really felt about our instructors or preceptors regarding our evaluations or examinations. I knew that even if a student made a negative comment about an instructor it could put a student's nursing dreams in jeopardy or could turn a happy moment into a moment of embarrassment. Jude reminded me that I was her anatomy tutor at the Nurses' Training College at Korle-Bu. It was very exciting for me to meet a former student. I had no recollection of her as the classes I taught those days were very large and it was quite difficult for me to remember every student in the class.

"I was trained at Korle Bu Nurse Training College." Jude said, when I asked her about her past experiences. She also talked about all of the other clinical areas she had worked in. I had clinical rotation and everything. As a result I can say I've worked in almost all the departments of Korle-Bu Teaching Hospital as a trainee including obstetrics and gynaecology department, ENT, the eye clinic and eye theatre, we've been to the theatres, the surgical wards, the medical wards, the emergency, the diabetic clinic, the sickle-cell clinic too and the polyclinics and all that. I've been through all that.

As Korle-Bu is a tertiary hospital it has excellent facilities and students who train here enjoy a wide range of opportunities for learning. Jude worked for many years at the same hospital she was trained at. Months later, when I returned to discuss Jude's narrative account with her, I learned she had been reposted to a Hospital in the Volta Region. Jude, as a young mother of two and a wife, needed her husband's support. Her husband had been transferred to the Volta Region and Jude requested a transfer to join him. When I met with Jude at Ho she was very happy to have moved.

In our conversation about the family support for nurses who chose to work in HIV care settings, Jude commented:

After my training and the clinical rotation, I was posted to the Fevers Unit and basically we take care of people living with HIV and AIDS. In fact my family they were not supportive at all. No! My parents were not supportive, and I think even my husband. At that time we were not yet married. Yes, but they were not happy about the decision to work with HIV and all that. So they put a lot of pressure on me to go to the administration for me to go to another department, they prefer it. So I have to educate them. But the first person who has come to understand me more was my father. He called me one day and told me, people living with HIV it means they're also human
beings like us and they need people to take good care of them so I should just go and work with them and be careful and just give my best to them. Show them the love. I think as of now they wish I'm working elsewhere, but I think with the education given to my family, I think now they're okay.

Exploring the support from her husband, Jude commented:

My husband, he doesn't talk about it now, but whenever the issue comes up he wishes I'm at a different place, not here because of the needles, injuries, the exposure and everything. But I always tell him I feel working here is better. Why? Because I know the status of my patients. So in that case I will take the precautionary measures from being infected, you know I will be so conscious unlike the other wards, you assume they're either positive or negative, you are not so certain about their status. So knowing the patients' status and working with the patients I think it's the best.

As I listened to Jude describe her family's resistance to her placement on the Fevers Unit, I was reminded not only of the stigma patients experience, but how at times this stigma extends to the staff.

**Hopeful elements.** I asked Jude to "tell me what makes her hopeful in working in HIV/AIDS nursing." Jude listened, cleared her throat, and repositioned herself before she began to speak. In a firm tone and confident voice she talked about the patient who searched for treatment for many years before arriving at the hospital. The opportunity to provide treatment to the patient was a hopeful experience for Joy.

What makes me hopeful is when I see other patients I already helped and they are recovering. I met a patient on the ward. Apparently the patient spent almost all his life,

money [and] wealth just to get healthy. He went to several places, both spiritual places and a whole lot. So when he came to the hospital he was diagnosed of a stone in the bladder and he was shocked. Yeah he was so shocked because he couldn't believe there could be a stone in the bladder for all those years and he has roamed from one place to another and it wasn't diagnosed and he has spent everything, he has sold his land, went to the spiritual kind of people and everything. So he was diagnosed, the surgery was scheduled, I prepared him. I took care of him personally; I brought him to the theatre. And later on when the patient realized that the stone was brought out and he was shocked [surprised]. Within a few days the patient recovered, he was so grateful he didn't even know how to thank us. So he was saying that he could have come here earlier, you know he was so happy . . . the way the patient appreciated us, I was satisfied.

The experience of being able to diagnose and treat a patient made Jude feel rewarded and hopeful. The power of fulfilment and professionally mediated compassion was vividly demonstrated here. By offering support and treatment to the patient, Jude's world of hope was opened up. The patient was flowing with thankfulness. She was given hope as well a confirmation that the patients were complying with the treatment regimen.

**Threats to hope.** At end of our third conversation, Jude told me that many things threatened her hope, particularly when working with PLWH. One of the key threads for her was the lack of support from agencies and families.

Yes! What threatens me most is the lack of support, support from organizations and families because when it comes to family support so far they are not really supportive when they get to know of the [HIV] status of a family member, due to the stigmatization.

And the organizations too, I'm expecting them to get involved, support financially, with our equipment, more medications, everything but I don't see much of that. So, without

family support and support from organisations [it] is difficult to sustain hope. Jude emphasised how family and organizational backing were lacking in the provision of HIV care. As I listened to her speak, her stories appeared to fit into larger social narratives of the neglect and abandonment of PLWH. She experienced this lack of support as a threat to her hope and felt this impacts negatively on her efforts. Both Jude and I felt that, initially, when little was known about the disease, many organizations supported patients. However, since the causes of the infections have become known there appears to be less support for the patients and also the care providers. I am reminded that nursing work is emotionally demanding. Support from members of society and organizations go a long way to instill hope—partially by demonstrating that the work holds value.

Jude also spoke about her concerns with patients who stop taking their medication as a result of remission in their symptoms.

A patient is on his way to recovering, getting better physically and everything. Suddenly this patient stops taking their medication, stops coming for review and everything and usually when they come for review much later they usually come in a very bad state. You have to start afresh with the care and everything. . . . You don't have any hope [when your patient comes back too late and in much worse shape]. In these case, you tend not to work hard or put in more nursing care for such a patient.

Jude was talking about PLWH who were in remission then went into relapse because they refused to take their medications or come for their scheduled visits to the follow-up clinics.

What Jude highlighted was how she found it difficult to stay hopeful when she had to begin again with a patient who was in a worse state than when she began working with them initially. She seemed to suggest that it was hard to stay hopeful when a patient did not continue to care for themselves. Jude raised important links between a sense of responsibility and self-care in patients and the links to her hope. I wondered if this sense of hopelessness was sustained or if it could be changed over time.

**Connecting to earlier times.** Jude had been at the unit for nearly 5 years. She joined the unit when ARV medications were already very accessible. Yet Jude also knew and could relate well to stories of the early '80s when there were no effective ARV medications. I was so glad Jude knew this history; knowing this history brought a different way of looking at treatment adherence and also helped us understand stigma better. Seeing patients returning to clinic with serious symptoms was heart wrenching and deflated Jude's hope. In some cases the patients come in so weak that they died.

They come in as unconscious, very weak, some even come and within less than minutes they are gone. Some even die during the conveyance to the hospital. So they come as

BID (brought in dead). So it is very threatening and it won't give you hope.

In our conversations it was clear that Jude was very distressed by the conditions of some of her patients. I often wondered what sustained Jude's hope in these encounters and moments.

**Involvement of family.** One of the things Jude pointed out was how much she valued the involvement of patients' families and friends in the care process; their involvement supported her hope.

Yeah! I think . . . the family; you know when a patient comes in whatever state, the way

the family shows support it encourages me to take care of that patient. You see a family who is ready to support you . . . buying of diaper, medications. And a whole lot, financial support from the family gives me hope to work more for that patient.

Jude asserted that where family support was evident she felt relaxed and her sense of hope increased.

When there is family support I feel less pressure and my hope is greater [... yet,] some patients that come ... they turn out losing their lives due to lack of family support. I still stand strongly on that family support gives me hope.

I noted in my field notes that the principle of family involvement in care was very significant in a typical day for a nurse who worked in HIV care. Activities such as assessments and interventions were all carried out with families' involvement if possible. However, the kind of support that HIV nurses need in the Fevers Unit, as inferred from the conversation with Jude, was more about financial support for buying prescriptions and food for the patients who were ill. All in-patients are expected to have an adequate supply of medications for the successful treatment of their illness.

Hope was present when families were there to provide support at the right time. Jude's hope experiences in such times were motivating and helped her devote greater attention to patients. On the other hand Judy experienced less hope when support was not forthcoming. In our conversation, Jude recalled that it was frustrating and sad to have a patient admitted in a relatively fit state, but that the patient's progress felt threatened because she realised that without family support the patient could not make it. As I listened to Jude, I discovered that even a good prognosis was insufficient to predict the possibility of recovery or a return home for some

PLWH. Jude explained it in this way:

I have realised sometimes it doesn't go that way because people can come in the second stage who are not really bad but due to a lack of support, stigmatization and everything, all [too soon] they get depressed, they don't want to take their medication. [In some cases] there is no money for medication and everything. They refuse food, before you realised the patient gets worse.

I really enjoyed my conversations with Jude. Even so, sometimes it was hard to hear how difficult her work was. Jude knew that an HIV diagnosis had many implications such as suffering, rejection, and discrimination. An awareness of these implications made Jude feel less hopeful. Jude was very serious in the campaign against stigmatization and discrimination to reduce the impact of suffering and pain related to the illness.

For Jude, one of the hopeful factors in her work as a nurse included the inpatient support fund. The fund allowed nurses to spend money towards meeting emergency needs and pays for things such as IV fluids, diapers, and medications where necessary.

**Stigma.** Reflecting on HIV prevention, Jude remembered that a key barrier to HIV prevention was stigma. Jude acknowledged that stigma was a serious issue and needed to be dealt with. It continued to be the major reason why people did not seek early treatment. While stigma played a key role in patients' care seeking behaviors, nurses were also impacted by stigma. Often times the stigma extended to nurses who worked with PLWH. Jude believed that education was an effective intervention in stigma reduction because it helped communicate society's social realities. Jude stated, "So when we all educate ourselves or learn about hope we are able to reduce the stigma."

Jude also recognised that some of the stigma was attached to things like the name of the unit. Jude asserted that hearing the word Fevers Unit did not call forth hope. In part this was linked to the lack of financial resources that the unit was faced with.

Working here I have realised that people [institutions, organization, society agencies, et cetera] don't have hope for . . . recovery of PLWH, so financially they don't want to put money in.

Jude tried hard to advocate for adequate resources for the Fevers Unit.

**Roots of hope.** According to Jude, hope experiences strongly influenced her education practices and that was how her hope affected others as well. Jude explained that by sharing her HIV nursing experiences with colleagues they, too, connected with their own hope. As colleagues they also found value in her experiential knowledge practices. Seeing colleagues and patients following her recommendations fostered Jude's hope. In our conversations, Jude talked about how, through health education, she changed their world views about HIV and AIDS and how clients became compliant and cooperative with treatment.

Jude was able to educate PLWH and their families based on her experience of hope. As a result of this, she gained confidence in her work and was able to render particular teachings.

Yes, with my family because of hope that we have through the experience you will be able to educate families, colleagues, even if a colleague doesn't have that hope you give that colleague an example or you remind that colleague of what you have gone through with experience to encourage such a colleague to have hope that when we do it this way there is hope for us and the patient.

Thinking with hope. Although hope may be considered a resource, it is not a tool to

work with. In describing the importance of hope, Jude stated, "Hope is very necessary in my nursing." She continued,

Before you even touch the patient if you don't have hope that the patient will get better you can't put in your best. So at the end of the day the result that you are expecting and the patient also is expecting will not come to reality.

Jude's interpersonal hope experiences with patients had provided her satisfaction with her career. I had taught for many years and found satisfaction and reward in teaching. Such life experiences inspired deeper reflection and motivation for my career. Jude reported another case where the condition of the patient was so bad that the patient died. However, the nursing intervention given to the patient at the end of the day made it satisfying. Jude said she felt the nurses provided comforting care to patients leading to a peaceful death. "Even though the patient didn't recover," she lamented, "he had a peaceful death, it was sad but I'm happy he died peacefully." Hope and death are not at opposite ends of spectrum, but they can also work together. In our conversations Jude and I often covered a vast terrain and we often returned to her family.

Jude was married with two young preschool children. The first child was 6 months old when we started this research conversation. At the time of this writing, the child was over a year old. Her parents and her fiancée at the time did not support her decision to work with PLWH but with education and probably persuasion they came to terms with her decision. However, they still wished she had another placement. Jude reported that her daughter had given her a lot of hope in her work.

I have patients who also have babies and we try to educate them to prevent an infection. I would say with the mother to child infection of HIV, we try to educate them. So with my child I am okay.

I wondered how the nursing career, and particularly HIV nursing, had affected Jude's life. She responded by saying:

I think yes it has, . . . it has really affected my social life, my religious life as well. But this is a profession; this is a noble profession, a calling. . . . I'm okay because sometimes you can just imagine a patient needs a nurse to take care of him or her, you leave that patient, you are off to church, you cannot even concentrate. So sometimes yes you're not at church but you are able to take care of a patient, to help the patients recover. It's satisfying, I'm okay, it's fulfilling. . . . . So long as I know I'm on the ward helping patients, I think I'm okay.

**Christian hope and work.** Jude reported that her Christian faith had influenced her work as she was happy saving lives, even if it were on a church attending day.

Well I can say it has affected my work a lot, because even if . . . as a Christian, the Bible says without hope, it is impossible to please God, and the way that [I came into ] nursing is a call. If you are really a Christian, you know that everything that we do is a call to serve humanity. The patients that we are taking care of, they represent God, because we are created in the image of God, so if you do harm to them, you also sin, so if you really . . . understand that as a Christian, if I have health, and I'm applying it in the care of my patients. I will do it effectively, as compared to someone who has belief in any other faith.

In our conversations, I wanted to understand how Jude's hope in God helped her deal with the stigma as well as the church's attitude towards HIV. Jude explained:

[In] the church, we consider ourselves as one . . . we should be each other's keeper, in happiness, in sadness. In sadness, maybe . . . like in sickness. In sickness you should also be able to . . . share that moment with your brother or sister, if you are a child of God, because it's one of the challenges that we go through in the world. We know that the world is never a comfortable place for us. God knows that it's full of challenges, but that is why he's there, to strengthen us. So I will say if we are real Christians, and maybe one of us is affected, it's that one of us being affected with malaria or hypertension, you should be able to accept that person, because that is not what God is going to use to stand on to judge the person, the person is going to hell or heaven. It depends on the person's ... righteousness, the faith that a person has. Even with the faith, it has levels with Christians, because it depends on your faith. If your faith . . . is like the mustard seed the mountains can move at your command . . . so someone can have this illness but can be healed through faith in God.

Jude made it clear that the goal of the church was to win souls for Christ according to the Gospel Commission [preaching about the Kingdom of God], and so fighting stigma was not the main focus. She said:

For the church . . . our aim is to go out into the world and bring out the lost sheep to the [fold] . . . so our concern isn't much, really, in preventing people from getting or contracting the infection, but when you win their soul, that is after you win their soul and the person is converted, then the person can lead a righteous life, not to be immoral, sexual immorality. So if that person is able to go by that, the person will not get infected, but once in a while, since it's bound to happen, but then it's okay, that is why you have to

ask for forgiveness of sin, but we do that one, but that isn't our main aim. That is why the health centre, who is around and the public health nurses, to sensitise the public education about the prevention of HIV. We do education about prevention, but comparatively, I will say it is minimal. The prevention is done through organising campaigns in the church against this kind of attitude of people towards sexual immoralities with a focus on winning soul for Christ. The Bible stated mankind cannot be able to overcome sin without help from God or the Lord Jesus Christ.

Jude continued:

Being able to stop sinning, it depends on . . . the help with the Holy Spirit, like it said when the Holy Spirit comes upon you; it gives you the strength that things that it was difficult for you to stop, you could stop it. So if you are just like that, maybe if you don't accept Christ, you don't have power over sin, but when you accept Christ you now have power over that sin. Now you can say . . . one time I won't involve myself in sexual immorality. First I use to have this number of partners, now I'm going to stop until I get married, so that helps.

The conversation shifted to the challenges in the church: discrimination and judgement. Jude stressed her feeling about the discrimination.

In the house of God, we are all one, it doesn't depend on . . . any situation that the person. God still loves the person, so you are not the one to say the person shouldn't attend, the church is not a man-made church. It will also help us a lot because if you don't go according to the rules, you will have the promise of a long life. If you are coming to get married, you have to go and check your status . . . for positive or negative. We are not in a position to tell the person they have to stop the marriage. You tell him that one has the infection, but if you are not careful, then that other person will have. So you have to decide for yourself, do you want to go ahead and marry that person, or not, but you are still a child of God, that person, you should tell that person . . . we still love you and we consider you as part of us.

I wanted to understand how the nurse's hope was threatened by stigma. Jude illustrated a parable from the Bible to help me better understand this.

As a result of individual differences every one response to the stigma is unique. As stated by the parable of the sower in the Bible. The seeds fell on different places, some fall on fertile ground and other on the stones. Everybody in the way accepts the message differently. For example, I saw a church member here [Fevers Unit], like when she saw me at the table [nurses station], she said hi. I meet her at church, I didn't ask her anything, but she's very committed. When I see her at the clinic I'm very happy, but I did not share with my husband that this person is HIV positive, that doesn't concern me. What I'm happy about is she has never been admitted before, and it was here that I met her. She doesn't even say anything, so when we see each other we talk about what we share in common, we didn't talk about that one [HIV]. This person is very regular church member, dedicated, very fit in appearance, not emaciated. She was always at church. She was not perturbed by our meetings at the clinic to daunt her from church attendance. Asking how she represented her hope in symbols, Jude reported a symbol of love in a picture with Jesus Christ.

The reason why I'm saying that is when Jesus Christ came, he took all sin, all our

problems, so we are no more under any condemnation. So there is hope for us when we look up to Him, and then there is love. If you have . . . He says to you love your neighbour, you not do . . . even if your neighbour is in any situation, you still accept him as your brother. So that is the symbol of love. To conclude, I will say, in life you have to be determined, and if you are determined, like inside or intrinsic, like determination comes with the hope that you . . . like, hope, I will say, thinking of what I'm going to do is going to end well. So like, if you think that way, whatever you do you will be successful in life.

What Jude drew to my attention in her narrative account was that hope was related to many things. It is rooted in experiences and a deep belief that things hold the possibility to turn out well.

#### Chapter Five: Narrative Threads Across Participants' Stories to Live by

When I met my supervisor on Sept 6, 2016 after my return from Ghana, she reminded me to present a text on exiting the field. My first reaction was silence. Silence enabled me to reflect upon the events that continued to transpire while being alongside participants. I was filled with the energy to write though occasionally filled with writing fatigue and could not focus until after a few days of rest. I also noted the importance of the process of exiting the field as a methodological necessity. Nonetheless, after the meeting I decided to re-read the chapters on the subject written by Clandinin and Connelly (2000) and, to my wonder, I was struck by the relational inquiry I had been involved in for the past year since entering the field in 2015. As I set forth to write this text on exiting the field, I was reminded of stories about myself from earlier times as well as stories from my participants. I experienced a continuum of past, present, and the future in my stories. The feeling of leaving the field is one of nostalgia for me.

Fieldwork in narrative inquiry is both challenging and rewarding for the reason that it occurs outside controlled settings and engages a more idiographic process that is open-ended (McCall, 2006). Exiting the field is one critical step in narrative inquiry that may involve almost as many steps backward as forward. It is withdrawing from the research site where experiential field text have been generated over a period of time. From a relational inquiry viewpoint it is at the core of the embedded process of disentangling oneself from the field. I was in the field for 14 months: in and out, and fully engaged during a 5-month physical presence. Exiting the field became more than a single act of ending relationships developed with research participants over a period of time. It was affected by past, present, and future connections which may be personal or formal. In the past, the thought of exiting brought memories of negotiation and taking care of

the stories we shared. The reflection of the past reminded me of adhering to the ethical responsibility and respecting the participant and researcher obligations. The present brings me to the actual reality of living the responsibility and the future impacts how I live alongside the participants' unfolding stories.

Exiting from the fieldwork is connected with changes in identities and emotions as enacted and experienced by both the researcher and participants. Understood in this way, exiting raises important questions about foundation of the field. I was changed by the stories that I listened to. I believe my hopeful self has been challenged. I have grown to be less critical and more tolerant with nurses' attitudes towards patients as I considered their working circumstances and the vulnerabilities that they were expose to. This experience was new to me.

On the one hand, inquiring from the inside made me feel immersed physically and psychologically in the field, and allowed me to experience fieldwork in more intimate ways. My social exchange in the field created more sympathy. Although I did not directly observe the nurses at work on the wards, the opportunity to converse with them in their work setting provided the opportunity to listen to occurrences within a context and hope at work. Experiencing an inside view and failing to see the responsibilities in changing the HIV-related stigma had become part of my blind spot. During my second and final trip to the field I reminded my participants of my impending exit. I noted in my field text "I feel homesick leaving the field but have no other choice but to finish this program and get back to work."

I acknowledge that the insights I gained from the literature on ending relationships in a narrative inquiry context needed to be applied carefully. Good empirical research is methodologically precise and discussing the exit contributes to this precision. Gephart (2004)

warns that "if it is unclear to the reader how research was undertaken, it may be difficult to connect claims in the paper . . . to the data presented" (p. 458). In order to gain the trust of the audience, I needed to provide rich details about how important decisions were made in the research process. This ultimately includes exiting or at least there is no logical reason to exclude it from such discussions. Only by analyzing how we left do we allow the audience to exit with us, because "leaving implies that we were there in the first place" (Coffey, 1999, p. 109).

At other times, when the researcher does not fully leave the field mentally and emotionally, it becomes challenging to discuss exiting. Particularly in fieldwork that is conducted for the purposes of inquiry from the inside, it is important to bring the reader close to the empirical setting where the researcher has been and thereby allow the researcher's voice to be heard (Bansal & Corley, 2011). Reflexivity about this role, defined as "the inclusion of the observer in the subject matter itself' (McCall, 2006, p. 3), is a key characteristic of most of this type of fieldwork. Golden-Biddle and Locke (2007) believe that the write-up and representation of the study is a co-operative effort of researchers, readers, and reviewers. While some other readers such as professionals may be fascinated with the technicality of the arguments and the level of sophistication of theory development and methodological execution, collegial and particularly general readers appreciate details that make them trust the author (see Van Maanen et al., 2007, on the distinction between these groups of readers). Bringing general readers to the field and inviting them along as the researcher exits increases the transparency, authenticity, trustworthiness, and resonance of published theories. At the end of the day, it is the readers who makes a theory live or die. While discussing exiting is impossible without reflexivity, I argue that writing about it goes beyond mere reflection; it is about analyzing data, the field, and

fieldwork, which means shaping the data and the relationships in the field. Thus, I do not advocate mere descriptions of exiting, but analytic discussions of it.

The field, as described by Clandinin and Connelly (2000) comprises the interactions with participants to co-create field text and then interim text, such as narrative accounts. Discussing hope and how nurses in HIV care live and practice hope is a complex phenomenon to tease from conversations. The participants' responses to my questions were lengthy and not straight to the point. The stories about family support and medicalization of patients are grand narratives exposing how society responds to PLWH. What I gained from the field led me to respond to the uncertainties in writing this dissertation. Continuity, for me, is lifelong learning and changing as I learn along the way. In this chapter, I now make visible the narrative threads<sup>4</sup> that resonate across the narrative accounts of the participants.

# Thread 1: Becoming a Nurse Working With PLWH Over Time

The lives of the participants in this study are complex as they are composed in many places, such as the hospital settings, homes, churches, and communities over time. As Carr (1986) reminds me to attend to the temporal nature of experience, in the current study only Berth worked in the role of the Deputy Director of care. Prior to accepting the Deputy Director's role, she worked at the unit as a nurse. The four other nurses were posted to the HIV Unit and worked alongside PLWH. The nurse participants chose to stay after being posted to the HIV setting as nurses to work with PLWH. They initially accepted the postings with feelings of anxiety, worry, uncertainty, confusion, and perplexity as they feared to work with the population because of fear of contagion (Chan, Rungpueng, & Reidpath, 2009).

<sup>&</sup>lt;sup>4</sup> Narrative threads are intersections, overlappings, dissonances, or resonances between stories (Bateson, 2000).

All of the participants started their HIV nursing journey at different times. Eva was posted to the Fevers Unit in 1998 after 8 years of nursing at different places and times. HIV at this time was known and the fear of it had spread among the general population. Eva continued to work at the unit as she become accustomed to discrimination.

Eva lived alongside PLWH for almost 2 decades (1998-2016). Her stories to live by were shaped by the contexts in which she worked over time. Making time visible Carr (1986) argues "[t]he reality of our temporal experience is that it is organised and structured; it is the "mere sequence" that has turned out to be fictional" (p. 25). Putting it another way, our experiences are not linear. Time shapes us in many ways as we interact with various contexts along the unfolding of our life. Eva began nursing when HIV was still feared even by many nurses. When she began nursing with PLWH, patients were arriving in debilitating conditions. At that time, Eva was uncomfortable working on the unit until she had worked there for a while. Her family—another context to her life—was supportive. Eva's everyday life consisted of routines around patient care, patient education, providing medication for patients, and patient and family counseling. Eva's everyday interactions were shaped by her past, as well they shaped who she became. As time went by having interacted within the HIV context for many years, she desired a reposting but that was not forthcoming. Although a transfer from the unit might relieve her of her feeling of wanting a change, she said that continuing to work at the unit was an important learning experience for her. While still working at the unit, she continued to participate in HIV-related workshops and conferences to enhance her skills. From the places, interactions, and relationships across time, Eva shaped her stories to live by.

Lana described being frightened when she arrived at the entrance of the Fevers Unit when

she was first posted there.

Actually for the first time I was transferred from another hospital to here [Korle-Bu]. When I came I was given a letter to come to the Fevers Unit. I was afraid. I became afraid.

The experience of being transferred and the transition to the Fevers Unit shaped Lana's life. She originally feared becoming an HIV nurse. The help and escort of a colleague helped her gain enough courage to enter the unit. She said:

But when I came I saw that most of the nurses they don't want to work here in the Fevers Unit. So I sat down and had a second thought . . . When I came to work I saw that this place is a better place to work than the other areas. Because you know the actual disease you are nursing here. You know the kinds of things you should use to protect yourself. But in other wards you won't get it like that. You do all sort of things before you find out that this patient is a PLWH. So me I like working here.

Lana came to know that working alongside PLWH was safer than working in other settings, despite the discrimination. Lana's experiences were also shaped as she observed many nurses at the unit were not happy working with the HIV population. Fear of stigma and discrimination kept many nurses away from the HIV population. Lana's experience was shaped by her conviction of her safety in working in the Fevers Unit.

Berth's experience of HIV nursing was shaped by an anxiety associated with working with PLWH. When she was positioned as a director she drew on her experiences as a nurse to work with the nursing staff.

I encouraged them, I talked to them. And I make sure that the things they need for the

work to take care of the patients are being given out. And once in a while we motivate them because it is not easy taking care of HIV patients, knowing the sort of patients that you are caring for. So sometimes I tried to allay, alleviate that anxiety that fear from them.

As an administrator, Berth was not alien to the setting. Her experiences were also shaped by her acknowledgement of her fear within the HIV landscape. She lived by a story of managing her fear.

Joy moved to the Fevers Unit as a nurse from the Polyclinic in 2012. She also grew to become an HIV nurse.

First, when I came here I said, this place I can't work for long but now I don't want to go out of this place. I can work even if they retain me here until I go on pension . . . I will be a source of happiness to a lot of people. Normally when they come for the first time, when I came here, when you see the patients you feel very scared but as time goes on and you keep on working and nursing you see them recovering you get some hope and then you also start feeling happy.

Joy learned to see that she could live a story of being a source of happiness for the patients when she was not overcome by fear. Her stories of being courageous in her work with PLWH were shaped over time as she became more aware of the daily routines of the HIV care setting. Joy practiced how to counsel, do referral, review medications, and how to take care of herself. Over time, she gained courage to strengthen her comfort level with HIV care. She, too, wanted to continue to nurse on the Fevers Unit.

Jude started nursing as an HIV nurse fresh from nursing school when her first posting

was to the Fevers Unit. Jude was attentive to how becoming a nurse working with PLWH would shape her family and vice versa. She educated her family to see PLWH as equal value to other patient populations. Her stories to live by, expressed as holding value of the lives of all patients, helped her to educate her family. She knew that educating her family about HIV was a process over time. It was an experience that was shaped by previous experiences and one that would continue to influence future experiences.

My family initially they were not in support of me working with PLWH . . . but along the way through education and the joy or the hope I get from the results of some of my clients I think they are now cooperating with me and they also have hope in the outcome of what I am doing.

Eventually, Jude began to experience support from her family. She told of how her life was shaped by the family support for her work with PLWH. Jude's experiences of becoming an HIV nurse were also shaped by the need for more equipment and infrastructure support for the HIV care setting. Her experience of becoming an HIV nurse was shaped by her deprived work setting that was shaped, in part, around the stigma of HIV and AIDS.

For years working here I have realised that people don't have hope in the result or the outcome or recovery of people living with HIV/AIDS, so financially they don't want to put in [money].

Jude also grew into the job and gained more understanding of HIV care. Her experiences in HIV care were shaped by the work setting and family support. She lived by stories of being proud to work with PLWH.

#### **Thread 2: Experiences of Practicing With Hope Despite Hope Threats**

Experiences in nursing practice, like any other profession, shape identity (Connelly & Clandinin, 1999). The identity or stories to live by of the participant nurses intersect with their narrative threads of hope threats. Hope threats or hope suckers have been described by others as a situation that diminishes or depletes our hopes (LeMay, Edey, & Larsen, 2008).

Nurse participants talked of their experiences in their nursing practices, particularly in relation to their attitudes towards PLWH and their families. They expressed their hope more vividly nonverbally than they did when asked to describe their hope verbally. For example, Eva responded in the following way when asked how she expressed her hope in her practice.

Whatever you are doing, you have to brighten your face, and you have to be approachable. To patients and patient relatives, even clients. Because you are nursing HIV patients you don't always have to frown, you should be approachable so people will be drawn near, closer to you, so they [patients will] come out with whatever is worrying them.

The participants recounted stories of hope as they related to PLWH and their families. All five nurses grew to overcome feelings around their fear of infection. These hopeful stories went a long way to shape their stories to live by as they overcame their fears and allowed themselves to become a hopeful resource to colleagues in the unit.

Each of the nurses experienced practicing hope in ways that were coherent with their stories to live by. For Lana, hope was "important because if you're doing something and you don't have hope it won't end up well so whatever I am doing I have hope that it will be well." She experienced practicing hope as part of her stories to live by around the power of believing that situations would work out well. For Jude, her experiences of hopeful practices were connected to patients taking "their treatment . . . though it is not curable . . . it prolongs their lives . . . And because we are educating the patients and they know how to live positively in their lives."

Joy's experiences of hopeful practice were linked to her patients' compliance and positive attitudes toward their illness. Joy said,

Formerly when there were no ARVs, we were losing most of our patients and then I will say there was no hope but now with the introduction of the HIV drugs that is antiretroviral therapy our patients can live, depending on their adherence to the medication and then also being on a good diet by taking care of their nutrition and then adhering to what we tell them.

Joy's stories to live by were shaped around experiences over years of working with patients. With the experience I have had here with patients who take their medication I have never seen them on admission. We have patients who were diagnosed in early 2000s that the medications were started with them since I came I have never seen them on admission before. And then when you see them it doesn't show on them. So I think with the introduction of the ARVs there is hope.

Joy's experiences of hopeful practice resonated with the experiences of Eva, Lana, and Jude. Joy's stories to live by were shaped by the role of hope in patient recovery as she became hopeful seeing the crucial role of medication in patient recovery. For Jude, her experiences of hopeful practice were shaped by seeing "other patients you already helped and they are recovering". For Jude she experienced hopeful practice when patients complied with treatment regimens. She said "what you are doing when you continue seeing the patients are complying, you get good results. So it encourages me to work more". For Jude, her stories to live by were entwined with living hopeful practices so that patients would have "good results".

For Berth, her experiences of hopeful practice involved working with "Models of Hope", patients "who use their lives as a source of encouragement to our clients. They use their lives as an example though they are people living with HIV but the way they take care of their lives is a way of encouragement to our clients." The models of hope are clients who volunteer to educate other newly infected clients by forming support groups that meet regularly.

As noted at the outset of this thread, participants did not often speak directly about hopeful practices but their lives and work were expressions of hope in ways that encouraged patients and relatives.

**Hope threats.** Hope threats are significant influences on nurses' experiences of hope. Hope threats create conditions that can shape nurses' experiences in ways that make him/her susceptible to discrimination and stigma. The five participants shared that their experiences of hope were threatened by patient noncompliance to medication or treatment, lack of resources, discrimination, and refusals to seek follow up care. HIV-related stigma was also a threat to the nurses' hope. Thinking narratively, interactions within the HIV context not only intersected with experiences of hope, but shaped the way nurses were and were becoming in their practice (Fleasker, 2015). It shaped their identity across the dimension of temporality, sociality, and place (Clandinin & Connelly, 2000).

Lana expressed how she sometimes experienced patients' behaviour as a threat to her hope, particularly when patients wanted to marry. Yea, some we tell them when they want to marry, when they approach any female or male they should bring the person to the clinic so that we counsel them and then test them [to see] whether the person they are going to marry he/she is OK or negative. We have a nice way to talk to them. And if he/she wishes to marry he/she will marry whether he/she is negative or positive. But they won't do that. They will go ahead and impregnate the other partner who is negative. We've talked about it and they are doing it. By doing so they keep on spreading the disease. So this is my worry.

Lana was aware that having HIV made it difficult for PLWH to live their sexuality. She experienced threats to her hopeful practices when PLWH ignored the testing before engaging in sexual relationships and, as a consequence, could re-infect themselves and others. Berth also spoke of a similar experience of being threatened by "the rate at which HIV is increasing" and the ways PLWH have "unprotected sex with other people and some of them do not live positive lives despite the education and some do not report to the clinic, they do not want us to know they are PLWH so that makes [the situation] more threatening." She experienced her hopeful practices as threatened when "some of them default in their treatment, in their nutrition, some do not have people to support them financially." She experienced threats to her hopeful practices when PLWH did not "even tell their partners because of stigmatization. They feel threatened telling their relations and in the long run the relations end up infecting themselves... Because of the stigmatization they don't want to break the news to the relatives."

Jude also experienced threats to her hopeful practices when PLWHs became complacent while still in remission, stopped taking their medication, and quickly relapsed. She explained that she experienced threats to her hopeful practices when patients "are recovering [and] they feel they have recovered enough and they stop taking the medications, and they go back becoming worst."

Eva also experienced threats to her hopeful practices when she worked in situations that were very uncertain: uncertain as to patient behaviours, uncertain as to whether she might become infected, and uncertain in the conditions in which she worked.

Fear of the unknown. Working here . . . hmm! One might think she will also be infected with the virus, nursing HIV/AIDS patients. Yes because we know the type of conditions that we are dealing with. If you don't take all precautions.

Jude also experienced threats to her hopeful practices, particularly around the lack of support from organizations and families.

Because when it comes to family support so far they are not really supportive when they get to know of the [HIV] status of a family member due to the stigmatization. And the organizations too, I'm expecting them to get involved, support financially, with our equipment, more medications, everything but I don't see much of that. So with [lack of] family support and [lack of] support from organisations is threatening.

Joy expressed similar stories of her experiences when she said:

What is threatening to my hope is some instances in this country that there is shortage of ARVs. When that happens we the workers here become very sad . . . when the patient skips one medication even for a few days it affects them so what will threaten my hope is when there is shortage of ARVs.

The nurse participants each experienced threats to their hopeful practices, threats that shaped their stories to live by, as nurses working with PLWH. While each nurse experienced

these threats somewhat differently, they each experienced threats. I can now see that the threats cannot be reduced to individual issues or incidents, but rather have to be addressed within the complexities of each person's life making.

# Thread 3: Faith in God from which They Gained Strength

A third narrative thread that resonated across the five nurses' experiences was linked to their experiences of being connected to faith in God. Faith in God was a significant aspect of all five nurses' stories. They described themselves as Christians signifying faith-based hope in God. Following the Christian Faith perspective, participants renewed their sense of hope by praying with their patients and talking to them. For Berth, her stories to live by were shaped by sharing her faith with her staff and patients through the use of the Scriptures.

We have a waiting room there when they [PLWHs] come [and] we meet them, we talk to them. So we give them words of encouragement we use the Bible. We have pastors here who preach to them every morning and we encourage them with motivational words.
Berth was connected to her hope when she became a Christian and her hope was preserved by her continuous trust in God. She said:

I learned about hope in the Bible . . . it says love, hope, and faith, and the greatest is love. So I learned of hope from the Bible . . . The Bible says that if you have God you have everything. So it is the grace and favour of God that helps me sustain that hope. I have hope in God. I trust in Him and I know that He will carry our patients through.

Berth's hope transcended the personal as she also connected to her faith that her patients might live or be taken through their current situation by the power of hope in God. Berth demonstrated that her hope was related to her patients' recovery. Joy expressed similar stories when she said:

I am a Christian and I am a Presbyterian. And they say without hope you can't please God. Without faith it is impossible to please God so what I say is you have to be determined. If you are determined to do something you always will be successful so it depends on the faith that you have. So I don't want people who when you want to do something they tell you it can't be possible. I want people who would say it would be possible because that is what God likes. He wants you to believe in Him because if you don't believe in Him how can He trust you?

Becoming more aware of her hope, Joy's courage in HIV care was strengthened as her relationship with PLWH in her career grew stronger. Joy was resolute in working alongside PLWH. She gained strength to stay, overcoming her initial fear through faith in God. Joy's story to live by was shaped by her community of faith who believed in possibilities. This experience allowed her to overlook the discrimination and stigma as her hope in God continued to shape who she was and was becoming. Joy's positive relationship with God preserved and strengthened her hope.

Eva also gained strength through her faith in God which deepened her career experiences with HIV care. For Eva it was essential to do the best and leave the rest to God. She said:

We are doing our best. We are doing what we can, usually when you are scared of nursing them rather . . . so you have to feel free and nurse them . . . do what you are supposed to do and God will help you . . . go through everything.

Eva described God as her helper in working alongside PLWH. Her openness about living faith-based hope shaped her stories to live by. Eva believed God helped her if she did her best

for her patients. Lana also gained strength from God as a sustainer of her hope. She said:

Oh! I can say I thank God that He has sustained my hope. He has given me hope to be able to work here for time I was posted here up to today. Because it hasn't been easy. Even when I came here my husband was against my coming here (laughing) but now he doesn't complain anymore. He had seen that I come to work every day and I didn't take any complaints to the house.

For Lana, God had worked out things for her such that her husband had begun to support her work with PLWH.

Jude practised faith and renewed her sense of hope through prayer. Describing her faith in God and how patients' recovery strengthened her hope she said:

As a Christian I pray and I have hope and faith, everything. Moreover, too what gives me hope is you care for patient, the patient gets better. It encourages you when you meet other patients with or without the same status. You know that with hope this patient will get better.

For Jude, her faith in God was also strengthened by experiencing patients' recovery. Jude's hope in God influenced her future outlook on patients that she might be caring for by describing them as they "will get better." Jude's openness to her connection to the recovering of her patients was an integral part of what had shaped her identity and who she was becoming. Narratively speaking her hope experiences shaped her stories to live by.

This thread shows that the nurses believed that their infinite hope came from God. All the five participants were, first and foremost, Christians and they expressed their sense of hope through prayer and word of encouragement from the Scripture. Knowing that God sustained their hope made a difference in their stories to live by by gaining strength to practice in the midst of stigma and discrimination.

## Thread 4: Learning to Live With Hope From Childhood

A fourth resonant thread that echoed across the experiences of the nurses was related to the ways their experiences in childhood shaped their stories to live by as they became nurses working with PLWH. Experiences such as general education (private or public), early neighbourhoods, changing careers, single-parenting, poverty, and personal characteristics contributed to how they learned to live with hope. While the participants did not relate their childhood experiences directly to their current contexts of practice, they related their career choices to their early life experiences such as contact with nurses and their interest in people. Eva said,

I was interested in people, I like people. And when somebody falls sick I really feel for the person. I remember one day . . . my mother (a seamstress) had this needle prick . . . That's a needle . . . went direct into her nail and into the skin. I had to remove it, remove it, people were scared, everybody was scared, but I was feeling for her and I had that courage to remove it. I have . . . that talent to care for people, so maybe that's one also contributed in coming into nursing.

In addition to hope, Eva also believed that she was naturally endowed with courage to act in heroic ways such as when she removed the needle from her mother's finger nail. For Eva, this early life experience created a space for her to enrol in the nursing profession, even as she showed how this event had a profound influence on her life. Eva spoke of how her teachers were important influences on her forward-looking stories, Our tutors sometimes I look at some of them as young as they were when they were teaching us. I hope one day I would become like them, so that made me learn harder ... they are like models or mentors, very young but standing in front of these people teaching. I said why I can't also be like this lady and it's through learning ... hard. So I was hopeful that one day I would be [like them]. I also learned harder and became what I am today.

Eva's lived experience narrated the significance of her early life stories in shaping who she was and who she was becoming.

Jude, another participant, had contact with nurses in early childhood in the neighbourhood where she grew up. She attended to nurses as customers who came by to buy from her mother's store. This early contact began to draw her attention to thinking about a profession in a hospital. She said:

I stayed close to a hospital and my mom had a very big shop so the nurses, almost all the staff of the hospital, they do come around. So from even there I would say I had in mind that I will work in the hospital.

Jude's interactional experience with her customers helped her see a connection between the training and employment and helped her make a decision to work in the hospital. She lived with this hope when she was growing up. It was the hope that was needed to focus on the opportunity of ready employment in the nursing profession rather than more uncertainty job prospects in studying pharmacy. Trusting in her feelings as a function of her hope, Jude filled her life with hope. For other participants major live events shaped their hope.

Joy and Lana both experienced the divorce of their parents. Joy said:

I remember when I was a kid our father left us. We were four and then we were lucky my mother was working at the bank but for her to be alone was difficulty. But God being so good I secured a scholarship to senior secondary school (SSS).

Joy lived hope in her early life by working hard while in SSS to achieve her dreams and her hard work earned her a scholarship to continue her education to senior high school.

Lana also lived experiences of hope that were related to poverty, her absent father, and barriers to general education. She said:

If I may relate it to my life . . . my father didn't look after me. And it was my grandmother who looked after me. I couldn't get life so easy. But I was hoping that I would become what I am today. I have seen that my hope has actually worked . . . Laughing.

Lana learned to live with hope through poverty, an absent father, and tensions with being educated as a female. Lana faced early life challenges of dominant patriarchal thinking about her education. This culturally socialized behaviour did not stop Lana from pursuing her education. As she acknowledged "I couldn't get life so easy" tells how her hope in those days has shaped her stories to live by.

Each participant's stories to live by were shaped in their early years at home with their families, in schools, and with their communities. Focusing on the participants' experiences, revealed how past experiences, circumstances, and significant events were related to the stories they lived by when working with PLWH. These early experiences influenced the development of their identities in becoming nurses.

#### **Discussion: Gathering Threads**

As I looked across the narrative accounts of each of the nurses, I came upon insights that I did not have before. Developing the narrative threads further helped me to see things in new ways. I was reminded of LeMay's (2014) "new understanding" about teachers' "experiences of working with hope-focused practices" (p. 185). According to LeMay et al. (2008), hope-focused practices are: "paying attention to hope, listening with whole being, encouraging reflection, engaging the 7C's<sup>5</sup> of hope and participating in community service" (p. 35).

As I reflected more closely on the four threads that surfaced and as I looked across their stories to live by: becoming a nurse for PLWH over time; practicing with hope, despite hope threats; faith in God from which they gained strength; and learning to live with hope from childhood, I pondered LeMay's notion of new understandings. With the notion of new understandings, I present what I learned from being alongside Eva, Lana, Berth, Joy, and Jude using the three-dimensional space of temporality, sociality, and place (Clandinin, Caine, Lessard, & Huber, 2016; Clandinin & Connelly, 2000).

In this study, I found myself puzzling over how nurses experienced hope in their professional practice settings when working with PLWH. I wondered how nurses experienced and sustained their hope after I had completed my masters work (Puplampu et al., 2014). As I continued to contemplate nurses' experiences of hope in HIV care settings, I felt tensions between my hope-focused (LeMay, Edey, & Larsen, 2008) self and how others storied me. I have always storied myself as a hopeful person but never thought of how I enact and engage hope in my nursing practice. As I looked across the participating nurses' narrative threads, I

<sup>&</sup>lt;sup>5</sup> The 7 C's of hope are community, communicating, coping, caring, creating, committing, and celebrating (LeMay, 2014, p. 39).

thought about how they appeared to embody a way of living over time with hope from their experiences. The stories of the participants showed how strongly they experienced hope in their practice. I use the three dimensional narrative inquiry space to discuss the four resonant narrative threads.

Temporality. Time impacted the nurses' experiences of hope, at different places and with different people: when the nurses were born, when they went to school, when they entered nursing, when they started families, and when the HIV epidemic surfaced. All shaped the participants' experiences of hope. Drawing on Clandinin and Connelly's (2000) narrative conception of experience, that is, that every event is linked to past, present, and future, I noted that past experiences of nurses in their practice shaped their growth and development to become nurses working with PLWH. The nurses entered nursing when the HIV epidemic had already surfaced. The participants all experienced fear initially, as many of their patients were dying. Farran, Herth, and Popovich (1995) noted that before the arrival of antiretroviral therapy (ART), persons with a diagnosis of AIDS had significantly lower levels of hope than persons with other terminal diagnoses. This low hope for patients with a diagnosis of AIDS corresponded to nurses' experiences of low hope in working with PLWH. The high death rates amongst people with AIDS were also connected with high stigma perpetuated by nurses, patients' families, and society. Stigma was a significant force in shaping the patients' and nurses' experiences. It was at this time (early 1990s), that Eva and Berth both worked as nurses in the HIV setting. When ARVs became available nurses' experiences were shaped in more hopeful ways. For the participants in this study, ARVs allowed them more hopeful experiences as the patients began to live longer.

Hope researchers Li and Larsen (2012) related cultural attitudes to hope's impact. Therefore it was not surprising that with the first surfacing of the HIV epidemic, the stigma was intense. However, the culturally motivated impact of stigma (Li & Larson, 2012) has continued unabated as deeply rooted cultural norms and religious beliefs deepen the "old wound".

The participating nurses' experiences began to shift from being fearful to hopeful over time. I learned that over time the nurses' experiences of hope shifted their stories to live by, who they were, and were becoming as nurses who worked with PLWH.

**Sociality.** Sociality, another dimension of narrative inquiry, draws "attention to personal conditions and, at the same time, social conditions where personal conditions include feelings, hopes, desires, aesthetic, reactions, and moral dispositions of both inquirer and participants" (Clandinin et al., 2016, p. 24). Nurses in this study experienced challenges to their practices because of the stigma of working with PLWH. Eva and Lana experienced hope threats from a colleague's attitude towards them as nurses working with PLWH. Lana was distraught as she wept at the entrance to the HIV Unit; Berth felt deprived for not receiving adequate supplies; Joy felt anger over the shortage of ARVs; and Jude experienced threats to her hopeful practices because of patients' non-compliance. Understanding their experiences helped me to empathize with the nurses and allowed me to continue to experience hope.

The participants also experienced deep personal beliefs in God. Their experience of faith in God was very conscious as the nurses demonstrated their renewed sense of hope in prayers and meditations as well as devotion with PLWH. Their belief in God gave them strength to continue to practice as HIV nurses as they believed the current situation will pass.

I understood what hope meant to them when caring for PLWH and how they had learned

to engage in hopeful practices. I believe that the conversations with the nurses about their stories to live by (Connelly & Clandinin, 1999) shifted their experiences of working with PLWH. Mill and colleagues (2013) point out that nurses who provide care for PLWH also have concerns about their well-being and health, the complexity of their role, and the HIV care related stigma. They showed that making hope visible can help nurses overcome some of the uncertainties and the fear about HIV and AIDS work. The conversations the nurse participants and I had about their experiences was a way for them to make their hope visible. As I contemplated the sociality of the nurses' experiences I was drawn towards my earlier readings of Herth (1990) who engaged in research with terminally ill persons and their experiences of hope in suffering. Herth reported that the patients used what she described as "hope-fostering strategies"<sup>6</sup> to support or restore hope. Although Herth was not focusing on the health care providers', the spiritually based strategies of supporting hope in the terminally ill resonated with the strategies used by the participants in this study. Another resonance was the connection with people such as priests, pastors, family, and spiritual leaders who participants often asked for prayers to protect them in their work. I thought about how hope practices give meaning to suffering. As I reflected on what I learned from being alongside the nurses, I imagined the possibilities of learning alongside others in future knowledge communities (Craig & Olson, 2002). In Craig's words "knowledge communities are safe storytelling places where educators narrate the rawness of their experiences, negotiate meaning, and authorize their own and others' interpretation of situations" (p. 116). Following from the support and safe space offered by knowledge communities they can be a buffer for suffering and help create meaning and make suffering visible.

<sup>&</sup>lt;sup>6</sup> "Hope-fostering strategies were defined as those sources that functioned to instill, support or restore hope by facilitating the hoping process in some way" (Herth, 1990, p. 1253).
In the study, people supported the nurses' hopeful practices. Some of these individuals included family, spouses, friends, and teachers; they influenced the nurses' experiences. Understanding these connections to the nurses will help stakeholders, nurse managers, and philanthropists to pay more attention to the nurses' experiences. For example, in practical terms managers like Berth relate well to their subordinates, sustaining their hopeful practices. DeYoung (2014) tells us that hope is important for life. DeYoung also points out that hope is relational and therefore is lived in relation to others. DeYoung's study affirms the work of Herth (1990) with terminally ill patients about how hope levels were positively impacted by the presence of loved ones and health care providers such as nurses. Hope threats are warded off when loved ones are near or supportive. Eva, Lana, Berth, Joy, and Jude told stories of their experiences of their family support. The five participant nurses were connected to stable families, patients, friends, and researchers who shaped their stories to live by as they learned to practice with hope in spite of hope threats.

**Place.** Ghana was the physical place of this study of five nurses' experiences of hope in HIV care. Ghana is a Sub-Saharan African country where the HIV epidemic has created panic and hopelessness for patients, their families, and health care providers. The experiences of the five nurses were shaped by the particularities of the Ghanaian context.

Clandinin et al. (2016) defined place as "the specific concrete and physical topological boundaries of place or sequence of places where the inquiry or the event take place" (p. 24). The conversations were opened at the Fevers Unit. The nurses told stories of their experiences of growing up, attending school, and of nursing before they came to work at the Fevers Unit. The nurses carried with them memories of places where they experienced hope. Eva, Lana, Berth, Joy, and Jude opened into the narrative inquiry with stories of places such as their hospitals of birth, childhood and youth neighbourhoods, primary and secondary schools, Korle-Bu nurses training college, other training facilities, and places of work. Lana experienced poverty as she had to sew to support herself financially in nursing college when she was at Cape Coast. This place of poverty reminded her of her experiences with hope. Her hope was interwoven with this place and became part of her stories to live by. Unlike Eva, Berth and Joy who were born in the city, Lana and Jude had rural neighbourhood experiences. Place shaped their experiences as they spoke of the need to feel safe in their places of work.

As Berth and Lana complained, the Fevers Unit's structures needed renovation and replacement. Jude said, "For years working here I have realised that people don't have hope in the result or the outcome or recovery of people living with HIV/AIDS, so financially they don't want to put in [money]". As I listened to Jude's story of her experiences of hope-focused practices in the Fevers Unit, she spoke more of a hope threat. I was reminded of a nurse's comments several year ago that sparked my research puzzle reverberating forward, when she said, "Let him [patient who was diagnosed with HIV] die he has given it to many people."

Working with nurse participants in this study showed the importance of sustaining nurses' hope through support and professional development. It was important to listen to the stories of the nurses in order to know how to support them. Engaging in narrative inquiry with the nurses offered a human face to the experiences of nurses who work with PLWH. To make more explicit the stories to live by and to clearly understand the conceptualization hope, I return to Farran et al.'s (1995) definition of hope:

Hope constitutes an essential experience of the human conditions. It functions as a way

of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one's world. (p. 6)

This definition makes visible the hope in human experience. LeMay (2014) drew on MacIntyre's (1981) work, who wrote that our lives are filled with "narrative fragments" (p. 17) and "represent, over time, the wholeness of who we are and are becoming" (p. 33). Narrative understandings of identity, or stories to live by (Connelly & Clandinin, 1999), emphasize that identity evolves over time, in relationships with oneself, others, and with the contexts in which we live. Narrative identity-making emphasizes the individual as the active composer of identity through experience, in relation to larger social, cultural, institutional, and temporal narratives (Clandinin, Steeves, & Caine, 2013; Connelly & Clandinin, 1999). Using the term stories to live by, Connelly and Clandinin (1999) assert that understanding professional practice in narrative terms cannot be separated from the development of identity and for the nurses in this study is also closely intertwined with hope.

#### Chapter Six: Summary, Justifications, and Implications

This study is grounded in my experience as a nurse working in the Fevers Unit at Korle-Bu Teaching Hospital in Ghana. I worked at the unit as an intern nurse after graduating from nurses' training college and before continuing my internship at the Allied Surgery Unit (orthopaedic unit). I returned to the unit after I completed my Bachelor of Nursing and was teaching at the Korle-Bu Nurses' Training College, the same college I attended.

It was while I was working with PLWH on the Fevers Unit that I met Kojo, a patient who had HIV. Working with Kojo I had an experience that made me feel hopeless as I could not respond to his question of "So am I going to die?" My transition into HIV nursing practice had been shrouded with the fear of getting infected. At the time I worked with PLWH, I lived with the thought of HIV being without a cure. It was a death sentence at the time. Following my experiences nursing in the Fevers Unit, and particularly after my experiences with Kojo, I began to wonder how, as a nurse, I could sustain my hopeful practices.

While there was much research on hope, most of the research was focussed on patients' hope. I found little research focussed on nurses' experiences of hope in relation to how they practiced. It was this lingering wonder about engaging in hopeful practices that brought me to my research puzzle in my doctoral work. The puzzle was around the question of what sustains nurses' hope when working with PLWH.

As I began to develop my proposal around sustaining nurses' hopeful practices, I engaged in an autobiographical narrative inquiry into my experiences of nursing Kojo and my experiences of nursing PLWH. In order to begin to understand this lingering wonder, I designed a narrative inquiry study to inquire into nurses' experiences of engaging in hopeful practices when working with PLWH. I engaged with five nurses who all worked in the same unit where I had worked when I finished my nursing degree. I engaged in a series of conversations with them about their experiences of hope within the HIV landscape. Following the conversations, I wrote narrative accounts of their experiences with narrative threads that emerged from, and across, their experiences. The nurses spoke of their experiences as grounded, not only in their day-to-day practices but also in their childhoods, in their training programmes, in their lives at school, and in their lives in and out of work. They also talked about their families and how the HIV-related stigma impacted their experiences.

I then looked across the five narrative accounts and discerned four narrative threads: becoming a nurse over time for PLWHs; practicing with hope, despite hope threats; turning to a faith in God from which they gained strength; and learning to live with hope from childhood. Coming to understand the experiences of the nurses working with PLWH offers important new information to the research literature around nurses' hopeful practices in nursing PLWH. I now turn to the justifications of my study.

#### Personal, Practical, and Social Justifications of Study

Clandinin and Caine (2013) argue that narrative inquirers, like other social science researchers, must be able to justify their research by responding to the questions of "so what?" and "why should we care?" They assert that these questions push us in the direction for the need to justify narrative inquiries in three main ways: personal, practical, and social/theoretical.

**Personal justification.** My research interest came out of my narratives of experience with Kojo and my inability to sustain hopeful practices alongside him; I wanted to learn more about hope. I had read about the importance of hope in nursing and in education and have also

experienced hope in my life. These deeper understandings of hope reminded me of times I heard nurses talk about experiencing no hope when they saw no possibility of recovery in a patient's illness, particularly when working with PLWH. At the outset of the study, my experience with Kojo made me wonder about the experiences of HIV nurses working with hope as a way of being in relationship with their patients and that led to my research puzzle around the question of what sustained nurses' hope when working with PLWH.

Although this wonder precipitated my research, it was not until I began to unpack the tensions in my experiences of practising with hope alongside Kojo that I began to understand tensions as an awaking to an inquiry. I opened up to recognizing tensions as a way of making a space for education and growth (Dewey, 1938). I learned, by inquiring into my experiences alongside Kojo, about the ways HIV and longevity intersect with and inform each other.

During my inquiry I stayed awake to Eva, Lana, Berth, Joy, and Jude's experiences of practising with hope in their life stories, alongside the tensions I felt about being storied as a less hopeful nurse in relation to Kojo. I learned, through listening to the stories of their experiences, about the need to allow adequate time to engage in the conversations over time to understand what sustained their hope as nurses. As I learned to listen to their experiences I learned how to engage in research through attending to tensions and to the importance of taking time to listen.

Further, attending to the experiences of the five nurses shifted my understanding of the importance of practising with hope in an HIV care settings. I awakened to another way of connecting hope, that is, to faith in God as the nurses storied themselves using faith in God to inform their hopes. I attended to Eva, Lana, Berth, Joy, and Jude's telling of their experiences about working with faith in God to inspire their hopeful thinking, acting, feeling, and relating.

Their stories of experience helped me to be more open to understanding the connections between hope and faith in God. By attending to how Eva storied her experiences as "always hopeful" living alongside PLWH, I wondered about places in my life that kept me hopeful and thought about ways to support HIV nurses. Eva awakened me to wonder about how I might attend to hope over time. I wondered about how I could become more independent, like Jude, to "family support", if it was not available in a particular time. Making a decision to live alongside PLWH without approval of immediate family helped me envision myself as practicing what I considered the greater good to the marginalized. Learning from the five nurses had strengthened my confidence and will continue to shape my stories to live by, that is, who I am as a nurse working with PLWH.

As I continued to live alongside the nurse participants who engaged with PLWH, I saw resonances of stigmatization in their experiences with hope threats, which seemed similar to mine when I engaged with Kojo. I saw how Eva was treated by her colleague when she mentioned the Fevers Unit, how Lana was told to request a transfer from the unit, and how Jude's family wanted her to decline acceptance of working at the unit. I think about how Joy used self-talk to diminish her fear. I now know that I need to embrace a way of being with hope alongside PLWH that allows me to stay open to the possibilities of being awake to what is possible when I am challenged, for example, being compassionate and accommodating in my approach and accepting everyone for who they are and are becoming strengthens my hope.

This rejuvenation of my hope brought me to pay attention to how I story other nurses. I was reminded of co-composing experiences and how I was also being part of the experience being studied (Clandinin & Connelly, 2000). As I stay awake to what I am learning I am

equipped to continue to raise tensions around how nurses' hope is shaped by the responses of their patients, administrators, patients' families, and other healthcare providers in working with PLWH.

As a result of my autobiographical inquiry and my experiences with the five nurse participants, I understand the importance of not imposing my ways of working with hope. There are multiple ways of engaging in practices with hope. I need to attend to, accommodate, and make space to discuss hope and hoping so that I do not diminish hope in my own life stories nor do I diminish hope in those who I come alongside, including patients, their families, and other nurses. I believe that creating spaces to inquire into the tensions that I experienced enabled me to continue to live on the nursing landscape in a way that was life sustaining. By staying awake to who I was and was becoming, I imagined myself participating in a future that was personally meaningful (Farran et al., 1995; Jevne, 1994; Stephenson, 1991) through working with PLWH.

**Practical justification.** As I transitioned from field texts to research texts, questions of the phenomenon under study lingered in my mind. My puzzle was focused on the experiences of hope among nurses in Ghana who were working with PLWH. Paying attention to the practices of the nurses revealed how vulnerable they felt in their work.

I awakened to how over time they could learn to practice in hopeful ways with PLWH but they could also lose their hope over time with hope threats. Understanding how nurses working with PLWH experience, practice, and live their hope was important in the face of this challenging work, as it can shape the care of and the relationships with their patients as well as shape their own lives. It is necessary to appreciate how a nurse's experience of hope in their daily practice can shape patients' living and dying, and also impact their families. Hope is critical when providing care for PLWH and their families due to several layers including stigma, chronicity, stress, discrimination, and fear of progression to AIDS.

In view of this importance, hope has been researched in many fields including physical and mental health, education, sports, and even business with a focus on practice to provide new knowledge on how hope can be effectively applied (www.ualberta.hopestudies.ca). In this study conversations allowed participants and I to think with hope and to make visible possible ways that hope could be sustained through caring relationships. Some possible ways to sustain a caring relationship include diverse sources of support from family, colleagues, administrators, and others, the sharing of information on hope and HIV, and the encouragement of closeness so that a sense of belonging is fostered. It is important to recognise hope as integral to their identity.

At the same time, it will also be valuable if hope is integrated into the nursing curriculum and delivered as a separate course. The course needs to bring forward individual experiences of becoming nurses, and in this way provide the opportunity to make hope more visible and show that hope has personal and social dimensions.

Through this narrative inquiry, nurses made visible what hope meant to them when caring for PLWH and how they had learned to make hope part of their practices. In understanding hope better, we can potentially inspire nurses' hopeful practices. HIV is flooded with stigma and discrimination, and HIV nurses had experienced many of these challenges. Yet, through hope they implemented more sustainable and meaningful care practices that sustained them as they continued to be HIV nurses. For example, the nurses in this study practiced with hope. Over time they overcame their fear and built confidence in their work with PLWH. Understanding nurses' experiences of their hopeful practices will better help nurses face the difficulties of the complex contexts of their work. Engaging in conversations such as in narrative inquiry can shift nurses' interactions with HIV and AIDS patients. As nurses have an opportunity to tell and retell their experiences of working in hopeful ways with PLWH, they will be more able to build bridges on and off their professional landscapes as they embrace who they are and are becoming alongside others in their nursing careers.

Another difference that this study has made is that it draws attention to the ways working with PLWH threatens nurses' experiences of hopeful practices. Attending to nurses' narratives of hopeful practices encourages nurses to continue working with hope and to maintain their hope in ways that mitigate the difficulty and vulnerability of nurses' work. Making hope visible can help nurses overcome some of their uncertainties and fears about working with PLWH. As hope practices are intentionally promoted in nursing schools, nurses are likely to become more courageous in the ways they engage in hopeful practices.

**Social justification.** Clandinin and Connelly (2000) wrote that in justifying narrative work in either social or theoretical terms, we need to pay attention to the contexts which are ever present in narrative thinking. Exploration of nurses' experiences of hope in HIV and AIDS care in the context of nursing in Ghana can provide new knowledge to inform policies that will support hope in HIV care.

According to Clandinin and Connelly (2000), narrative inquiry stems from the epistemological standpoint taken by Dewey's (1938) pragmatic philosophy, a view that supports a realistic approach that views knowledge as rising from a dynamic involvement of humans with their environment. Dewey claimed that humans gain understanding (or come to know) through

being in connection with the physical, social, and the personal dimensions of their respective experiences as time unfolds. Conceptualization of hope offers a unique opportunity to intensify hope practices in nursing as the concept becomes more flexible and adaptive to nursing work. I believe that hope practices in HIV and AIDS care do not only provide a buffer for the challenges associated with such areas of nursing practice, but also have the potential to address the stigma and the discrimination often associated with PLWH. Unlike other scholars (Bally et al., 2014; Harris, & Larsen, 2008) who used other ways of understanding hope, narrative inquiry methodology of studying hope practices offers a human face to nursing and therefore can contribute to nurses' experiences of hope and hope inspiration.

Moreover, scholars of hope have established that hope is "a necessity in daily life as well as in times of adversity" (Jevne & Miller, 1999, p. 7). Following from what Jevne and Miller state, hope then would be vital in health care, especially in terminal and chronic illnesses where daily life is threatened. In this study, I tried to make hope visible by living alongside HIV nurses. Jevne and Miller (1999) noted the importance of attending to experiences of hope as a way of life. There is agreement from both hope scholars and healthcare providers that experiences of hope are important for well-being (Mok et al., 2010). Through making visible the nurses' experiences of living hope in their practices, the study may have contributed to the nurses' well-being.

Hope is a process that unfolds in various ways across one's life. The nursing literature suggests that nurses are an important source of hope to the less hopeful and the helpless (Cutcliffe & Gant, 2001; Haugan, 2014; Herth, 1990, 1996; Moore, 2005; Stephenson, 1991). Accordingly, having a sense of hope in their work will be a valuable resource. Jevne and Miller

(1999) also remind us that hope is essential for quality of life. If we want nurses to do well in their practise, they need to feel a sense of hope.

I was intrigued by how using narrative inquiry helped bring attention to the nurses' physical environment as a contributing factor to low hope and poor nurses' outcomes in nursepatient interaction. These findings showed that low hope can shape nurses' interaction with not only patients but with their own experiences and their identities as nurses. Not only does hope help them to face their concerns and view their challenges from different perspectives, it also equips them for continued care in HIV. This study is particularly significant for HIV nurses given their comparatively less favourable health outcomes of their patients.

Many hope scholars (Clayton et al., 2008; Cutcliffe, 1995) explored other ways of understanding hope mostly by means of interviewing participants at one sitting, to tell how nurses instill hope in their patients. While these studies provide patterns that highlight the need to pay attention to the prevailing hope factors, none of those studies reflect hope as way to reduce stigma. I also recognize that those studies do not speak to the storied experiences of HIV nurses. I wondered if the nurses' stories to live by shifted during moments of conversations. I remembered how difficult it was for the participant nurses to describe what hope was about. Yet through the conversations I could see that their hope practices evolved over time and shaped their identity and their practice.

As I read these research stories, I was brought back to the stories Eva, Lana, Berth, Joy, and Jude shared during our time together as they told stories of what made them hopeful. For Eva and Berth the patients' dedication to being models of hope for PLWH was a way they could each experience hope over time and compose new stories to live by, that is, new stories of who they were as nurses. I learned that as Lana transferred to the Fevers Unit, she learned to hope and overcame her fear over time. While I heard of their struggles, I also heard about their experiences of hope; these were sustaining stories that made Eva, Lana, Berth, Joy, Jude, and their patients live hope every day.

I wondered how policies could be shaped around the storied experiences of hopeful nurses. I wondered how we could create hope education spaces for HIV nurses as they experienced multiple transitions in their lives. I wondered how we could better attend to their experiences and work with them as they composed lives within challenging landscapes of hope threats. Being a nurse and researcher, I wondered if we should create an HIV care providers program in health care settings that centred on hope. While I see an openness in wanting to become more attentive to HIV nurses and their patients' lives, the intention of this narrative inquiry is not to offer a guide on addressing the needs of HIV nurses. What I want to make visible is that it is important that HIV nurses think with, and work with, their experiences of hopeful practices in order to open conversational spaces and inquiry spaces where they can share and inquire into their hope experiences. I echo Jevne and Miller's (1999) feelings about the ubiquitousity of hope. Hope is everywhere, they said. As a researcher, nurse, nurse educator, and human being it is important for me to see HIV nurses as hope inspirers. To be able to shift and narrate our own stories to live by, it is important to honour all lives with an understanding that we are all connected to hope. Moreover, it is important this study offers some implications for practice.

#### **Implications for Practice**

To state some implications of this study there is a need to review the study's main aim which was to understand what sustains nurses' hope when working with PLWH. The five nurses' experiences of hope were shaped over time as they began to be less fearful. Over time, they told of their experiences of learning to engage in hopeful practices with PLWH.

One major practical implication of the present study is that it provided research texts on the ways nurses experienced working with PLWH. These close up accounts of nurses' experiences, seeing big in Maxine Greene's (2015) terms, allows policy-makers, nurse educators, consultants, and stakeholders to design initiatives and actions based on the nurses' daily experiences. While most of the focus in the past has been on providing nurses with educational and mentorship opportunities to enhance their knowledge and skills about HIV and AIDS, and/or to create positive attitudes towards PLWH, the present study allows us to understand nurses' experiences of hope when working with PLWH. With this knowledge there could be the possibility of redesigning pedagogical possibilities for nurses working with PLWH. For example, when nurses stay wakeful about how they are experiencing their practices, they attend more carefully to their practice. If policy makers focus on creating conducive environments for nurses to engage in hopeful practices rather than focussing on only improving the practices through professional development programmes, nurses' experiences may change.

As the present study shows, the nurses, over time, began to experience less fear and concern about working with PLWH. As they sustained their hopeful ways of engaging in their practices, perhaps they showed themselves, and others, that the powerful stigmas around HIV were less pervasive. Perhaps over time their practices may minimize the feelings of negative

behaviours and discrimination, and over time reduce the stigma. According to Fredrickson (1998) and Jevne (2005) hope can function as a protective factor to disapproval, consequently it follows to reason that positive and hopeful practice enhancement activities can reduce the stigma and promote cultivating positive attitudes toward PLWH and their health care providers. The results of the present study resonate with the study by Mill et al. (2013) who highlighted as problematic the glaring stigma which contributes to nurses' stress and challenges them to provide meaningful care experiences.

As the present study shows, the five participating nurses learned, over time, to sustain their practices. It is important that nurses' voices are heard in policy formulations to influence decisions that affect PLWH and the nurses who work with PLWH. This can be done through active participation in lobbying and initiating policy change actions such as presentations at forum or seminars. Policies that support nurses' experiences of engaging in hopeful practices may, over time, reduce their experiences of hope threats, that is, reduce what can cause them to stop engaging in hopeful practices. In this sense, the present study is especially timely in the face of the stigmas that HIV nurses face daily in their work.

While the present study adds to existing knowledge about the five nurses' hopeful experiences in the context of HIV, the experiences of the nurses may also provide some insight into the larger cultural, social, and institutional narratives that shape all nurses' experiences of working with PLWH. For example, the experiences highlighted the importance of family support from relatives or families of PLWHs in relation to the nurses' hope as well as PLWH's wellbeing. Another institutional narrative is the lack of infrastructure support to the Fevers Unit which is the largest HIV health facility in the country. Moreover, the nurses' hopeful

experiences also speak to the cultural narrative of unprotected sexual practices that reflect PLWH's lack of attention to the danger they pose to their non-infected partners when starting a sexual relationship. The nurses' experiences also spoke to the social stigma, emanating from cultural beliefs of the promiscuity of persons who contract HIV, phenomenon associated with fear of contagion. These reflectors of the cultural, social, and institutional narratives are related to the nurses' experiences of hope and provide important information about HIV as a social illness in the health landscape.

The research text is a useful source of knowledge given the in-depth conversations focused on exploring the experiences of five HIV nurses that relate to both the personal and the social aspects of the experiences of HIV nurses in Ghana. Hence, this study could be making visible the institutional stories of HIV care in a specific HIV setting. Nurses working with PLWH work in poor conditions, a direct reflection of the economic situation and related policies that affect nurses' work in Ghana. Since the Korle-Bu Fevers Unit is the largest unit for HIV care in Ghana, the larger social and institutional issues that shape the Ghanaian health context are magnified there.

Another implication of the present study relates to the narrative thread of faith in God from which the participating nurses gained strength. The findings show how the participants' deep faith shaped their experiences and practices of hope. Working from deep beliefs in God shows the ways the participating nurses overcame stigma and judgmental attitudes to see PLWH first as humans and not as stereotypes. However, I wonder how their care would be impacted if patients did not share their beliefs. Nurses, by ethical standards, are obligated to be fair and nondiscriminatory towards their patients, and to provide care to all, no matter their colour, creed, or religion. Faith-based hope is important but must not be imposed.

Another implication of the present study is the importance of attending closely to the ways that childhood experiences shape nurses' experiences of engaging in hopeful practices with PLWH. The findings suggest that living with hope, understood as a series of practices that support, foster or hamper continually evolving hopeful experiences, is a personal and social experience that is learned over time beginning in nurses' early life experiences. Furthermore the study shows the ways that particular contexts such as place, poor purchasing power of PLWH and their families, and relationships shape nurses' experiences of engaging with hopeful practices. The research suggests the importance of attending to the contexts of nurses' practices so that they do not lose their ability to sustain their hope over time. For example, through professional development or continuous education, hopeful practices could be taught, developed, and improved through a constant self-reflective way. Reflections will provide a continual monitoring of nurses' personal and social contexts and will help sustain the practices of hope. The present study suggests the main dimensions of a framework for reflecting on the personal hope of HIV nurses. Such dimensions, which were derived from the three-dimensional narrative inquiry space (Clandinin & Connelly, 2000), shows the nurses carry memories of their experiences and how they were shaped over time.

#### **Theoretical Contributions**

Previous research has shown that hope makes a differences in the lives of terminally ill patients and is perceived as a motivational force interacting between agency and pathways. Other researchers (Farran, Herth, & Popovich, 1995 also provide us with the dimensions of hope, including the experiential, spiritual, relational and rational attributes. Hope allows people to feel, think, behave, and act in ways that promote wellbeing. While almost all research has focused on looking at the experiences of hope in patients, my research in particular advances the theory of hope in relation to nurses. In my study I show that hope matters to nurses and that it matters to their practice. I demonstrate that paying attention to one's hope can lead health care professionals, such as nurses to increased strength, that hope helps to ward off the stigma associated with HIV, and that hope can help nurses' better deal with the discrimination and fear that is present in HIV care. Specifically, the mere discussion about hope among HIV nurses leads to increased attention to hope, which brings forward hope-focused practices. Through my research I have experienced that the increased attention to hope results in an increased nurturing of hope. This research provides a unique theoretical contribution to hope theory and shows that hope is always in flux, that hope can grow and that hope can also be taken. Hope is closely link to the identity of the nurses I worked with in this study. This way of understanding hope, reflects a narrative conceptualization of hope.

By carefully listening to participants experiences, and by reflecting on my experiences alongside participants, we can see that hope matters, but that it can not to be imposed. This research shows that hope grows, that hope is not static and that in order to grow in our hope, we need to practice hope. Counter to what one might expect, hope grows in hard times and hope grows over time and hope experienced at earlier times can sustain us long after it is experienced. The availability of resources and supportive environments are shown to sustain hope, particularly at times when nurses find it difficult to practice or are faced with challenges.

#### **Future Research Possibilities**

This study suggests four possible future directions for research, both in terms of honouring personal knowledge and understanding of nurses' experiences of hopeful practices.

First, the present study could be extended in longitudinal and comparative ways. For example, the present study shows how nurse participants' experiences are grounded in their childhoods. These early childhood experiences around hope shaped their further experiences. Engaging in additional studies with nurses who were born at later times when there was the availability of ARVs may show that younger nurses experience more ease in moving into work with PLWH.

Second, further research about the experiences of nurses now in their work could also take a historical perspective and ask if the work of HIV nurses has significantly changed in the last several decades, with particular attention to hope and stigma. Also further research can help inquirers to understand if the current management of HIV as a chronic disease has had any positive impact of reducing the stigmatization. For example, in the early days of the epidemic many PLWH could not become Models of Hope, but over time they overcame the stigma and became ambassadors for HIV prevention and early reporting. In this sense such a study would provide valuable information to those tasked with educating nurses as it would suggest specific kinds of professional development training needed to help nurses sustain their hope. It could also be used to signal the equipment needs of the nurses to support their hopeful practices alongside PLWH.

Third, another study could be how nurses' experiences with their managers help them sustain their hope. Understanding nurses' experiences with their managers in the HIV landscape

would provide information on how collaborative relationships work, and how supportive managers can shape nurses' hope. Such a study would provide highlights for manager-nurse relationships that allow for sustaining hopeful practices. It could also allow researchers to understand how managers work with hope in relation to nurses.

Fourth, further work is necessary to examine the practices of hope and HIV work at the level of trainees, rather than practicing nurses. The opportunity to educate nurse-trainees about nurses' work and HIV, and to open an inquiry into nurse trainees' experiences of hope will likely keep them awake to attitudes, feelings, and thoughts about HIV work. Further research can thus shed light on how hope shapes nurse trainee's transitions into HIV nursing work. It could also direct researchers about how nurse trainees develop hope and sustain hope, particularly in the face of hope threats.

In closing this chapter, I note that nurses' experiences of hope could alleviate some of the tensions brought on by HIV-related hope threats (such as stigma) so that HIV nurses could be in a position to practice their profession with the goal of enhancing wellbeing and health outcomes for themselves as well as PLWH and their families. This study represents one of the first qualitative inquiries into the hope experiences of nurses who work in HIV care at the Korle-Bu Teaching Hospital in Ghana. All of the five participants showed us how deeply hope was impacting their practice as nurses and how their stores to live by were marked by hope over time. Over time the participants practiced with intentional hope and showed that hope practice in HIV care is an imperative in today's world of nursing. My work echoes LeMay's (2004) narrative conceptualization of hope.

#### Conclusion

In summary, this study explored nurses' experiences of hope in the context of HIV in Ghana. It shows that participant nurses' experiences were shaped over time as they worked with PLWH and as they learned to practice with hope. In this sense, the nurses' hopes were shaped from their early years as they experienced hope in their homes, schools, and communities. This study also pulled forward the importance of understanding how nurses experience working with HIV and AIDS and suggests ways that we can work with them to sustain their hopeful practices through support and professional development. The study shows the relations between the Ghanaian nurses working with PLWH within the HIV world of nursing practice; yet it also left me with puzzles and uncertainties about the ways in which the Ghanaian nurses negotiated hopeful practices within institutional and social narratives of stigma and poverty that were often discouraging. The study made visible shifting identities among the Ghanaian nurses as they shaped, and were shaped by, the landscapes and relations within which they lived and worked. The study further developed narrative understandings of identity as stories to live by (Connelly & Clandinin, 1999) in HIV nursing. This complemented my justification of exploring what it meant to be and live and practice with hope as an HIV nurse.

Finally, as nurses continue to practice care for PLWH and hope for cures for the illness of HIV and AIDS, they, and we, will continue to face challenges to experiencing hope in their practices as they continually face poverty, stigma, and lack of resources. Despite such challenging contexts, we need to find ways to sustain nurses in their hopeful practices.

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#### Appendix A

#### **Information Sheet letter**

#### April 08, 2014

Dear participant (I will insert names after contacting participants)

This letter is an invitation to consider participating in a study entitled: **Narrative Inquiry Into Experiences of Nurses working with Hope in HIV and AIDS Care Setting** that I am conducting as part of my PhD degree in the Faculty of Nursing at the University of Alberta under supervision of Dr. Vera Caine and Dr. Solina Richter. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

#### Background

Over the years, nurses have played a significant role in HIV and AIDS nursing services delivery, and research in the past decade suggests participation in this sector is rapidly increasing. Coincidentally, HIV infection is becoming a chronic disease and nurses in this area are likely to increase their capacity to cope with workload, burnout, and associated unpleasant attitudes due to the impact of the stigma and discrimination. Thus it is not surprising that there seems to be a report of burnout and issues of wellbeing among nurses who work with people who have HIV and AIDS. Interestingly, how nurses in HIV and AIDS are able to experience hope in their work is beginning to develop in nursing. If we knew more about how nurses work with hope in HIV and AIDS nursing we may be able to overcome some of the discouragement and burden of emotional stressors associated with HIV and AIDS care among nurses, and increase the numbers of nurses choosing to work in this expanding area.

## Purpose

The purpose of this study is to investigate how nurses work with hope in HIV and AIDS nursing. This study will focus on identifying strategies that have shaped nurses' hope work with individuals who have HIV/AIDS. When faced with an infectious disease, such as the HIV/AIDS, it is important to understand how nurses work with hope in such fields. I would like to invite you to participate in my study. I believe that because you are actively involved in providing care for people with HIV/AIDS, you are best suited to speak about how you work with hope and what threatens your hope in this area.

#### Procedures

The study will involve up to number of conversations of approximately 45 to 60 minutes each and will take place in a location that we mutually agreed upon. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time by advising the researcher, with no questions asked. With your permission, the interviewer will audio recorded the interview, so that it can be transcribe to facilitate analysis. All information you provide is confidential. Your name will not appear in any thesis or report resulting from this study, with your permission, however, anonymous quotations may be used. All study materials will be kept in a locked office in my supervisor's lab. Only my committee members and I will have access to it.

## **Possible Benefits**

You would not receive any remuneration for participating in the study. I hope, however, that the results will benefit organizations that provide care for individuals with HIV as well as individuals with HIV and AIDS who receive care provided by nurses specialized in this area.

#### **Possible Risks**

There are no known or anticipated risks to you as a participant in this study.

#### Confidentiality

Your personal records will be kept confidential. Any research data collected about you during this study will not identify you by name, only by your initials and coded number. Your personal information will not be disclosed. Any report published as a result of this study will not identify you by name. By signing the consent form you give your permission for the collection, use and disclosure of your views and reasons that inform your hope practices in HIV care. In Canada, study information is required to be kept for 5 years; Even if you withdraw from the study your biographical data will not be destroyed for the duration of this period.

#### **Voluntary Participation**

Participation in this study is voluntary. You are free to withdraw from the study at any time and will not affect you in any way.

#### **Contact Names and Telephone numbers**

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at (780) 977.0970 or by email at **puplampu@ualbert.ca**.You can also contact my supervisor, **Professor Vera Caine** at (780) 492.7201 or email **vera.caine@ualberta.ca**. I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Health Sciences Research Ethics at the University of Alberta and the Office of the Noguchi Memorial Institute of Research, University of Ghana, and Ghana Health Services However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact the Chair, **Prof. Glenn Griener** (Panel B: Social and Behavioral Health Research) at (780) 492.6582 or email to **glenn.griener@ualberta.ca or** *Chair* **Dr. Samuel Ayete-Nyampong** (The Noguchi Memorial Institute for Medical Research IRB) at 233 21 501 178 or email to **director@noguchi.mimcom.org** 

Please be advised that this office has no affiliation with the study investigator and supervisors.

I hope that the results of my study will be of benefit to nurse in HIV and AIDS care in Ghana and Korle Bu Teaching Hospital that is directly involved in the study as well as to the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Gideon Puplampu

PhD Candidate Faculty of Nursing, University of Alberta

#### **Appendix B**

#### **Consent Form**

# Title: Narrative Inquiry into Experiences of Nurses working with Hope in HIV and AIDS Care Setting

Your signing of this consent form does not waive your legal rights nor are you discharging the investigator from his legal and professional responsibilities.

I have read the information letter about a study being conducted by Gideon Puplampu PhD student of the Faculty of nursing at University of Alberta. Yes  $\Box$  No  $\Box$ 

I have had the opportunity to ask any questions related to this study and have received satisfactory answers to my questions, and any additional details I wanted. Yes  $\Box$  No  $\Box$ 

I have received a copy of the information letter  $Yes \square No$ 

I understand who will have access to my personal information. Yes  $\Box$  No

I agree that my interview may be audio recorded to facilitate data analysis. Yes  $\Box$  No  $\Box$ I agree that excerpts from my interview may be included in the thesis and/or publications that may come from this research, with understanding that the quotations will be anonymous.

Yes  $\Box$  No  $\Box$ I was informed that I can withdraw from the study at any time without penalty by advising the<br/>researcher.Yes  $\Box$  No  $\Box$ I understand there are no risks or benefits attached to this study except for possible emotional<br/>risk and that which treatment will be available if required.Yes  $\Box$  No  $\Box$ This research project has been reviewed by, and received ethics clearance through the Office of

Research Ethics at the University of Alberta and Nuguchi memorial research institute, university of Ghana. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Chair **Prof. Glenn Griener** (Panel B: Social and Behavioral Health Research) of the Ethic Board. *Yes*  $\square$  No  $\square$ *Chair* **Dr. Samuel Ayete-Nyampong** (director@noguchi.mimcom.org) *(*The Noguchi Memorial Institute for Medical Research IRB) *Yes*  $\square$  No  $\square$ 

With full knowledge of all foregoing, I agree of my own will, to participate in this study.

Signature of investigator ...... Date......

Yes  $\square$  No  $\square$ 

## Appendix C

#### Guiding questions (Adapted from EDPY 546 with some modifications)

- 1. Please tell me the story of what makes you hopeful in working in HIV/AIDS nursing.
- 2. When you think about the future, what is it that threatens your hope as HIV/AIDS Nurse?
- 3. . How hopeful are you on a scale of zero to ten, where zero represents no hope?
- 4. How do you explain the number you chose? Why isn't it higher? Why not lower?
- 5. Is there anyone whose presence or behavior influences your hope?
- 6. Are there days that you feel more hopeful than others? How do you explain that?
- 7. How does your hope impact others in your practice?

## Appendix D

## Ethical approval from University of Alberta

#### hero@ualberta.ca

10/21/15

to gideon.puplampu



## Amendment/Renewal to Study has been Approved

Amendment/Renewal ID:	Pro00052132 REN1
Study ID:	MS1_Pro00052132
Study Title:	A Narrative Inquiry Into the Experiences of Hope in Nurses who Work With People Living With HIV
Study Investigator:	<u>Gideon Puplampu</u>
Description:	The amendment/renewal to the above study has been approved.
	Click on the link(s) above to navigate to the HERO workspace.
	<b>Important</b> : Please be reminded that the <u>REMO system works</u> best with Internet Explorer or Firefox.
	Please do not reply to this message. This is a system- generated email that cannot receive replies.
University of Alberta Edmonton Alberta Canada T6G 2E1	

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## hero@ualberta.ca

to gideon.puplampu



## Ethics Application has been Approved

ID:	Pro00052132
Title:	A Narrative Inquiry Into the Experiences of Hope in Nurses who Work With People Living With HIV
Study Investigator:	<u>Gideon Puplampu</u>
	This is to inform you that the above study has been approved.
	Click on the link(s) above to navigate to the HERO workspace.
Description:	<b>Note</b> : Please be reminded that the <u>REMO system works best with</u> Internet Explorer or Firefox.
	Please do not reply to this message. This is a system-generated email that cannot receive replies.
University of Albert Edmonton Albert Canada T6G 2E	a

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## **Appendix E**

## **Ethical Approval from Nuguchi-Ghana**

## NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH

Established 1979 A Constituent of the College of Health Sciences University of Ghana

Phone: +233-302-916438 (Direct)

+233-289-522574

Fax: +233-302-502182/513202

My Reference: DF 22

September 20, 2017 PhD Cand. Gideon Lawer Puplampu Uni.of Alberta, Faculty of Nursing,Level 3, Edmonton Clinic health academy Edmonton - Alberta

RE: Our Study # 044/14-15 RESEARCH-IRB At: NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL

Dear Gideon Lawer Puplampu:

Meeting Date: 3/8/2017 RESEARCH-IRB Protocol Title: At: NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL

A Narrative Inquiry into the Experiences of Hope in Nurses who Work With People Living With HIV

This is to advise you that the above referenced Study has been presented to the Institutional Review Board, and the following action taken subject to the conditions and explanation provided below.

Reason 2:

Internal #:1621Expiration Date:3/7/2018On Agenda For:RenewalReason 1:Progress ReportDescription:RenewedIRB ACTION:RenewedCondition 1:ActionExplanation:Image: State of the state of t

Yours Sincerely, NMIMR-IRB





**IRB** Administrator

## NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH Established 1979 A Constituent of the College of Health Sciences University of Ghana

Phone: +233-302-916438 (Direct)

+233-289-522574

Fax: +233-21-502182/513202

My Reference: DF 22

September 20, 2017 PhD Cand. Gideon Lawer Puplampu Uni.of Alberta, Faculty of Nursing,Level 3, Edmonton Clinic health academy Edmonton - Alberta

**RE: Our Study #** 044/14-15 RESEARCH-IRB At: NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL

NMIMR-IRB

581

P. O. Box LG

Dear Gideon Lawer Puplampu:

 Meeting Date:
 1/6/2016
 At:
 NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL

 RESEARCH-IRB
 Protocol Title:
 Protocol Title:

A Narrative Inquiry into the Experiences of Hope in Nurses who Work With People Living With HIV

This is to advise you that the above referenced Study has been presented to the Institutional Review Board, and the following action taken subject to the conditions and explanation provided below.

Internal #:1202Expiration Date:1/5/2017On Agenda For:RenewalReason 1:Progress ReportDescription:RenewedIRB ACTION:RenewedCondition 1:ActionExplanation:Image: State of the state of t

Reason 2:

Yours Sincerely, NMIMR-IRB IRB Administrato

