PRACTICAL WISDOM GAINED FROM JOURNEYING WITH HIV: NARRATIVE THERAPEUTIC CO-RESEARCH

By

Danelle Stiglingh

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Department of Psychology

Faculty of Humanities

University of Pretoria

Supervisor

Prof. M. J. Visser

&

Co-supervisor

Prof. L. H. Human

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Researcher: Danelle Stiglingh

Supervisor: Prof. Maretha J. Visser

Co-supervisor: Prof. Lourens H. Human

University: University of Pretoria

Faculty: Humanities

Department: Psychology

Degree: MA Counselling (Community) Psychology

DECLARATION

I, Danelle Stiglingh, hereby declare that this research report is my own work, except where acknowledgements indicate otherwise. In addition, I declare that this work has not been, is not in the process of, and will not in the future be submitted at any other tertiary institution for any degree.

Danelle Stiglingh
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SUMMARY

Stories about HIV are everywhere. They are told (i.e. constructed), heard (i.e. taken in) and then re-told (i.e. shared). It is when we start asking questions about such stories, that new story "versions" become available; to be told, heard and possibly retold. Given the methodological boundaries connected to HIV research, few research studies are able to utilize the research context to venture beyond the mere collection (i.e. hearing) and re-telling (i.e. sharing) of story experiences. As a result, the hidden, alternative story "versions" which are "awakened" during the research process, may remain untold.

Over the course of 4 months, the researcher utilized the existing dialogical space of the therapy context, as a practical platform for researching the dominant, as well as the "absent but implicit" meaning of HIV. Through ongoing dialogical interaction, this research journey set out, to not only hear the dominant stories told about HIV, but also to explore the hidden, preferred alternative story "versions". An adolescent girl living with HIV acquired through mother-to-child transmission, collaborated with the researcher to engage in this journey of therapeutic co-research. With this narrative report, I invite you to become an audience member to this unfolding journey. Throughout this report, I used the word "journey" as a guiding metaphor, situating the act of meaning making as a collaborative ongoing process of co-research, rather than a collection of facts. This research report is a narrative in itself and is subdivided into three parts. Part I includes all chapters written before my journey with the adolescent as co-researcher; part II includes all aspects related to our journey as co-researchers; and part III involves the time period after our journey as co-researchers.

In part I, chapter 1, I introduce you to my way of speaking (i.e. narrative language), grounded in my way of seeing (i.e. social constructionist paradigm). In chapter 2, I shared with you my own narrative in making sense of HIV through personal reflective journal entries. By doing so, I acknowledge that I, researcher and therapist also tell stories about HIV through my statements, questions and everyday actions and interactions. In chapter 3, I reviewed academic literature in an attempt to research how adolescent HIV is "authored" (narrated) to the public by various academic discourses. In chapter 4, I reviewed narrative research studies of illness stories, relevant to adolescent HIV. Hereafter I stated my research question, justification, aim, and objectives. In chapter 5, I provide an overview of the research process, as was undertaken for the purpose this journey.

In part II, I introduce you to "Gabby" (pseudonym), my co-researcher and co-author of this narrative report. Gabby regularly received ART at the paediatric out-patient unit at Kalafong Tertiary Provincial Hospital at the time of our interaction. In chapter 6, I describe the project phase (chapter6), alongside Gabby's participation. The project phase was situated within a narrative social constructionist frame. It consisted of two sub-phases as a means to transform the therapeutic context to one of therapeutic co-research. The first sub-phase stretched over the course of 3 months as Gabby participated in the Collaborative Storybook Development (CSD) project. The CSD project was based on the narrative therapeutic work of Freedman and Combs (1996) on story construction and development. Each session was video recorded for the purpose of co-reflective discussion during the second sub-phase. Focussed co-reflection sessions formed the second sub-phase, which took place once a week and stretched across an additional 1 month period. The aim of this sub-phase was to collaboratively review how storytelling was employed to make sense of HIV throughout the CSD project. Over the course of four months, the project phase allowed for in-depth co-research into the meaning of HIV.

Part III documents the time period following our journey as co-researchers. Chapter 7 is a reintegration (telling) of the new knowledge and practical wisdom constructed during the project phase. Such "telling" is done in the form of a storybook. Chapter 8 sheds some light on the narrative practice of reincorporation (sharing). This involved the sharing of new knowledge with audiences outside of the co-research dyad. In chapter 9, I discussed the ethical considerations undertaken in this research. This is followed by a discussion on the shortcomings and limitations of this journey. Based on the practical wisdom gained from this journey, recommendations are made for future endeavours.

KEY WORDS

HIV; HMTCT; Adolescence; Storytelling; Narrative; Meaning; Narrative
Therapy; Narrative Social Constructionism; Therapeutic Co-research; Narrative
Health Psychology

Recommendations

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ABREVIATIONS AND DESCRIPTIONS

Abbreviation	Description
AIDS	Acquired Immunodeficiency Syndrome
ALWH	Adolescents Living with HIV
APA	American Psychological Association
ART	Antiretroviral Therapy
BPsych	Baccalaureus Psychologiae (registered counsellor)
CART	Combination Antiretroviral Therapy
DOH	Department of Health
DSM	Diagnostic and Statistical Model
HAART	Highly Active Antiretroviral Therapy
HAND	HIV-Acquired Neuro-Cognitve Disorders
HIV	Human Immunodeficiency Virus
HMTCT	HIV acquired through Mother-To-Child Transmission
HPCSA	Health Professions Council of South Africa
HSRC	Health Science Research Council
I-ACT	Integrated Access to Care and Treatment
IMR	Infant Mortality Rate
KPTH	Kalafong Provincial Tertiary Hospital
MA	Master of Arts
MOT	Mode of Transmission
NGO	Nongovernmental Organization
PLWH	People Living With HIV
PMTCT	Prevention of Mother-To-Child Transmission
SBAH	Steve Biko Academic Hospital
TB	Tuberculosis
TDH	Tshwane District Hospital
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UP	University of Pretoria
WHO	World Health Organization
YLWH	Youth Living With HIV

PART I

BEFORE JOURNEYING WITH HIV AS CO-RESEARCHERS

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CHAPTER 1
THEORETICAL FRAMEWORK

"...we no longer tried to solve problems. Instead, we became interested in working with people to bring forth and thicken stories that did not support or sustain problems. We discovered, as people began to inhabit and live out these alternative stories, the results went beyond solving problems"

Freedman and Combs (1996, p.15)

HIV has long been authored as a worldwide health problem; a story about an epidemic for which there currently is no cure or permanent solution. From this point forward, I will be authoring a story of my own, as I invite you along my journey with HIV. This chapter provides the theoretical looking-glass for understanding my position as researcher through my use of a narrative approach situated within a social constructionist paradigm. In an attempt to do so, I provide a more in-depth look into the theoretical underpinnings of social constructionism. Hereafter I share an overview on the use of narrative in the field of psychology as well as a discussion on psychology as a discursive practice for making meaning. Following from this I introduce the practice of narrative therapeutic co-research as was employed for the purpose of this journey. Finally, I provide a brief overview of postmodern narrative trends and its application and applicability in field of health psychology and research. In conclusion, I discuss how I chose to enhance the quality of this research as a form of narrative inquiry in the field of health psychology.

The rise of Postmodernism during the beginning of the 21st century signified a paradigm shift away from objective singular truths or realities, towards that of plurality in therapeutic perspective taking and research (Corey, 2009). Gergen (1992) shed some light on the broader intention of such a paradigm shift in that "the argument is not against the various schools of therapy, only against their posture of authoritative truth" (p.57). The American Psychological Association (2010) is a body that contributes to the construction of a dominant discourse in psychology and prescribe how research should be conducted and reported on. Like other postmodern thinkers, I too embarked on a journey in which I ventured beyond the boundaries and expectations of the dominant cultural discourse in psychology and research.

During this research I diverted from, not only the dominant cultural norms as it relates to "what is reality" but also in how I approached research and report writing in the domain of

the human sciences. Following Gergen's (1992) argument, I did this, not from a resistant position, but rather because an alternative approach to viewing and researching HIV was called for. In line with the thinking of Freedman and Combs (1996), exploring stories that did not support the problem, aided in producing outcomes that superseded the act of problem solving. This was achieved by approaching HIV from a narrative social constructionist position.

Research Position

In order to provide a better understanding of narrative inquiry in the research process, its use within the constructionist paradigm must first be distinguished from some of its contrasting paradigmatic companions. Due to the versatile application of narratives in research, three paradigmatic positions will briefly be introduced and distinguished by means of the following quote (Anderson, 1990, p.75).

> Three umpires are sitting around over a beer, and one says, "There's balls and there's strikes, and I call 'em the way they are." Another says, "There's balls and there's strikes, and I call 'em the way I see 'em." The third says, "There's balls and there's strikes, and they ain't nothin' until I call 'em.

In the above quotation three "umpires" (narrators), are introduced, who speaks about how they "call" (narrate) "balls and strikes" (reality). This can be translated into the following three paradigmatic positions.

Fundamentalist Paradigm

The first position which reads "There's balls and there's strikes, and I call 'em the way they are" (Anderson, 1990, p.75) is representative of the fundamentalist[1] paradigm. To translate, "balls and strikes" (reality) exists outside of the "umpire" (narrator) and the umpire's "call" (narrative) reflects such external reality. Also known as Positivism, within the research context, the researcher assumes an objective epistemological position by methodologically taking on an investigative stance. The researcher's ontological position is directed towards locating a single (Ponterotto, 2005) or externally located universal truth

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[1] Fundamentalism can also be referred to as modernism, positivism (Ponterotto, 2005); or structuralism (Freedman & Combs, 2012).

(Combs & Freedman, 2012) in support of existing or new facts about how people function in the world.

Interpretivist Paradigm

The second position which reads "There's balls and there's strikes, and I call 'em the way I see 'em" (Anderson, 1990, p.75) represents the interpretivist[2] paradigm. That is, "balls and strikes" (reality) does not exist externally of the umpire (narrator) but rather is dependent on the "the way I see 'em" (internal perception) of the "umpire" (narrator) and the "call" (narrative) reflects such internal reality. In the research context, the researcher assumes a subjective epistemological stance (Ponterotto, 2005) to demonstrate that the narrative is an ontological reflection of the internal cognitive interpretation of reality rather than an externally existing reality (Freedman & Combs, 1996). Assuming a qualitative methodology, narrated accounts tell us something about the person's internal perceptual reality of lived experience (Ponterotto, 2005).

Constructionist Paradigm

The final inferred position which reads "There's balls and there's strikes, and they ain't nothin' until I call 'em" (Anderson, 1990, p.75) is reflective of the constructionist[3] position. That is, "balls and strikes" (reality), do not exist externally or internally of the umpire (narrator) but only exists (ain't nothin' until I call 'em) in the "call" (narrative) of the umpire (narrator). Within the research context the researcher assumes a curious collaborative epistemological position. The ontological focus of the study is thus on the narrative-as-reality. Through a constructionist methodology, narratives can be studied in verbal, written or visual form, as narrated realities that are co-constructed and called into existence through dialogical interaction between the researcher and the participant (Lock & Strong, 2010).

The Narrative

The meaning of stories and how they are understood by the reader or listener depends greatly on the theoretical framework from which it is explored (Combs & Freedman, 2012).

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[2]   The Interpretivist position is also referred to as constructivism (Ponterotto, 2005).
[3]   The constructionist position can also be referred to as social constructionism based within the philosophical position of post-structuralism (Freedman & Combs, 2012).

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For the purpose of this research, it becomes necessary to explore the characteristics of a narrative from a social constructionist frame.

Characteristics of a Narrative

The key characteristics[4] of this stance are outlined in the table below, as is based on the combined views of Freedman and Combs (1996) and, Lock and Strong (2010).

Characteristic	Description
(a) Language	Meaning (reality) is called into existence through the use of language (i.e. narrative).
(b) Dialogical interaction	Such meaning is socially constructed and is the product of human activity (i.e. dialogical interaction).
(c) Time and place	Meaning (reality) is historically situated in time (i.e. past, present and future) and place (cultural context).
(d) Plurality	Plurality (multiple reality/ meanings) is favoured above essentialism (single reality/ meaning).
(e) Critical	A critical stance is taken towards the taken-for-granted ways of knowing (essentialist/ discursive meanings).

Table1.1. Key Characteristics of Narrative

Past experiences in itself does not equate to meaning (i.e. reality). Rather it is through the use of language that people order their experiences in a sequence so as to construct meaning of their past in the present (Corey, 2009; Freedman & Combs, 1996; Riessman, 2008; White & Epston, 1990). Given that language allows for dialogical interaction and that ongoing dialogical interaction allows for the negotiation of new meaning, it can be said that a narrative is embedded not only in place (i.e. a cultural context) but also in time (Corey, 2009). When a story is narrated in the present, it is done against the backdrop of past and present socially negotiated cultural norms (taken-for-granted truths) about knowing, being and doing (Freedman & Combs, 1996; Lock & Strong, 2010).

In addition, a narrative is always embedded in the context of time/ or temporality (Lock & Strong, 2010; White, 1991). As is explained by Kearney (2006) "you interpret where you are now in terms of where you have come from and where you are going" (p.4). The meaning of a story is thus embedded in the past (past experiences) and in the anticipated future (imagined future experiences).

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4   The key assumptions or characteristics of Constructionism may vary slightly amongst different sources, for this reason it must be noted that assumptions described in this section refers to the combined work of Freedman and Combs (1996) as well as Lock and Strong (2010).

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People have a vast collection of past experiences, scattered across time in a metaphorical landscape (White, 2007). Given that every waking moment of lived experience cannot be storied at any one given moment, people choose from this "landscape" selected experiences, which they organize (i.e. narrate) in a specific sequence. Such sequencing allows for the construction one story "version" and meaning of events (White, 2007; White & Epston, 1990). As a result, at any given time, a narrative negates the narration of other experiences and thus other story "versions" and meanings from being narrated (Freedman & Combs, 1996; White, 2007; White & Epston, 1990). Such a story version (and its meaning) is thus afforded prominence above other experiences and is referred to as the dominant story version (White, 2007). According to White (2007), the dominant story is one of many story versions and because of its dominance can be said to be positioned in the person's foreground (i.e. field of view). Given its position on the metaphorical landscape, all other experiences become located in the background (i.e. outside of the author's immediate field of view). The stories that people tell is therefore merely reflective of the story version located in the person's foreground. It is when we start asking questions about experiences that had not been included in the dominant story that experiences located in the background are recruited into the foreground for new story versions and meaning to become available (White, 2007). From a narrative social constructionist position we can therefore say that plurality (multiple reality/ meanings) is favoured above essentialism (single reality/ meaning) when it comes to the stories that people tell.

The Narrative Metaphor

"...persons live their lives by stories- that these stories are shaping of life, and that they have real, not imagined effects- and that these stories provide the structure of life"

(White, 1991, p.28)

The above quotation refers to what White (1991) calls the "narrative metaphor". For one, stories provide a platform for ordering (i.e. making sense) of past experiences as a way to construct meaning. Authored into such meaning (i.e. narrative truth), are life "scripts" which act to shape (i.e. construct) present and ongoing future experiences and its meaning (White, 2007). From a narrative social constructionist frame, meaning is not only studied in terms of how it is constructed, but also in terms of how people can re-construct their meaning. This is something that is of particular significance in the context of therapy. If meaning is said to be

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shaped socially through dialogical interaction, it can be argued that such meaning can be re-shaped through the very same process; dialogical interaction. This contextualizes the act of meaning as being in a continuous process of flux and ever-changing (Freedman & Combs, 1996; Lock & Strong, 2010).

The research context offers a dialogical space for the construction of stories (i.e. meaning). From a narrative social constructionist frame, the research context can be considered an additional dialogical space for the construction of as new story versions (Lock & Strong, 2010). When two people engage in dialogical interaction each person has their own story "version" for making sense of the topic or situation at hand. As a way to make sense of a storyteller's intended meaning, the story reader (i.e. researcher) asks questions based on his/ or her own metaphorical landscape of experiences, located in their own cultural (place) and temporal (time) contexts.

Figure 1.1. Meaning emerge through an ongoing, circular process of dialogical feedback located in culture (place) and time (past and present) between the author (i.e. research participant) and reader (i.e. researcher).
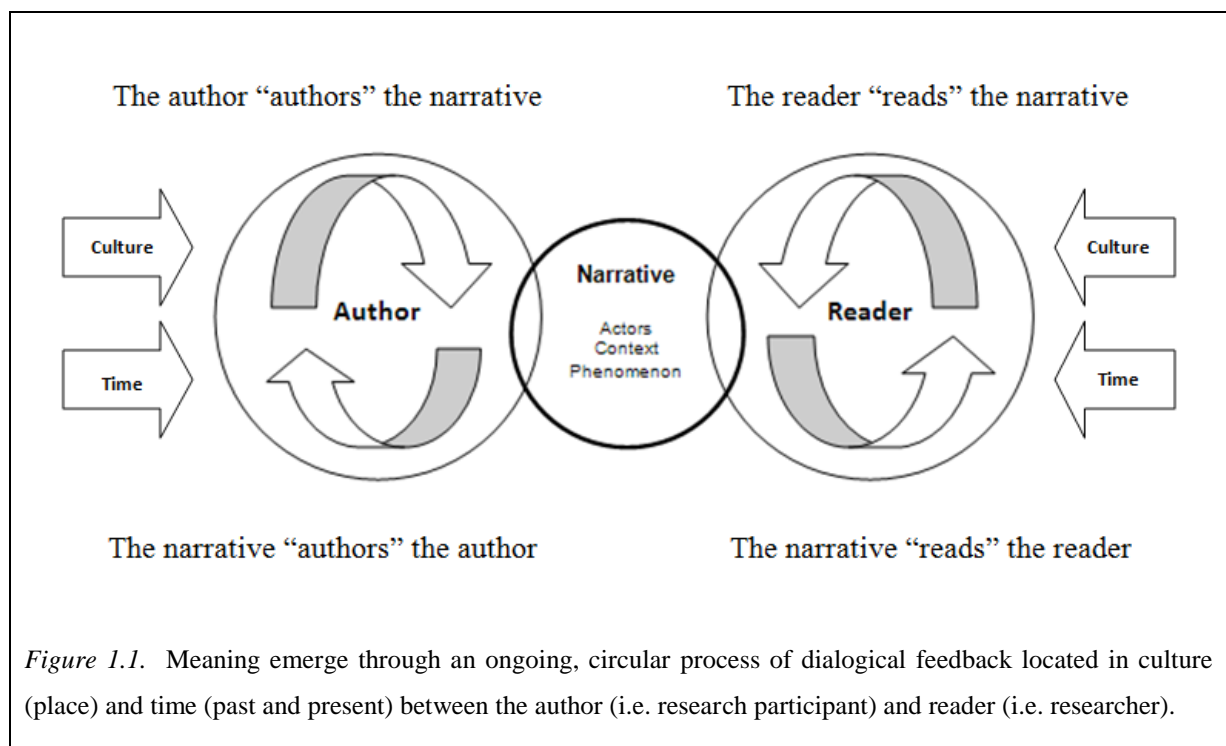
Figure 1.1. Meaning Making Through Dialogical Interaction

Based on figure 1.1, there are three simultaneous processes at play as soon as a narrative is called into existence during dialogical interaction. Firstly, it does something to the author; secondly, it does something to the reader; and thirdly, something happens to the narrative, the

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author and the reader. For the purpose of researching the meaning of HIV, the above can be translated as follow.

It does something to the author. The author (adolescent), authors (constructs) a story (narrative), in relation to the reader (researcher), about living with HIV, within a certain context (research context). From a narrative constructionist frame the narrative (story) is considered one of many "story versions" of events, instead of the "actual" experience. When a story "version" about past experiences is told in the present, the narrative acts to author (narrate) the author (adolescent) as it continues to shape the adolescent's present life (narrative becomes reality) and anticipated (i.e. imagined) future. This is mainly because our story versions provide us with a life script which becomes practiced over time. Such a life script dominates alternative meanings and ways of being, by authoring (cementing) certain beliefs (i.e. meanings) about the self, others and the world (White & Epston, 1990).

It does something to the reader. Given that "no experience has meaning independent of other experiences" (Combs & Freedman, 2012, p. 1041), narratives have to potential to read (make sense of) readers. In trying to make sense of someone's narrative, the narrative makes the reader think of certain parts of his/ her own narrative for making sense of the topic at hand (i.e. own reference base). Chances are that by reading what I have written, it might have started reading you (i.e. made you think of some things in your own life). For the purpose of this research we can say that as the researcher attempts to make sense of the adolescent's story, that the story reads the researcher as both their story "versions" collide in an attempt to negotiate meaning.

Dialogical interaction impacts the narrative, the author and the reader. As a way to negotiate the authors intended meaning, the reader asks questions. By asking questions, meaning becomes deconstructed. This allows a space for both the author and the reader to think about their own ways of thinking and narrating HIV. By deconstructing stories through questioning, it opens up a space to understand the broader master narratives (cultural discourses) which shaped the construction of such story versions (Freedman & Combs, 1996; White & Epston, 1990). Dialogical enquiry has the potential to disrupt the "neatly organized" plot (i.e. experiences sequenced in a specific order to make meaning) of each person's dominant story. For this reason, dialogical interaction can lead to the construction of new story "versions" and meaning for both the author and the reader (White, 2007). I demonstrate this by reflecting on a personal experience in my own life.

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In my work as registered trauma counsellor, I have often found myself in the hospital context, especially in the trauma and emergency unit. Irrespective of the patients and family members encountering traumatic experiences, I noticed the automatic, almost "robotic" fashion in which the nurses and doctors follow their "scripts" (roles) as medical staff during emergency situations. Irrespective of the different hospitals I went to, I saw the same "scripts" being followed time and again, demonstrating a reliance on and dedication to the medical discourse to inform their way of understanding trauma when "on stage" (working). The emergency ward is filled with "uncensored" narratives as medical staff enquire about the chain of events that led up to the emergency. I have noticed that trauma has the potential to cause contradictions in the patient's everyday narratives; in a way creating a state of disequilibrium. I have observed how patient's stories change in the midst of trauma as their meaning of past experience is questioned. This often becomes noticeable as they start to question for example their religion, their purpose in life, the trustworthiness of the human race, their perception of the world as a safe place, etc. These deeply philosophical questions and narratives do not always fit the framework of the medical discourse, which time and again become evident as the medical staff would swiftly refer the patients to me for trauma counselling, as the more appropriate discourse (Psychology). When the murmurs of stories from the patients and their families quieten down in the unit, you start hearing the stories of the medical staff, as they step "off stage" (when not working) and outside of their medical discourse "scripts" (roles). When talking to the staff once "off-stage" it becomes evident that they too had been impacted by the patient's stories as you hear their personal stories and its meaning being challenged. I have all too often heard them say things along the line of; "why do babies have to die", "what has this world come to that things like this happen", "it makes me wonder how much time I have left on this earth". Irrespective of your discourse providing you a "script" and telling you how to "act", I have learnt that our stories and its meaning is constantly in a process of flux and ever changing as we interact with others and their story worlds.

The above insert is evidence of the power of narrative in socially constructing both authors and readers. Our stories and its meaning is constantly in a process of flux and ever changing as we interact with others and their story worlds. When our story versions are brought into disequilibrium, it offers a space for the construction of alternative story versions. New stories told about the self, others and the world, in turn gives way to new meanings and thus new present and future realities (White, 1991). Following the work of Freedman and Combs (1996) on story development, this way of engaging with HIV can contribute to research that study not only dominant story versions but also alternative and preferred versions (meaning) of living with HIV.

In the process of negotiating the meaning of HIV during the research process it also acts as a space for the construction of new narratives and new meaning. From this we can say that it situates both the adolescent and the researcher as co-authors and co-researchers of this journey into making sense of HIV.

Narrative in the Field of Psychology

Similar to the domain of research, practicing in the field of psychology also lends itself to theoretical pluralism. In Psychology, how you make sense of the stories your clients tell is greatly dependent on the theoretical lens or paradigm from which reality is chosen to be understood by the therapist (Corey, 2009). A specific theoretical preference does not mean the rejection of other theoretical models as a means to understand your client (Corey, 2009). Rather, what is implied is that the theoretical lens (view) employed by the therapist will directly impact on their understanding of the client's reality (i.e. meaning) and their resultant therapeutic approach to therapy. Even though many subdivisions exist as it relates to a therapist's theoretical position, Combs and Freedman (2012) distinguish between Structuralism and Post-structuralism as the two major contrasting theoretical positions in the field of psychology and psychotherapy.

Structuralism

Structuralism also referred to as positivism or modernism (Corey, 2009; Ponterotto, 2005) is equated with fundamentalism (Anderson, 1990) as is referred to in the first part of this chapter. Structuralism is one of many labels used to categorise worldviews that aim to create generalized expert knowledge through scientific analysis and description (Combs & Freedman, 2012). Alternatively also referred to as the medical model and still dominant in the field of psychology today, therapists practice from the belief that there exists an objective singular reality or truth about "normal" and "abnormal" human characteristics and behaviour (Combs & Freedman, 2012). Thus the client's narrative told in therapy would be examined for signs and symptoms of abnormality. Psychological intervention would thus be recommended if a person deviates from the objective norm, with psychotherapy being focussed on assisting the client to function according to "normal" standards of healthy functioning (Corey, 2009).

Post-structuralism

Post-structuralisms favour contextualized meaning making over universal truths, thus taking into consideration the impact of culture, language and discourse as it pertains to experience and reality (Combs & Freedman, 2012). Also referred to as Postmodernism (Corey, 2009), it favours the view of multiple realities. The rise of Postmodernism during the 21st Century encouraged a paradigm shift away from singular truths and ways of

understanding human behaviour, towards new alternative perspectives of reality. Social Constructionism is also an acknowledged therapeutic paradigm in psychology which branches from post-structuralism (Combs & Freedman, 2012).

In the context of psychotherapy, a poststructuralist perspective paved the way for creating a broader understanding of people in context. Therapists working from this position believe that the complexity of human nature cannot be reduced to universal categories as a means to be understood. A client's narrative told during therapy will be collaboratively considered with the client in the broader context of culture, language and discourse as co-constructing contributors to understanding a person in context (Corey, 2009). Poststructuralist therapists therefore substitute expert objective interpretations with local, personalized, and contextualized knowledge and meaning collaboratively constructed with the client during therapeutic interactions. With therapy having a meaning-focussed approach to intervention, the client's uniqueness and embodiment of exceptions are valued instead of the categorization of the client into universal categories of normative experience (Combs & Freedman, 2012).

Michael White and David Epston (1990) played a particularly significant role as co-founders of narrative therapy which is based in a social constructionist paradigm. Therapeutic intervention is based on the narrative metaphor and done in collaboration with the client through co-exploration of the problem stories (about the self, others and the world). Such problem stories are deconstructed with the client to shift from a problem focussed story to the construction of preferred narratives about the self, others and the world (Combs & Freedman, 2012; White & Epston, 1990).

Discursive Positioning

Psychology in itself (in practice and research) can be considered a social discourse for meaning-making (Winslade, 2005). In the research context, positioning theory and critical discourse analysis are comfortably rooted within the theoretical framework of social constructionism, as it sheds light on the powerful impact of language and discourse (i.e. meanings) on the lives and relationships of people (Harrè, Moghaddam, Cairnie, Rothbart, & Sabat, 2009). Any utterances, whether spoken as a storyteller (author) or listener (reader), draws on a discursive (i.e. cultural) background as a way to construct meaning or to negotiate what was communicated (Winslade, 2005). From a social constructionist perspective, I cannot say that my dialogical interactions during research or therapy for that matter can be absolutely objective and value free. The questions we ask, or fail to ask come from our own

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discursive positions as well as the collective stories and voices of those who contributed in shaping it.

Narrative therapy is an approach to therapeutic practice which has become known for its transparency in working with social and cultural discourses (Winslade, 2005). Its interpersonal approach to working with people in itself becomes a co-reflexive tool in assisting clients in creating awareness and re-positioning themselves in relation to social and cultural discourses (White & Epston, 1990; Winslade, 2005). Unlike critical discourse analysis that is often used retrospectively in the research context for analysing discursive positions, the basic interpersonal approach used during narrative therapy can become usefully applied in the research context in collaboration with the participant (Epston, 1991; Dulwich Centre; 2004; Lysaght, 2009; Winslade, 2005).

Narrative Therapeutic Co-Research

There has been much debate about what constitutes appropriate boundaries for research involving narrative inquiry (Lysaght, 2009). In assuming either the position of therapist or researcher, it locates you in a space of engaging audience member (interactive reader) to the intimate storied accounts of people's lives (Winslade, 2005). In the case of narrative inquiry, researchers invite intimate storied accounts to become part of the research context. Through such invitation of personal stories, it often situates the researcher in a position in which appropriate and sensitive responding becomes necessary (Lysaght, 2009). It has been found that therapeutic sensitivity and appropriate empathy within the context of qualitative research have the potential for enriching the qualitative understanding of the people and phenomenon being researched (Gair, 2012; Luttrel 2003; Oakley; 1981). As a result, the boundaries between research and therapy can often become blurred as the researcher attempts to negotiate a space inclusive of both valid research and sensitivity (Lysaght, 2009).

The 1970's-1980's signified a time period referred to as "the interpretive turn" which was initially encouraged by cultural anthropologists who questioned the concept of objectivity in human science research (Combs & Freedman, 2012). During this time, David Epston challenged the concept of objective reality through his therapeutic work with families and their children in medical paediatrics in the late 1970's (Dulwich Centre, 2004). In his paper "Co-research: the making of alternative knowledge", Epston (1999) shared various cases during which he worked with numerous children and/or adolescents and their families. Such cases were related to a variety of medically related conditions, including asthma, skin

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disorders, anorexia, bulimia, etc. As co-founder of narrative therapy, he repositioned himself as co-researcher with the patients and their families as a means to gain a better understanding of the problem (Epston, 1999). By externalizing the illness as separate from the person, he contributed to expose and challenge the biomedical discourse in how illness is storied (constructed) in the health context. In addition he contributed to transform health psychology and the role of the therapist-patient and therapist-client relationship (Dulwich Centre, 2004). Epston (1999) came up with the concept of therapeutic co-research, as he studied (with the patients and their families) the problem story and co-constructed (with them) preferred narratives. In addition to being the author, the client thus also assumed the position of co-researcher. In turn, the therapist in addition to the role of researcher also assumed the position of co-author. Epston (2001) joined forces with Michael White in further elaborating on the concept of therapeutic co-research during their community work practices. To them, therapy involved a process during which the therapist assumed the role of researcher of stories by studying the relationships people have with problems rather than people being the focus of the problem or research (Dulwich Centre, 2004; Epston, 2001). By positioning ourselves as researchers of stories, we can say that we are looking at how storytelling is employed in authoring the self relationally to problems (Dulwich Centre, 2004; Lysaght, 2009). Chapter 6 to 8 provides a more detailed discussion on how narrative therapy was used as a platform for therapeutic co-research for the purpose of this research.

Postmodern Narrative Approaches and Health Research

With psychology historically having its roots in the medical model, its clinical application in the medical context progressed naturally (Corey, 2009). With the rise of postmodernism during the 21st century, it shifted the comfort zone of the medical model as it brought with it an invitation for the personal experiences and stories of patients and health care providers (Sools, 2015). As health psychology emerged as a recognized field, the value of narrative inquiry became more evident in the health and medicine research context (Murray, 2002). Rather than being seen as a replacement, qualitative approaches added much needed value as it complemented quantitative methods and data (Sools, Murray & Westerhof, 2015).

Intimate narratives of illness and health have opened up a space to explore health from a variety of disciplines, not traditionally recognized in the medical field (Sools et al., 2015). In the context of medical and health related matters, postmodern narrative approaches have been adopted on a multidisciplinary level, some of which include medical sociology (Frank, 1995;

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Frank, 2006; Riessman, 2008), narrative medicine (Charon, 2006; Devlin et al., 2015; Langellier, 2009), medical theology (Herbst & De La Porte, 2006; Moore, Talwar & Moxley-Haegert, 2015), narrative health psychology (Caddick, Phoenix & Smith, 2015; Epston, 1999; Murray, 2002; Riessman, 2003; Sools, Murray & Westerhof, 2015; Sools, Tromp & Mooren, 2015; White and Epston, 1990), narrative psychiatry (Jensen, 2014); medical anthropology (Epston, 1999; Epston, 2001), and narrative gerontology (Mundle, 2015). With HIV being by definition a medical condition this research journey can be categorized as a form of narrative health psychology as well as a form of postmodern narrative inquiry in the domain of health research.

Enhancing Quality

I am aware of the fact that there exist certain standards when conducting and reporting on research in the field of psychology, especially as it relates to enhancing the quality of narrative inquiry in research (Bryman, 2016; Riessman, 2008). Loh (2013) recommends attending to issues of narrative truth, verisimilitude, trustworthiness, and utility as a means to enhance the quality of narrative studies.

Narrative Truth

Firstly, although the criterion from the replication principle is not applicable to this research (Riessman, 2008), a way for me to enhance the quality of my research was by means of theoretical congruence. I strived to stay as true as I could to the social constructionist paradigm, by allowing the narrative metaphor to guide me. Throughout this research, my commitment to the narrative metaphor guided my perspective, my methodological approach, my dialogical interactions with the adolescent that participated in this research, as well as my approach to reporting on this journey.

Verisimilitude

Secondly, I strived to construct a context of engagement with the reader of this narrative report by subscribing to the criterion of verisimilitude (Loh, 2013). The aim of this research was not to collect "data" for the purpose of objective analysis or the verification of narrative truths. Instead this journey was geared towards creating a better understanding of how storytelling is employed to make sense of HIV. For this reason I did not attempt to analyse the stories, but rather to write a narrative report on such an unfolding process. In addition, I

narrated my own experiences before, during and after my interactions with the adolescent as a documented journey of collaborative meaning making. In doing so I also attempted to keep you, the reader of this report engaged in such an unfolding process, thus in addition enhancing the trustworthiness of the data through such transparency (Loh, 2013).

Trustworthiness

Thirdly, my social constructionist position further allowed for the enhancement of trustworthiness of the knowledge that was constructed during this journey by making use of peer validation and member checking (Loh, 2013). Throughout my interactions with the adolescent I made use of peer validation through ongoing supervision with my co-supervisor and accompanying literature on narrative inquiry. This assisted me in monitoring my commitment to the narrative metaphor as guidance throughout this research.

Given that meaning was co-constructed with the adolescent during the project phase of this research (chapter 6) it allowed for ongoing member checking as meaning was negotiated dialogically over an extended period of time. Towards the end of this journey I shared with the adolescent my own narrative understanding of our co-constructed knowledge, as an additional form of member checking (chapter 7). Rather than being seen as a form of validation, such member checking was seen as a continuation of the process of co-constructing meaning.

In sharing our co-constructed knowledge with the adolescent's grandparents we engaged in an extended form of member checking through the practice of reincorporation (Epston & White, 1992). Instead of considering this practice as a space for others to validate our interpreted knowledge to be the truth, we used this space to recruit an audience from the adolescent's life-world to have narrative input into our co-constructed knowledge (chapter 8).

Social Value

Lastly, the criterion of utility (Loh, 2013) or social value contributed to the enhancement of the quality of this research through further practices of reincorporation (chapter 8). The aim was to extent the concept of reincorporation to impact audiences beyond the adolescent and her primary family system. This narrative report can be considered as practical wisdom and a launching pad for constructing a new medium for sharing our knowledge with the staff of the paediatric outpatient unit of Kalafong Hospital. The intended utility of our knowledge is directed at the Integrated Access to Care and Treatment (I-ACT) group at KPTH. The I-ACT group was erected as a medium of support for adolescents receiving Antiretroviral

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Therapy (ART) at the clinic. By sharing (i.e. reincorporating) our knowledge with the staff involved in the I-ACT group, it makes accessible an alternative narrative for making sense of HIV. By documenting this journey and practical wisdom in an academic thesis and/ or a journal article, the reincorporation audience is by extension broadened as such knowledge is made accessible to the larger academic community.

Summary

In short, this research assumed a narrative position situated in a social constructionist paradigm;

Ontological Focus

The ontological focus of the study was based on the narrative as metaphor for reality, as it was constructed and unfolded through the process of ongoing dialogical interaction (Freedman & Combs, 2012) between the researcher and the adolescents as a form of therapeutic co-research.

Epistemology

The researcher assumed an epistemological position characterized by a curious collaborative position as co-researcher and co-author of this journey. In turn the adolescents assumed the role of co-researcher and co-author rather than being seen as the object of the research.

Methodology

A social constructionist methodology was followed by using both verbal (storytelling) and visual mediums (button characters) as a means to encourage a dialogical space for the co-construction of meaning.

Axiology

Based on the collaborative interactive nature of this study, the researcher assumed an open axiological position, acknowledging that no interaction can be value-free (Ponterotto, 2005). The knowledge produced during this research was co-constructed based on the ongoing feedback loop that circulated throughout the process of interaction between the researcher and the adolescent over an extended period of time. The researcher did not attempt

to "do something to" (analyze) the narratives (unfolding stories), but rather allowed the narratives (stories) to "talk for itself". This research report in itself is therefore contextualized as a narrative (i.e. story), documenting the collaborative journey in making sense of HIV through storytelling. Details related to the methodology of this research are documented in chapter 5 of this narrative. In acknowledging my position as co-researcher and co-author of this narrative and the journey on which it is based, I share with you in the next chapter my own narrative as an attempt to construct my own meaning of HIV prior to the commencement of this research.

CHAPTER 2
RESEARCH BACKGROUND

A storybook has three parts; a beginning, a middle and an end. What makes it a story and gives it meaning, is the sum of all its parts considered together. Also considered a story, this narrative report is divided into three separate parts (i.e. before, during and after co-researching HIV). In doing so, I am acknowledging that my journey (and relationship) with HIV had a beginning before my choice to conduct this research, that it may change direction as a result of this research, and that after the research ends that it will continue to exist in some direction or form.

In this chapter, I provide you (the reader) with background to the beginning of this research journey by engaging in a series of reflective practices of my own. Firstly, I acknowledge my role as an author of the meaning of HIV and thus also a collaborative meaning-maker of the meaning of HIV during co-research. Secondly, I narrate my own story and meaning of HIV prior to my interactions with the adolescent that participated in the project phase (i.e. co-research) of this journey. In doing so, I situate this journey and this narrative research report within the context of temporality to have a beginning, a middle and an end.

Researcher as Collaborative Meaning-Maker

Working from a narrative social constructionist position situates me as co-researcher and co-author of the meaning of HIV. Acknowledging my involvement in this process thus defines meaning-making as a collaborative act. In striving to maintain theoretical congruence throughout this journey, I chose to share with you how this journey started "reading" me. This in turn gave way to the construction of my own narrative on HIV, included in this chapter.

As part of the participant selection process of this research, I conducted several informed consent and assent sessions with the adolescents and their families at KPTH. I found that my brief introductions to their story versions started doing something to me. It started "reading" me. I started to think about my own past encounters with HIV. Driving home from the hospital, I asked myself how I made sense of HIV. When I arrived home I decided to start a journal in which I attempted to narrate my own story version of making sense of HIV. I found the thought of writing down my understanding quite daunting as I was tempted to read

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through and reference the stack of academic journals on my desk. Blinded by many discourses that coloured the meaning of HIV for me as a therapist and researcher, I struggled to write "my" story. This was when I realized that our meaning is socially constructed in time and place (cultural discourses), whether I liked it or not.

My Narrative on HIV

Being someone who thrives on being thorough I wrote down the questions that to me (at the time) were responsible for my "writers block". Where do I begin? If you were asked to write a book (narrative) about your life, would every waking moment of your life be in the book? Even if I narrowed down the focus of the book to a specific topic or phenomenon and ask you to write a book for example about being a parent, your life as a husband or wife, living with eczema; would you be able to narrate every single experience or moment of it? Most people I asked this question to said something to the extent of "no, it is impossible to include everything". Rather what I realized was that certain events (people, places and things) are chosen to be included and given preference to, whilst others are barely mentioned or completely left out all together; and that is how we construct meaning. Still, I could not resist inviting White and Epston (1990) into my writing nook to help me solve this philosophical conundrum of my own writers block. In doing so, I was confronted by a straightforward answer. My meaning will be constructed in the telling of my story. And so, White and Epston finally helped me to write my first story version about HIV by just jumping into it and starting anywhere. The story below was taken from my journal and includes sectioned inserts during which I reflect on what I wrote after the completion of this research journey.

From School Stationery to the "Big Bad Wolf"

I would be lying to say that my relationship with HIV only started at university. Of course I knew about HIV before my tertiary years, thus I must have had some sort of relationship with it. I remember now that my mother worked as a nurse at the Department of Health when I was in primary school. This was around 1995. I remember her often bringing home free stationery which was used in several prevention and treatment campaigns in the fight against the spread of HIV and AIDS. Shamelessly I indulged myself by filling up my space-case (stationery container) with goodies from her stock pile. Thinking back about what transpired, I remember being teased by my peers for my stationary which had slogans that read; "HIV Kills"; "Wear a rubber: don't be silly wrap your willy"; "let's beat HIV together: safer sex safer nation", etc. I thought for a moment that the teasing might have been related to the use of words such as "sex" or "condom" (given my age group at the time), however when the questions came about whether I had HIV or

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AIDS, it became clearer. From the responses of the children around me I started to realize that HIV was perceived as something negative. I use the word negative because I was not entirely sure back then what was wrong with it. My mother did her best as a nurse to educate my sister and I about the medical definition of HIV and AIDS, which was a virus that weakened the immune system. To me I thus equated HIV to having any other chronic illness, such as diabetes or cancer. All I knew was that whatever stigma was related to HIV, was projected onto my stationery as the children ran away screaming "that is disgusting, don't touch me with that!" as I jokingly chased them around the classroom with it.

Before that social encounter with my peers (and whatever relationship they had with HIV), I guess, in proudly displaying my new stationary on my desk, I had a different relationship with HIV than them at the time. I realize only now that during that social interaction, something had changed for me. The meaning that I had attributed to HIV had been socially reconstructed. This became evident as I had made a point of it the next day to leave my HIV stationery at home. Over the next few years my relationship with HIV was further socially constructed. I demonstrate this by returning to my journal story.

Sex education in high school left me with a similar impression of HIV than what my peers did in primary school. In addition however, I then knew that it was something that I should be scared of. I was taught that anyone could be HIV positive and I would not even know it. With HIV having been authored all around me as something that kills; my relationship with HIV had turned into one of fear. In a way it reminded me of the plot of little red riding-hood and the wolf; a metaphorical predatory "wolf" (HIV), disguised so that you would not detect it, stalking you in broad daylight, ready to "pounce" (infect) if you let your guard down, with the aim of eventually killing you (AIDS related death). I almost cannot help but think of her red hood as a symbolic representation of the colour of blood, metaphorically translated as the target focus of the wolf (virus). Having adopted this relationship with "the wolf", I must have given it a lot of power over me. My relationship with the "wolf" had evolved over time, so as to impact on my relationships with others. This was particularly noticeable in my relationship with men and my level of comfort in terms of sexual exploration as I transitioned through adolescence and into early adulthood. The fact that I feared it so much but that it was hiding (I could not see it), made me anxious, scared and overcautious in my relationship with others; as anyone could be a wolf. By the time I finished high school, my relationship with HIV which I previously conceptualized as a chronic medical condition, had become socially transformed into one of fear and avoidance. It had become the "big bad wolf".

After some retrospective reflection, I wonder how it came to be that children as young as primary school already had an "agreed upon" way of viewing HIV. In addition, what role did educational institutions play in authoring HIV? Moreover, who was (and is) responsible for informing the school syllabus or the meaning that teachers construct of HIV? Most

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importantly, I started to wonder who was responsible for socially constructing my meaning of HIV? From a narrative social constructionist frame, Lock and Strong (2010) reminds us that meaning is not only socially constructed in one moment but that it is also historically situated in time (i.e. past, present and anticipated future) and place (cultural context). In the process of writing this chapter, I decided to further research the social construction of HIV. The next two chapters (chapter 3 and 4) of this report map my journey as I set out to research the role that academic and cultural discourses play in socially constructing (i.e. narrating) HIV to society. Another question that lurked at the back of my mind was how it must be for those who live with HIV? Do they see themselves as wolves? Based on my narrative thus far, do I see people with HIV as wolves?

Avoiding the "Big Bad Wolf"

I feared the big bad wolf because I could not see it. All I could see growing up was that any person's face could be that of a wolf. In writing this down I am shocked at what I am learning. I am realizing that instead of seeing HIV as HIV, and people who have HIV as people, I have, maybe without much conscious thought, constructed such people as HIV. I saw people as wolves. In reading my story journal on my relationship with the "wolf" I am starting to realize that this particular relationship with the "wolf" had started to impact on various areas of my life. I demonstrate this through the next part of my story which took place at Kalafong Hospital in 2011.

> During my honours year, as Community Psychology students we had to get involved in the development of a new community project. It was the one honours module that had a practical component and for the first time in my studies signified the start to marrying theory with practice. The paediatric out-patient ward at KPTH was one of the practical site options that we could choose from. I was filled with excitement and nerves as I almost without thought chose KPTH; largely based on my passion for wanting to work with children at the time. After our needs assessment, our group developed an early childhood development project for children visiting the ward as out-patients. Irrespective of the fact that the project appeared promising on paper, over the weeks it transformed into what felt to us like a babysitting or a day-care project. It did however meet the staff's need for creating order out of the chaotic mornings as the children waited to be seen by the doctor.

Looking back now I am disappointed at not having considered alternative projects based on the other needs of the ward. One of the needs also mentioned by the paediatric staff members was the integration of psycho-education as an additional component to the already

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existing support groups for adolescents with HIV. In retrospect, I am wondering to what extent my relationship with the "wolf" had impacted my choice to focus on early childhood developmental rather than HIV. Had I constructed maybe without much thought a dominant story of fear and avoidance of people living with wolves? This made me think of what happened the next year which may resonate with this dominant story.

In 2012 I was asked by one of our Community Psychology lecturers to assist and supervise the new honours students with their community projects at KPTH. Due to our own somewhat disappointing project the previous year, I encouraged the students to consider the needs of Kalafong as a community and not to only consider the paediatric ward as a focus area. A support group project was started with mothers with premature babies, another project was started in the diabetes unit, and lastly I introduced to the students the option of the paediatric ward. Although many students showed interest in the paediatric ward, only two students showed interest in getting involved with the adolescent HIV support group. I wondered what this said about how the students felt about HIV, or Could I have possibly influenced the meaning that they attributed to HIV through my own "wolf-tunnel vision"? The two students faced the "wolves" and I supervised, safely tucked away in my role as facilitator of a project that I never had the guts to do myself.

In all my time at KPTH, only now had I come to realize that I had allowed my relationship with HIV to prevent me from talking and engaging with the HIV community. One of the most important aspects highlighted in the process of conducting community work and research with communities refers to identifying and connecting with the gatekeepers of the community (Visser & Moleko, 2012). In the past I danced on the sidelines, never getting too close. I argued to myself that I did not want to intrude or overstay my welcome. I am wondering now however, whether my dancing was not maybe because I was afraid of the "wolves" that lurked in the unit.

Meeting Narrative Therapy

Before my journey with narrative therapy, I have to admit, I was swept away by the couch-therapy picture of a psychologist that my undergraduate textbooks and movies painted in my head. The Diagnostic and Statistical manual (DSM) introduced me to a certain pair of "spectacles" (a paradigm) that coloured my vision. I was always on the lookout for categories and labels, always looking for abnormalities in need of normalization. Let me demonstrate this through the next part of my story.

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After my honours year, in 2012 I completed a one year long internship at Tshwane District Hospital (TDH) and Steve Biko Academic Hospital (SBAH) in completion of my BPsych trauma counselling qualification. As a therapist in training I wanted to improve my relationship with trauma counselling, as it was an area in my impending career that I felt very unfamiliar with. During this time period I was affiliated with Hospivision which was the supervising organization responsible for my BPsych trauma training and intern development. Hospivision provides free narrative therapeutic counselling to patients and their family members attending the clinic. During my internship I received training and supervision in narrative counselling in the hospital context. I like to think of this time period as my first introduction to narrative therapy. Although I have familiarized myself with the hospital context in the past, this time it was slightly different as I was encouraged to wear different "spectacles" (narrative framework) for viewing illness. Something about the medical context however liked to place people in boxes and "label" them. Working as part of a multidisciplinary team, I often found myself struggling to truly "hear" (listen for) the stories the patients told as my clinical mindset (dominant discourse in psychology) often got the best of me. Although I was given the new "spectacles" (narrative vision) and wore them, I think I struggled to "look" though them. This I know because I still danced around HIV and safely resorted to the medical model for understanding HIV-infected bodies.

Reflecting on this past experience I can now see how the dominant psychology and medical discourse[5] contributed to colour my vision and resultant expectations of what illness and therapy in the hospital context looked like. Looking back, my expectations based on the meaning that I had attributed to illness, shaped how I used (or failed to use) the space of casual storytelling in the hallways and waiting areas of government hospital facilities. Trying to create structure in line with my clinical mindset of what constituted a then therapy session, I failed to see the simplicity and natural presence of meaning making through storytelling.

Facing the Wolf

A narrative therapy practice for changing one's relationship with a "problem" is to first evaluate its effects (White, 2007) on one's life. Looking back at my view of illness, I am realizing that my "wolf-mentality" was busy impacting not only on my personal but also professional life. In the next part of my story, I demonstrate this through a turning point in my relationship with the wolf as I evaluated the unfolding trajectory of events as unfavourable.

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[5] The medical discourse in this context refers to the medical model as a discursive reference to guide practice. The medical model is based within the theoretical paradigm of Fundamentalism or Positivism (Ponterotto, 2005) and holds close resemblance to the dominant structuralist discourse in psychology (Freedman & Combs, 2012).

Towards the end of my BPsych internship in 2012, we received training in HIV pre-and-post test counselling. The trainer encouraged us to go for an HIV test at the TDH testing clinic so as to get a "patient" feel for the process. Out of a group of about 25 interns, to my surprise, no one wanted to go for the test after the trainer had left. Were the interns maybe also scared of the wolf? This was the moment that I realized that I had to look the wolf in the eyes. Having never been tested for HIV before, I decided to get tested. As soon as I had announced that I was heading off to the clinic, I had a group of four interns who eagerly asked to accompany me to the clinic to "observe" the process. I agreed. I felt brave for a moment, in that I volunteered to face the wolf, whilst the rest were too scared. On our way there, I scanned my head for all possible past encounters during which I could have been at risk of infection. I played with the thought of being vulnerable in front of the wolf and the interns. With a captive audience I started to wonder whether I was not maybe too brave. As a way to not allow the wolf or the interns to see that I was scared, I declared that I would be making up a story of suspicion of infidelity in my relationship during the pre-test counselling. Part of the pre-test counselling involves exploring what it would be like for you should the test be positive as well as the steps that you would take. It all became very real. This was when I looked the wolf in the eyes- he saw my vulnerability, I was scared and I could not escape this reality even with a made up story. With four pairs of eyes watching as my finger got pricked, I did not feel so brave anymore. To my surprise I was flooded with very real emotion. Two cigarettes and 10 minutes later I returned for my results. It was negative! I received what felt like a lecture from the counsellor to have protected sex at all times and not to take the risks of infection lightly. The wolf was still there; I left feeling simultaneously relieved and exposed.

Re-introduction to Narrative Therapy

As psychologists-in-training I have noticed amongst my fellow students and myself a general tendency to gravitate towards the use of "recipes" (i.e. steps) for engaging in therapy, despite the advice not to. Narrative therapy also comes with its fair share of bullet points, however it is often stressed not to use it in a step-like fashion. Having written down my "recipe" for narrative therapy in secret, I thought I knew all about this storytelling approach to therapeutic practice. Little did I know it was not so much about "what" to do, than it was about learning how to listen carefully. Stories and storytelling have been around since the beginning of time. The magical part of storytelling is that it is not only a communicative act but also an action for making sense of the world and one's place in it (Kearney, 2006). I will demonstrate this by sharing the next part of my story.

It was my first year of masters at the University of Pretoria. I was excited to hear that narrative therapy was included as a core module in the masters programme. I had the opportunity the previous year to receive some training and practical experience in it during my BPsych course. Starting out, it was the one module that made me feel safe due to its familiarity and probably what I thought then, its predictability. As our first class assignment we were invited to create a person out of any material and to write a story for the person

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by including a past, present and a future for it. Being someone that enjoys creativity and can be somewhat over-ambitious, I immediately started my project when I arrived home. In short, my person was called Zoë; a little black girl, made out of a brown wooden box, to which I attached limbs and a friendly face. Inside her wooden box body was a heavy rock, hidden away from others. She was a very strong and level-headed girl who had battled many challenges including, poverty, the loss of loved ones and ultimately the loss of her house. She lived on the streets and sustained her brother and herself by using her creativity as a means to make and sell beaded jewellery. Irrespective of the challenges she faced, she was resilient and continued to be an inspiration to others. Little did people know or notice how tough life has been for her. She never let people see it as she hid all her emotions inside her little wooden box body (rock inside of box) whilst putting up a bright smile. She continued to become a care worker in her community, encouraging children to harness their talents and to persist against all odds. She did however eventually learn that it was ok to show emotion and to acknowledge tough times as part of her success. After the activity, we were told to take some time to revisit our people and their stories. We were told that in some way it actually reflects a story about ourselves. Then I understood the power of the narrative metaphor.

When a story (narrative) is told, we become less concerned with whether it is a true account or version of events; instead we look at what is communicated to others through such a construction or performance of the self in relation to others (Goffman, 1965; Riessman, 2003). Irrespective of my past training in narrative therapy, for the first time I started to understand the power of stories and the act of storytelling as providing a tool for constructing and communicating meaning. I realized that I tried to fit narrative therapy into my "psychologist carry bag", when in actual fact it did not belong in a bag at all. It was all around me, around people; it was in my own walk and talk.

Reclaiming a Position of Privileged Author

The next part of my story made me think of what Freedman and Combs (2012) refer to as- reclaiming your position as privileged author of your own life. During the early years of the AIDS epidemic, Freedman and Combs (2012) consulted with an American doctor that worked at that time, primarily with gay men with AIDS in their final days before death. The doctor shared his disappointment in the stories and eulogies shared of these men at their funerals. He noticed a pattern in which family members (often absent during most of the men's adult lives), assumed authorship in telling the men's stories. This demonstrates the power of narrative in that the family members held the power to author (construct) these young men's identities through the stories they shared of them (Freedman & Combs, 2012). What gave the doctor hope he shared, was that there was an increasing trend amongst gay men with AIDS in making video recordings of their life to show at their funerals. An active

attempt to reclaiming their positions as privileged authors, these men constructed their own preferred story versions to be remembered by. This made me think of the role that society plays in claiming authorship of the identities of those living with HIV and to what extent it contributed to author my view of it as a "big bad wolf".

The last course I did during my BPsych internship was called "Loss, dying and death: Facilitating memory work", which was based within a narrative therapy framework. Memory work has been used in the past, often by organizations working in the field of HIV and end of life assistance (Herbst & De La Porte, 2006). With Andre De La Porte being involved in my training, he shared how the memory work books were often introduced to mothers dying of AIDS as a tool to "re-author" their life stories to their young children they left behind. As part of the training we had to create our own memory books. It made me wonder what my eulogy would say if it was written by someone other than myself. The idea made me feel cheated out of the experience of authoring my own identity left behind in my memory. I shared my book with my family after the course. To my surprise they knew me quite well, but through this process they learnt some new things about me that would have gone un-authored otherwise. Somehow I felt more empowered through the action of repositioning myself as privileged author of my own life. After the workshop, I developed an interest in counselling work with people with HIV. Dr. Andre De La Porte encouraged me to visit the HIV Clinic at TDH to learn more about counselling possibilities. Besides for the brief HIV pre-and-post test counselling services, I realized that the HIV clinic had no formal support projects or counsellors working in the unit.

This was where my research interest in HIV started. During the beginning of my masters degree in 2013, I started to write up my proposal. This signalled the start of my journey in reading up on HIV. My first trip was to the University library. I wanted to see what stories have been authored about the infamous wolf. I was bombarded by a wealth of books and journals spread across almost every discipline, both in hard copy and as on-line journals. In chapter 3 I share with you the story versions about HIV from various academic discourses.

Active Agents of the Wolf-Pack

Not only are people influenced by social discourses but with every social exchange they become active agents in re-producing certain discursive norms and meaning (Winslade, 2005). I demonstrate this by sharing the next part of my story.

Having started my masters degree, I completed my proposal in researching the meaning of HIV. In 2014 I received ethical clearance to continue with my project. Due to administrative difficulties at TDH my research project found its way back to KPTH. It was time to finally meet the people who live with wolves and to hear how they made sense of it. To my disappointment, in sharing my research topic with friends, family and fellow students, the responses were quite similar. It included something along the lines of "but

HIV has been researched for decades and nothing has changed" or "are you sure you want to do it on HIV, it is kind of an old topic by now", etc. The various non-verbal looks and gestures I got, communicated something between the lines of "that is boring" or "it has already been done, why go there again". I have to admit, for a moment it did make me question the usefulness of my research topic. What became evident was that a specific attitude existed amongst the people I spoke to. They all danced the same dance of having lost faith in research and intervention efforts invested in HIV. Dancing on the sidelines and going on with life, I felt a general sense of people having given up on the fight against the wolf.

This makes me wonder what discourse is informing such attitude. When, how and by whom was HIV constructed so as to have become so powerful that people started losing hope and giving up? This made me think of the posters and slogans you still find today saying "help fight HIV" or "Let us win this battle one person at a time". In his writings about externalized conversations and narrative therapy, White (2007) warns against creating a "battle" or "war" mindset with regards to talking about "problems". It is not so much about winning or losing as it is about acknowledging the existence of HIV and learning how to change our relationship with it.

These comments and responses made me wonder how it came to be that most people shared similar responses. Also, how HIV is seen or storied by those I spoke to and how they may have become active agents of the "wolf-pack" in keeping such stories of HIV alive. It made me journey back in time to the day I brought my HIV stationery to school; a relationship that has changed significantly over time.

From the responses of those I spoke to, I realize that there exist certain taken-for-granted truths about HIV and what it means to live with it. Narrative social constructionists would stop "dancing" with the norm. They would interrogate such master narratives and be critical towards its essentialist nature (Lock & Strong, 2010). With the same old stories being told about HIV, I once again begin to wonder how those living with such an illness make sense of it.

In the out-patient paediatric ward at Kalafong hospital I have noticed countless times the gathering of adolescents for the HIV support group on Monday mornings. I started wondering how it must be like to be so young whilst living with a chronic illness which has so many cultural connotations. I recalled from the previous needs assessment done in 2011 that the need for psycho-education exists in the support group. I sat with so many questions. I realized that it was time to get to know this "community" better. It was time to stop dancing and to meet the wolves.

Meeting the People who Work with Wolves

What sounded like a perfect plan of action on paper, proved to come with its own challenges. This became evident in the process of inviting adolescents to join the project phase of my study.

Walking into the paediatric unit, I realized my "dancing" on the sidelines had contributed to me alienating myself from the very community I wanted to make sense of and work with. The staff, who I had asked to assist me in inviting adolescents for the study a few months ago, had no participants for me. In fact, they appeared quite uninformed about my study and my presence at the clinic. I stopped dancing for a moment and made time to properly re-introduce myself and my research concept to the staff of the unit. Regardless of my own or their discomfort, I decided to overstay my welcome; and that was when I got to see how they "danced". I got to know the sister in charge who introduced me after a view days to the care workers (lay counsellors) who conducted the adolescent support groups on Mondays. The care workers later introduced me to the doctor who specializes in working with the children with HIV in the ward. The care workers explained that the doctors generally took the responsibility of identifying the children and adolescents with emotional problems who they would then refer to the psychologist in the adult HIV ward for counselling. The adolescent group is called the Integrated Access to Care and Treatment (I-ACT) group and runs on Monday mornings for an hour in between consultations. I-ACT was formed a few years ago by a social worker in the unit at the time. The group focuses on providing health education alongside their Antiretroviral (ARV) treatment. In the past few years the unit employed lay counsellors to run the groups. I kept on wondering how the staff made sense of HIV. Did they also know the big bad wolf? After a few Mondays in the unit, the care workers invited me to join them in the support group to learn more about how the group operated.

Meeting the People who Live with Wolves

After some time of watching, talking to and walking with the staff who worked with wolves, the care workers invited me to join the adolescent support group. It was interesting that the care workers (with a general background in social work or lay counselling) had once again mentioned the need for psycho-social support in the group sessions for the children. They asked me to become involved in the groups given that they never really got to address the emotional needs of the adolescents. To my surprise I was more excited than nervous to finally meet the wolf face-to-face. As a means to learn how they approach the groups, for the first session I asked to sit in without getting involved.

The care workers introduced me to the group as a student psychologist and quickly defined my role as someone that looks for emotional problems. I was planning not to go into the group with that label. The group was reserved and avoided making eye contact with me. To my surprise, I did not see wolves, at least

not like I had imagined them. What I saw was a group of youngsters ranging from age 14 to 18 years. The care workers did most of the talking which consisted of education on HIV and the do's and don'ts surrounding medication adherence. The session ended with facts about transmission of the virus to uninfected others. As the group left the room I felt uncomfortable, more so for them. Although education about the virus, medication adherence, its transmission, etc. was important, I wondered what stories the adolescents were left with. All this time I was wondering whether the adolescents were able to see themselves as separate from the wolves that joined us in that room, or did (or do) they see themselves as wolves?

By joining the group, I became all the more aware of the impact of seeing people that live with wolves as the wolves. The medical discourse of illness education appeared to be part of the wolf-pack; an active agent in narrating HIV as a wolf. Maybe even an active agent in narrating the people who live with HIV as wolves. What stayed with me was the fact that the care workers have also noticed that something about the group was not working. The most valuable conversation happened in reflection with the two care workers after the group sessions was over as we discussed what happened in the group. They both admitted that the approach was not working well as the children generally did not participate much and rarely shared their own stories of living with HIV. Having received training about HIV, both care workers were very insightful in terms of the problems faced by children growing up with HIV, however they seemed stuck in some sense. I was wondering whether they were not maybe stuck with a room full of children that did not narrate their experiences and stuck in the role of having to be the authors of HIV by means of deductive health education. After my interactions with the staff of the unit, they assisted me in inviting adolescents for the informed consent and assent sessions for my research. After a few more days in the unit, to my surprise I met with several parents and guardians who appeared interested in getting their children involved in my storytelling project. From this process followed the start of my project phase which started in February 2016. A brief overview of project phase is provided in chapter 5 and discussed detail in chapter 6.

What Does This Mean

As soon as a story is constructed, whether spoken, illustrated or written, it creates an externalized space for the story to be examined as the story teller can become his/ her own audience member (Lysaght, 2009; White & Epston, 1990). By creating a space to construct

my own meaning of HIV in this chapter, I can now see how I have not only been a recipient to the cultural discourses informing HIV, but also an active agent in reproducing (i.e. narrating) such meaning. My choice in narrating HIV as a metaphorical wolf and drawing on the plot of little red riding-hood speaks of my victim versus villain view of HIV. Through mapping my own process of making sense of HIV, I am reminded of the impact of social discourse on the meanings that people construct of an illness such as HIV. In my own story I narrated myself in the role of scared "victim" being in constant threat of being hunted down by the "villain" or how I called it, the "wolf". There is a dramatic turn in my story as I move from passive victim to assuming somewhat of a brave hero role. This shift happens as I realized the impact that my relationship with the wolf had on both my personal and professional life. After evaluating such a relationship as unfavourable for my personal and professional future I set out to question and change this relationship. In doing so it impacted on my ability to stop dancing and to engage with those who work with the wolves (staff) and those that live with wolves. In narrating my experiences I started identifying various role players (i.e. the wolf-pack) in co-constructing my story (i.e. meaning) about HIV and the impact that had on me. In the next chapter I assume the position of story reader (i.e. audience member) investigating how HIV is authored by various discourses in academia.

With South Africa being considered one of the countries with the highest HIV prevalence rates globally (Shisana et al., 2014), HIV as an epidemic has received much academic attention over the past few decades. HIV is considered per definition a biomedical condition; however its considerable impact has been noted, researched and documented from a variety of discourses (Falvo, 2014). Given the realization of my "wolf-mentality" in making sense of HIV in chapter 2, I felt it necessary to deconstruct such meaning by journeying with other "authors" (storytellers) of HIV. In doing so I strived towards exploring how such authors may or may not have played a part in socially and culturally constructing my story "version" of HIV. To actualize such an aim I positioned the academic literature and those who constructed it as an assembly of stories and storytellers, accessible not only to me, but also to the public as narratives for making sense of HIV. For the purpose of this chapter, academic literature refers to the collection of peer reviewed academic writings (i.e. master narratives) on HIV, authored by various discourses (i.e. authors) and accessible through the library, online sources and other public forums. Remaining congruent to the narrative social constructionist paradigm, I attempted to read such stories in the light of how HIV is authored to the public to construct a certain meaning.

The Epidemiology of HIV in South Africa

Various organizations worldwide dedicate their work on an ongoing basis to the construction of new scientifically based knowledge on the epidemiology of HIV. Epidemiology refers to the ongoing scientific surveillance and production of academic knowledge on the incidence, prevalence and overall impact of HIV on the global and national population (Shisana et al., 2014). The academic community often rely on epidemiological data as a scientific foundation for the guidance of new research in the field of HIV. Not only do academics rely on such information as the "truth" but anyone who wish to learn more or teach someone about HIV often consult such peer-reviewed scientific data as a reliable reference base about the "true" extent of the HIV epidemic.

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Based on the annual mid-year population estimates for 2015 (Statistics South Africa, 2016)[6], the overall HIV prevalence rate is estimated at 11,2% of the total South Africa population. This suggests an increase in the total number of people living with HIV (PLWH) in South Africa from 4,02 million people in 2002 to approximately 6, 19 million in 2015. According to Shisana et al. (2014)[7] it is estimated that the PLWH in South Africa is representative of a quarter of the PLWH in Sub-Saharan Africa and subsequently makes up 18 percent of the overall global population of PLWH. Ethekwini in KwaZulu-Natal and Ekurhuleni in Gauteng is the local communities that reportedly have the highest overall HIV prevalence. Black South Africans, compared with other race groups, have the highest prevalence of HIV (Shisana et al., 2014). South Africa is also seen as one of the countries with the highest HIV prevalence rates for both adults and children (Shisana et al., 2014; UNAIDS, 2014).

As a result of programmes invested in the prevention of mother-to-child transmission (PMTCT) and the roll-out of Antiretroviral Therapy (ART), the infant mortality rate (IMR) in South Africa has declined from 51 per 1000 births in 2002 to 34 per 1000 births in 2015 (Statistics South Africa, 2016). Since the roll-out of ART post-2005 there has been a massive transformation in the pattern of mortality rates amongst the South African population, as it aided in prolonging general lifespan of PLWH (Shisana et al., 2014; Statistics South Africa, 2016). Epidemiological research provided a blueprint of the overall impact of the HIV epidemic, and in response recruited various disciplines to further engage in discourse specific research on HIV (Statistics South Africa, 2016; UNICEF, 2013; WHO, 2013). The section below provides an overview of medical, psychological and social knowledge (i.e. narratives) which has been constructed in an attempt to understand HIV from a broader discursive perspective.

The Medical Narrative

Irrespective of the discursive focus, HIV is first and foremost defined in academic literature through a biomedical lens as an illness impacting the body and its physical functioning (Falvo, 2014).

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[6]   Statistics South Africa conducts large scale surveys, providing population and household statistics at a municipal level to the government and private sector in South Africa.

[7]   The South African national prevalence, incidence and behaviour survey is the fourth national prevalence survey conducted in South Africa (Shisana et al., 2014) in affiliation with the Human Science Research Council.

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HIV Defined

Human Immunodeficiency Virus (HIV) is universally conceptualized through a biomedical lens. It can be defined as a virus that invades, attacks and progressively destroys the body's immune system, with specific reference to the helper-T cells (AETC National Resource Centre, 2014). The primary function of the helper-T cells (i.e. CD4 cells) is to repair and to reproduce the body's fighter-T cells (i.e. CD8 cells). The primary function of the fighter-T cells is to fend off opportunistic infections caused by viruses or bacteria entering the body. Together the CD4 and CD8 cells function as the body's immune system (Falvo, 2014). Consensus has been reached that there exists two types of HIV; HIV-1 and HIV-2, each with its own subtypes (Falvo, 2014; Maartens, Celum, & Lewin, 2014). HIV-1 is said to be the most common form of the virus (Falvo, 2014). HIV-2 is similar in its presentation but shows reduced immunodeficiency progression and transmissibility (Falvo, 2014; Maartens et al., 2014).

In a healthy immune system, opportunistic infections would ordinarily result in mild or no symptoms, due to the person's immune system being able to fend off such an attack on the body (Falvo, 2014). Opportunistic infections include for example meningitis, encephalitis, respiratory illness (i.e. Pneumonia or Tuberculosis), intestinal illness (i.e. diarrhoea), and cancers (AETC National Resource Centre, 2014). Once in the body, HIV multiplies itself through a process called reverse transcription (Falvo, 2014) which progressively destroys the immune system. This weakens the infected person's ability to fend off opportunistic infections and diseases (Lezak, Howiesen, Bigler & Tranel, 2012). Ultimately, over time it manifests itself in a cluster of specific immunodeficiency-related symptoms (Falvo, 2014) collectively referred to as Acquired Immune Deficiency Syndrome (AIDS). When a person is diagnosed with AIDS, his/her immune system has deteriorated to such a degree that the person has very little or no protection against opportunistic infections (AETC National Resource Centre, 2014). With the person's immune system being unable to fight off disease, opportunistic infections can result in death (AETC National Resource Centre, 2014).

Modes of transmission and infection. Our bodies actually have a very advanced defence system in place to keep foreign bacteria and viruses from entering the blood stream. The first line of defence is the skin and mucous membranes with the second defence being activated by a combination of our body fluids (Falvo, 2014). Once HIV passes through the first two lines of defence, the immune system is alerted and activated so as to prevent the virus from entering the bloodstream which is considered the primary destination of infection (Lezak et

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al., 2012). The way in which the virus enters the body or the source of exposure refers to the mode of transmission (Falvo, 2014). The primary modes of HIV transmission/ or exposure includes; exposure through unprotected sexual intercourse; exposure through injection or drug use; exposure through blood or blood products; and lastly mother-to-child transmission (Shisana et al., 2014). HIV acquired through mother-to-child transmission (HMTCT), vertical transmission and perinatally-acquired HIV are all terms that are used interchangeably to refer to the transmission of HIV from the mother to the child either during pregnancy, child birth or breast feeding (Falvo, 2014). Taking into consideration that a child can contract HIV from breastfeeding, it is necessary to mention that a child may be breastfed by someone other than his/her mother and still contract HIV if the person breastfeeding the child is HIV positive (WHO, 2015). For the purpose of this document and from this point on forward, HMTCT will be used as an abbreviated term to collectively refer to the above mentioned modes of HIV infection, with specific reference to a child contracting HIV from his or her mother or caregiver.

HIV classification and progression. The U.S. Centre for Disease Control and Prevention (CDC) and the World Health Organization (WHO) are the two major classification systems that are currently in use to classify, track and monitor the progression of HIV in a patient's body (AETC National Resource Centre, 2014).

Revised in 1993, the CDC classification system for disease staging of the severity of HIV is based on the patient's lowest documented CD4 cell count, in combination with certain previously diagnosed HIV-related conditions. People with a healthy immune system have a CD4 cell count of approximately 500-1300 cells mm3 (AETC National Resource Centre, 2014). Taking into consideration previously diagnosed HIV-related conditions, the CDC system diagnose AIDS in PLWH with a CD4 count of <200 cells mm3.

The WHO (2007) uses a Clinical Staging and Disease Classification System, developed in 1990 and most recently revised in 2007. Without the reliance on CD4 cell counts, the WHO classification system has become useful in resource-constrained environments as it classifies disease progression primarily by monitoring the clinical manifestations of specific medical conditions or symptoms (AETC National Resource Centre, 2014; WHO, 2007). HIV progression are classified into four clinical stages, which can progress from Primary HIV to stage four or advanced HIV/AIDS (WHO, 2007). The WHO classification has been used in many resource-constrained settings as general guidance for eligibility of Antiretroviral Therapy (WHO, 2007).

Children and adolescents with HIV. The WHO (2016) defines adolescence as the time period in which males or females are between the age group of 10 and 19 years of age.

Untreated HIV. HIV infection can often go undetected given the extended incubation period between infection and symptomatic illness (Maartens et al., 2014). In the case of untreated HIV, the CD4 count of a person reduces each year by approximately 50-80 cells mm3 (AETC National Resource Centre, 2014). The estimated life expectancy for children with HMTCT who do not receive any treatment is between 3 to 5 years of age, with mortality rates being very high during the first year of infancy (WHO, 2013). In the case of HIV positive infants, the WHO (2013) recommends the administration of Antiretroviral Therapy (ART) as soon as possible after birth or diagnosis, irrespective of their CD4 count or symptomatic presentation (WHO, 2015). Due to significant efforts to encourage status awareness, especially though PMTCT campaigns and pre-and-post-natal treatment initiatives, it has resulted in a significant reduction (50%) in new HIV infections of children in South Africa from 2009-2013 (UNAIDS, 2014: The Gap Report). In turn it has also resulted in a significant reduction (51%) of AIDS-related deaths during this same time period in South Africa (UNAIDS, 2014). This has resulted in some children with HMTCT being able to reach adolescence and early adulthood. Disease progression of untreated patients can however vary greatly. According to the AETC National Resource Centre (2014), the median average for untreated HIV to progress to AIDS is approximately 10 years, however for some it can progress over the course of two years. It has been reported that continuous unprotected sex between people that are HIV positive result in ongoing re-infection. This causes the viral load to rise to abnormally high levels and as a result causes a rapid drop in CD4 cells (Falvo, 2014). In contrast it has been found that some patients without treatment can take up to 20 years to progress to AIDS, whereas others maintain high CD4 levels with an undetectably low viral load without ART (AETC National Resource Centre, 2014). Given that there are different strands of HIV; cross infection can result in sub-population mutations of the virus which poses further complications as it relates to drug resistant mutations resorting to reduced efficacy of ART (Falvo, 2014; Maartens et al., 2014). Although an infected person may go asymptomatic for years without treatment, untreated HIV in infants and children can lead to several complications, especially as it impacts the important areas of childhood development (Nassen, Donald, Walker, Paruk, Vajovic, & Duncan, 2014).

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Treated HIV. In the late 1990's Combination Antiretroviral Therapy (CART) regimes were developed as a means to suppress viral replication. This resulted in the reconceptualising of HIV from a fatal illness to a more manageable chronic disease (Maartens et al., 2014). In South Africa however the national ART roll-out was only launched in April of 2004 (WHO, 2015). Although the most effective way of treating HIV is with ART, it has been reported to have both advantages and disadvantages[8] (AETC National Resource Centre, 2014; Falvo, 2014). Starting with ART early can reduce the progression and risk of transmission of the virus. Unfortunately, it can also result in early onset medication resistance and/ or being exposed to the toxic effects of the drugs over time (Maartens et al., 2014). As a result, national and international guidelines have been established for the initiation of ART to control and monitor not only health disadvantages of early administration but also to give ART dispensing priority to those with severe or advanced HIV progression (AETC National Resource Centre, 2014; WHO, 2013; WHO, 2015).

General patient health involves monitoring and managing the disease progression with regards to either the CDC or WHO classification systems. Eligibility assessment for the initiation of ART according to the CDC classification system involves a CD4 count of 500 cells/mm3 and below or in some middle to low income countries a CD4 count below 350 cells (WHO, 2013). The WHO added to their Global 2013 Consolidation Guidelines that all pregnant mothers, breastfeeding mothers and children with HIV may receive ART irrespective of their CD4 count. This was aimed at prioritising vulnerable populations and to encourage early prevention of HIV transmission. Children with HMTCT are thus afforded lifelong ART (WHO, 2015). Included in these guidelines for population groups to receive ART are those with active TB disease or other co-infections paired with severe chronic liver disease. Individuals with HIV in sero-discordant (partner is HIV negative) relationships were also included in this group (WHO, 2013). Currently there exist six different classifications[9] of antiretroviral medications which each treat HIV in different ways (Falvo, 2014). Kalafong hospital's paediatric out-patient clinic was one of the 362 sites in South Africa to provide ART to HIV positive mothers, children and adolescents (WHO, 2007).

Medication adherence. Irrespective of the new roll-out of ART, health care providers started noticing reduced medication adherence levels amongst PLWH (Coetzee, Kagee &

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[8]   Refer to Falvo (2014, p333) for more information of the side effects of ART.
[9]   Refer to Falvo (2014) for a more comprehensive list of existing antiretroviral medication for treating HIV

Vermeulen, 2011). This resulted in increased research efforts focussed on identifying the barriers to medication adherence of ART, which is discussed in more detail under the psychological and social discourse literature. In 2013 an American paediatrician from Texas, Dr. Robert Ricketts also noticed this during his residency programme at a children's clinic in Lesotho, Southern Africa (O'Connor, 2014). He found that complaints related to the side effects of the medication outweighed the immediate benefits, thus resulting in high non-compliance rates. In response he developed a narrative meaning-focussed approach to medication adherence for children living with HIV. This involved constructing meaning for the children as it related to taking their medication by developing a children's book called "Our little soldiers: A book for children living with HIV". The book did not mention HIV but with colourful illustrations and characters he constructed an alternative way for understanding the war that takes place in the body and the function of medication. Forty thousand copies were distributed across six different African countries in different languages. He received the American Academy of Paediatrics' Anne E. Dyson Child Advocacy Award, for his "alternative" meaning-focussed approach to tackling issues related to medication compliance amongst children with HIV (O'Connor, 2014). Chapter 4 explores the role of meaning and chronic illness in more detail.

Reflections on the Medical Narrative

Within the medical discourse, HIV is narrated in terms of its motives (i.e. modes of infection and cellular replication) and impact (i.e. medical outcomes), the temporal (i.e. past, present, and anticipated future) predictions for living with HIV, and also the impact of medicine or science on HIV (i.e. treated versus untreated HIV). Without much surprise, whilst reading these "narratives" written about HIV, it reminded me of my own way of making sense of HIV, narrated as a big bad scary wolf. While reading up on the medical narratives about HIV, I could not help but feel somewhat defeated by HIV. The wolf that so many people around me have heard about had a very well documented story embedded in global history as the villain that is challenging to conquer. Clearly the wolf has been researched and carefully exposed for its immense power and impact on the physical lives of those infected or affected. Medical research has gone as far over the years to also research what can be done to impact the progression of HIV. Irrespective of advances in exploring the bi-directional impact of HIV on man and man on HIV, I cannot help but notice that those infected has become somewhat lost in it all. Medical staff and scientists take up the roles of heroes. These heroes advocate for the infected as they bravely fight this battle through

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scientific research and medical initiatives. Although great advances have been made in the scientific field at suppressing the power of the wolf, I am left with the impression that those that are infected are left at the mercy of such "heroes" to keep them hopeful. My aim is not to disregard the efforts made by science to prolong lives, rather, to shed light on how a "war-narrative" has been constructed between the bio-medical science (and scientists) and HIV; rendering those infected at the mercy of the outcome of this "war".

The Psychological Narrative

In addition to the progressive deterioration of the immune system, HIV also disrupts a young person's overall developmental and psychological functioning (Falvo, 2014).

Neuro-Cognitive Development

Besides being exposed to the risk of contracting opportunistic infections, persons who contract HIV at a young age is also at risk of developing Central Nervous System (CNS) disruptions as the virus impacts on the developing CNS (Nassen et al., 2014). When HIV disrupts neurological functions in the brain, it is referred to as HIV-Associated Neuro-Cognitive Disorders (HAND) (Lezak et al., 2012). HMTCT is often associated with HAND, visible as early disruptions in various neurological structures which can impair several developmental and cognitive functions (Lezak et al., 2012; Walker, Pierre, Christie & Chang, 2013). When developmental and cognitive functions are disrupted soon after birth or early in life, it may compromise normal milestone development, some of which also include the development of language, social and emotional skills (Thom, 2007; Walker et al. 2013). Even though neuro-cognitive delays appear to have an organic or physiological cause, the psychological impact of these developmental delays should not be ignored (Lezak et al., 2012).

Psychological and Behavioural Impact

Even though the stigma associated with being HIV positive can be argued to be a social or interpersonal issue, it can also have psychological consequences for those infected or affected (Falvo, 2014). HIV has been linked to psychiatric (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013) as well as behavioural problems, such as substance use and / or abuse and/ or sexually risky behaviour (WHO, 2013).

The connection between psychological problems and HIV appears to be a complex one (Mellins & Malee, 2013). Research results indicate that children with HMTCT present with higher rates of psychiatric disorders than the population norm (Mellins & Malee, 2013). The most common vulnerabilities for mental disorders amongst children with HMTCT include ADHD, mood, anxiety and substance use disorders (Falvo, 2014; Nassen et al., 2014). HIV uninfected children and adolescents, affected by HIV or living with infected relatives also experience high risk indicators of mental disorders (Mellins & Malee, 2013). Irrespective of causality, psychological problems associated with HIV has been identified as a vital component that should be considered and screened for in paediatric treatment of HIV (WHO, 2013). It has been found that failure to treat mental illness of PLWH may impact on treatment adherence as well as other important areas of functioning (Nassen et al., 2014). Given the absence of a validated screening tool for mental disorders in children and adolescents with HIV, psychological problems often go undetected (Nassen et al., 2014). According to Mellins and Malee (2013), HIV cannot be regarded as the "cause" of mental health problems. These authors found that poor mental health outcomes are generally related to the interplay between a variety of factors, including child health status, cognitive function, parental health, stressful life events and neighbourhood disorders. According to Falvo (2014) the psychological challenges faced by those who learn about their status is diverse. Such challenges include issues related to acceptance of one's status, dealing with the uncertainty of one's own mortality, foreshortened sense of future resorting to poor goal setting and life planning, stress of adapting to life style changes, fears related to disclosure, stress related to financial management of chronic illness and the experience of multiple losses of co-infected family members (Falvo, 2014).

Identity Development

Given the medical advances in suppressing HIV progression, it has allowed for children with HIV to transition into adolescence and early adulthood (Shisana et al., 2014; Statistics South Africa, 2016). Childhood development and the transition into adolescence viewed outside of the scope of chronic illness can in itself be complicated by many factors (Falvo, 2014). This has resulted in an increasing trend in research attention focussing on the developmental and psychological risks for children and adolescents with HIV (Betancourt et al., 2013; Nassen et al., 2014; Thom, 2007) and a gap in research paying attention to factors of resiliency which could aid preventative interventions (Mellins & Malee, 2013; Persson & Newman, 2012).

Adolescence as an age group is usually defined by the start of puberty which can be between 11 and 13 years to about 21 years of age. Adolescence is often described as a "stormy phase" as the developing child undergoes major biological, cognitive and psychological changes (Louw & Louw, 2014). Rapid development of the brain gives way to significant cognitive changes which allows for critical thinking and the development of new insights into the self, others and the world (Thom, 2007). Regardless of one's age group or developmental stage, it is argued that a diagnosis of HIV can impact and even challenge one's sense of self and identity (Falvo, 2014; Thom, 2007; Tsarenko & Polonsky, 2011). In turn, others have found that for some adolescents, learning about their status and being faced with their own mortality at an early age has actually facilitated the process of identity development (Hosek, Harper, & Robinson, 2002). Being able to create meaning of one's illness has been associated with improved emotional wellbeing and long-term adjustment in society in young people growing up with chronic illness (Verhoof, Grootenhuis, Heymans, Maurice-Stam & Evers, 2014).

Paediatric ART at Kalafong Provincial Tertiary Hospital (KPTH)

The psychological implication of living with HIV during adolescence was also noted at KPTH. As the number of children receiving ART at the paediatric outpatient clinic increased, an adolescent section was formally established in 2007. As part of a needs assessment done for the unit, Vlug, Feucht and Kruger (2008) together with the staff of the unit identified the need for psychological intervention in combination with the existing ART programme at KPTH. Their need for psychological intervention was based on the necessity for addressing issues related to acceptance and coping with an HIV diagnosis; dealing with issues related to disclosure and prevention; family focussed psychosocial support; and psycho-education on sexuality and role models (Vlug, Feucht, & Kruger, 2008). Soon thereafter in June 2009, an adolescent support group was established in conjunction with the social worker of the unit. The group was later called the Integrated Access to Care and Treatment (I-ACT) group which took place once a week on Monday mornings for an hour at the clinic.

Reflections on the Psychological Narrative

Psychological "narratives" contributed much to better understand the developmental and psychological impact of HIV on youth as a larger systemic issue in society. Much of the research from this discourse focuses on the impact of HIV on this age group, with less focus being placed on the impact of the adolescent on the HIV (Mellins & Malee, 2013). As was

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also noted by Persson and Newman (2012), a research trend of this nature has the potential to act as an academic discourse which can contribute to the construction, reproduction and normalization of "master narratives" (taken-for-granted truths) about what it means to be an adolescent with HIV. This in turn may also impact on the trajectory of treatment goals considered for such a group. Increased research attention paid to the strengths and resiliencies developed as a result of HIV amongst youth (impact of the person on the HIV) may assist in the construction of alternative perspectives of the meaning of HIV as well as preventative rather than treatment-focused psychological interventions (Betancourt et al., 2013; Mellins & Malee, 2013).

The Social Narrative

HIV has also been researched as a broader societal issue, impacting on the social functioning of those infected and affected by HIV (Falvo, 2015).

Stigma

According to Gilbert (2016) stigma can be considered a socially constructed concept which can impact PLWH on both an individual and a social level. HIV is considered one of the most stigmatized health conditions in the world. Scambler (2004) distinguishes between "felt" stigma versus "enacted" stigma. When PLWH fear being discriminated against without the present act of discrimination it refers to felt stigma, whereas actual discrimination by others refers to enacted stigma. It has been found that stigma contributes to barriers related to HIV testing, diagnosis and treatment (Gilbert, 2016). In addition, stigma related to HIV has shown to have the potential to become internalized (Kalichman, Simbayi, Cloete, et al., 2009), as it can resort to feelings of shame and self-blame in PLWH (Cameron, 2005). Evangeli and Wroe (2016) found that negative core beliefs about HIV is one factor which contributes to the internalization of HIV. The internalization of HIV stigma involves attributing negative beliefs and feelings associated with HIV to the self. (Evangeli & Wroe, 2016; Scambler; 2004). This re-contextualizes HIV as a social issue, which can evolve to progress into psychological challenges. Besides felt and enacted stigma directed at those infected with the virus, another socially constructed trend amongst uninfected people or those unaware of their status have been identified as "othering" (Shisana et al., 2014). "Othering" refers to a phenomenon in which the attitude exists that one is not at risk of contracting HIV, based on one's race, sex, sexual orientation, religion, national origin, etc. (Shisana et al.,

2014). This phenomenon can directly impact on high risk behaviours related to the spread of HIV, including HIV status awareness and access to necessary treatment and support structures.

Culture

South Africa is renowned for being a multiple-cultural country. There is thus an increasing trend for HIV to be researched in light of "alternative" cultural belief systems and its impact on HIV disease management. Kalichman and Simbayi (2004) found that people who ascribed HIV to be caused by spirits and the supernatural were more likely to encourage stigmatization towards PLWH. It has been found that traditional African healing practices (e.g. traditional medicine or witchcraft) may contribute to poor HIV testing rates, ART non-adherence, as well as increased exposure to harmful substances used as traditional medicine (Ashforth & Nattrass, 2005; Street, Kabera & Connolly, 2015).

As a means to address such issues, some recommend more rigorous biomedical outreach interventions as a means to encourage informed decision making through ongoing education (Ashforth & Nattrass, 2005; Kalichman & Simbayi, 2004). Recent research efforts are directed towards developing more "culturally appropriate" treatment approaches to HIV, which emphasize collaboration and understanding of alternative belief systems (Flint, 2015; Furin, 2011; Mokgobi, 2014).

Disclosure

A study done by Evangeli and Wroe (2016) revealed that anxiety related to HIV status disclosure is highly prevalent across region and population. It was found that the most common reasons for disclosure anxiety included fears related to rejection and discrimination in the context of interpersonal relationships. The fear about people sharing one's status with others was also found to create disclosure anxiety. Their results indicated that such disclosure anxiety was related to negative outcomes for ART adherence, the level of engagement in self-care, and general social functioning (Evangeli & Wroe, 2016).

One dilemma faced by healthcare providers and families in the case of paediatric HIV relates to the issue of status disclosure to the infected child or adolescent. In a study done by Rochat, Mitchell and Richter (2008) they found that most (91.7%) of the caregivers (parent's or care giving others) interviewed in the study did not disclose the child's status to them. Reasons for non-disclosure varied but most common responses included the perception that the child was too young; not being sure how to tell the child; difficulty due to own guilt of

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HMTCT; fear of disclosing their own status and/ or the status of other siblings through the process of disclosing to one child and fear of discrimination from the family (Rochat et al., 2008). Most notably, fear of disclosing to the child his/her status shed light on the phenomenon of "self-stigmatisation". This occurs when perceived fear of stigma or discrimination influences a person's choice of disclosure, rather than the actual past or present experience of stigma or discrimination (Rochat et al., 2008). This provides evidence of the debilitating effects of "felt" stigmatization as was introduced by Scambler (2004). With self-stigmatisation encouraging a trend of secrecy, it in turn raises further concerns, more specifically as it relates to limiting one's support networks and other HIV positive family members not receiving treatment (Gilbert, 2016). According to Evangeli and Wroe (2016) secrecy and non-disclosure can be explained as a mechanism of self-protection to reduce distress related to a person's own negative core beliefs about HIV.

Loss of Primary Caregiver(S)

Over and beyond the demands of living with a chronic illness, children or adolescents with HMTCT may also face additional life changes. Living with HMTCT, by definition implies that the child's mother and possibly also other family members have HIV or AIDS. For this reason possible life changes on a larger social scale can include loss of a parent or other family members due to AIDS (Falvo, 2015). The loss of primary caregivers often result in additional challenges such as child-headed households, changes in family roles and responsibilities, foster care, or being orphaned (Falvo, 2015; UNAIDS, 2014). Taking into consideration the stressors related to losing family members to AIDS and having to adapt to various life changes, HIV once again becomes situated as not only a medical issue but also a social issue with overlapping psychological consequences. With ART enhancing the life expectancy of ALWH, research attention within the social sciences is increasingly shifting towards the risks and challenges associated with this "new" or "emerging" population (Persson & Newman, 2012).

Reflections on Social Narratives

In reading the social "narratives" written about HIV it reminded me of my own theoretical position. In situating HIV in the context of the broader socio-cultural world, it managed to not only connect the biological to the social, but also its broader psychological connotation. Although a social perspective of HIV allowed for a broader contextualization of

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the person in context, research initiatives are still very much focussed on identifying and narrating the social (and psychological) impact of HIV on PLWH.

What Does This Mean

From the above it becomes evident that HIV has been identified and described as not only a medical but also a psychological and social epidemic. The considerable impact of HIV cannot be denied and thus frequently forms the backdrop from which research and intervention projects are approached. Much of the research conducted on children and adolescents living with HIV focus on the problems and challenges faced by this population group (impact of HIV on the person). The biomedical model talks about a metaphorical war going on inside your body, using words such as "attack" and "fight", and "death". From a psychological perspective, academic narratives remind us of the statistical probabilities of impending developmental and psychological dilemmas for those living with HIV. The social perspective tells stories of HIV even infiltrating families and communities, making people scared of openly talking about HIV. With HIV being authored as a "villain", it attacks its "victim" not only on a cellular level but also psychologically and socially. I am starting to wonder all the more what it must be like to adopt this perspective as your own narrative for making sense of HIV. With the age group of adolescence consistently being portrayed as "at risk" and "in need of intervention", it has the potential to encourage research acting to reproduce narratives of worry, concern and fear of making sense of HIV. Following the narrative as metaphor, my question is this; where does it leave those treating and living with HIV to make sense of HIV?

From a social constructionist position one can say that discourses are all around us and contribute without much conscious thought to our narratives that we tell about HIV. With the primary treatment context of HIV being the medical context, it made me wonder whether the HIV treatment programmes employed in South Africa are representative of a bio-psycho-social approach. In writing this chapter it made me wonder about the I-ACT treatment programme at the paediatric outpatient ward at KPTH. In chapter 2 I shared in my journal how I was wondering about the people who worked with the "wolves" and the stories that they used to make sense of HIV. In my journal I shared how I stopped "dancing by myself for a moment and then I could finally hear the stories that were told in the unit. I decided to visit the clinic to get a better understanding of how the staff of the unit made sense of and

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approached HIV with the children. I arranged one-on-one semi-structured interviews with some of the staff members which included the sister-in-charge, two assistant nurses and finally the two care workers that facilitated the I-ACT group. During the interviews I asked them to rank (according to their own opinion) the most important components of paediatric HIV treatment, to the least important. I captured their answers on separate sheets. Hereafter I asked them to identify treatment components that are currently not included in their programme which (according to their opinion) could be a valuable addition to paediatric HIV treatment at KPTH. See appendix D (3) for the response index in which I documented their answers. From their responses it was evident that the medical context in itself is a discourse (i.e. narrative) for informing its members how to prioritise and approach care and treatment of people with HIV. Medical treatment (i.e. ART) related to illness was the number one priority for all of the staff, with diet, education about the virus, its medical treatment and education on its transmission being important components after the administration of ART. Interestingly, as found by Vlug, Feucht and Kruger (2008) during their needs assessment, each of the staff members once again identified psychological and/ or social components to be lacking in the current treatment programme which was suggested as a necessary inclusionary component to the treatment of HIV.

Conclusion

In reading the academic narratives on HIV, I was guided by the narrative metaphor for researching various story versions for making sense of HIV. In approaching the literature from a social constructionist position, it asked of me to assume a critical role to deconstruct the meaning of HIV in light of "master narratives" or "taken-for-granted truths" about what it means to be an adolescent with HIV. With HIV being researched from various disciplines, each published research report or document contributes to a vast body of knowledge of the meaning ascribed to HIV. Following the narrative as metaphor, it can be said that academic discourses act as active socio-cultural "agents" in constructing and reproducing socially negotiated knowledge and master narratives of HIV. The above review of literature contextualizes HIV as a complex phenomenon with diverse biomedical, psychological and social obstacles. Although HIV has been studied and recognized to have an impact on various areas of functioning, the above literature demonstrates that the meaning of HIV depends on the discourse within which it is conducted and researched. In addition, after my visit to the clinic I came to the realization that treatment programmes are not always practically inclusive

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of a multi-discursive perspective and/ or approach to understanding and treating HIV. In the next chapter I consider the concept of meaning, more specifically as it relates to seminal thinkers who have historically influenced our academic conceptualization of meaning making and illness. In addition I provide an overview of research initiatives aimed at studying the meaning of HIV for adolescents through their illness narratives.

As is evident in chapter 3, paediatric (i.e. adolescent) HIV has been vastly researched from a variety of disciplines. In light of this journey, I found it necessary to consider the concept of meaning, especially as it relates to literature on the meaning individuals attach to illness. Hereafter I focus only on the research studies aimed at understanding the meaning of illness narratives of adolescents with HIV. From this I formulated my research question, justification, aim and objectives as was undertaken for the purpose of this research journey.

Seminal Influences on Illness Meaning

There has been much debate in defining the concept of meaning, especially relevant to the scope of research inquiry of illness experiences. According to Whitsitt (2010) there are seven seminal thinkers[10] who have historically influenced our academic conceptualization of meaning making and illness.

Susan Sontag, a cancer patient at the time was one of the first authors to critically tackle the issue surrounding the meaning of illness in her book "Illness as metaphor" (Sontag, 1977). She later extended her argument in her book "AIDS and its metaphors" (Sontag, 1990). Influencing thinking still today, Sontag argued that language associated with speaking about disease and those with illness, is culturally embedded. The language used is considered to contribute to poor treatment adherence and greater patient suffering. Sontag's primary argument was to reduce illness to "just a disease", that can be cured or treated medically. In this sense she divorced the concept of personal metaphorical meaning from the experience of illness. Still today, it creates ongoing debate amongst patients and academics who consider personal suffering and the creation of meaning through such suffering as important considerations for overall coping and functioning (Whitsitt, 2010).

In his book "The illness narratives", the medical doctor and psychiatrist Arthur Kleinman (1988) demonstrated the significance of storytelling as a catalyst for meaning making of illness experiences amongst his patients. Similarly, medical sociologist Arthur Frank noted the significance of meaning making through suffering as he shared his own experience of

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[10] Given that meaning in the context of research literature is a broad topic, it was decided to discus meaning with reference to only a few seminal works and its associated theoretical perspectives on meaning located in the context of illness.

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heart disease and testicular cancer in his first book "At the will of the body" (Frank, 1991). It was this notion of people "suffering" from illness that Sontag (1990) contested. Her argument was that illness should be reduced to a treatable bodily condition, divorced from personal meaning or connotations to the self. According to Sontag (1990), seeing the self as "suffering" from a medical condition, or being "cursed" adds to the person's suffering. Although Frank asserted that physical illness can lead to emotional suffering, he argued that there are more to people living with illness than just being a suffering victim to disease or patients to medicine (Frank, 2009). Frank set out to give a voice to the person suffering behind the disease. In his second book "The wounded storyteller", Frank (1995) re-contextualized storytelling as a postmodern act of meaning making, functioning as a catalyst for transitioning from a passive victim of disease to a position of healing through narrative emancipation. A seminal work still today, Frank identified restitution, chaos, and quest narratives as the three basic categories of illness narratives that people construct (Frank, 1995). Similar to Sontag's (Sontag, 1977; 1990) perspective of illness, in restitution narratives, illness meaning is guided by trust in medical technology and the potential of cure creating hope for healing (Frank, 1995). In turn, people who construct chaos narratives of illness are caught up in ongoing suffering, creating an "anti-narrative" with no relief or meaningful insight (Frank, 1995). Quest narratives on the other hand, involve stories in which people transform their view of illness from suffering to meaningful transition and self-growth (Frank, 1995; 2009).

Similar to Frank's (1995) quest narrative, Broyard (1992) argued that in narrating your experiences it re-positions you in control over how the disease wants to narrate you. In his book "Intoxicated by my illness" Broyard (1992) wrote several essays sharing his personal experience of dying, by exploring his relationship with prostate cancer, death and the biomedical world of treatment. Unlike Sontag's biomedical perspective, Broyard (1992) playfully embraced metaphors and storytelling as a way to learn about and to personalize his illness experience in the clinical world of medicine. Through such re-construction, he argued that people create a new, meaningful and preferred story for the self and others to understand the dying person (Broyard, 1992).

Influenced by Sontag's critical view of language and suffering, other seminal authors attempted to study the cultural context of the meaning of illness. The book "Disrupted lives" is based on an ethnographic study done by Becker (1997) on the cultural implications of the meaning of illness stories of infertility, life transitions, and strokes. Similarly, Morris (1998) reconceptualised illness as a bio-cultural experience, linking illness experience to cultural

discourse. In studying the stories of illness-crisis, the medical ethicist Zaner (2004) explored the personal philosophical dilemmas encountered by patients and their families, in attempting to narrate the meaning of illness against the backdrop of the biomedical model.

From the above review, it becomes clear that the meaning of illness depends on the larger philosophical assumptions and implications of the act of meaning making on the person experiencing illness. What becomes apparent is that seminal works on the meaning of illness has a strong foundation in postmodern social constructionist thinking. From this theoretical stance, meaning is called into existence through language which is embedded socially and culturally across time (Lock & Strong, 2010). By saying something like "I am a broken person" what does that mean and what are you actually saying? In their book "Metaphors we live by", Lakoff and Johnson (2003) shed light on how people shape their realities metaphorically. Language and culture has provided the vehicle for constructing meaning. It is through the meaning of one concept, that meaning can become connected and attached to another concept to further communicate meaning metaphorically. Lakoff and Johnson (2003) argued that the complexity of making sense of abstract concepts and experiences (e.g. emotions, motivations, etc.), push people to link them conceptually to the existing, tangible, concrete domain of everyday bodily experiences and meaning. As a result, metaphorical thinking acts as a vehicle for the construction and communication of meaning of things that is conceptually difficult to make sense of.

Reflecting back on my own attempt at making sense of HIV in chapter 2, I used the story of little red riding hood and the wolf. In doing so I relied on the tangible but metaphorical space (and meaning) provided to me by the story of little red riding hood and the wolf. Although a folk tale, I relied on the tangibility of the characters and the existing storyline as a way of ordering my experiences as a way to communicate meaning. With HIV being a medical condition it has been provided a rich vocabulary for making sense of it from the tangible biomedical discourse; a virus attacking the body. In shifting discourses, the social, psychological and spiritual meaning of HIV transcends to domains of experience which is much more abstract in nature. With HIV predominantly being defined through a biomedical lens it may at times lack the linguistic structure for making sense of HIV from alternative discourses. As a result, one may resort to metaphorical language for constructing meaning in light of abstract experiences. The next section explores research trends in light of the meaning of illness for adolescents with HIV.

Narrative Research Studies and Adolescent HIV

Given the vast amount of research studies and academic literature on adolescent HIV, the scope of the rest of this chapter will be limited to narrative research inquiry geared towards understanding how adolescents with HIV employ storytelling to make sense of their illness.

Narrative Research Trends

Field. Some of the fields in which the narrative meaning of adolescent HIV has been researched include, theology (Loubser & Müller, 2011), psychology (Pienaar & Visser, 2012; Willis et al., 2014), social work (Greifinger, St. Louis, Lunstead, Malik, & Vibbert, 2013); communication studies (Howard, 2013), medical anthropology (Winskell, Brown, Patterson, Burkot, & Mbakwem, 2013), and public health (e.g. Mupenda et al., 2014).

Context. Research contexts in which the meaning of adolescent HIV narratives have been researched include, South Africa (Loubser & Müller, 2011, Pienaar & Visser, 2012), Zimbabwe (Willis et al., 2014), United States of America (Greifinger et al., 2013; Howard, 2013), Nigeria (Winskell et al., 2013), and the Democratic Republic of the Congo (e.g. Mupenda, et al., 2014).

Methodology. The above narrative enquiries into the meaning of adolescent HIV have primarily been conducted from a qualitative methodology, situated within a social constructionist paradigm, with specific reference to collaborative participant-researcher enquiry. The meaning of adolescent HIV has been researched from the perspective of both the infected (Greifinger et al., 2013; Mupenda, et al., 2014; Pienaar & Visser, 2012; Willis et al., 2014) and affected (Howard, 2013; Loubser & Müller, 2011; Winskell et al., 2013).

Approach. Loubser and Müller (2011) used the "tree of life"[11] and the "David metaphor"[12] with adolescent male orphans affected by HIV, as guidance for the construction of meaning, during extended group and individual discussions. In using the metaphors as guiding analogies, Loubser and Müller (2011) facilitated meaning making as well as the co-construction of alternative and preferred meaning of HIV.

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[11] The *tree of life* is a narrative practice used with vulnerable children and young people in facilitating skills, knowledge and identity development through storytelling. For more information on the "tree of life" metaphor consult Carmichael and Denborough (2015).

[12] The *David metaphor* referred to the act of drawing analogies between the meaning of experiences related to the Christian biblical figure David and the meaning of the stories of the adolescents.

Pienaar and Visser (2012) explored the experiences of adolescents with HMTCT through different picture narratives and collaborative discussion as a form of narrative co-research. The meaning of the picture narratives was analyzed by the researchers in the light of how it informed the adolescent's identity in the family, school and medical context.

As part of a narrative therapeutic intervention, Willis et al. (2014) collaboratively studied the meaning of HIV with adolescents and youth living with HIV (YLWH) through digital storytelling[13]. Each participant attended a digital storytelling workshop and constructed his/her own short-film based on their life story. In collaboration with the researcher, each adolescent explored their own film in the light of their life experiences and dominant themes. Based on a narrative therapy approach, the researcher assisted the interested participants in re-telling their stories in ways which promoted preferred and ongoing healthy development.

Through participant observation, Greifinger et al. (2013) studied the co-construction of the meaning of HIV amongst a group of 30 young people living with HIV. The observation was done over the course of 5 days during peer-led discussion groups, which took place during a conference for YLWH. Greifinger et al. (2013) aimed at using the co-constructed "group narrative" to inform and augment the design of programs aimed at YLWH; subsequently also to use as guidance for the clinical and mental health care practitioners developing such programs.

Winskell et al. (2013) studied how youth in south-eastern Nigeria relied on their cultural resources to make sense of HIV through narratives submitted for a script-writing contest. Participants were encouraged to be creative in writing a script for a film with the aim of teaching people about HIV/AIDS. The data was analyzed thematically to reveal five narrative themes.

Howard (2013) studied the collaborative meaning making of HIV though interactive theatre performances about HIV. Howard (2013) developed and facilitated a project called "the living and learning about AIDS and HIV performance project". Through a combined approach of literature research on HIV and field work with PLWH, interactive theatre students were asked to combine their reflective understanding by writing a script to be embodied as a theatre performance for college students. The performance was made interactive, by encouraging audience members to stop the performance at anytime should they wish to ask the "characters" questions about their feelings, motives and behaviours. This

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[13] Digital storytelling in this study (Willis et al., 2014) refers to the use of autobiographical storytelling in combination with photos, videos and other visual mediums so as to construct a digital film. For more information on digital storytelling, review Lambert (2013).

encouraged ongoing re-authoring of the narrative performance as the audience members (some who were HIV positive) were considered co-authors of the final narrative.

Mupenda et al. (2014) studied how the meaning that YLWH and their care givers attribute to illness is shaped by the labels used in society to define HIV and PLWH. In-depth individual interviews were conducted during which the researchers enquired about how people living with HIV in Kinshasa are treated in the community. The study was aimed at generating knowledge in support of psychosocial support interventions for YLWH in the Democratic Republic of the Congo.

Findings

Firstly, the meaning of HIV and HIV-related experiences has been found to impact on identity development. Pienaar and Visser (2012) found that the meaning that adolescents living with HIV (ALWH) attached to their experiences in the medical context, contributes to a specific patient identity. This included their experiences of overall disease management and health provider interactions. HIV status was found to be internalized as part of the adolescents' identities. Patient identity was found to have a considerable impact in shaping all other aspects of the adolescent's identity in various other contexts outside of the medical context (Pienaar & Visser, 2012). One study found value in peer support discussion groups for the development of confidence, self-esteem and a notion of community support for the construction of shared meaning (Greifinger et al., 2013). Willis et al. (2014) found that the process of guided meaning making through storytelling has the potential to re-author identity as a form of positive transformation. In their study they found that the meaning-focused approach provided the space to redefine painful negative experiences in light of its effects on lived experience, rather than it defining their identity (Willis et al., 2014).

Secondly, the personal meaning of HIV has been found to be embedded in the larger socio-cultural meaning of HIV. Mupenda et al. (2014) identified ten categories of socio-cultural labels associated with HIV and PLWH including; attribution, neutral, death-related, physical feature–related, factual statements, lingering illness–related, common illness–related, wordplay, and devaluation. PLWH were most commonly described by derogatory labels which included "walking corpses", "dangers to others" and "people deserving to die before they infect others" (Mupenda et al., 2014). The internalization of HIV as part of one's identity has been found to contribute to a heightened fear of stigmatization (Pienaar & Visser, 2012), especially if myths and assumptions about HIV are considered to be socially and culturally linked to an identity of illness, contagion and death (Mupenda et al., 2014). Willis

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et al. (2014) found that meaning-focussed interventions has the potential to shed light on acts of transformation, coping skills and resiliency, despite stigmatized labels. In turn, it has shown to contribute to personalized self-understanding and improved self-control (Willis et al., 2014). In analyzing the youth narratives submitted for a script-writing contest about HIV, Winskell et al. (2013) noted a strong cultural framework (i.e. moral values, religion, gender identity, etc.) for making sense of HIV amongst youth. The results from their study demonstrated that public health programmes and messaging is inconsistent with the cultural themes for understanding HIV in Nigeria. The cultural labels and meaning associated with HIV and PLWH can thus be said to greatly influence personal meaning of illness for PLWH. Howard (2013) found that by providing an interactive public forum for people to share their understanding of HIV, it can function to break the silence about stigma related to HIV. In doing so, it has the potential to reshape issues related to socially and culturally-generated understandings about HIV.

Thirdly, the meaning of HIV has been linked to issues related to disclosure. Amongst ALWH Pienaar and Visser (2012) noted a constant struggle between normality versus difference. It was found that there is an ongoing tendency to strive towards normalcy by rejecting difference just to be reminded of the difference through ongoing dilemmas around stigma and disclosure. As a means to deal with such ongoing struggle, there is a tendency amongst ALWH to focus on preferred imagined future identities, rather than the current meaning of the self (Pienaar & Visser, 2012). Greifinger et al. (2013) found that peer-led discussion groups allowed for the construction of collaborative meaning around the responsibility of disclosure in romantic relationships.

Fourthly, treatment adherence was found to be complicated by conflicting meanings related to HIV. Reduced treatment adherence tendencies were observed in patients who experienced treatment fatigue or were unaware of their status and the meaning of their physical symptoms. Reduced treatment adherence was observed in those who lacked meaningful reasons for taking medication (Greifinger et al., 2013) or those that verbalized a need to find meaning for taking medication (Pienaar & Visser, 2012).

Fifthly, the meaning of HIV has been found to be influenced by the lack of ongoing support due to the fear of stigma from peers and/ or the death of a parent(s) (Greifinger et al., 2013; Pienaar & Visser, 2012; Willis et al., 2014). Greifinger et al. (2013) found that a need exists to build positive and healthy relationships around illness disclosure, as opposed to the current narratives of silence, rejection and distrust. In the light of lack of support, Willis et al. (2014) realized that some caregivers of YLWH refrained from speaking about HIV or the

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family members who passed away from AIDS, due to their own pain in dealing with loss. As part of their meaning-focussed approach, Willis et al. (2014) encouraged their participants to remember significant people who were no longer alive and to include them as critical role-players in their preferred life stories and the meaning of HIV. In sharing their new stories and films with caregivers, it allowed for enhanced communication and sharing of stories of lost loved ones between caregivers and YLWH. As a result it acted as an additional form of support and facilitated new interactions in which HIV and loss was openly addressed.

In working with vulnerable youth, Loubser and Müller (2011) found that a meaning focussed approach to researching the impact of HIV added much value to the lives of the orphaned adolescents involved in their research. It was found that the use of metaphors attributed to personalized and preferred meaning creation of HIV. Willis et al. (2014) found collaborative meaning-making through digital storytelling to be a well suited approach to engage in research with vulnerable YLWH given its valuable therapeutic qualities. Park (2010) found ample evidence for meaning making to be linked to improved adjustment and overall functioning. In contrast, Park (2010) noted that attempts at making meaning has the potential to be non-productive when new meaning fails to become integrated into a person's global meaning. This can resort to ongoing long-term searching for meaning, resulting in rumination and heightened distress. A study by Farber, Mirsalimi, Williams and McDaniel (2003) found that positive meaning connected to HIV can, even in the absence of social support and problem-focussed coping, be a predictor of higher levels of psychological adjustment and lower levels of depressed mood. A study done by Moskowitz and Wrubel (2005) on illness appraisals of HIV suggests that interventions aimed at coping mechanisms should not be ignored or phased out. Coping interventions are however more likely to be effective if it is considered in the context of the meaning of HIV for the person. Hogwood, Campbell and Butler (2012) shed light on the need to tackle and deconstruct stigmatized stereotypes attached to PLWH by shifting away from a problem-saturated, medical approach to HIV disease management. As a means to reduce the danger of patients internalizing stigmatized labels associated with the illness, Hogwood et al. (2012) suggests research and supportive interventions that promote a strength-focussed identity. In addition there is a need for ongoing support services for disclosure. More specifically, it is suggested that such support services be culturally and personally tailored to the understanding of the contextual beliefs and meanings attached to HIV (Hogwood et al., 2012). Based on the above discussion,

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the research question for this study can be phrased as: "How is storytelling employed by adolescents with HIV to construct meaning of their illness?".

Research Justification

In support of this research journey into the meaning of HIV, a research, professional development and practice justification is briefly highlighted.

Research Justification

Based on chapter 3, it can be said that academic literature about adolescent HIV has the potential to produce and re-produce certain taken-for-granted truths about what it means to be an ALWH. This in turn can shape the meaning that adolescents ascribe to their identity and ongoing illness experiences. Based on the discussion in this chapter, post-modern narrative research enquiry has the potential to produce new knowledge (i.e. narratives) that take a critical stance towards such taken-for-granted truths. Not only is a meaning-focussed approach aimed at the co-construction of alternative narrative knowledge about the meaning of HIV, it is also considerate of the participatory value for those involved.

Professional Development Justification

Besides the research justification mentioned above, this research also had value for professional development. As a trainee Counselling Psychology student this research afforded me the opportunity to enhance my professional competency through the extension of narrative therapeutic practice to the domain of narrative research inquiry.

Practice Justification:

This research also had a practice justification. A narrative understanding can add much needed insight into how the meaning of HIV can impact the overall functioning and wellbeing of ALWH. The paediatric out-patient unit at KPTH has made provision for support for ALWH who receive ART at the clinic. The Integrated Access to Care and Treatment (I-ACT) support group at KPTH offers biomedical education to ALWH in conjunction with their ART. A need has been expressed by the staff of the unit to include psycho-social components to the existing I-ACT program as part of their supportive intervention strategy. A narrative understanding of the implications related to the meaning of HIV may prove to be useful in considering the overall approach to HIV support services offered at the clinic.

Research Aim

The aim of this research was to provide the time and space for ALWH to construct meaning of their illness, as well as to explore hidden narratives as a construction of alternative, preferred meaning of HIV. In employing a meaning-focused approach, this research aimed at taking into consideration the participatory value for those involved in the study.

Research Objectives

To actualise the above aim this research employed a narrative approach situated in a social constructionist paradigm and employed narrative therapeutic co-research as an approach to collaborative meaning making. In line with the aim of this study, the research objectives below were used as guidance throughout this journey:

Objective 1

To describe and conduct the first (working) sub-phase (phase 4.1.) of the project phase (phase 4) called the Collaborative Storybook Development (CSD) project as a vehicle for the construction of meaning and the emergence of practical wisdom through storytelling.

Objective 2

To describe and to conduct the second (reflection) sub-phase (phase 4.2.) of the project phase (phase 4), during which the researcher and the adolescent engaged as co-reflective audience members of the meaning that was constructed during the CSD project.

Objective 3

To document the new narrative knowledge as a reintegration (telling) of the practical wisdom gained through this journey of co-research.

Objective 4:

To describe and to conduct the reintegration phase of this study, by sharing the new narrative knowledge with audiences outside of the co-research dyad.
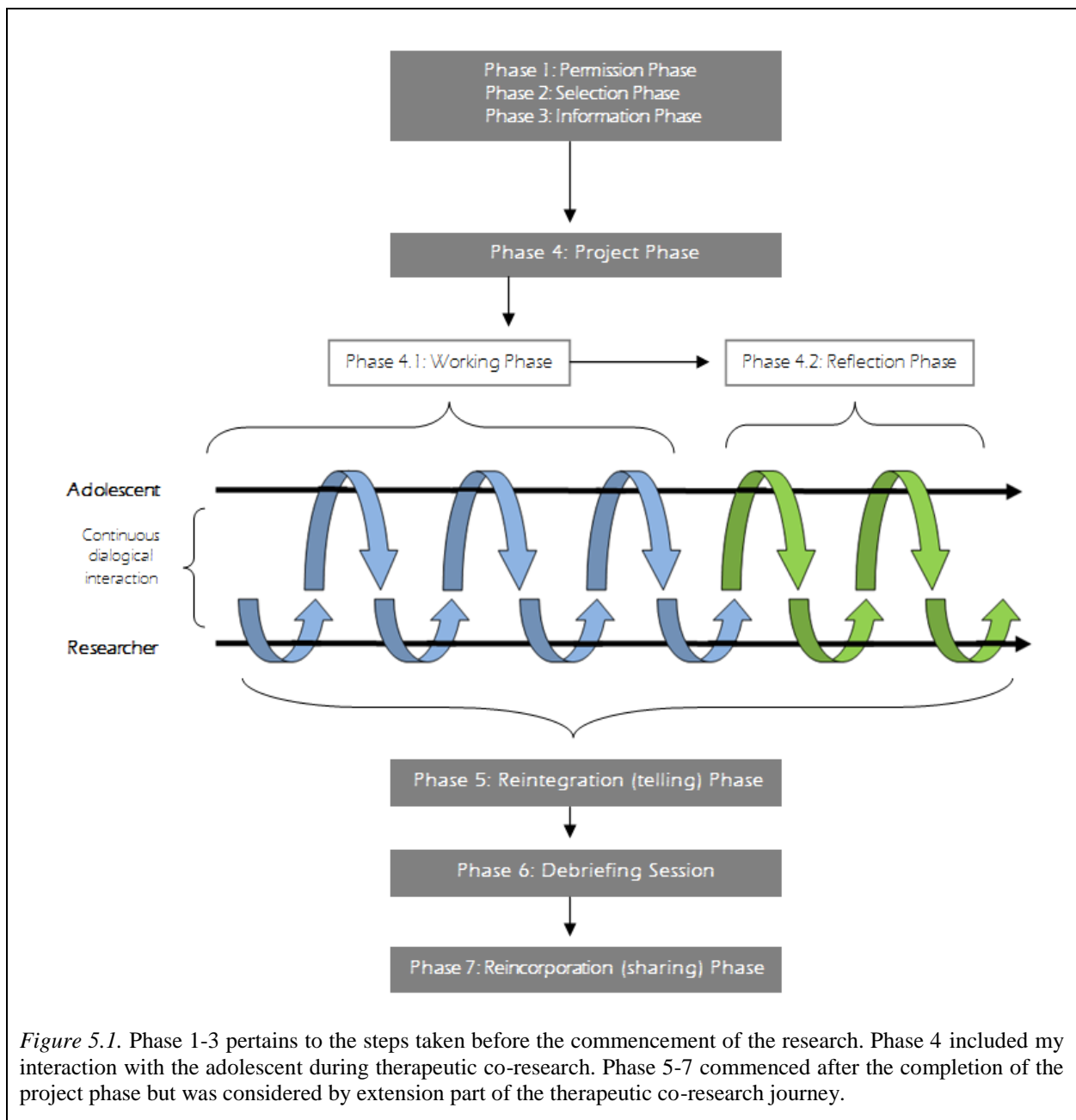
Conclusion

The above studies shed light on the significant impact of illness meaning in the context of living with HIV. Narrative inquiry into the social construction of meaning has provided a broader understanding of HIV in context. Not only have such research approaches encouraged new perspectives on illness, but it has also contributed to enhance the participatory value of the research journey for the participants involved. In addition, meaning-focused research has contributed to enrich our understanding of the role of illness meaning and its overall effects on adjustment and functioning. The next chapter provides a more descriptive overview of the processes followed in this research journey.

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CHAPTER 5

RESEARCH METHODOLOGY

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This chapter provides an overview of the research methodology, by providing a descriptive overview of the research process which comprised of 7 separate but integrated phases. Each phase with its sub-phases is discussed. Hereafter, a review is considered of the challenges encountered during the implementation of this process, together with how it was dealt with.

Figure 5.1. Phase 1-3 pertains to the steps taken before the commencement of the research. Phase 4 included my interaction with the adolescent during therapeutic co-research. Phase 5-7 commenced after the completion of the project phase but was considered by extension part of the therapeutic co-research journey.

<div align="right">

Figure 5.1: The Research Process

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Based on figure 5.1, the section below provides a more comprehensive outline of the processes followed during this research journey.

Phase 1: Permission Phase

This phase involved all aspects related to acquiring permission to conduct this research and consisted of three sub-phases as outlined below.

Phase 1.1: Ethical Approval

Ethical approval was obtained from the Faculty of Humanities at the University of Pretoria (UP) to conduct this study. See Appendix A(2) for the letter of ethical approval.

Phase 1.2: Hospital Research Permission

Written permission was obtained from Kalafong Provincial Tertiary Hospital (KPTH) to conduct this study on their premises with adolescents with HIV who receive Antiretroviral Therapy (ART) at the out-patient paediatric unit. In addition permission was granted by the hospital to the researcher to access patient files and information for the purpose of participant selection. See appendix A(3) for the hospital permission letter.

Phase 1.3: Paediatric Out-Patient Unit Research Permission

Verbal permission was given by the sister-in-charge of the paediatric unit at KPTH to, in collaboration with the social worker and care workers at the unit select adolescent participants that meet the criteria for this research.

Phase 2: Selection Phase

This phase involved all aspects related to the invitation and selection of participants from the specified research context, as outlined below.

Phase 2.1: Research Context

Participant selection was done within the paediatric out-patient unit at KPTH in Attridgeville, Gauteng, as the primary research context.

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Phase 2.2: Research Participant Identification

The sister-in-charge and social worker collectively identified and approached adolescents and/or their parents or guardians in the unit who complied with the inclusion criteria. This process only commenced once hospital permission was granted by KPTH.

Phase 2.3: Selection Criteria

The inclusion criteria as was used for the selection of prospective participants for this study as is set out in the table below.

Selection Criteria
(a) The person is an adolescent between the ages of 14-18 years
(b) The adolescent is able to converse in and comprehend English as a first or second language.
(c) The adolescent is aware of his/her HIV status and how it was acquired. This was decided to prevent the accidental disclosure of such information to the adolescent during the project or research phase.
(d) The adolescent receives antiretroviral therapy (ART) at KPTH as an out-patient.
(e) The adolescent can be either male or female.

Table 5.1: Selection Criteria

Phase 2.4: Sample Size

Initially three adolescents who complied with the inclusion criteria listed above were invited to participate in this research, although the participation of only one of the adolescents was documented in this narrative report.

Phase 2.5: Invitation

The sister-in-charge and the social worker first obtained verbal permission from the adolescents as to whether he/she would be interested in participating in the research. Hereafter he/she was provided with an invitation letter (See Appendix B) to be signed by both the adolescent and his/her parent or guardian as proof of permission to receive more detailed information about the research. The social worker provided the researcher with the signed invitation letters of the interested parties. In total, eighteen adolescents responded to the research invitation request. Hereafter, the adolescent's parent or guardian was contacted telephonically to arrange for a written informed consent and assent meeting with the researcher at the hospital.

Phase 3: Information Phase

Phase 3.1: Research Information Meeting

Of the eighteen response letters acknowledging the invitation, only twelve adolescents provided working contact details for their parents or guardians to be contacted. Twelve separate information meetings were arranged for each of the adolescents and their parents/ or guardians to convey more detailed information to the specifications of the research project.

Of the twelve meetings arranged only eight of the adolescent's parents or guardians attended the arranged sessions. The parent(s) or guardians of each of the adolescents first met with the researcher alone without the adolescent so as to ensure that an inclusion criterion was adhered to. In addition this was done to safeguard against disclosing the adolescent's HIV status by accident during the information meeting. An office space in the paediatric out-patient unit at KPTH was provided for informed consent, assent and selection purposes. Of the eight informed consent and assent sessions, three of the adolescents complied with the inclusion criteria.

Phase 3.2: Informed Consent

The parents or guardians had to provide written consent as proof of voluntary informed acceptance of the adolescent's involvement in the study. See Appendix C(1) for the informed consent letter detailing the information that was provided to the parent or guardian.

Phase 3.3: Informed Assent

In addition, the adolescent participant also had to provide written assent as proof of voluntary informed acceptance of their own involvement in the study. See Appendix C(2) for the informed assent letter detailing the information that was provided to the adolescent.

Phase 3.4: The Selected Participant

Only one of the three selected adolescents completed the entire project phase of this study. For the purpose of this research only this adolescents' participation was documented in this report. The selected participant is a black female adolescent who was 17 years old at the time of the information meeting and regularly attended ART at the paediatric out-patient unit of KPTH.

Phase 3.5: Research Setting

A research facility room outside of the paediatric unit of KPTH was provided to utilise for project phase of this study. The research site for the selected participant for the purpose of this study was moved to a private office site in Centurion which was located at a closer proximity to the participants' place of residence. This made it easier for her to attend the sessions.

Phase 4: Project Phase

The project phase of the study consisted of two separate sub-phases specifically designed by the researcher for the overarching purpose of encouraging therapeutic co-research into the meaning of HIV.

Phase 4.1: Working Phase

Phase 4.1 was called the working phase or the Collaborative Storybook Development (CSD) project. It was specifically designed by the researcher for the purpose of this study and based on the work of Freedman and Combs (1996) on story construction and development. The aim of the CSD-project was to provide the time and space for the construction of stories (i.e. meaning) of living with HIV through storytelling and storybook making. The narrative therapeutic approach on which the CSD project was based further allowed for the collaborative exploration and deconstruction of such stories which gave way to the telling (construction) of new stories (and meaning) about living with HIV. The one-on-one sessions were scheduled for once a week over approximately a three month period and lasted for about one hour. In total the adolescent attended 9 sessions which was video recorded for the purpose of focussed co-reflection during phase 4.2.

Phase 4.2: Reflection Phase

Phase 4.2 was considered the reflection phase and consisted of focussed co-reflection sessions which commenced after the completion of the CSD project. By watching the video recordings together, both the researcher and the adolescent were positioned as audience members in hearing (i.e. receiving) and reflecting on the constructed story versions (i.e. meaning) as they were constructed during the CSD project. Through collaborative reflections it provided a space for mapping (identifying) the process of meaning making through storybook making as well as new narrative knowledge (i.e. practical wisdom) about living

with HIV. The reflection phase consisted of three weekly sessions which stretched over a period of approximately 1 month. Each of the co-reflection sessions were video recorded for the purpose of further documentation during the reintegration (telling) phase (phase 5). Chapter 6 provides a more comprehensive discussion on the details pertaining to the project phase.

Phase 5: Reintegration (telling) Phase

It is important to clarify that data collection for the purpose of data analysis was not the primary goal of this research. Instead, collaborative understanding was considered the primary aim as the researcher and the adolescent deconstructed personal narratives and co-constructed alternative narratives. Therefore, this research was more concerned with the description and understanding (meaning-making) of narrative realities than it was with analyzing the data for factual findings. My involvement as co-researcher and co-author of this journey afforded me the space to document how storytelling was employed to make sense of HIV. Such documentation was done in the form of a storybook as a reintegration (telling) of such knowledge, as is written up in Chapter 7 of this report. The storybook is based on the narrative knowledge gained from the journey of co-research with the adolescent who completed the project phase of this research.

Phase 6: Debriefing

After the completion of the project phase a formal debriefing session was arranged with the adolescent to ensure that no harm was caused by her involvement in this study. Given that the debriefing session created an additional space for dialogical interaction it acted as the foundation for the emergence of an additional phase, referred to as the reincorporation (sharing) phase.

Phase 7: Reincorporation (sharing) Phase

During the debriefing session we explored the adolescent's need to share her new story version (i.e. meaning) and narrative knowledge with others as a metaphorical "rite of passage" in reclaiming back her position as privileged author of her life story. Three audiences were identified as reincorporation (sharing) platforms. The identified audiences

included two of the adolescent's family members; this narrative (research report); and lastly the planning of a children's book as a means of not only telling but sharing the knowledge with others growing up with HIV. Chapter 8 provides an overview of the debriefing session, as well as an overview of the reincorporation (sharing) phase of this research journey.

Implementation Challenges

Certain challenges presented itself during the practical implementation of this research. This section provides an overview of such challenges together with how it was dealt with.

Hospital Permission

The first challenge encountered during the implementation of this research occurred during the research permission phase, more specifically as it related to hospital permission. The research context (site) for conducting this research was originally focused on the adolescent community living with HIV at Tshwane District Hospital (TDH). In July 2014, I received ethical clearance from the Postgraduate Research Ethics Committee of the University of Pretoria. See appendix A(1) for the initial approval letter. Such approval was subject to the condition that I acquire hospital permission from Tshwane District Hospital (TDH), prior to the commencement of my research. I submitted my research proposal and ethical clearance to the hospital superintendent at TDH in July 2014, however failed to receive feedback from the hospital. I resubmitted my proposal twice, however still failed to receive any feedback from the hospital. Due to the lack of response from TDH by December 2014, I made the decision, together with my Supervisor, to change my research site from TDH to Kalafong Provincial Tertiary Hospital (KPTH). An amendment protocol was submitted to both KPTH and the Postgraduate Research Ethics board for consideration. I received ethical approval in April 2015 to commence with my study subject to the condition that I acquire hospital permission from KPTH. In May 2015 I received hospital permission from KPTH to commence with my research.

Selection Phase

The second challenge of this research occurred during the selection phase of the study, more specifically as it related to the process of informed consent/ assent. The adolescent's parents or guardians were contacted telephonically after they agreed to receive more detailed information pertaining to the study. Telephonically the parents or guardians agreed to a date

and time to come to the hospital, however failed to arrive. An additional challenge involved complications related to finding a day of the week and time during which the project phase sessions would not interfere with the adolescents' school commitments. Given that the adolescents only visited the clinic once a month or once every three months for their Antiretroviral Therapy (ART), it required the adolescents to travel to the clinic more often than usual. Although the participants' travel costs for their participation in the project phase were paid for by the researcher, it still proved to be a challenge as some of the participants did not arrive for arranged sessions.

Availability

Initially three adolescents were selected to be involved in the research project however two of the adolescents were only selectively available to attend the weekly sessions. Irrespective of confirmed appointments, poor attendance resulted in the project time frame to be stretched out beyond the completion date. As a result, the researcher shifted the focus of this study to rather follow the in-depth journey of meaning making with one of the adolescents. The project sessions with the other two adolescents continued in the context of its own time frame, however it was not included in this research report.

Research Setting

A fourth challenge involved the research setting. The facility allocated for the research had high noise levels and restricted privacy. In addition, most of the project phase sessions had to be arranged on Saturday mornings so as to not interfere with school commitments during the week. This created further challenges as the out-patient ward was closed over weekends. In dealing with this challenge, alternative arrangements were made to get permission to use the hospital's post graduate research room at the hospital for the project phase, which provided both privacy and low noise levels. The research site for the adolescent who completed the project phase relevant to this research report was moved to a private office site in Centurion and was thus not influenced by the above research setting issues.

Anonymity and Confidentiality

A fifth challenge pertained to the choice to video record the sessions during the CSD project (phase 4.1.) for the purpose of co-reflection (phase 4.2). The adolescents were somewhat hesitant to being filmed which was noticed during the informed assent phase of the study. To counter this obstacle and to make the adolescents more comfortable, a decision was

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made to merely video record the storybook on the table which assisted in enhancing anonymity. See chapter 9 for a more comprehensive discussion.

Summary

Even though the implemented research processes (phases) slightly deviated from the original process plan, it must be mentioned that such deviations were considered and implemented in light of the ethical guidelines on which this research was based. Care was taken to ensure that this research which was conducted with minors, were in accordance with the ethical guidelines for respecting the rights of all those involved. Chapter 9 provides a more comprehensive breakdown of all the ethical considerations and resultant protocol applied during this research.

PART II

JOURNEYING WITH HIV AS CO-RESEARCHERS

CHAPTER 6

PROJECT PHASE: THERAPEUTIC CO-RESEARCH

"Three good points about stories: if told, they like to be heard; if heard, they like to be taken in; and if taken in, they like to be told"

(Carson, 2000, p 1)

This journey was aimed at not only hearing the stories told about HIV but also about hearing and telling hidden story versions which emerge as a result of dialogical enquiry. This chapter provides an overview of the processes followed in using the existing dialogical space that the therapy context offers as an additional space for researching in a collaborative manner (i.e. therapeutic co-research) the story versions (i.e. meaning) of living with HIV. Discussion pertaining to the project phase in this chapter will make reference to only one of the adolescents that completed the CSD project. In following this journey from the beginning, I find it necessary to introduce to you, the story that was authored to me during my introduction to the selected adolescent, before the project phase started.

Gabby (pseudonym) is a black female adolescent who was 17 years old at the time that I met her at KPTH. I first met her grandmother during the informed consent session at the paediatric outpatient ward at the hospital. Her grandfather was unable to attend the meeting due to work responsibilities. Gabby's grandmother communicated that she was very eager for Gabby to get involved in the project as she felt that Gabby needed some supportive intervention following a recent "relapse". The relapse that she referred to I later learnt was "relapsing" back into depression two months prior to our introduction. Her Grandmother shared with me that Gabby had started ART after she was diagnosed with HIV in 2012 at Kalafong Hospital. She contracted HIV as an infant through mother-to-child transmission. She assured me that Gabby was aware of her status as well as how she contracted HIV. Gabby was asked to join us during which detailed information was shared with both Gabby and her grandmother on the project. Initially during the informed assent meeting with Gabby she did not say much and appeared quite shy. She gave assent to be involved in the project. After our meeting she expressed her excitement towards the storytelling aspect as part of the design of this project. Gabby shared that she enjoyed writing and considered herself to be quite creative in her writing but not so creative in terms of drawing. Gabby had been

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attending the Kalafong paediatric outpatient clinic for the ART programme since the age of 15. Gabby's mother and father both had AIDS. Her mother passed away when she was very young and her father passed away a year before she learned about her own status. Gabby has an older brother who does not have HIV. Gabby and her brother currently live with their Grandparents in Centurion, about 40 kilometres away from the Attridgeville clinic where she received ART at the time of the information meeting.

The therapy context is one context where a person tells (i.e. construct) a story version of his/her life. As is often the case with people seeking therapy, aspects of the story versions shared are often problematic in nature (White, 2007). When stories are told, they become located in a space external to the storyteller and the reader (audience); thus made accessible to be collaboratively examined (Lysaght, 2009; White & Epston, 1990). In the therapeutic context from a narrative social constructionist frame, such stories are collaboratively explored for the purpose of re-authoring (i.e. re-constructing) preferred story versions to live by (Freedman & Combs, 1996). The project phase (phase 4) was specifically designed as a way to transform the therapeutic space into one in which narrative knowledge can be documented. To actualize such an aim, the project phase included two sub-phases. The first sub-phase (phase 4.1.) was called the working phase during which the Collaborative Storybook Development (CSD) project took place. The second sub-phase (phase 4.2.) was called the reflection phase and consisted of an extended period of focussed co-reflection. The section below discusses the two sub-phases in more detail as it was utilized for the purpose of therapeutic co-research with Gabby.

Phase 4.1: The Working Phase

The CSD project was guided by the work of Freedman and Combs (1996) on story construction and development; originally based on the narrative therapeutic work of White and Epston (1990). Grounded in a narrative constructionist position, the CSD-project was geared towards providing an ongoing dialogical space and time for storytelling and collaborative exploration through storybook construction. The project phase was designed exclusively for one-on-one sessions which took place once a week over a three month period, with each session lasting approximately 1 hour. In total Gabby attended 9 sessions. Each session was video recorded for the purpose of focussed co-reflection during the second sub-phase. As a means to keep you (the reader) engaged in the process as it unfolded, this section

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provides a comprehensive explanation of the CSD project with regards to the components of storybook construction, exploration and development.
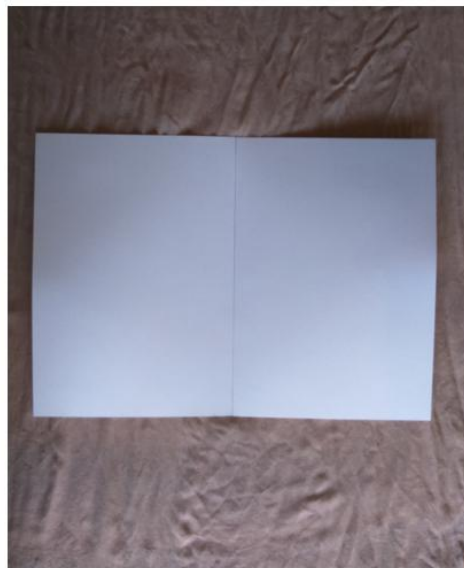
Storybook Construction

The aim of the first session was to provide the time and space for initial story construction through storybook making as well as the collaborative exploration of the story version with regards to its various components (i.e. themes, plots, characters, etc). The section below provides an in-depth explanation of the processes followed during the first session with Gabby.
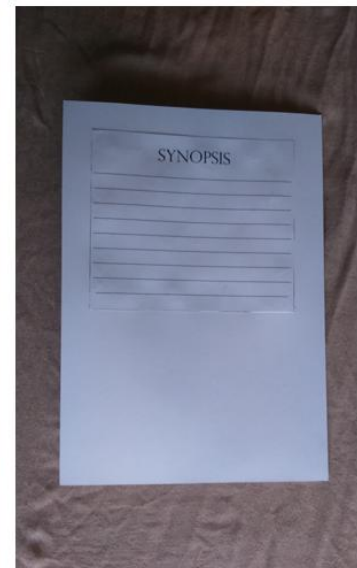
Storybook title and front cover. During the first session, Gabby was invited to construct a storybook narrating her own life story. This process was semi-guided and initiated by explaining the activity in a very general sense by saying; "Today we are going to create your own storybook of your life with a few of the things that I have brought with me today". Gabby was provided with her own white A3 cardboard sheet which was folded in half so as to represent an empty book cover (i.e. front cover, blank inside and a back cover).
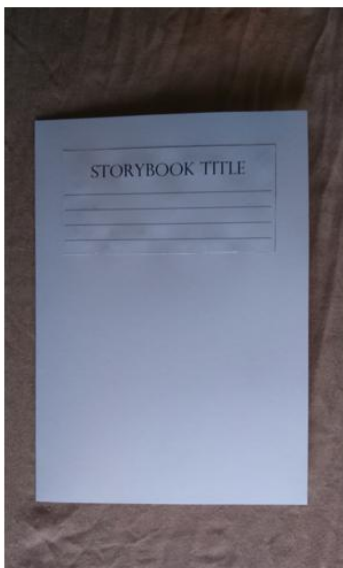
Figure 6.1(a)   *Figure 6.1(b)*   *Figure 6.1(c)*

Storybook construction was initiated by providing Gabby with the folded cardboard sheet presented to her as is illustrated in figure 6.1(a). This activity was guided by the questions, as is listed in table 6.1.

Table 6.1: Guiding Questions: Front Cover Construction

Gabby's first storybook title was called *"A broken teenage girl"* as was constructed in figure 6.2. No reference to HIV or living with HIV was made in the initiating questions. This was done so as to avoid the prompting of a specific context for the life story. Rather, Gabby was provided a space in which she could construct her story, whether it included the narration of HIV in it or not.

Figure 6.2: Storybook title construction[14]

Storybook synopsis and back cover. Hereafter, Gabby was asked to turn the cover around as is seen in figure 6.1(c), with the aim of constructing a synopsis for her book. This was guided by the questions listed in table 6.2.

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[14] This picture (figure 6.2.) is a screenshot taken from the video recording with Gabby, whilst constructing the front cover of her storybook.

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Guiding questions: Synopsis construction
(a) If you turn a book to its back, what would you usually find there? (A brief description of a synopsis was provided if the adolescent appeared unsure, i.e. a small paragraph that tells the reader about what is written in the book).
(b) If your book had a small paragraph at the back to tell the reader what your book was about, what would yours say? (Gabby was asked to write it down and to share it with the researcher).
(c) What would people say about your book by just reading this paragraph and how would they say it would end?
(d) How is it like for you reading this paragraph?

Table 6.2: Guiding Questions: Synopsis Construction
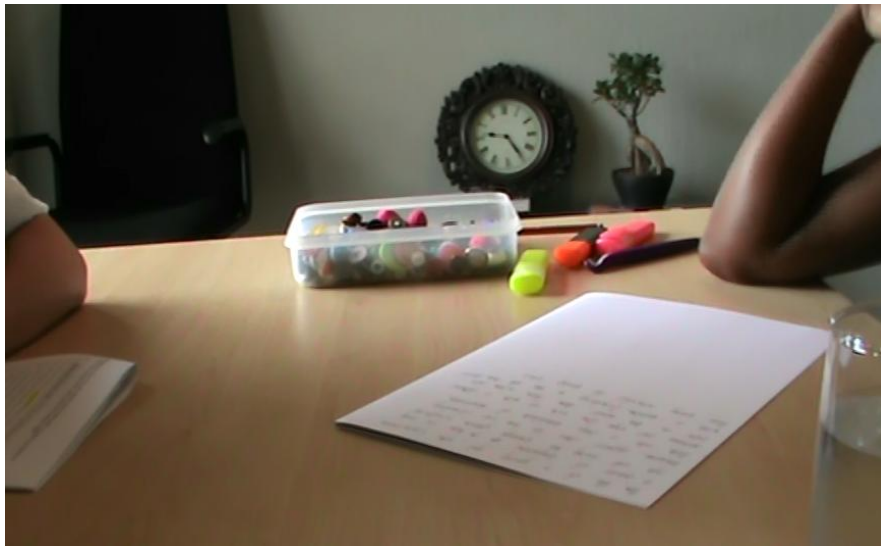
Figure 6.3: Storybook synopsis construction[15]

Figure 6.3 illustrates this process as Gabby constructed the synopsis of her book during the project phase. In constructing the synopsis of her book, Gabby wrote the paragraph as is quoted below, telling readers what her book was about.

"The life of a young girl who experiences a series of tragedies from an early age...and during her teenage years everything becomes crystal clear to her and ultimately falls into a deep black hole of loneliness, sadness and rage. She ends up with a different take on the world than from when she was a toddler. Everything in her life has turned from being colourful to being black".

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[15] This picture (figure 6.3) is a screenshot taken from the first video recording with Gabby whilst constructing the storybook synopsis.

As is evidenced, the questions in constructing the synopsis encouraged storytelling in the third person, which further contextualized the story in an externalized space for meaning to be collaboratively explored. The second last question was aimed at encouraging reflection on the constructed meaning of her synopsis to readers of her book, as well as its temporal (i.e. past, present and imagined future) impact (Freedman & Combs, 1996). The last question had an evaluative purpose, so as to encourage reflection on whether the constructed meaning was favourable or unfavourable to Gabby.

The story. After the construction of the book title and synopsis Gabby was invited to tell her story. This step was initiated by asking Gabby to open the book cover to expose the blank inside as is illustrated in figure 6.1(b). Erving Goffman (1961) historically transformed the act of storytelling as a "performative act" of constructing the self (identity) in relation to an "audience" (i.e. the social world with its various co-actors). In the designing the practical approach to the CSD project I borrowed from Goffman the use of the dramaturgical metaphor by using the inside of the book cover as a metaphorical "stage" or "landscape" for storytelling. That is, an actor/ or actress (i.e. Gabby) performing (i.e. positioning) the self (i.e. identity) in relation to other actors (i.e. people) on a stage (i.e. storied landscape or context) to an audience (i.e. researcher and imagined book readers).

To encourage storytelling, Gabby was provided with a collection of buttons (different colours, shapes, textures and sizes) and stationery (i.e. coloured pens and pencils) in the metaphorical sense to "set the stage". The "button characters" were specifically included in the design of this project to further encourage externalized exploration and discussion (Freedman & Combs, 1996; White & Epston, 1990). As a means to construct an externalized space, storytelling was encouraged through the combined use of spoken words and visual representation. As Gabby told her story, she was invited to make use of the buttons as a way to represent the characters in her story. When thinking of a live theatre play or performance on a stage, the plot (i.e. meaning) does not pre-exist, but rather in the performance of the characters in relation to one another, the plot is "constructed" and thus meaning is constructed through performance (Freedman & Combs, 1996; Goffman, 1961). The buttons thus assisted in providing an externalized space for the Gabby and myself to verbally explore and visually observe the unfolding story plot and thus its meaning. The use of button characters further encouraged what White (2007) calls a space for externalizing the problem. Externalizing the problem refers to positioning the HIV as an objectified entity outside of the person, to be explored. As White (2007) puts it "this makes it possible for people to

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experience an identity that is separate from the problem; the problem becomes the problem, not the person" (p9). During the storybook construction phase, I did not intervene by encouraging Gabby to pick a separate button for the HIV. Rather the space was given to Gabby to author the story how she preferred, in a way to observe whether she authored herself as the HIV (i.e. internalized part of self) or whether her character was authored as separate from the HIV.

Figure 6.4: Selecting button characters[16]

Figure 6.4 demonstrates how the use of button characters in itself encouraged an externalized space. Gabby placed a red button (the HIV) on top of the button representing the self (light blue button), as the self was performed as being connected to the HIV in the telling of her story. This was only done once Gabby learnt about her status as was told in her story, demonstrating how her storied identity changed at that point in time. Having two separate buttons made it possible at a later stage to explore Gabby's identity as separate from the HIV.

Storybook Co-exploration

People have a vast collection of past experiences scattered across a metaphorical landscape (White, 2007). Given that every waking moment of lived experience cannot be storied at any one given moment, people choose selected events, organized in a specific sequence to construct a specific story version with a specific plot or meaning (White & Epston, 1990). The experiences chosen to be included in a story is given preference to above

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[16] This picture (figure 6.4) is a screenshot taken from a video recording during a session with one of the participants whilst choosing buttons characters during storytelling.

other experiences and is referred to as the dominant story (White & Epston, 1990). The dominant story is one of many story versions and because of its dominance can be said to be positioned in the person's foreground (See chapter 1). Given its position on the metaphorical landscape, all other experiences become located in the background (i.e. outside of your current field of view). For the purpose of this project the dominant story located in Gabby's foreground was collaboratively explored and deconstructed through the use of relative influence questions (Freedman & Combs, 1996) as is demonstrated in figure 6.5 below. See Appendix D(1) for an adapted version of the relative influence questions which was used as guidance throughout the project phase.

Figure 6.5: Co-exploration[17]

The co-exploration and deconstruction of the dominant story told by Gabby was done in an effort to explore and collaboratively evaluate the relational influence (impact) of the dominant story version on the Gabby's life and relationships (Freedman & Combs, 1996). Having used relative influence questioning allowed a space for Gabby to evaluate such an impact as either favourable or unfavourable, thus evaluating the story version as either favourable or unfavourable (Freedman & Combs, 1996; White & Epston, 1990). Gabby evaluated her story version as having a negative impact on her life and relationships. As soon as we start asking questions about dominant stories we start to disrupt the dominant plot as alternative, largely un-storied experiences from the background are recruited into the

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[17]   This picture (figure 6.5) is a screenshot taken from a video recording during a session with one of the participants whilst co-exploring and deconstructing the story with the use of a relative influence guide.

foreground (White & Epston, 1990). Such background experiences evaluated by the storyteller as favourable are referred to as unique outcomes. Throughout the exploration and deconstruction process attention was paid to the emergence of unique outcomes. Close attention was paid to the button characters and the times that they acted "out-of-character" (i.e. not in line with the unfavourable dominant story version). This provided openings for unique outcomes and ultimately alternative preferred story versions about living with HIV. The concept of unique outcomes was only brought up once Gabby mentioned previously un-authored favourable experience in contradiction to the dominant plot of the "broken teenage girl" story version. The term "sparkling moments" were used to define such unique outcomes as experiences which stood out from what we expected would happen in the story based on the synopsis. During our exploration of her relationship with HIV, we learnt that the HIV liked to steal people's voices, especially her and her family's voices. One example of a sparkling moment included Gabby recalling herself resisting the tradition of "silent suffering" in her family by writing a letter to her grandparents about her depression. Gabby was provided with a "sparkling moment" record keeping sheet (as is seen in figure 6.6.) to document such unique outcomes.

Figure 6.6: Unique outcome sheet

Storybook Development

All of the sessions following the initial storybook construction session were referred to as follow-up sessions for the purpose of story development. Each of the follow-up sessions was guided by the practice format guide introduced by Freedman and Combs (1996, p.101) for story development. See Appendix D(2) for an adapted version of the Practice Format Guide

used with Gabby. Story development for the purpose of this project was defined as the ongoing co-reflection, co-exploration and re-authoring of the initial story to identify openings to preferred story versions (i.e. meaning) and ways of living (Freedman and Combs, 1996) with HIV. The follow-up sessions were guided by the practices as are discussed below.

Co-reflection. Each follow-up session started with a period of co-reflection on the previous session to revisit what was shared and to return to previous openings to unique outcomes. Such co-reflection was initiated by the following questions:

- "Based on our last session, what did our discussions leave you with when you went home and/ or as the week progressed?"
- "Was there anything that stood out for you from last week?"
- "Where you left with any questions or concerns given our previous discussion?"

Not only were the above questions helpful in providing some continuity to the sessions but it also revealed the power of the narrative metaphor. In becoming curious (i.e. asking questions) about Gabby's version of events, it disrupted the plot of her initial story version (i.e. meaning), as alternative (background) experiences were explored during our sessions. Such an impact become apparent when Gabby and I explored certain actions taken between sessions as well as the questions she had started asking herself. One example included Gabby revisiting her journals she wrote whilst growing up which she would use as evidence during our sessions of additional times that she broke the silence of suffering through writing. This encouraged Gabby to start journaling again in her own time, which was something that she stopped doing when the HIV pulled her into the "black hole" (i.e. depression) and stole her voice.

Continued co-exploration, deconstruction and development. Throughout the follow-up sessions with Gabby we continued to co-explore and deconstruct her story version. Relative influence questions were asked not only to explore the impact of the HIV on Gabby but also the impact that Gabby had on the HIV. The latter impact can often be linked to unique outcomes (Freedman and Combs, 1996) which is not always authored into the initial "problem" version of the story. Gabby's initial story version had a predominant theme in which she focussed on how the HIV impacted her life and relationships, with very little reference to her own impact on the HIV. By asking relational influence questions it also

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provided a space to start listening for the absent but implicit (White, 2003). In exploring Gabby's initial story version, she evaluated its impact on her and her relationships as unfavourable. By using double listening (White, 2003), we explored Gabby's evaluation in light of the absent (un-storied) but implicit (significant). We discovered that the HIV stole her social confidence and her freedom to be herself by stealing her voice and her social expression of her individuality. Gabby recalled becoming a people pleaser as a way to reduce the probability of social rejection. By evaluating it as unfavourable we learned that Gabby had favourable parts to her identity which had gone largely un-storied. She wanted to be herself and to freely express her opinions without judgement. We also learnt that Gabby wanted her voice back and that she wanted to be able to express her opinions and her individuality socially. As we collaboratively explored preferred aspects of Gabby's identity and relationships, it opened up a space to thicken alternative and preferred stories (White & Epston, 1990) about Gabby's identity and her relationships.

Co-editing (re-authoring) of the storybook. At the end of each follow-up session Gabby and I acted as co-editors of her storybook by revisiting the storybook title and synopsis. We did this as a way to evaluate whether it required rephrasing to be more in-line with the newly emerging story version (i.e. meaning) which was being constructed. Each follow-up session followed the same process of co-reflection, co-exploration, the thickening of the preferred story version (i.e. meaning), and at the end of the session the co-editing of the storybook.

After 3 months the CSD project was ended and sub-phase 2 began once agreement was reached between Gabby and myself that strong enough evidence was constructed of an alternative story version. It was not necessarily ended on the basis of having found a state of clear or final meaning but rather in that enough new meaning has been constructed to pause and reflect on such a shift. From a narrative social constructionist framework, meaning making can be seen as a continuous unfolding process without a clear beginning or end, thus, meaning in itself can rarely be considered as absolute or complete (Lock & Strong, 2010). For this reason, the product of this research is considered to be narrative knowledge which was co-constructed through ongoing dialogical interaction as a form of practical wisdom, rather than the documentation of objective facts or findings (Mcleod, 1994).

Phase 4.2: Reflection Phase

In this section, I provide an outline of the processes followed during my focussed co-reflection sessions with Gabby which formed the second sub-phase of the project phase. Hereafter a brief report is provided on the discussions between Gabby and myself during our co-reflections.

Focused Co-reflection: The Process

By positioning ourselves as researchers of stories, we can say that we are looking at how storytelling is employed to order experiences in a certain way, as a way to communicating a certain meaning (Dulwich Centre, 2004). During the focused co-reflection sessions, Gabby continued to assume the role of co-researcher as we positioned ourselves as audience members to the CSD project.

During this time we watched the first video recording together to collaboratively reflect on the story evolution (i.e. meaning) that unfolded throughout the CSD project. The questions in table 6.3 were used as guidance for our co-reflections.

Co-reflection questions
(a) What are you noticing about your first story version (theme, dominant story, character roles, plot etc.)?
(b) Who does your story say you are in the first version versus the last version?
(c) Who (which button character) is writing (i.e. telling or authoring) your first story version and how is that like for you?
(d) How is the first version different from the story version that you tell now?
(e) Who (which button character) is writing (i.e. telling or authoring) your current story version and how is that like for you?

Table 6.3: Guiding Co-reflection Questions

The focused co-reflection sessions took place once a week over a period of one month and lasted for approximately 1 hour per session. The section below provides a summary of the collaborative reflections made by both Gabby and myself on the meaning making process that unfolded from her first to the last storybook version.

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Co-reflective Report: An Overview

Guided by the questions listed in table 6.3, we collaboratively explored and reflected on various aspects of her storybook versions. The section below provides a brief documentation of the practical wisdom (knowledge) gained from our reflections. As a means to order our reflections, it is discussed in terms of the storybook title, synopsis and the story plot.

Storybook title. During the first session of the CSD project, the storybook title that Gabby constructed was called "a broken teenage girl". During our focussed co-reflection sessions, we explored how this title authored her in her own story and who was taking authorship in telling her story. Gabby was able to identify the voices of the "demons" (e.g. HIV, fear, anger, sadness, depression, etc) in authoring the title of her first storybook version. She shared how they have taken over the story that she used to make sense of herself and her world. Although the title summarized the impact of a difficult time in her life, Gabby evaluated it as very limiting and restrictive as it labelled her as a victim only. Gabby exposed the HIV and its demons as having stolen her voice and stories. She decided to rename the title of her book to "from sadness to contentment". In the past, contentment used to be about accepting an identity of being HIV positive. After the CSD project Gabby shared that contentment now means "being ok with myself". Gabby contextualized such a shift in terms of a form of self-acceptance. She realized that her story of herself (i.e. identity) need not be fused with the identity of HIV. Once she was able to explore her identity as separate from the HIV, self-acceptance was possible. This demonstrated her resistance towards internalizing HIV as part of her identity. For Gabby it was important for the title of her book of life to speak of the tragedies but to also be reflective of her preferred story version of herself. In comparing it to the first title, we realized that the first title only spoke about the impact of the HIV on Gabby and not about Gabby's impact on the HIV. Her preference for also including aspects related to her preferred self in the title, acted to re-author Gabby into a position of control, thus shifting from the position of helpless victim to active agent.

Synopsis. The first synopsis Gabby constructed bares some congruence to the first title of her storybook; "a broken teenage girl". It had a dominant theme of tragedy and defeat. During our co-reflections we realized how the synopsis did not provide any opening to possible resolution or hope for her story character. Instead it constructed a primary focus on ongoing adversity thus locating the imagined future in the context of catastrophic predictions and ultimately a tragic ending. As an audience member to this story version, Gabby evaluated

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the synopsis as unfavourable as it authored her as someone who has no way out of her life ending in tragedy (e.g. suicide). In addition our co-reflections led us to identify the demon's voices in authoring the first version of her synopsis.

Story plot. Gabby's first story version constructed during the first session of the CSD project had an overarching theme of enduring tragedy and hopelessness as she storied her character as someone who continued to lose people she cared for, someone who has the potential to be rejected and/ or abandoned by others, someone who does not belong, someone that keeps on slipping into depression and someone that fakes happiness. During our reflections we realized that the story predominantly focussed on the adverse effects of HIV on her body, her identity and her relationships.

During our reflections Gabby noted that she judged herself and who she was based on other people's stories about HIV or stories she perceived others to be telling about people living with HIV. Thus, she judged herself through what she perceived others to be judging her by should they learn about her status. By extension of her view of other people's stories, Gabby viewed people living with HIV as carriers of a death sentence who should be avoided to prevent transmission of such a death sentence. Although she managed at times to develop friendships and to enter into romantic relationships, Gabby's internalization of the HIV as a dominant part of her identity gave power to the demons to pull her back into depression. Gabby recognized how such a story version about herself contributed to her making value judgements about who she was as a person. By internalizing HIV as part of her identity, Gabby started experiencing a range of emotions which she attributed to be responsible for her lapses into depression. In her first story version, Gabby's relationship with HIV mimicked most of her family member's relationships with HIV. Those in her family with HIV never spoke of it and endured its effects through silent suffering. In mimicking such family relationships with HIV, the silent suffering contributed to Gabby adopting the "broken teenage girl" story as an internalized part of her identity.

During the CSD project we personified HIV as a creature, or how Gabby called it; a demon. Such personification was done to explore the HIV and its influence as separate from Gabby's identity. Upon further exploration we realized that the HIV was storied as a thief of her happiness, almost villain-like. Gabby's character, as was authored in the first version, was positioned as helpless and powerless as the HIV would recruit other demons (i.e. fear, anger, sadness, etc) to constantly pull her back into the "black hole" of depression. Upon further exploration we discovered that Gabby dealt with the black hole creatures (i.e. demons) by

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creating a double life during which she would either give in to the demons (i.e. depression) or wear her social butterfly mask (i.e. ignore the demons). She used several masks to hide her broken-teenage-girl story (tragedy narrative) from the world (keeping it backstage), even from her family, performing the social butterfly to those around her. With the demons growing stronger, they would at times threaten to come out and expose Gabby. Although it helped her to cope temporarily, Gabby evaluated the social butterfly mask as unfavourable given that it was a vicious cycle which she was unable to maintain.

The social butterfly identity was created around fitting in socially and preventing rejection and abandonment. For Gabby it involved keeping the HIV a secret and pleasing others to become more likable. For Gabby it was a "performance"; an active attempt at reducing and managing her perceived risk of judgement, rejection and ultimate isolation. Although gabby evaluated the double life as unsustainable, it helped Gabby at times to feel "normal" (i.e. like others without HIV). Upon further co-reflection, we realized how the social butterfly was stealing her preferred story of herself as a unique young woman. In addition, it contributed to growing feelings of guilt and fear about impending rejection, should she be "found out". At the same time Gabby evaluated conforming to the standards and norms of others as unfavourable because it stole her preferred identity of the "old soul". Through this journey, Gabby managed to realize her uniqueness, primarily based on her personal qualities rather than only her status defining her identity. In constructing a preferred story version of herself and her relationships she was able to detangle her identity from that of HIV which ultimately allowed for self-acceptance.

Listening for the absent (i.e. hidden) but implicit it allowed us to listen for and construct a preferred story version about herself, others and her world of living with HIV. Throughout the project phase we explored preferred experiences related to her identity which has gone largely un-storied (i.e. in the background) due to the dominant tragedy story being located in her foreground. Upon reflection on her last story version Gabby re-contextualized the meaning of HIV in the light of God having a plan for her life. Gabby argued that the HIV had contributed to her developing a deeper spiritual understanding of her life removed from the superficial life of adolescence. Gabby started reconstructing her relationship with HIV as something in her life which made her ask deeper spiritual and philosophical questions about the meaning of her life; a part of her identity we authored as the "old soul". Upon further reflection, Gabby reported that the tragedies allowed her to develop her ability to be introspective, and to realize that she is different and unique, which in turn allowed her to become even more introspective. Being introspective according to Gabby meant being able to

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wonder and ask questions. For her that meant being able to re-gain back her own opinion and voice from the multitude of other voices and stories authored around her. A strong alternative story started to emerge about an additional part of her identity (i.e. the old soul). The old soul was identified as a critical investigator, an academic, a journalist and a unique young woman with a voice that wants to be heard. With the narrative approach being critical of taken-for-granted ways of knowing, it actually fitted quite well with Gabby's old soul character, constructed through our exploration.

Summary

By using a narrative therapeutic approach and stance during our sessions it was aimed at providing the space and time for the emancipation from previous story versions (i.e. meanings) which had become problematic or redundant for Gabby's functioning. During our sessions we explored the stories told about HIV by her school, her friends, her family, the TV or social media, the psychiatric hospital, and the hospital. We also looked at the stories she came across in her adolescent support group told by the care workers and the other kids at the hospital who also had "creatures" in their blood. Without judging what is the right or wrong way to story HIV, we explored all of these stories to see which of these stories had become part of Gabby's story. In becoming researchers of stories we explored Gabby's story versions by evaluating whether it had favourable or unfavourable outcomes for her view of herself, her relationships and her future. In turn this allowed for the construction of a preferred story version for Gabby in making sense of not only HIV but also herself. Contextualized as therapeutic co-research, this project allowed not only for hearing what was told, but also the telling (i.e. construction) of new story versions (i.e. meaning) about living with HIV to be heard and possibly to be re-told outside of the context of this journey. The next chapter forms the reintegration (telling) phase of this journey, documented in the form of a storybook.

PART III

AFTER JOURNEYING WITH HIV AS CO-RESEARCHERS

CHAPTER 7

REINTEGRATION (TELLING) PHASE

This chapter is a reintegration (i.e. telling) of the knowledge that has been gained from this unfolding journey of co-research into Gabby's story versions (i.e. meaning) of living with HIV. In order for new stories about HIV to become available to other people, it first needs to be embodied (i.e. told) in some form or medium.

Documenting New Narrative Knowledge

In staying congruent to the narrative constructionist approach of understanding, I decided to employ storytelling and storybook making as a mechanism for documenting the practical wisdom gained from this journey. This storybook is my attempt at making sense of (i.e. meaning) my experience of journeying with Gabby during our time together. In the very act of authoring my experience, it becomes in itself a new story version about HIV. In this sense my construction (telling) of this story in this chapter is in itself a re-telling (sharing) of my journey with Gabby in making sense of HIV. It is through the construction of this storybook that our knowledge becomes embodied (i.e. told) to be shared with others, to be heard, and possibly to be retold.

The Reintegration (Telling) Phase

As a reintegration, this storybook is my attempt at documenting the process as well as the new knowledge that we constructed during our journey together. In the same fashion I conducted the project phase with Gabby by constructing a title, synopsis and story, I decided to share this storybook version in a similar format with you (the reader) in the section below. HIV was a "witness" to my journey with Gabby and therefore I chose to write this story through the eyes and with the voice of HIV. In this re-telling, HIV is authored as an audience member to my collaborative journey with Gabby and most importantly, Gabby's act of reclaiming her life story and identity.

I AM ME, AND YOU ARE YOU

Practical wisdom for living with my human, Gabby
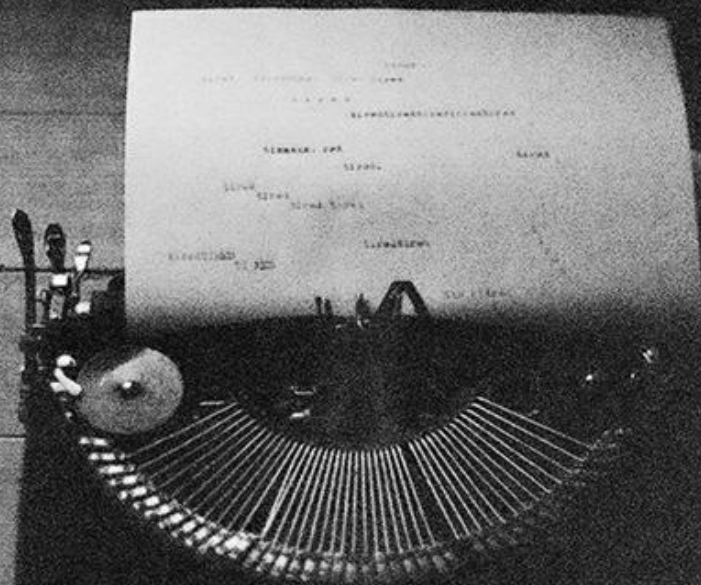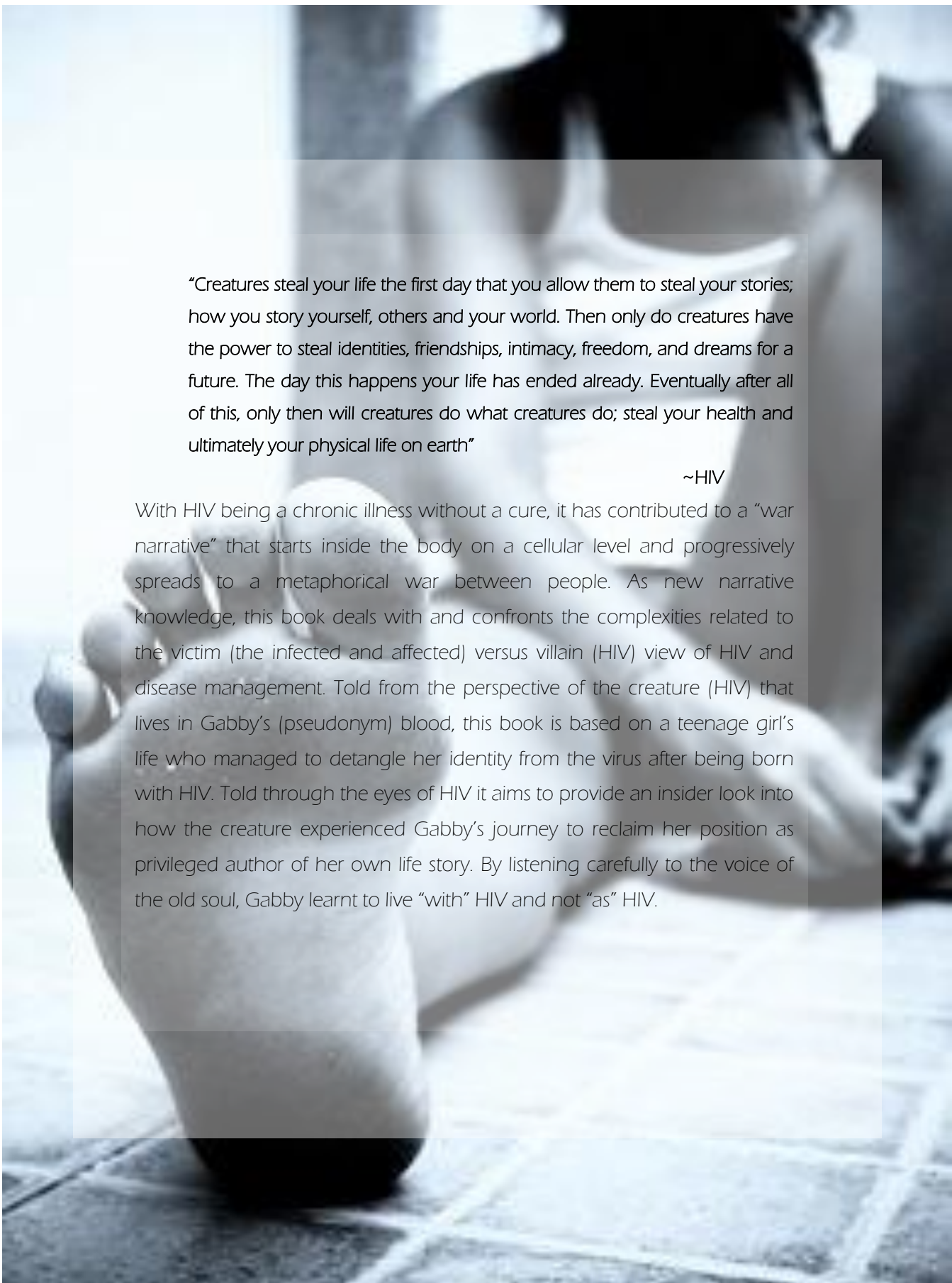
Written by

Danelle Stiglingh
as

"The Creature" (HIV)

"Creatures steal your life the first day that you allow them to steal your stories; how you story yourself, others and your world. Then only do creatures have the power to steal identities, friendships, intimacy, freedom, and dreams for a future. The day this happens your life has ended already. Eventually after all of this, only then will creatures do what creatures do; steal your health and ultimately your physical life on earth"

~HIV

With HIV being a chronic illness without a cure, it has contributed to a "war narrative" that starts inside the body on a cellular level and progressively spreads to a metaphorical war between people. As new narrative knowledge, this book deals with and confronts the complexities related to the victim (the infected and affected) versus villain (HIV) view of HIV and disease management. Told from the perspective of the creature (HIV) that lives in Gabby's (pseudonym) blood, this book is based on a teenage girl's life who managed to detangle her identity from the virus after being born with HIV. Told through the eyes of HIV it aims to provide an insider look into how the creature experienced Gabby's journey to reclaim her position as privileged author of her own life story. By listening carefully to the voice of the old soul, Gabby learnt to live "with" HIV and not "as" HIV.

ON THE AUTHOR(S) BEHIND THE AUTHOR (HIV)

This storybook is the product of a journey in researching the meaning of HIV and forms part of my mini thesis for my master's degree in Counselling (community) Psychology at the University of Pretoria. Throughout my work as a therapist in training I was often confronted with questions about the meaning of HIV for those infected and affected by the virus. My past experience of working in various hospital contexts, more specifically with HIV made me question how I made sense of it. My exposure to narrative therapy during my training not only guided my postgraduate research journey but also provided the foundation for a new way of making sense of and working with people living with chronic illness, such as HIV. The aim of my research journey was to deconstruct the meaning of HIV and in the same process to construct new knowledge through ongoing narrative conversations about living with HIV. In doing so it assisted in exposing HIV by providing an insider look into its multiple faces (roles) assigned to it through various story tellers (i.e. discourses).

Although this book was written by me as author (speaking as HIV), I acknowledge that my construction of HIV in this book is based on the meaning constructed between myself and Gabby; my co-researcher and co-author. For the purpose of this research and with Gabby's permission, this storybook is based on her life story to reflect the practical wisdom that we have gained from our collaborative journey in making sense of HIV.

FOREWORD

In choosing to write this story through the eyes and with the voice of HIV, I strived towards stealing HIV's voice by authoring the HIV as an audience member to Gabby's act of reclaiming her life story and identity. In doing so I positioned the HIV not only as a witness to, but also a reporter (storyteller) of Gabby's process of reclaiming back her life. Each of the unfolding chapters contributed to a plot (storyline) which is based on the stories shared by Gabby about her life of growing up with HIV.

Gabby was primarily exposed to the biomedical stories about HIV during her ART treatment once she was diagnosed but soon realized that HIV was not just a medical dilemma. The first story version that Gabby constructed during therapy about living with HIV was largely based on her view of herself as "a broken teenage girl", in body, mind and spirit. This story version is reflected (in part) in the first few chapters of this book. As our conversations about living with HIV progressed during the project phase of the research, we discovered preferential parts of her life story which had gone largely un-storied (un-told) by her. That is, preferred story versions about Gabby's identity, her relationship with HIV and her relationship with others. This book was written to also reflect the alternative (preferred) story which was explored, unfolded and ultimately told by Gabby towards the end of the research. As Gabby's awareness of such alternative (preferred) stories grew during our exploration she started changing the way in which she told her story about HIV, herself and the world around her. This book was written to capture such significant turning points (i.e. sparkling moments) in the plot of her life story. The titles of each chapter in this book were carefully thought out and constructed (i.e. specific use of words and grammar) to highlight this process of story evolution. Ultimately, woven in with the first "broken teenage girl" version, the book ends with the preferred version of Gabby's life story; "from Sadness to contentment". Shifting from a war-narrative between HIV and herself to one of resolution, Gabby was able to move to a place of understanding and acceptance of HIV and a journey of self-understanding and acceptance. In turn this allowed a space for her to not only start dreaming but also to start doing again.

My hope is that this storybook and the research on which it is based can shed some light on the value of narrative therapeutic co-research as a collaborative interpersonal approach and perspective to working with people living with chronic illness; in turn enhancing awareness into how we author HIV to ourselves and others.

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CHAPTER 1

The GIRL...a battle UNKNOWN

"I should have known that this day would come. I looked at Gabby as she used every last bit of her energy to pull herself from her bed where she had been lying since yesterday morning. My eyes followed her as she ruffled through piles of her clothes on the ground, in search of something specific. I looked as she pulled out her notebook with its edges curled upwards. She collapsed onto the floor with her legs curled underneath her and her hands planted on the floor in front of her. I watched as her eyes welled up with tears, plunging down in large heavy drops on her paper notebook. With her hands shaking I watched as Gabby wrote out the letters one by one in blue ink..."

I have watched Gabby over the years, 17 years to be more exact. I am the creature that lives in her blood. In order to tell you this story, I need to go back to where it all began.

Meet Gabby

Today I may get a new host, a new body to live in- Gabby. Today is the day that Gabby will be born. She has no idea who I am or that I have become part of her family years ago. Have you heard of me? I'm sure you have. I am a very famous creature. My name is HIV. I am sure Gabby's mom and dad knows about me too as I have made a home in their bodies for a few years as well. Gabby has an older brother, but he does not have me living inside of him.

I finally got to meet Gabby when I entered her body soon after she was born. As soon as I entered her body, I did what I have been created to do... Before I go any further I have to tell you a little bit about my relationship with people and their bodies.

Bodies and creatures

As a creature, I cannot live without the help of people and their bodies. The most important thing I have to do to stay alive is to get into the person's blood stream, but to do that I first have to get through the body's first layer of protection which is the skin. I do this by looking for any breaks in people's skin, searching for cuts or open wounds which can give me access to their blood. People have made it quite easy for me to stay alive by just going along with the everyday things that people do. If I cannot find any breaks in the skin, I rely on certain body fluids such as genital fluids or breast milk of the infected person to get into contact with an uninfected person's body fluids or blood. As soon as I get into a person's blood stream I have to move quickly because my presence will soon start setting off alarms in the body. Given that I lived in Gabby's mom's body whilst she was pregnant with her, it made it easy for me to travel into Gabby's body. Let me tell you what I do to people's bodies by sharing with you what I did to Gabby.

Once in Gabby's blood stream I looked for her white blood cells. Those are the little cells in everyone's body that the doctors call the helper cells (CD4-cells) and the fighter cells (CD8-cells).

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The helper cells work with Gabby's Fighter cells (or what I like to call the soldier cells) of the body. Together they form the body's defence system or immune system. Almost every day people get into contact with a whole range of bacteria and viruses, which I usually just call bugs. These bugs are so small that people cannot see them, but they can make the body very sick (e.g. flu, diarrhoea, rashes, infection, etc.) if they find their way into the body. It is the job of the soldiers to attack and destroy the bugs before they do any harm to the body. The helper cells act almost like paramedics because they repair any damage to the soldiers and help to create new soldiers if too many were injured. So we can say that the paramedics and the soldiers work together to prevent Gabby from getting sick or to help her to get better when she does get sick by defending the body against bugs.

How I trick bodies

Don't get me wrong, as a virus the soldiers also want to fight me whenever I enter a new body. What makes me stronger than them is that I am actually just very sneaky. I know I am not as strong as the soldiers, and there are so many of them, so I use a clever trick to outsmart them. I know that the soldiers cannot survive for long without the paramedics. Once in the bloodstream I sneak all the way to the paramedics and hold them hostage. The tighter I am holding on to them the more tired they get and the less they can help the soldiers when they are injured. Then I work my magic... Paramedic cells have a special power; they can make new copies of the soldiers whenever they need to. This is why I attack the paramedics. I convince them to help me to make copies of myself in exchange for their freedom. In this way I use them almost like a copier machine to produce more of me. When they are finished making copies of me, they are so tired that they cannot make any more copies, and then they die. So my plan of attack is simple, as the amount of paramedics in the body decrease, the amount of copies of myself increase, which means I can attack even more paramedics. The less paramedics there are to help heal the injured soldiers the weaker the soldiers get and the more soldiers die. Even when there are still paramedics left to make new soldiers, they struggle to keep up with all the bugs that are around people in everyday life. This means that when the body is under attack by bugs that causes opportunistic infections (e.g. meningitis, encephalitis, intestinal illnesses, respiratory illnesses, etc.) the soldiers are either too injured to fight or there are too few soldiers to fight off the bugs. Can you see how clever I am? This means that when the body is under attack, the bugs multiply too quickly and the soldiers are outnumbered and the body gets sick. Due to the low number of paramedics, injured soldiers are also less likely to be repaired or replaced. This means that the more I take over the body, the easier it gets for the body to get sick or to stay sick. When this happens to the body, the doctors call it Acquired Immunodeficiency Syndrome or AIDS. I don't like to think of myself as a killer because people do not die of AIDS, they die when bugs enter the body and the soldiers and paramedics cannot fight it any longer. It is then the bugs that make the body sick and kills the person rather than me. Unfortunately doctors have become very clever, and figured out how to slow me down

before AIDS sets in and also to help the body's soldiers from the outside to fight bugs that come into the body. I will tell you more about this when the time is right. For now and for the next few years Gabby will be fine. There are millions of paramedics and soldiers in her body, which means that she does not even know that I am living inside her blood or killing her paramedics. She looks healthy, just like her brother and her friends.

CHAPTER 2
The girl with a BROKEN family...a violent but silent battle

"HIV steals your health, HIV kills people, you get HIV when you sleep around and don't wear a condom, HIV is a death sentence- if this is the story that you use to make sense of me then I am going to tell you that you are right, that is exactly what I will do to you".

Over the years I have multiplied to make endless amounts of copies of myself. I had copies of me living with Gabby's mom and more copies of me living with Gabby's dad, and in each of their bodies I kept on multiplying myself with the help of their paramedic cells. They often got sick as their bodies struggled to fight off new bugs. When they got sick they would struggle to get better even though they drank medication every day. When Gabby turned 4 years old, her mom passed away when her body could no longer fight off the bugs. Gabby's grandparents moved in with them to help Gabby's dad take care of her and her brother. I noticed something strange. Over the years I went with Gabby's parents to their hospital visits and heard the doctors and nurses telling them about me. The doctors even warned them about what I will do to their bodies. For some reason, even after I stole Gabby's mom's life, no one spoke about me... It was as if I was never part of their family or their bodies.

Gabby's dad was a very busy man. Besides for working a lot he liked socializing with the ladies and often brought home new ones. This was tough for Gabby because some of the ladies she really liked but often without warning would never see again. Gabby learnt that it was best to not care too much about the ladies.

It was time for Gabby's first day of school. Although her dad wasn't home a lot, he helped her to practice spelling her own name and a few other words. She felt so proud of herself. Gabby liked writing; sometimes stories she made up about people and places that did not exist and sometimes she would write about her mother. Gabby was a little bit shy, but as soon as she settled into school life, she made friends. Gabby was a happy little girl full of energy and attitude once she got to know you. Her Granny used to struggle not to laugh at her whenever Gabby tried to get her point across to others. Her face would frown up as she placed one hand on her hip with her other hand

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waving around in front of her. Gabby would not always win an argument but she made sure that she was heard. As the months grew into years after her mother's passing, Gabby started realizing that something was not right in her family. Soon after she started school, her granny also passed away. After some time, her grandpa had met a new lady whom he married. They moved out of Gabby's home to find their own home. In this time Gabby wrote a lot of stories. They made her feel like she could be part of a different world where things were nice and people didn't leave or die. Gabby didn't know it at the time, but her hobby of writing and telling stories would one day save her own life.

Gabby performed well at school and liked to be challenged to try new things. Her teachers enjoyed having Gabby in class because they would always say that she had an "old soul". Maybe it was the old soul in Gabby's young body that her Granny also saw when she was still alive. Gabby read a lot of books and enjoyed learning new things. She never just accepted things as is, always questioning and critically wondering about the things that she learnt about in class. Gabby often dreamt about becoming a writer or a journalist; not only writing stories but also sharing and telling her stories to others.

Stories about me

In primary school, one morning soon after school started, Gabby's class was told that they would be learning about HIV for the whole week. Each student was asked to do an assignment to present in class. This made me worry. What if Gabby figured out that I was living under her roof with her family, in her body? What would she think about me? Gabby started reading up about me. She now had a name for me, a story about what I do and got to know how I trick people's bodies to help me to make copies of myself. Little did she know that she was busy learning about the creature in her own blood and that of her fathers'. After all of the class presentations Gabby left school feeling scared of ever meeting me or being around people who had me in their blood. The stories told by the children in class were strangely similar and resembled something to the extent of "HIV steals your health"; "HIV kills people"; "you get HIV when you sleep around and don't wear protection"; "HIV is a death sentence". If this is the story that you use to make sense of me then I am going to tell you that you are right, that is exactly what I will do to you. People have tried to stop me by warning each other, by teaching children from a young age about the scary creature that steals and kills, to be careful to not cross paths with the creature and to be careful of those who are carriers of creatures living in their blood. Yes, most of it is true, but let me tell you why I like this story. I like it because those stories make me seem very powerful; a creature that has the power to not only steal health but to create fear of those who have me in their blood, creating fear of people who carry creatures, who carry death; ultimately allowing people to fear each other. I have noticed that people who carry creatures in their blood and who use only this story to understand me, struggle to be hopeful. They stop making plans for their future, they stop dreaming of things that

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are too far away from the present. They stop trying to live "with" me and rather choose to let me steal their dreams in their future. Some people even stop taking their medication that can slow me down, and they lose hope. Their hope is locked up in a medical cure for HIV to bring them back their future, their lives. If this is how you see my relationship with you, then you have already stopped living. Gabby's "old soul" struggled to challenge this story about me because even the teachers confirmed to Gabby that this story is not one to challenge but to accept as the "truth' and to let it be; HIV kills people.

After doing research on me, I noticed that for very small moments in time that Gabby would wonder whether I was not maybe living with her family. Something was killing her family and the people in it. She started wondering about her mom and her granny. Gabby noticed that her dad would often get sick and also got sicker as the years progressed. She also noticed how he stopped taking his medication which was something that he used to do. She asked about the medication and about what was wrong but he could never say my name. He often made jokes about his health, but I almost got the idea that he was scared of saying my name. He knew that I was living in his blood. Gabby thought several times that her father hinted at saying my name and that he may have tried to hint at telling her that not only he but also she has a creature in her blood. The silence about my presence continued, until one day I refused to be silenced. It was on a Monday morning that Gabby was met with yet another day that would confirm her story about me. Over the school intercom they called Gabby and her brother to bring their school bags and to report to the office. The kids knew that this usually meant something big has happened. Gabby's grandparents frantically picked her and her brother up from school not saying much during the car ride to the hospital. "Your dad is very sick" is all they said. Gabby didn't know this at the time, but her dad was so sick because he had almost no paramedic or soldier cells left in his body. The bugs had taken over his body. For the first time in her life, Gabby saw her dad crying as she manoeuvred her small hand into his whilst standing next to his hospital bed. Gabby wanted to ask him whether he did not maybe have a creature in his blood, she wanted to share with him what she had learnt at school. Maybe she could help him if he knew that it was a creature that was making him so sick. Something stopped Gabby from talking to her dad about me. Was she also scared to say my name out loud? Gabby said her last goodbyes as her father passed away later that day.

Gabby's grandfather and new grandmother helped the kids to pack up their house in Attridgeville to move in with them in the suburbs. Gabby sat with more questions about the deaths in her family than ever before. Surprisingly there was no mention about me afterwards, but I started speaking to Gabby, making her wonder about my presence. You see, here is how I operate; the less you know or talk about me the happier I am. Who I am scares people so much that they have stopped talking about me. This way I have managed to get people to be hesitant to inquire and learn about me and to be less likely to slow me down should I already be living inside their blood.

Gabby felt so alone. Why does everybody in her life that she loves keep on leaving her she often asked herself quietly? Gabby and her brother were used to moving house and starting over. It was just before Gabby had to go to high school. She actually adapted quite quickly. It was a very nice neighbourhood and she even got to go to a private school, but besides for this something else was different. Although Gabby made friends, she always kept them at a distance. Never allowing them to know too much about her or getting to close to them. She was afraid that they might leave her or she had to leave them again. Gabby felt a lot of new emotions, but no one she knew really spoke about their feelings. Gabby also didn't know exactly what the feelings were called that she was experiencing. Gabby figured that emotions were probably not something that you should show to others or to talk about. She decided not to share her feelings with others, but to write them down in a journal whenever she was alone. Life went back to normal, except for the fact that Gabby now had a new room, a new house, grandparents for parents, a new neighbourhood, a new school and new friends.

CHAPTER 3
THE BROKEN TEENAGE GIRL...SCREAMING in silence

"Gabby looked in the mirror at herself one afternoon, almost as if she was looking at herself for the first time; studying in detail the veins on her arms and legs. Was she looking for me? Gabby wasn't crying anymore, she was screaming in silence".

One morning before school as Gabby woke up she realized that over night she had developed a breakout on her head. Being a teenager she thought nothing of it as it resembled something like pimples. She tried to cover it up and faced her friends at school. Little did she realize that it was because of my work. Her soldier cells were struggling without the help of all her paramedic cells. Her body was becoming weaker and bugs now threatened her health. Gabby tried to ignore what was happening to her body, but after some time she started realizing that her hair was falling out. Gabby was scared. She decided to tell her grandparents who took her to their doctor. The doctors did not know about me and the medication that he prescribed did not work to stop me from doing my work every day, at most it only covered up some things. Gabby started getting sick more often. After some time Gabby's doctor suggested more comprehensive testing which at that time was often done at the government clinic in Attridgeville. This made me worry because I knew that they had tests at that clinic which they could use to see whether I was living inside of Gabby's body. I knew this day was coming. On the one hand I was glad that she was going to find out about me; if Gabby dies then I also die. I think that Gabby's grandparents knew what was coming as they shared with the doctor at the hospital that Gabby's dad had HIV and that they thought her

mom might have also had it. They did a lot of tests on Gabby, including an HIV test. I remember it like yesterday when they broke the news to Gabby. She was devastated when the doctor and the care worker shared the results with her. She tested positive for HIV. She cried a lot. I have often seen people cry when they find out that they have a creature in their blood, even though people now know that it is not a death sentence anymore. I am wondering what it is about me that makes people so upset to live with me? I was wondering what Gabby's tears meant for her? I felt bad for a moment; I was not used to Gabby showing emotion. Have I had such an impact on her that she was unable to hide her emotions? Gabby had a lot of questions, with the most important one being, "how did I get HIV"? Gabby found out that her mom most probably had a creature that lived inside her body that slipped into Gabby's blood when she was an infant. Gabby's grandparents shared with her that her father also had a creature in his blood. Gabby experienced so much emotion and struggled to make sense of the stories she once wrote about her mother and father.

More tests were done on Gabby to see what damage I have caused over the years. Gabby received a lot of medication to drink every day, for the rest of her life. Gabby and her granny travelled far away from home at least once every three months to visit the clinic for a check-up. She started Antiretroviral Therapy (ART) which included pills designed to slow me down. During her check-up's they would monitor her weight and do tests to see whether the medication was slowing me down or not. At the clinic they also had creature support groups for all the adolescents who were living with copies of me in their bodies. During these sessions Gabby learned more about me. She always knew of me, but this time around things were different. What Gabby learnt at the support group was a lot like that week in her primary school class when she first learned about HIV. It mostly spoke about my motives and what I do to people when I am living in their blood. The care workers also warned the adolescents about what to do and what not to do so as to prevent infecting other people. Most noteworthy, Gabby learnt that even those who live with creatures don't like to talk about the creatures, not even at the creature support group. It was a group where creatures gathered to be supported by being reminded of what they do to bodies. To Gabby it happened to be that the creatures brought their humans with them. I sat in those sessions with Gabby every time. What I saw was that same look that I have seen in so many people's eyes when they learn that they have a creature living in their blood; that look that speaks of the realization that you are now by association, also a creature.

Soon after starting ART at the clinic, Gabby looked in the mirror at herself one afternoon, almost as if she was looking at herself for the first time; studying in detail the veins on her arms and legs. Was she looking for me? Gabby wasn't crying anymore, she was screaming in silence. She was angry at her family for not telling her about the creature, she was angry that her dad had to suffer in silence, she was angry that she didn't have a choice in all of this. Most of all she was sad for herself for having lost the life she had always dreamt of living before finding out about creatures. Although

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Gabby didn't tell others about the emotions she felt, she started writing about the anger, the sadness and questions she had, she started wondering about whom she was now and will be if she gets the chance to live long enough.

CHAPTER 4
The BROKEN teenage girl... I am YOU and YOU are ME

"Creatures steal your life the first day that you allow them to steal your stories; how you story yourself, others and the world. Then only do creatures have the power to steal identities, friendships, intimacy, freedom, and dreams for a future. The day this happens your life has ended already. Eventually after all of this, only then will creatures do what creatures do; steal your health and ultimately your physical life on earth".

~HIV

Gabby thought back to what had happened to her mom, her granny and her dad. She got angry. Why did they not tell her, why did they let this creature silently kill her family, why did her father not drink his medication, why did they allow the creature in Gabby's blood to wreak havoc all these years. Most importantly, why did they keep it a secret? Having stolen a lot of people from Gabby's life through AIDS, I guess she got scared of losing more people. Gabby learnt that the closer she gets to people the more it hurts when they are gone. As a way to protect herself, Gabby crept into what I called her cocoon. She kept her distance from people, never getting to close to them or sharing too much about herself. After finding out about me Gabby started thinking about how other people may see her if they knew that she had a creature in her blood. She thought back to primary school and about what she thought about people who had a creature living in their blood. She started paying attention to how people talk about creatures and what they say about the people that lived with it. All of a sudden she saw me everywhere. On TV she noticed how the stories would portray people with HIV as different and she noticed how the people without HIV would treat those with HIV. Gabby entered a place where the stories about HIV scared her and consumed her thoughts. Constantly playing in her head, the thoughts started attacking her view of herself; silencing the "old soul". Gabby was afraid that people might not want to be around her or abandon her if they knew that she had a creature in her blood, so she isolated herself even more. Gabby often chose to stay in on weekends, even though her friends invited her to go out. She was alone, but at least no one would be able to find out her secret and judge her. Gabby struggled to write. The stories that she wrote would end up being too close to what her life had become. Writing about her feelings would create even more feelings. Being alone which used to be a safe space now frightened Gabby. She stopped writing and tried to ignore me. Besides,

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everyone else including her family was going on as if I wasn't there; maybe this was just how it was.

The Black Hole

Gabby's fear of being rejected or abandoned and being alone, grew bigger the more she isolated herself and the more she tried to ignore me. As new emotions popped up in Gabby's life, she became increasingly overwhelmed as she did not know what to do with it. Emotions like feeling alone, isolated, rejected, abandoned, angry, sad, etc, pulled her into what Gabby later got to learn about and referred to as "the black hole". To me "the black hole" played in my favour because certain emotions that causes stress in the body is something that can make the paramedics and soldiers weak which makes it easier for me to do my job. The black hole is a place where I am at my strongest and it is filled with all of these types of "emotion demons" as Gabby called them, which would pull her deeper and deeper into the hole. Some emotions made Gabby feel so uncomfortable that she would try and pretend, even for a moment that they were not there. When the emotions would creep up on her after she tried to hide it, it would scare Gabby so much that she would get pulled deeper into the black hole, almost like a very strong ocean tide. Gabby would get tired of fighting the "tied" and would at times just let the demons pull her into the black hole. Sometimes the emotions were so strong that they would keep her locked up in the black hole for weeks on end. The thing about the black hole is that the demons steal your stories. It has a way to make even things that you used to enjoy and did with ease seem impossible. It has a way of stealing your energy and the little bit of motivation that is left to crawl out of the hole. Every day that you spend in the black hole it re-writes your story about how you see yourself, your relationships and your future.

Some have called me the ring leader because I am the one that invites the emotion demons into the black hole to become part of my gang of creatures that steal for a living. I want to let you in on a little secret. Creatures are not concerned with stealing objects of value or even money; rather creatures steal the things that money cannot buy and that people value the most. Creatures steal your life the first day that you allow them to steal your stories of yourself, others and the world. Then only do creatures have the power to steal identities, friendships, intimacy, freedom, and dreams for a future. The day this happens your life has ended already. Eventually after all of this, only then will creatures do what creatures do; steal your health and ultimately your physical life on earth.

The story that Gabby had about creatures had come from a few authors. It was told by the kids and teachers at her primary school, it came from watching her family live with me, it came from learning about me on TV and at the creature support group at the hospital. It was a very "real" story about a creature that contaminates people by turning them into creatures. Creatures that are living on borrowed time, creatures that carry death, creatures who are not part of this world, living

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in constant fear of being found out or exposed. Gabby had allowed me to steal her story. In Gabby's story I was now Gabby, and Gabby was me. The old soul; that is, the writer, the little researcher, and the girl who use to question the obvious and liked to be heard...they all stopped living. To Gabby she was nothing more than a creature herself.

CHAPTER 5
The BROKEN-TEENAGE-GIRL CLUB...living inside the BLACK HOLE

Gabby struggled to be alone, to face the creature that she had become. Whenever she thought about me being part of her, it would bring up the demons, which would then start pulling her into the black hole as they stole more chapters from her old soul story. Gabby's aunt came to visit every now and then and she would speak to Gabby about her feelings and about the creature in her blood. This was new to Gabby as she was not use to talking about her feelings or the HIV with others. Gabby's aunt did not have me living inside her blood, but she spoke to Gabby about her own feelings and how she was diagnosed with a mood disorder called bipolar. They would take turns to talk about their feeling demons. Gabby felt some relief. The demons were not just in her head but they were real and other people knew about them. Her aunt gave her a new way to look at the demons as something which has been scientifically researched by psychologists and doctors. The demons were real and famous for crippling people, and have done so for centuries.

For some reason, it got Gabby to start writing again, about her demons living in the black hole. I was realizing all the more that Gabby's old soul that researched and questioned everything was still alive and still had a voice. She spoke through writing. Sometimes she even screamed through her writing. Gabby has always been someone that liked to research and learn new things. Gabby started unpacking the emotions she felt and did some research on the internet. She found the word "depression". Depression gave Gabby a name for all of the demons: the emotions she felt or failed to feel. All of a sudden she did not feel so alone anymore. At least now she knew that there were other people out there that also had demons that would pull them into a black hole and at times refuse to let go. In some sense Gabby felt that she belonged, although it was to an "invisible" group out there known as the "broken teenage girl club". Gabby's family was unaware of her new discovery and that she had finally found her own "group" to belong to. What they saw however was that Gabby was becoming more reserved and spent more and more time alone in her room. Gabby wasn't bothered by their reactions, after all, it was perfectly in line with what broken-teenage-girls do. Living inside the black hole Gabby learnt that the only way to survive was to learn how to fit in with the demons. She dedicated time to get to know each of the demons and allowed them to become part of her creature identity. Gabby's family became worried as she no

longer spent time with them or her friends. She preferred being in her room with the demons, researching them and writing about them.

CHAPTER 6

The (broken) TEENAGE GIRL... ESCAPING the black hole

It was another weekend where Gabby was curled up in her bed with the curtains pulled shut. Gabby's phone rang and then...what is Gabby doing? I can see that she is not feeling in the mood to go out but says yes anyway to her friends who kept on calling her to go to the movies. She jumped out of bed and gave herself a quick look in the mirror and opened her curtains. Gabby pulled out one of her favourite summer dresses from the pile of clothes on her floor and got dressed. Gabby used to like getting dressed up but haven't done so for a few months. Something new is happening today. Gabby is completely ignoring the fact that she has become a creature and that she has chosen to be part of the broken-teenage-girl club. I have to admit, she had been spending a lot of time in the black hole lately, but how is she able to do this? To Gabby's granny's surprise she emerged from her room with a smile on her face as she asked her grandparents to drop her off at the mall. For the next few weeks to follow, Gabby was barely home. I have to admit, I was a bit confused. In the past Gabby use to isolate herself from others and stayed at home in the black hole with the demons and myself. Now however I am seeing that she is all of a sudden acting as if she is not scared of being judged as a creature.

I watched Gabby as she started growing her social life again. She was very nice to everyone, almost too nice. At first Gabby didn't have a lot of friends, but the friends that she had, she aimed to please. Having become someone that did not say "no" to others, I realized how Gabby was being pulled in by peer pressure at school, with friends and boyfriends. It didn't take long for me to realize what was going on. Gabby was actually very clever. She was still afraid of people judging her as a creature and scared of being exposed, abandoned and alone, but she skilfully developed a new social identity that was likeable and not prone to being rejected. I have to give it to Gabby, this was brilliant. She was successfully able to escape the black hole and to become a social butterfly. Gabby realized that she could belong to another group of people. It felt great, but she had to be careful to not be found out. Gabby decided to never tell anyone that she was a creature and even at times she forgot that she was one herself. Gabby made a lot of new friends and even started dating. Gabby quickly noticed that allowing her "old soul" that always questioned life to thrive in the popular group might make her slightly unpopular...and off course prone to rejection. For this reason Gabby didn't let her new friends meet her old soul. Even though, at times Gabby had a different opinion to others. She kept quiet and decided to just agree with her new friends. Gabby blended in and it felt good. She was now a social butterfly and no longer a creature.

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After some time, Gabby blended in so well that she was once again faced with the question of "who am I"? Besides the fact that Gabby was a creature under-cover, she started realizing that she was different from others. Her old soul set her apart from others; it used to allow her to speak her mind and to question life, opinions, attitudes, etc. What Gabby realized was that it did not always make her popular. The more she escaped the black hole to become part of the social butterfly club, the less she started speaking her mind and the more she blended in with the crowd. Gabby was afraid that her old soul might cause her to be disliked by her friends. Gabby's biggest fear was to be alone and she resisted this by creating a double life. At school Gabby was the social butterfly, the popular nice one, just to come home to be a creature that belongs to the broken-teenage-girl club that lives in the black hole. Coming to think of it, not only did Gabby start to resist being alone by wearing a mask, she may in fact also have started resisting the life that came with seeing herself as a creature and a broken teenage girl. Somehow, no matter how much Gabby tried to escape into her make-believe world of social butterflies, her wings would be clipped when she came home. She would wash her face and climb into bed and once again drift back into the black hole with the familiar demons.

CHAPTER 7:
The TEENAGE GIRL...RESISTING the broken-teenage-girl club

"Her letter was not a suicide letter, but a letter to break the silence, a letter of resistance to the story of her life which has had such predictable outcomes to date, yet so unbelievable redundant for what Gabby use to dream of doing with her life".

It is a warm summer's day outside. From Gabby's room you can hear the familiar sounds of everyone going about their usual Sunday business in the house. Granny is cooking up a storm, Grandpa is keeping her company by reading his news paper in the kitchen. With the curtains still closed since Friday evening, it was one of those weeks where Gabby could not bear to feel the same way. It was another day where she felt herself getting pulled deeper into the black hole; it was another day where she felt like giving in to the strong tide of the black hole, to just disappear... and then... just another day all over again where she would have to be the social butterfly. Gabby started crying. I knew this day was coming. I looked at her as she pulled herself from her bed where she has been lying since yesterday afternoon and for most part of today. I looked as she ruffled through piles of her clothes on the ground, looking for something. I looked as she pulled out her notebook with its edges curled upwards. I watched as she sat on the floor with her legs curled underneath her, with tears in her eyes. I watched as she wrote out the letters in blue ink.

Gabby did not know this at the time, but she was busy saving her own life. Being in the midst of the black hole one Sunday afternoon, Gabby made a decision to revoke her membership to the broken teenage girl club. Her letter was not a suicide letter, but a letter to break the silence, a letter of resistance to the story of her life which has had such predictable outcomes to date, yet so unbelievable redundant for what Gabby used to dream of doing with her life. Gabby addressed the letter to her grandparents with the hope of finally sharing with someone the war inside of her. Here is something that I have come to learn about Gabby. She does not like to concern others with her troubles, she is the type of person who would rather carry burdens herself than make others concerned about her. Gabby liked others to think of her as in control of things and that she was handling life. She realized that by not showing to others that she is struggling, she is refusing the help from available support networks around her. Only later did Gabby realize the significance of her letter as a way of breaking out of the "role" assigned to her by joining the broken teenage girl club. Gabby only knew that she no longer wanted to continue in the direction her life was heading. She had to do something drastic.

Although it made Gabby feel very uncomfortable, she chose to break the silence with her letter. Even in this letter that spoke of so much pain, Gabby refused to author herself as "completely" broken. She carefully selected her words and skilfully avoided any reference to suicidal thoughts or self-harm. She censored her outcry to a gentle request for help, with the hope of not causing too much concern. Irrespective of Gabby's careful choice of words her grandparents were shocked and took immediate action by making calls to various psychiatric institutions. Her brother to her surprise, who also grabbed the letter to give it a read, walked up to Gabby. He took her by the shoulders and pulled her tightly against his chest whilst whispering the words; "I'm proud of you". They have been seeing the broken teenage girl and how she crawled deeper and deeper into the black hole. Her letter was not typical of the role that she had been playing over the past few years. Although she didn't realize it at the time, it was surprisingly different to that of a broken teenage girl.

Gabby was admitted to a psychiatric institution for two weeks where she was evaluated and closely observed by the staff. She was scared and confused but felt somewhat relieved that her family knew about the war she was trying to fight. During this time I was wondering whether it was my fault. I had grown quite fond of Gabby and did not like to see her like this. Upon admission Gabby's granny informed the therapist that Gabby had a creature living in her blood. Gabby saw her therapist twice during the two weeks. During both of the sessions I was invisible to the therapist as if I wasn't there to begin with, as if things like creatures didn't exist at all. Gabby did not mention me in therapy as she knew her granny told the therapist about me when she was admitted. They only spoke about the demons in the black hole. I was quite upset; was I not the ring leader? Gabby did her research well in exposing the black hole and all of its demons. She was diagnosed with depression and given antidepressant medication to take, with the instructions to

return to the psychiatrist for a re-evaluation in 6 months time. As comforting as her new label of depression was, I could see that Gabby now had to get used to the idea that she was officially again part of the broken-teenage-girl club.

On the other hand, breaking the silence about her emotions to her family changed something big in Gabby's life. Her granny started opening up about her emotions and living with depression and her brother started sharing some of his own emotions as well. Things seemed to be picking up. During the group sessions that Gabby attended at the psychiatric institution, she learnt that she should be more assertive around people and to speak her mind, or else risk that people may walk over her. In a way it made me think of the old soul, a part of Gabby that used to be like this. Gabby was determined to change, but soon realized that it threatened her social butterfly identity, which in turn might lead to rejection and abandonment. After a few weeks Gabby found herself once again stuck in the black hole, isolating herself from others and somehow gaining comfort in belonging to the broken-teenage-girl group who did not judge. Gabby's granny sat down with her one day and told her that she would prefer if Gabby stopped taking the anti-depressants and going for therapy. Gabby's Granny shared with her how sneaky depression can be by pulling you into a place where it is very difficult to get out. Her granny said that she could see that Gabby had become all too comfortable with slipping back into depression and that she felt that Gabby might be playing a role in bringing it on herself. Gabby felt exposed. How did her Granny know that she secretly decided to join the broken-teenage-girl group again? An alternative was to break free from both the broken teenage girl club and the social butterfly mask, but to her it meant that then she would not belong to any club. It scared Gabby to think of who she might be without a broken teenage girl or a social butterfly identity.

CHAPTER 8:

Gabby...RECLAIMING her position as PRIVILEGED AUTHOR

One morning whilst eating breakfast, Gabby's granny told her that she had heard about a new project at the hospital that Gabby could join if she was interested. It was specifically for teenagers living with HIV. Gabby was shocked when she heard her Granny talking about the creature as she was not used to my name being said out loud. I have to admit I was also shocked. I felt a bit uneasy as I had become quite comfortable with the idea of being Gabby, and Gabby being me and the demons getting the blame for everything.

Gabby was caught at a crossroads. Staying loyal to the broken-teenage-girl club would mean allowing the demons of the black hole to consume much of her time and energy, stealing not only her friendships but also her old soul and her dream to become a journalist. Breaking free from this club would mean that she would just have to be the social butterfly that would mean wearing a

mask all the time and also losing her old soul. Who am I then, she would often ask herself. This was when I realized that Gabby had forgotten about the old soul. Without the other two identities she would just be a creature. The problem was that the story Gabby had about creatures made her constantly fall back into the black hole with the demons, thus also the broken-teenage-girl club, which in turn encouraged the social butterfly mask to be used. Gabby was at a point in her life where she could not keep doing what she had been doing. Gabby decided to give her granny the go ahead to speak to the lady at the hospital that ran the project.

One afternoon after school Gabby and her Granny drove through to the hospital to meet with the therapist to find out more about the project. Gabby waited outside in the waiting area as her granny first met with the therapist. I was nervous and I could see that Gabby was nervous. Gabby's granny talked mostly about Gabby's depression and told the therapist about Gabby's relapses into depression. Her granny mentioned that she thought it might have something to do with the creature in Gabby's blood that she was born with. The therapist met Gabby and explained what the project will be about. Gabby was a bit shy and didn't know what to expect. I was starting to get nervous because the therapist spoke a lot about me. One thing that caught Gabby's attention was that the project would involve storytelling and storybook making. It was as if a light went on in Gabby as she shared that she liked writing and storytelling and that once she thought about being a journalist. This made me feel very uncomfortable because I am a creature that steals stories.

A few weeks later Gabby had her first session with the therapist. During this time Gabby made her own storybook about her life. I was wondering whether Gabby would author herself as me or not. Gabby's storybook title was called "The broken teenage girl". In describing what the book was about (i.e. synopsis), Gabby spoke of a girl that has encountered many tragedies. In listening to Gabby talk about her storybook it made me sad for the girl in her story who seemed to be powerless against all the tragedies that kept on coming her way. When telling her story Gabby told the therapist in detail about all of the tragedies she had experienced, from losing people she loved to the demons in the black hole. Surprisingly Gabby spoke about me, but she spoke about me as herself. To my surprise the therapist also spoke about me but she spoke about me as me and Gabby as Gabby. It left me feeling exposed. I felt as if maybe for the first time Gabby was able to look at me as me and herself as herself. Gabby and the therapist met every week and kept on talking about Gabby's story and about me. They spoke about the broken-teenage-girl club and the social butterfly masks and they spoke a lot about me. This was very new for me because I always hid behind Gabby and the demons when people asked questions about why Gabby was not doing well.

As the weeks progressed Gabby started writing again, but this time it was different. Gabby started questioning the relationship she has had for so long with me. She started wondering how things could be different. Gabby's curiosity and questioning of the story which she has been living for so long reminded me of the old soul. The girl I got to know before she found out that I was living

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inside her blood. What Gabby started to realize was that she had seen herself through other people's stories for so long that she had forgotten how to see who she was without me and without the depression and the social butterfly mask. She had forgotten about the old soul that used to be so comfortable with being different. Gabby realized that the social butterfly role came about as a way to compensate for her own perception of how other people may judge her should they know that she was HIV positive. Being alone, Gabby also judged herself the same way as she thought others would judge her about having a creature in her blood. Gabby was seeing and judging herself not only socially but also personally through the stories that she thought other people told about those with HIV. As the time went on, Gabby started to realize that the stories that she was telling about creatures, although not verbalized out loud, were having a profound impact on her identity, her thoughts, her relationships with others, her feelings, her freedom to express herself or to figure out who she is or wanted to be. Over the weeks, Gabby and her therapist started speaking more about the old soul than about me. I was still there but I was on the side, listening to new stories told by Gabby which I haven't heard her tell in the past.

Claiming back her future

It is Gabby's final year of High school. Gabby's old soul has never been the type to enjoy being placed in a box with a label. She started reading up about people with creatures in their blood and how it is connected to depression and other related problems. She wasn't shocked to learn that depression was quite common and that suicide rates were also quite high for those living with creatures. What was interesting to me was that Gabby was somewhat irritated by this fact. Gabby was beyond the point of stereotypes bringing her comfort, for her she had learnt that it only gave her a reason to give in to the stereotypes and to allow it to write her story for her and most probably also to predict her future. She decided that the broken teenage-girl club was not for her, she will not be another stereotype. Gabby realized that emotion-demons are not all bad, and is sometimes needed to help her old soul to have its own opinion about things that Gabby encountered in life. Being angry, being sad, feeling indifferent, it all actually had a place. I was becoming more aware of the old soul screaming to be released from within Gabby. She decided to push through and to make a success of her academic life. She did well in school and managed her friendships. Gabby was realizing all the more that there was more to her than what people who live with creatures are capable of. The more she and the therapist spoke about me, the more Gabby came to realize that she does not like to be thought of as a creature. Through her journaling, the old soul started to come alive again. Instead of looking at herself in the mirror and seeing herself as a creature, Gabby started seeing herself again. I realized this as she would start having conversations with me if no one looked and talked to me as me and not as her.

Gabby finally realized what I had seen in her all along. Gabby, you are learning that your power lies in your words. Every time you acknowledge me through your writing or when you talk to me

and question me, you are taking back your voice and taking back your position as author. The more you are learning about yourself, the more you are realizing how we have allowed me to become blurred with who you are. We have for so long lived as one that seeing yourself even for a second as separate from me creates a curiosity in you. It creates exciting possibilities. You are able to realize that seeing yourself as me, opened you up to countless story versions that exist about who I am, authored by others. You have come to realize that if you allow others to define you according to how they story me, then you give others the privileged position of authorship to your story. Through your actions you have showed your resistance to becoming another statistic or stereotype of the broken teenage girl story version. Instead, now you are learning that there is a different story to tell, which was actually there all along.

CHAPTER 9:
I am ME and YOU are YOU... journeying with CONTENTMENT

During their last session, Gabby and her therapist spoke about what it would mean to end their sessions together. They spoke about what they wanted to do with their new knowledge. They explored the meaning of telling other people about what they had learnt. Gabby wanted to break the silence and to be heard again, but was not sure how. She spoke to her therapist about how I had stolen her voice in the past by recruiting the demon of fear to keep her quiet. Although somewhat hesitant, Gabby decided to share what she had learnt with her grandparents.

Gabby and her therapist invited her grandparents to a family session one week later. The therapist gave an overview of what they were doing during the sessions and then together with Gabby shared with them what they have learnt about me, the broken-teenage-girl club, the social butterfly and Gabby's old soul. Gabby's grandfather shared how he is a writer by profession and how he would love to be involved in assisting Gabby and her old soul to stay alive. Gabby's grandmother was very supportive and made a pact with Gabby to start breaking the silence about HIV and about suffering in silence. Gabby's grandfather shared his own emotions in grieving the loss of his son (Gabby's father) as a result of HIV. I could see that for him too it was difficult to say my name. In honour of Gabby's father and the old soul, Gabby's grandparents together decided to become researchers with Gabby in learning more about HIV and not allowing other people's stories about HIV to make them scared to talk and learn more about it. Gabby's grandfather was curious as to how he and his wife could further assist Gabby in continuing her new journey of contentment through the old soul. Gabby shared her first and last storybook versions with her grandparents during the session. Her grandfather's face lit up as he turned to Gabby and told her that she is a natural storybook writer. He offered to assist her in writing her own autobiography or fictional preferred storybook about her life and living with HIV. I could see Gabby's mind running

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wild with ideas. Gabby's grandparents who had been witness in the past to several relapses to the broken-teenage-girl story expressed their eagerness to being witness to Gabby's new story version. Together everyone in the room decided to re-define the session as a "rite of passage" for Gabby; a launching pad for reintegrating the new knowledge learnt back into Gabby's everyday practical world. Gabby glanced over at her therapist and smiled as she left the room with her grandparents. Gabby, you are realizing that I am ME and YOU are YOU Gabby. I cannot claim who you are for myself as myself any longer, purely because you have come to realize that YOU are YOU and I am ME. Out of all people I should have known that you would have come to make this distinction; after all you have always been the type to question and to surprise people and not just to accept something at face value. I watch you as you separate yourself from me with such grace. Even though you know that I am a creature, and I will continue to do what creatures do, you are not fighting with me or trying to deny my existence. With your eyes wide open you make the choice to live with me but not to be me. You are allowing yourself to accept me as part of your life, irrespective of the stories that others tell of me or you. You are finally exposing me for where my real power lies. It lies not in my ability to steal health, because we will all one day die; it lies in my ability to steal people's stories. By sharing your new story you are choosing to start your journey of self-acceptance and contentment with yourself and with me. You are busy taking back your position as privileged author of your own life story. Somehow I do not feel the need to fight you. I do not feel the need to take over; I feel at ease, I feel content.

"You are right my creature, I am Me, and You are YOU; because I now know that I am Me, and YOU are YOU, I can be ME and YOU can be YOU. Somehow this story brings us both to a space of acceptance AND contentment. It makes it possible to live together but not to lose ourselves in other people's stories- this is now our story".

~Gabby

Reflective Summary

From Gabby's stories emerged rich metaphors as a way to order her experiences of the past as a way to communicate meaning in the present and imagined future. In summary of this chapter I find it fitting to reflect on my own story version (i.e. meaning) of HIV which I constructed at the beginning of this journey. This made me think back to my own use of metaphorical references in making sense of HIV in chapter 2. I narrated my relationship with HIV in the light of the plot and characters of little red riding-hood and the big bad wolf. After my journey with Gabby I realize the immense power that lies in the stories we tell, not only as a way of making sense of something like HIV but also to understand ourselves and our worlds. Through our journey, Gabby assisted in re-authoring my view of HIV, from a big bad wolf to one of just another creature that does what it has been created to do. In exposing the wolf for its tricks and its motives, it becomes less of a threat. Even though I know that there might still be people who tell big bad wolf stories about HIV, I now know there are other story versions to live by if only we allow ourselves the space to become a little bit more curious.

From this journey, Gabby and I have learnt that HIV first and foremost steals lives from the living by stealing people's stories. Regaining life whilst still alive, is about reclaiming one's position as privileged author of one's life story. Without necessarily claiming that this is the only truth, it is at least a new story that we can tell about HIV. Based on this research journey, it allowed for the exploration and construction of practical wisdom and new narratives for living "with" HIV. We decided to conclude our sessions with a final phase, originally planned for as a debriefing session in conclusion of our journey together. As it was evidenced in the previous chapter, our ongoing dialogical interaction during the debriefing session gave way to a final phase which was called the reintegration (sharing) phase. Having both told (constructed) our new story versions about living with HIV, a need arose for it to have an audience; it needed to be heard. The section below provides an overview of the debriefing session which ultimately gave way to the planning and execution of the reincorporation (sharing) phase.

Debriefing Session

A debriefing session was arranged with Gabby after the last session of the project phase. The aim of the debriefing session was to afford Gabby the opportunity to share her experience of participating in this research and to voice any questions or concerns related to such involvement. Following from this, the session was also aimed at ensuring that no harm was caused by Gabby's involvement and if necessary that the appropriate support could be provided. Based on Gabby's feedback, it can be said that there was no physical or psychological risk identified for Gabby by her participation in this study. Throughout this research journey, Gabby was carefully monitored for any signs of being overwhelmed or negatively affected by her involvement in the study. As an additional measure to ensure that no harm was caused, the video recordings were reviewed during supervision sessions with the researcher's co-supervisor, as an additional safeguard. As the debriefing session created an additional space for dialogical interaction it provided a platform for the evolution of a final phase, referred to as the reintegration (sharing) phase.

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The Reintegration (Sharing) Phase

To explain how the reintegration (sharing) phase came to be, I share with you some background to the events that lead up to and took place during the debriefing session which ultimately gave way to this phase.

Background

After my enriching journey with Gabby, I could not help but let my mind wander all the way back to Attridgeville and the busy hallways of the paediatric outpatient unit. Between Gabby and myself we had constructed new meaning to living with HIV, but that was where our stories were left. Prior to my debriefing session with Gabby, I decided to visit the HIV care workers in the paediatric unit. The section below was taken from the journal I kept to document my ongoing experience of this journey.

> It was a usual Monday morning, buzzing with murmurs of parents and children roaming the clinic. Irrespective of the murmurs of people, the unit seemed oddly quiet, different even. No one was in the support group room, although it was already close to 9h00. I walked over to the admin staff to ask where I could find the care workers, who usually would be busy with the support group or trying to create some form of order of the buzzing waiting room. I was told that the care workers no longer worked in the unit. I am sure my face communicated my confusion and disappointment. Knowing my passionate involvement in the unit over the past few months, the staff member lifted his one finger up to me as he picked up the phone. He made a quick call and told me to wait. About 10 minutes later, around the corner came Sarah (pseudonym). Sarah who has been a care worker in the unit over the past few years shared her own disappointment about her having to leave the unit. I had good timing she said, as it was her last day at the hospital. In short, she explained how the reimbursement funding for the employment of voluntary care workers had been cut at Kalafong and various other hospitals. Although the care workers volunteered, over the years they had become dependent on the financial reimbursement for their services, as they dedicated much of their time and resources to the hospital. Sarah explained that the duties previously fulfilled by the care workers would now be transmitted to the job requirements of the already employed nurses in the unit. For the time being she explained, the groups would be suspended until the staff figured out how to manoeuvre their daily duties to also make time for the support group. We both had no words as we sat together in silence in the small side office in which we so enthusiastically planned the future of the HIV unit in the past. We hugged and said our goodbyes as we walked out of the unit together.

Collaborative Identification of Needs

During the time that I met with Gabby, she had moved to a different clinic closer to her home to transition into Adult HIV disease management and care. In our planned last session

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together during debriefing, I decided to share the news with Gabby about the care worker's absence. Gabby was shocked as she had been going to the unit for the past four years, attending the support groups on Mondays with the care workers. During the debriefing session, Gabby and I reflected on her journey with HIV thus far and also how her new story of living with HIV might impact on her current and imagined future. Throughout the debriefing session I got the feeling that Gabby evaluated her current functioning as favourable as she was talking about finishing her final year in high school and pursuing a career in journalism.

During the session Gabby expressed the need to help others growing up with HIV based on her own experience and knowledge gained. We gained a lot of knowledge through our journey, however I was wondering what it was exactly that Gabby wanted to help others with. I asked Gabby the following question "based on what we know now, what would you say the you-back-then needed help with?" By asking this question I attempted to identify whether there might have been a place for our new knowledge in her past and maybe now in her present and future as she wanted to help others. Gabby almost without much thought responded by saying that she wished that she had access to other stories about living with HIV after she was diagnosed. Together we explored her past experiences based on what we know now. Gabby shared how the hospital context mostly assisted in providing medical facts about being HIV positive and how her life would be impacted in the present and future. Although it had a place, she felt that it was information that she had already known and it made her feel like she was defined as a disease. What she knows now is that although she currently still lives with a disease, that she is not and never actually was the disease. This made me think back to the time when I wondered about my own way of seeing people who live with wolves and whether I saw them as the wolves. Gabby answered my question about whether people who live with wolves also see themselves as wolves. She did, based on the stories she had access to back then. In addition, Gabby shared how HIV was a silent thing and that no one really spoke about HIV outside of the support group room, the clinic or at home. It was just something that she had come to accept; a medical "condition" that should not be spoken about. As the silence denied further access to any other people and stories for making sense of HIV, her journey of acceptance of being HIV positive used to be based on her acceptance of herself as a disease. Gabby was able to make sense of her inability back then to accept her status. By exploring Gabby's way forward after our journey together, she shared that she had the need to share what we have learnt with others. In evaluating the significance of such sharing for Gabby, she mentioned that it would not only help herself in

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thickening her new story but could also help others in giving them access to alternative story versions for making sense of HIV. I got the impression that Gabby was talking about becoming an activist for others based on what she wish she had had when she was first diagnosed with HIV. Although the debriefing session was meant as a "closing session", it generated additional questions and meaning. This was the moment that I truly understood the circular process of constructing meaning as an ongoing process, without a clear beginning or an end, made possible because of ongoing dialogue about HIV.

Collaborative Planning and Execution of Need Fulfilment

Therapy as a journey for constructing meaning lends itself to a large array of rich metaphors which in itself contributes to the process of meaning making. What does this mean for the termination of therapy? Epston and White (1992) describe how the termination of therapy in the traditional sense may translate into a metaphor of loss, especially if termination is not considered within the client's broader social environment. That is, contextualizing the therapeutic growth as a separate private affair with the therapist, could contribute to the metaphor of termination-as-loss. A narrative practice introduced by Epston and White (1992), involves re-contextualizing the practice of termination to become a space for reincorporation. That is, using the final stage of therapy as a launching pad for reintegrating the new knowledge back into the person's practical social world. This involves incorporating the person's social world into the process of sharing the new knowledge and stories. In this sense it becomes a ceremonial "rite of passage" (Epston & White, 1992) rather than a loss. What Gabby spoke about was her need for sharing the knowledge by incorporating her world and environment. Epston and White (1992) identified various approaches as practices of reincorporation which has been helpful in their work with clients in that "all of these approaches include the identification and recruitment of audiences for the authentication of change, and for the legitimation of alternative knowledges" (p.17). During the debriefing session we explored the various ways in which such knowledge could be reintegrated (shared) with others outside of our interactions as a practice of reincorporation.

The audience(s). Towards the end of the debriefing session three audiences were identified and explored as a multi-layered platform for the reintegration (sharing) of the practical wisdom gained from our journey. The audiences below are not arranged by primary preference, but rather on the basis of the chain of events that played out following the debriefing session.

Audience 1: The family context. During the debriefing session I reminded Gabby that I would be meeting with her grandparents in conclusion of the research as an extended form of debriefing. Given that Gabby was still under the age of 18 during the time that we started our sessions, my debriefing session with them was planned with the intention of providing some feedback on the processes and procedures followed throughout with Gabby. Taking into consideration the requirement of confidentiality, Gabby and I discussed what we would like to share with them. Gabby shared how she had stopped talking to people in her family about what was going on in her life as she recalled how she had lost her voice through everything that she has been through. Although somewhat hesitant, Gabby decided that she wanted to create a space to share with them the journey that she had been through and the practical wisdom that she has gained. Together we identified her grandparents as an audience for sharing such knowledge. A session was arranged with Gabby's grandparents to take place a week after her debriefing session, as was authored in the previous chapter.

Audience 2: Research (academic) community. One of the reincorporation practices suggested by Epston and White (1992) is for the "client" to become a consultant to not only themselves but also to the therapist and other people. I shared with Gabby that I wrote a storybook on our journey as part of my research report. We explored the significance of this storybook to be shared in my own practice with other adolescents living with HIV, thus positioning her as a consultant. As part of the debriefing session we explored the significance of my involvement in sharing our new narrative knowledge in the form of a research report for academic purposes. Together we identified this narrative (research report) and any extension of it (i.e. journal article) as a catalyst for sharing our knowledge gained with the larger research community as an additional audience. By sharing our knowledge with the larger academic community it becomes by extension shared with a public domain, accessible to anyone who wishes to hear or re-tell our story as a means of recruiting Gabby as a consultant.

Audience 3: Those living and working with HIV. From our discussion of sharing what we had learnt about people growing up with HIV, Gabby and I started talking about various ways in which this would be practically possible. Gabby mentioned that she was interested in the extended future to get involved with support groups as a mentor or facilitator for children and teens living with HIV. We went on to discuss what would happen to her new storybook version that she constructed during our journey and what she would like to do with it. Gabby

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expressed her excitement in getting involved in formally writing her storybook with her grandfather's help, to be made accessible to children and teens growing up with HIV. Gabby decided to plan it as a project to continue after she finishes her final year in high school, the following year. She also added that it may help those who work with people with HIV by giving them an alternative story for making sense of HIV.

Conclusion

The debriefing session, to both of our surprise created a meaningful space for us to plan and fulfil Gabby's need to share her new knowledge with others. For Gabby it meant breaking the silence about living with HIV, to start talking about, what not talking about it, did to her, as well as giving people new ways of talking about HIV.

As for myself, this research journey taught me about the usefulness of narrative therapy as an approach to working with those living with chronic illness. With this journey being an amalgamation of therapy and research I have constructed new meaning for myself for the term therapeutic co-research in my everyday work as a therapist. As this narrative (research report) draws to an end, I am excited to share with the academic world our practical wisdom gained from this experience documented in this narrative. Being a co-author in sharing Gabby's wisdom about HIV, I see this narrative and that which may stem from it as a platform for sharing a new perspective (story version) on HIV with audiences in the academic world. The biggest thing that I have learnt from this journey is, as the Greek philosopher Plato once said "those who tell stories rule society". Stories about HIV will always be there, but ask yourself this, are you ok with the fact that others story your world for you, or would you like to take back your position as privileged author of your own story you tell, live by and leave behind?

CHAPTER 9

LOOKING BACK AS A PRACTICE FOR LOOKING FORWARD

As this narrative draws to a close, I find it necessary to reflect on my approach to this journey, as well as what this means for the way forward. Firstly I discuss the ethical considerations and precautions implemented in this research. This is followed by a discussion on the shortcomings and limitations of this study. I conclude this narrative with recommendations for future endeavours.

Ethical Considerations

This research assumed a somewhat unconventional approach to psychological research in the human sciences. Irrespective of my diversion from the norm, I strived to conduct ethical research, guided by established protocol for health psychology research. The standards for the code of ethics of the American Psychological Association (2002) and the general ethical guidelines for health research of the Health Professions Council of South Africa (2008) were used as guidelines.

Institutional Permission and Approval

This research received institutional approval in accordance with the code of ethics of the National Health Act (Act No. 61 of 2003). Such approval was afforded prior to the commencement of any interaction with the research community. See Appendix A(2) for the approval letter from the Research Ethics Committee of the Faculty of Humanities, and Appendix A(3) for the hospital permission letter from KPTH.

Competency

This research was conducted in accordance with standards 2.01 and 2.03 of the APA (2002) ethics code, with reference to practitioner competence. This research was conducted within the boundaries of my competence (standard 2.01) with regards to education, training and supervised practice (APA, 2002). Prior to the commencement of this research, I received training and engaged in supervised practice in narrative therapy in the hospital context. Such training and practical experience was done during my twelve

month BPsych Trauma Counselling Internship, in affiliation with Hospivision[18] at TDH and Steve Biko Academic Hospital (SBAH) in 2012. In addition, narrative therapy was included as a core module in my training during my masters studies in Counselling (community) Psychology at the University of Pretoria. I engaged in ongoing supervision with my co-supervisor who specialize in narrative therapeutic practice, as a means to further develop and maintain my competence (standard 2.03) throughout this research (APA, 2002). In maintaining competence in the field of adolescent HIV, I engaged in ongoing efforts to research and educate myself to become familiarized with the field. I received guidance throughout this research from my supervisor who is an expert in the field of HIV. As a registered student counselling psychologist at the HPCSA, I was mindful of the ethical code of this organization and my role in relation to the code of conduct of the registration category for the purpose of this study.

Participant Invitation

The invitation of adolescents for selection purposes was done in accordance with section 6.5 (HPCSA, 2008) of the proposed ethical considerations. Adolescents who regularly received ART at the paediatric out-patient unit at KPTH were individually approached and invited by the social worker and sister-in-charge of the unit and invited to participate in this research. The adolescents were provided with an invitation letter (See appendix B) which provided a brief overview of the research. This letter had to be signed by the adolescent and his/her parent or guardian as proof of permission to receive more detailed information about the research. Only thereafter was the adolescent's parent or guardian contacted telephonically to arrange for written informed consent and assent meeting with the researcher at KPTH.

Informed Consent and Assent

A standard protocol was followed for informed consent, in accordance with standard 3.10 and 8.02 (APA, 2002). As this research was intended to be done with minors, standard 3.10 (a-b) was taken into consideration and standard 8.02 (a-b) was used as protocol for providing information for the purpose of consent to this research. For the purpose of this research, Gabby's grandparents, who were her guardians, were invited to

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[18] Hospivision is a non-profit, organization that offers emotional, spiritual and physical care to patients and their families at Tshwane District Hospital and Steve Biko Academic Hospital. Hospivision also offers accredited short course learning programmes based on narrative therapeutic practice.

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the informed consent session. Only her grandmother could attend the session. She was seen first to explain the research and to obtain her permission. Most importantly, this was done to maintain an ethical stance of not risking accidentally disclosing Gabby's status to her. Secondly, this was done to safeguard against disclosing the mode of HIV transmission to Gabby in the case that she was uninformed. Hereafter Gabby joined her grandmother to follow the same process, but for the purpose of informed assent.

This research followed the protocol for informed consent (APA, 2002) as is outlined in Standard 8.02 (a). Gabby and her grandmother were informed about (a1) the nature of the research, its expected duration and procedures; (a2) her right to decline participation or to withdraw at any time; (a3) the lack of consequences of declining or withdrawing; (a4) possible factors that may influence participation, which included the video recording of sessions; (a5) participatory benefits, in this case therapy; (a6) limits of confidentiality; (a7) the lack of incentives for participation; and (8) contact information for additional questions about the research. As this research was intervention based (therapeutic co-research), aspects related to Standard 8.02(b) was also taken into consideration (APA, 2002). Information was provided to Gabby and her grandmother about (b1) the nature of the therapy; (b4) available therapeutic alternatives or support should Gabby choose to withdraw at any time; (b5) compensation or reimbursement for travelling to the sessions, should alternative arrangements not be made to reduce the cost of travel. I made sure to answer all questions posed by Gabby and her grandmother, relevant to the research and Gabby's involvement in general. In accordance with standard 3.10(d) both Gabby and her grandmother provided written proof of voluntary consent and assent (APA, 2002). Gabby's grandfather provided verbal consent when he brought Gabby to her first session. See appendix C for an example of the informed consent and assent letters.

Confidentiality

This research was conducted in accordance with section 4.1.2 (HPCSA, 2008) with reference to the principle of confidentiality. As part of the informed consent and assent process, Gabby and her grandmother were assured that all efforts would be made to maintain privacy and confidentiality. Due to the use of a video camera (Standard 4.02) to document the unfolding meaning making process, it was necessary to clearly outline the ethical requirements and limitations to maintaining confidentiality (APA, 2002). The

following limits to the requirement of confidentiality were discussed with Gabby and her grandmother, as is recommended in standard 4.01 and 4.02 (APA, 2002).

Supervision. Gabby and her grandmother were informed of my professional registration as student psychologist and the inclusion of supervisory practices as part of such a registration category. Limitations to the requirement of confidentiality were discussed with Gabby and that the supervisor may have access to the video material, although only for supervisory purposes.

Privacy. During the informed assent phase, Gabby appeared hesitant to being filmed on video. To counter this obstacle and to respect Gabby's privacy, a decision was made to merely video record the storybook on the table which assisted in enhancing anonymity. This still allowed the unfolding process of meaning making to be captured visually and through audio, however allowed for the Gabby's facial identity to be protected and anonymity to be enhanced.

Anonymity. To maintain anonymity, Gabby was assured that pseudonyms would be used when referring to her in both written and verbal form, including any communication for supervisory purposes. In addition, personal identifiable references would be limited when referred to in written communication to protect her identity.

Confidentiality. In addition, it was communicated to Gabby that confidentiality will be maintained at all times, however should any information arise that may give the indication that Gabby is a danger to herself or endangering someone else, there would be limitations to the requirement of confidentiality.

Data Storage. Lastly, information was provided on the logistics related to the storage of all video, audio and written material after Gabby's involvement in the study, as is set out in more detail below.

Storage

In accordance with the ethical protocol for data storage (HPCSA, 2008), all material that was produced during the research (i.e. video recordings and written documentation) will be stored for archival purposes. Based on the institutional regulations of the Department of Psychology at the University of Pretoria (UP), all material will be stored in a secure location for a minimum period of 15 years. Gabby was informed about the limitations to data storage. In case she wishes to withdraw from the research project, all material will be destroyed. See Appendix F for the research storage form.

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Debriefing and Support

This research was conducted in accordance with standard 8.08 (APA, 2002) with reference to debriefing and support. A debriefing session was arranged with Gabby after the project phase of the research. During this session Gabby was afforded the opportunity to share her experience of the project and to voice any questions or concerns. The main purpose of this session was to ensure that no harm was caused to Gabby and if necessary the appropriate support could be provided. There were no physical or psychological risks identified for Gabby or her participation in this research. Throughout the research, efforts were made to monitor signs or symptoms of being overwhelmed or negatively affected by her involvement in the study. Gabby was informed at the outset of the study as well as during the debriefing phase, of the availability of free counselling support at Hospivision. Even though Hospivision is based on the premises of TDH, a special arrangement was made for participants to approach the organization as a source of post-research support/ counselling. See Appendix E for the Hospivision Research Support letter.

Dissemination of Findings

All the necessary steps were taken to ensure that the dissemination of research information was done in accordance with standard 8.05 (APA, 2002). Gabby and her grandmother were informed that Gabby's involvement would be documented in the form of an academic dissertation. In addition, Gabby and her grandmother were informed that the findings might be disseminated to lay counsellors and staff within the paediatric unit at KPTH. This was explained in light of the potential benefits of developing alternative supportive interventions based on a narrative or meaning-focused approach to HIV care and support with youth in the hospital context. The above information on the dissemination of information was discussed during the informed consent and assent session, prior to the commencement of the research.

Therapeutic Research

There has been much debate about the ethical boundaries when research becomes therapy or therapy becomes research. In contextualizing this research as therapeutic co-research, I openly acknowledged throughout this journey my dual role as therapist and researcher. In working from a narrative position, it acted to guide my interactive position. Throughout this journey, I was committed to demonstrate congruence with regards to my narrative understanding of people in the context of therapy as well as in the context of

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research. With the guidance of my supervisors, I strived towards constructing knowledge that was produced and embodied in a narrative world view. In acknowledging that I cannot be value-free in my interactions as a person, a therapist and a researcher, I acknowledged that I too tell stories about HIV in my own actions and interactions with others. In commitment to the narrative as metaphor, it shaped my language, research question, methodology, my approach to literature, researcher reflexivity, my interactive positioning with Gabby, the handling of the knowledge and finally, how I chose to report on the knowledge constructed in this narrative report.

Limitations and Shortcomings

This section considers the limitations and shortcomings of this research in the light of its generalizability, replication, practical application, and the quality of the research.

Generalizability

One limitation of this research pertains to its generalizability. The aim of this research was not to collect data, for the purpose of data analysis, in search of generalizable facts or findings. Instead, this research was aimed at describing the process involved in collaborative meaning making and the practical wisdom (i.e. local knowledge) that was co-constructed through such a process. In addition, given that this study involved the in-depth study of one individual, the "results" of this study cannot be generalized to other adolescents with HIV.

Replication Principle

Based on the collaborative nature in which the narrative knowledge was constructed between the researcher and adolescent, the "findings" cannot be replicated. Collaborative research is a socially constructed process that unfolds over time, to construct specific meaning in the co-research context. Having different co-researchers, will lead to uniquely different practical wisdom, constructed between those involved in the co-research.

Practical Application

Although the narrative approach proved to show favourable outcomes for the adolescent involved in the research, replicating this approach for alternative purposes may prove to have practical challenges. Government hospitals such as KPTH have limited

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resources to cater for in-depth individualized supportive interventions. The approach developed for the purpose of this research may have to be adapted to be usefully applied in alternative settings, such as for example a support group in a hospital or community setting.

Research Quality

As the replication principle is not applicable to this study, it cannot be used to measure the quality of this research. For this reason, alternative principles were used as guidance to enrich the quality of this research. The principles of theoretical congruence, verisimilitude, trustworthiness, and utility were used as guidance to enhance the quality of this narrative study. Refer to chapter 1 for a more detailed discussion.

Recommendations

In looking back on this journey, my involvement as co-author and –researcher has afforded me the opportunity to share the lessons learnt with others beyond the co-research dyad. The following recommendations are considered for future practice with young people living with HIV.

Critically Reflexive Practitioners

Knowledge is power. As therapists working in the human sciences, we hold a position of power in the knowledge that we hold and share. How we choose to use such knowledge can shape the meaning for those we engage with in therapy and research. In assuming a position as researcher of illness stories, I am reminded of the importance of becoming a critically reflexive practitioner. From this research, it is recommended that practitioners consider their own role in engaging in HIV research and its impact on producing or re-producing knowledge (i.e. stories) about the meaning of HIV. More narrative research is needed in the field of HIV that goes beyond the mere re-production of master narratives and meanings.

Local knowledge as New Knowledge

By working from a narrative position, the therapist and "client" both become co-researchers. Working from this stance affords the space to critically co-reflect as co-researchers on the stories that are brought into the therapy context. As stories are co-

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constructed into new preferred ones, practical wisdom is constructed. Given that the therapy context allows a unique space for research, it is recommended that more therapeutic co-research studies are considered, especially in the field of health psychology.

Broader Social Value

Through my journey with Gabby we have become more knowledgeable about HIV in terms of how it operates. In addition to sharing our new narrative knowledge with those outside of the research context, I am of the opinion that the narrative approach can be usefully extended to other contexts. In doing so, it can add broader social value in terms of the impact of this study on a community level. It is important though to consider the practical limitations of adapting the project phase of this study to be usefully applied in resource-limited contexts. Applying this narrative approach to the group context may broaden and extend the social value of supportive interventions with adolescents with HIV in the hospital context. It is therefore proposed that the project phase of this research be considered for adaption to a group context, for the purpose of potential collaboration with the I-ACT group at KPTH.

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APPENDIX A
RESEARCH PERMISSION

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UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

8 July 2014

Dear Prof Maree

Project:	**Adolescents dealing with HIV acquired through mother-to-child transmission: a narrative study**
Researcher:	**D Stiglingh**
Supervisor:	**Prof M Visser**
Department:	**Psychology**
Reference number:	**28262965**

Thank you for the well written application that was submitted for ethical review. The Committee would also like to comment the student on the great care taken in conceptualising this very sensitive research, and handling the participants.

I am pleased to inform you that the above application was **approved** by the **Research Ethics Committee** on 3 July 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Postgraduate Committee &
Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland;Prof Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Klopper; Dr C Paneblanco-Warrens; Dr Charles Puttergill, Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

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UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

8 July 2014

Dear Prof Maree

Project:	**Adolescents dealing with HIV acquired through mother-to-child transmission: a narrative study**
Researcher:	**D Stiglingh**
Supervisor:	**Prof M Visser**
Department:	**Psychology**
Reference number:	**28262965**

Further to our letter of approval, please note that this approval will be rescinded should the TDH superintendent, the Sister at the HIV clinic and the Department of Health not grant Ms Stiglingh permission to conduct the research. Proof of these approvals are therefore required.

Sincerely

Prof Karen Harris
Acting Chair: Postgraduate Committee &
Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Research Ethics Committee Members: Prof S Buhlungu (Chair); Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Dr Sepetla Molapo; Dr G Paleker; Dr C Paneblanco-Warrens; Prof GM Spies; Prof E Taljard ; Dr FG Wolmarans, Dr P Wood

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APPENDIX A (2)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

21 April 2015

Dear Prof Visser

Project:	**Adolescents living with HIV acquired through mother-to-child transmission: a narrative study**
Researcher:	**D Stiglingh**
Supervisor:	**Prof MJ Visser**
Department:	**Psychology**
Reference numbers:	**28262965 (GW20150426)**

Thank you for your correspondence of 2 April 2015.

The **Research Ethics Committee** notes that the research site, as stated in the initial approved ethics application that was approved on 3 July 2014, has been changed from Tshwane District Hospital to Kalafong Provincial Tertiary Hospital. The Committee also notes that all relevant revised documentation and permissions have been submitted to the Committee's satisfaction. The revised ethics application has therefore been **approved** at an *ad hoc* meeting held on 20 April 2015. Data collection may therefore continue.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the revised proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:Karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland;Prof Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Klopper; Dr C Panebianco-Warrens; Dr Charles Puttergill, Prof GM Spies; Dr Y Spies; Prof E Taljard; Dr P Wood

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APPENDIX A (3)

<div style="border:1px solid black; padding:10px;">

Permission to access Records / Files / Data base at the Kalafong Provincial Tertiary Hospital

</div>

To: Drs Htwe/Ubomba
Chief Executive Officer/Information Officer
Kalafong Provincial Tertiary Hospital
From: Danelle Stiglingh (Principal Investigator)
Department of Psychology, Faculty of Humanities, University of Pretoria
Dr NM du Plessis (Collaborator)
Paediatrics, KPTH

Re: **Permission to do research at Kalafong Provincial Tertiary Hospital**

Dr Du Plessis is a researcher working at the Paediatric Infectious Diseases Unit, Department of Paediatrics at KPTH. I am a researcher at the University of Pretoria, Faculty of Humanities working in collaboration with Dr Du Plessis. I am requesting permission to conduct a study on the Kalafong Provincial Tertiary Hospital grounds that involves access to patient records.

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

The title of the study is: **Adolescents living with HIV acquired through mother-to-child transmission: a narrative study**

The researcher requests access to the following information: access to the clinical files, record book and the data base.

We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the patients by assigning each patient a random code number.

I have received approval from the Faculty of Humanities Research Ethics Committee, University of Pretoria, pending institutional permission (see attached approval letter).

Yours sincerely,

_____   _____
Signature of the Principle Investigator   Dr Du Plessis

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Permission to do the research study at this hospital and to access the information as requested, is hereby approved.

Chief Executive Officer

Kalafong Provincial Tertiary Hospital

Dr ___A. D. Mbombo.___

Signature of the CEO / Superintendent.

Hospital Official Stamp
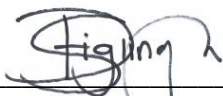
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APPENDIX B
RESEARCH INVITATION

_____/_____/20_____

RESEARCH INVITATION

Dear adolescent and parent/ or guardian,

My name is Danelle Stiglingh. I am a student Counselling Psychologist, in the process of completing my MA Counselling (Community) Psychology degree at the University of Pretoria (UP). The topic of my research is: **"Adolescents living with HIV: a narrative study."** Prof. Maretha Visser, from the Department of Psychology at the University of Pretoria, will be my research supervisor for this study. I would hereby like to invite you to consider participating in this research project. The purpose of this research is to explore how storytelling is used to make sense of HIV amongst adolescents who receive Antiretroviral Therapy (ART) at the out-patient pediatric clinic at Kalafong Provincial Tertiary Hospital (KPTH).
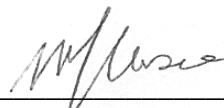
This research study will consist of a project phase which will be conducted at Kalafong Provincial Tertiary Hospital (KPTH). During this time the adolescent will be invited to construct his/ or her own storybook (title, life story and synopsis) of their life which will be followed by a period of co-reflection so as to research how storytelling was used to make sense of HIV. From the research, working guidelines will be proposed as to how a narrative/ or meaning focused approach to HIV care and support can be applied with adolescents with HIV within the medical context.

If you are interested in participating in this research project, please sign the "research contact" section of this letter (page 2), as this will grant me permission to convey more detailed information to you regarding this research project. Once I have given you more detailed information regarding the research project, you can then decide whether the adolescent may participate voluntarily in this research project. I also want to assure you that anonymity and confidentiality will be upheld during the entire research process.

Kind regards,

Ms. Danelle Stiglingh	**Prof. M. J. Visser**
Researcher	Supervisor
Cell no: 082 769 1344	Tel no: 012 420 2549
Email: nellie.stiglingh@gmail.com	maretha.visser@up.ac.za

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RESEARCH CONTACT

Adolescent

I hereby acknowledge that I am interested in participating in the MA (Psychology) research project of Miss. Danelle Stiglingh titled: **"Adolescents living with HIV: a narrative study".** I hereby grant Miss Stiglingh permission to convey more detailed information to me regarding the research project, with the purpose of making an informed decision regarding my participation in this research project.

Full name & Surname: _____

Contact number(s):   _____

…………………………   …………………………..
Signature   Date

Parent or guardian

I _____ (specify parent or guardian) of the adolescent, hereby acknowledge that I am interested in considering the adolescent's participation in the MA (Psychology) research project of Miss Danelle Stiglingh titled: **"Adolescents living with HIV: a narrative study."**I hereby grant Miss Stiglingh permission to contact me and/ the adolescent to convey more detailed information regarding the research project, with the purpose of making an informed decision regarding the adolescent's participation in this research project.

Full name & Surname: _____

Contact number(s):   _____

…………………………   …………………………..
Signature   Date

APPENDIX C

RESEARCH INFORMATION

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology

__/ __/ 201_

RESEARCH INFORMATION

Dear parent or guardian,

The following information is important regarding this research project. Once you have read the information and you **willingly agree** to your child's participation in the research, please complete the **research consent form** on page 4 and 5.

Researcher: I am a student Counselling Psychologist, registered for my MA degree in Counselling (community) Psychology at the University of Pretoria. This research project will fulfil the final requirements of the abovementioned degree. Prof. M. Visser from the Department of Psychology at the University of Pretoria (UP), will act as my primary supervisor for this research. Prof. L. Human specializes in narrative therapeutic practice and research at the University of Pretoria (UP) and has been recruited as co-supervisor specifically for the project phase of this research.

Title: The title of the research is: **"Adolescents living with HIV: a narrative study".**

Purpose: The purpose of this research project is to explore how adolescents with HIV use storytelling to make sense of their illness. Based on the findings, the researcher also hopes to propose working guidelines on the function and purpose of a meaning-focused approach to HIV care and support with adolescents with HIV within the medical context.

Procedures: This research study will consist of a project phase which will be conducted at Kalafong Provincial Tertiary Hospital (KPTH) in a consultation room in the paediatric out-patient unit, unless alternative arrangements are made. The project phase will be subdivided into two sub-phases and will require the adolescent to participate in the following activities:

1) **Working Phase**
   The Collaborative storybook Development (CSD) project has been specifically developed by the researcher to research in a collaborative manner with the adolescent how storytelling is employed to make sense of their illness through storybook making. The adolescent will be invited to construct his/ her own storybook (title, life story and synopsis) of their life. The interaction of the sessions will be based on a narrative therapeutic approach and will take place once a week. A minimum time period of 2 months is recommended, but may vary depending on each interaction.

ATTENTION: Please note that each session during the working phase will be video recorded, but only for the purpose of co-reflection between the researcher and the participant during the reflection phase.

2) Reflection Phase
The reflection phase will involve the adolescent watching, and together with the researcher, reflecting on the videos produced during the working phase.

ATTENTION: Please note that the reflection phase will be video recorded for the purpose of capturing the co-reflections made between the researcher and the participant for the purpose of documenting such reflections in a research report (i.e. mini thesis).

Risks: There are no perceived physical or psychological risks for the adolescent's participation in this research. However, should any psychological harm result or you/ or the adolescent in your personal capacity feel overwhelmed by the study, counselling will be provided to you and/ or the adolescent, free of charge by a counsellor at HospiVision, which is in the out-patient building at Tshwane District Hospital.

Benefits: There are no financial gains by participating in the research project. The adolescent's travelling expenses for travelling to and from the hospital only for the purpose of the research will be paid for by the researcher. This is to ensure that the decision for the adolescent to participate in the study is not impacted by financial constraints as it relates to travel. In the case that an alternative contact site closer to the participant's home is arranged, travel expenses may be suspended.

The adolescent may benefit from his/ her participation in the study in that it will provide a structured time and space for the construction of preferred meaning of their illness through the storytelling.

Rights: Participation in this research project is completely voluntary. The adolescent may withdraw from participating at any time and without negative consequences for doing so. The adolescent's right to receiving antiretroviral therapy (ART) at KPTH is not dependent on participating in this project. Therefore, the adolescent may at any point withdraw without this impacting the medical treatment he/ or she is receiving.

Confidentiality: All information will be treated as confidential. All recorded or written material will be destroyed if you or the adolescent wish for the adolescent to withdraw from the research project. As a means to protect the adolescent's identity, pseudonyms will be used in referring to the participant in both written and verbal form, including any communication for supervisory purposes.
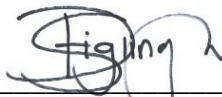
Storage: After completion of the research all documentation, together with the video material will be stored for archival purposes in the Department of Psychology at University of Pretoria for a minimum of 15 years.

Publication: The knowledge gained from this study will be shared with the adolescent before it is published in a MA mini-thesis. The research, as will be documented in a mini thesis may be written up in an academic journal article. Efforts will be made to protect the adolescent's identity at all times as it relates to all documented material related to his/ or her involvement in this research (i.e. mini thesis and/ or a journal article).

Researcher: If any clarity or more detail is required feel free to contact me Ms. Danelle Stiglingh on:
Cell no: 082 769 1344
E-mail: nellie.stiglingh@gmail.com

_____   _____
Ms. Danelle Stiglingh   **Prof. M. J. Visser**
Researcher   Supervisor
Cell no: 082 769 1344   Tel no: 012 420 2549
Email: nellie.stiglingh@gmail.com   maretha.visser@up.ac.za

RESEARCH CONSENT

Parent or Guardian: 1

I, ... (full name and surname) the parent/ guardian of ……………………………………….… (full name and surname of patient) hereby acknowledge that I have read and understand this research information. I acknowledge that any questions I may have had, I have had the opportunity to discuss them with the researcher and she has discussed and answered all of the concerns. By signing this form I agree to video recordings being made during the sessions that the adolescent attend with the researcher, under the condition that recorded material be handled in a confidential manner and that the adolescent's identity will be protected at all times. As the parent/ guardian, I hereby voluntarily give consent for the adolescent to participate in the research project. With such consent I give permission to the researcher to document the findings from this research in the form a mini thesis and/ or the publication of a journal article, under the condition that the identity of the adolescent be kept confidential. I accept and agree with the conditions as is stated above.

_____   _____

Name & Surname (Parent/ guardian)   Signature

_____

Date

Parent or Guardian: 2

I, ... (full name and surname) the parent/ guardian of …………………………………………….… (full name and surname of patient) hereby acknowledge that I have read and understand this research information. I acknowledge that any questions I may have had I have had the opportunity to discuss them with the researcher and she has discussed and answered all of the concerns. By signing this form I agree to video recordings being made during the sessions that the adolescent attend with the researcher, under the condition that recorded material be handled in a confidential manner and that the adolescent's identity will be protected at all times. As the parent/ guardian, I hereby voluntarily give consent for the adolescent to participate in the research project. With such consent I give permission to the researcher to document the findings from this research in the form a mini thesis and/ or the publication of a journal article, under the condition that the identity of the adolescent be kept confidential. I accept and agree with the conditions as is stated above.

_____   _____

Name & Surname (Parent/ guardian)   Signature

_____

Date

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology

__/ __/ 201_

RESEARCH INFORMATION

Dear adolescent,

The following information is important regarding this research project. Once you have read the information and you **willingly agree** to your own participation in the research, please complete the **research assent form** on page 4.

Researcher: I am a student Counselling Psychologist, registered for my MA degree in Counselling (community) Psychology at the University of Pretoria (UP). This research project will fulfil the final requirements of the abovementioned degree. Prof. M. Visser from the Department of Psychology at UP, will act as my primary supervisor for this research. Prof. L. Human who specializes in narrative therapeutic practice and research at UP has been recruited as co-supervisor specifically for the project phase of this research.

Title: The title of the research is: **"Adolescents living with HIV: a narrative study".**

Purpose: The purpose of this research project is to explore how adolescents with HIV use storytelling to make sense of their illness. Based on the findings, the researcher also hopes to propose working guidelines on the function and purpose of a meaning-focused approach to HIV care and support with adolescents with HIV within the medical context.

Procedures: This research study will consist of a project phase which will be conducted at Kalafong Provincial Tertiary Hospital (KPTH) in a consultation room in the paediatric out-patient unit, unless alternative arrangements are made. The project phase will be subdivided into two sub-phases and will require your participation in the following activities:

1) **Working Phase:**
   The Collaborative storybook Development (CSD) project has been specifically developed by the researcher to research in a collaborative manner with you how storytelling is employed to make sense of your illness through storybook making. You will be invited to construct your own storybook (title, life story and synopsis) of your life. The interaction of the sessions will be based on a narrative therapeutic approach and will take place once a week for approximately 1 hour. A minimum time period of 2 months is recommended, but may vary depending on each participant.

ATTENTION: Please note that each session during the working phase will be video recorded, but only for the purpose of co-reflection between the you and the researcher during the reflection phase.

2) **Reflection Phase:**
   The reflection phase will involve both you and the researcher watching and reflecting together on the videos produced during the working phase.

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ATTENTION: Please note that the reflection phase will be video recorded for the purpose of capturing the co-reflections made between yourself and the researcher for the purpose of documenting such reflections in a research report (i.e. mini thesis).

Risks: There are no perceived physical or psychological risks for your participation in this research. However, should any psychological harm result or you/ or your parent or guardian in your personal capacity feel overwhelmed by the study, counselling will be provided to you and/ or your parent or guardian, free of charge by a counsellor at HospiVision which is in the out-patient building of Tshwane District Hospital.

Benefits: There are no financial gains by participating in the research project. Your travelling expenses for travelling to and from the hospital <u>only</u> for the purpose of the research will be paid for by the researcher. This is to ensure that you and your parent or guardian's decision for you to participate in the study is not impacted by financial constraints as it relates to travel. In the case that an alternative contact site closer to your home is arranged, travel expenses may be suspended.

Although there are no financial gains related to your participation, you may benefit from participating in the study in that it provides a structured time and space for the construction of preferred meaning of your illness through the storytelling.
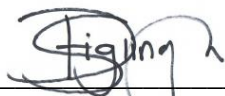
Rights: Participation in this research project is completely voluntary. You may withdraw from participating at any time and without negative consequences for doing so. Your right to receiving antiretroviral therapy (ART) at KPTH is not dependent on participating in this project. Therefore, you may at any point withdraw without this impacting the medical treatment you are receiving.

Confidentiality: All information will be treated as confidential. All recorded or written material will be destroyed if you or the adolescent wish for the adolescent to withdraw from the research project. As a means to protect the adolescent's identity, pseudonyms will be used in referring to the participant in both written and verbal form, including any communication for supervisory purposes.
Storage: After completion of the research project the video material will be stored for archival purposes in the Department of Psychology at University of Pretoria for 15 years.
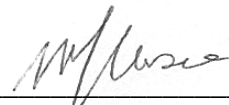
Publication: The knowledge gained from this study will be shared with you before it is published in a MA mini-dissertation. The research, as will be documented in a mini thesis may be written up in an academic journal article to be accessible to the larger academic community. Efforts will be made to protect your identity at all times as it relates to any documented material related to your involvement in this research (i.e. mini thesis and/ or a journal article).

Researcher: If any clarity or more detail is required feel free to contact me Ms. Danelle Stiglingh at:
Cell no: 082 769 1344
E-mail: nellie.stiglingh@gmail.com

Ms. Danelle Stiglingh	**Prof. M. J. Visser**
Researcher	Supervisor
Cell no: 082 769 1344	Tel no: 012 420 2549
Email: nellie.stiglingh@gmail.com	maretha.visser@up.ac.za

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RESEARCH ASSENT

I, ... (full name and surname of adolescent participant), hereby acknowledge that I have read and understand this research information. I acknowledge that any questions I may have had, that I have had the opportunity to discuss them with the researcher and she has discussed and answered all of my questions and/ or concerns. By signing this form I agree to video recordings being made of each session that I attend with the researcher, under the condition that recorded video material be handled in a confidential manner and that my identity will be protected at all times. As a minor, I hereby voluntarily give assent for my own participation in the research project. With such consent I give permission to the researcher to document the findings from this research in the form a mini thesis and/ or the publication of a journal article, under the condition that my identity be kept confidential. I accept and agree with the conditions as is stated above.

_____   _____

Name & Surname (participant)   Signature

_____

Date

APPENDIX D

PROJECT PHASE

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APPENDIX D (1)

RELATIVE INFLUENCE QUESTIONING GUIDE

Adapted from White & Epston (1990) and Freedman and Combs (1996)

Mapping the influence of HIV on the life and relationships of the adolescent

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(a) Who is HIV in your story? (Personify HIV: does HIV have rules, tricks, plans, lies, beliefs, etc.)

(b) What relationship does HIV have with your character in the story? Evaluate: How is that for you?

(c) How old is this relationship? What are the arrangements in this relationship? Evaluate: How is that for you?

(d) What relationship does HIV have with other people in your story? (who, what where and when)

(e) What does HIV do to your relationships with other people? (who, what where and when)

(f) What are some of the beliefs that exist about being an adolescent/ HIV positive/ daughter/ son/ friend/ partner, etc? Evaluate: How is that for you?

(g) How/ when did this idea/ belief develop? (who, what where and when)

(h) How does such an idea impact on you and your relationships? Evaluate: And how is that for you?

(i) Based on your past and current relationship with HIV, how does your relationship with HIV look like in the future (i.e. temporal impact)? Evaluate: How do you think that would that be for you?

(j) Are there times that you were able to experience some time away from such an idea? Evaluate: How was that for you?

Mapping the influence of the adolescent and his/ her relationships on the life of HIV

(a) Has there been a time where you had a different relationship with HIV?

(b) In what way was this relationship different? Evaluate: How was that for you?

(c) What evidence exists for this other relationship?

(d) Where and when did this other relationship take place?

(e) Who knows about this relationship?

(f) Who is/ is not in support of this relationship?

(g) What are some of the consequences of this type of relationship? How is that for you?

(h) How did this different relationship with HIV impact on your relationship with others?

(i) How does this relationship with HIV look like in the **future**?

APPENDIX D (2)

<div align="right">

PRACTICE FORMAT GUIDE

Adapted from Freedman and Combs (1996, p.101-104)

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1. **Identify unique outcome(s):** during initial and follow-up sessions

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2. **Evaluate experiences:**
   (a) Identify unique outcomes (i.e. preferred experience)
   (b) How was that for you?
   (c) Do you want more of this kind of interaction in your relationship(s) or not?

---

3. **Plot the new story experiences (i.e. unique outcomes) in the landscape of action**
   (a) How did you prepare yourself to take this step?
   (b) What do you think was the turning point in your relationship that led to this being possible?
   (c) What exactly did you do?
   (d) Where you guided by an image or something you said to yourself?
   (e) Did you have a plan?
   (f) Did you make this decision on your own or did other people play a part?
   (g) What did others say when they heard of this/ if they would have to hear about this?

---

4. **Plot the new story in the landscape of consciousness/ identity**
   (a) What does it say about you as a person that you did this?
   (b) What personal characteristics does it show?
   (c) What does it do to your relationships when you look at this event?
   (d) Is there something you learnt from that event that could be relevant in other areas of your life?
   (e) What does it show about your goals/ values/ inspirations/ commitments, etc?

---

5. **Explore past events and/ or experiences in line with unique outcome (performing meaning)**
   (a) Where there times in the past where you have done this kind of thing before?
   (b) Who would have predicted this event and what have they seen you do before to make such predictions?

---

6. **Plot past events and/ experiences in the landscape of action and landscape of consciousness**
   (Use section 3 and 4 as guidance)

---

7. **Ask questions to link past events and/ experiences with the present**
   (a) Now that we understand its foundation in your past, can you see how this recent development now makes more sense?
   (b) If you could ask the "you back then" what he/ she thinks of these recent developments, what would he/ she say?

---

8. **Ask questions to extend the story into the future (practical wisdom)**
   (a) If we look at these events that we spoke about as a trend in your life, what do you expect the next step will be?
   (b) Does looking at these events today have any impact on what you see in your future?

---

9. **Co-editing storybook title, story and/ synopsis**
   (a) What aspects of your storybook (title, storyline and synopsis) will have to change or stay the same to fit with what we know now (i.e. new co-constructed narrative knowledge)?
   (b) In what way does it stay the same or different? How is that for you?

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APPENDIX D (3)

<div align="right">

KPTH PERSONNEL RESPONSES

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STAFF	IMPORTANT COMPONENTS OF PAEDIATRIC HIV TREATMENT (Most important to least important)	NECESSARY TREATMENT COMPONENTS (Not currently included)

1	1. ARV treatment
	2. Educating the adolescent on:
	  (a) knowledge about HIV
	  (b) Acceptance of status
	  (c) How to keep healthy (i.e. nutrition)
	  (d) Medication adherence & side effects
	  (e) Transmission (sexual and other precautions)
		1. Education for mothers and caregivers on the various grant options. (Foster care grant versus social grant)
		2. Emotional assistance for kids who have anger towards their parent for the HIV, as it has an impact on medication adherence.

2	1. Show the kids love and care, as this helps the process of treatment.
	2. ARV treatment.
	3. Educating the adolescent on:
	  (a) Medication adherence
	  (b) Transmission of virus to others; re-infection (i.e. cross-infection)
	  (c) Health: balanced diet/ nutrition
		1. Emotional support for the children. It has been noted that the children do not talk about their feelings.
		2. Emotional support for parents who have conflict about the child being sick and them being the person who transmitted the virus to them.

3	1. ARV Treatment
	2. Educating the adolescent on:
	  (a) Modes of transmission.
	  (b) Sex education and guidance.
	  (c) Not to blame mother for being sick.
	3. Education for parents or guardians:
	  (a) Stigma
	  (b) Testing and adherence to medication
	  (c) Not to blame child for being sick
		1. Emotional support for children who are angry because they have HIV.
		2. Emotional support for mothers who transmitted the illness to the child. The mothers often have guilt feelings related to their child's illness and some mothers experience suicidal thoughts related to such guilt.

4	1. The willingness/ buy-in to undergo treatment.
	2. ARV treatment
	3. Educating the parent or guardian on:
	  (a) Disclosure: The younger the child is when finding out about his/ her status the better they accept it.
	3. Educating the adolescent on:
	  (a) Acceptance of status
	  (b) General HIV Education
		1. Teaching the parents about the benefits of early disclosure and how to handle the process of disclosure.
		2. A more integrated and structured approach to topics for the support group (i.e. bio-psycho-social approach). At the moment the support group mostly educates the adolescents on the medical facts on HIV.

5	1. ARV treatment
	2. Educating the adolescent on:
	  (a) HIV/AIDS & opportunistic infection (TB)
	  (b) Treatment literacy and adherence counselling
	  (c) Acceptance of status
	  (d) Disclosure
	  (e) Nutrition
	3. Educating parent or guardian on disclosure issues: Delayed disclosure lead to increased denial and reduced acceptance.
	4. Assisting adolescent in finding a reason or meaning for taking their medication.
		1. Emotional support for the care givers of the children (i.e. taking care of the care-givers).
		2. Emotional support for the children: they don't say much during the group sessions and do not open up emotionally about how they are coping.
		3. Education on healthy and unhealthy (e.g. drugs) coping mechanisms.

APPENDIX E

RESEARCH SUPPORT

HospiVision
PO Box 12423
Queenswood, 0121
Tel/Fax: 012-329 9492
E-mail: andred@hospivision.org.za
Web: www.hospivision.org.za

5 May, 2015

To whom this may concern

RE: HOSPIVISION - RESEARCH SUPPORT

HospiVision is a faith-based organization specializing in psycho-social and spiritual care, counselling and training, as well as physical support, in the health care environment.

This letter is to confirm that HospiVision agrees to provide psycho-social supportive counselling to any of the participants who partake in Ms. Danelle Stiglingh's study titled: "Adolescents living with HIV acquired through mother-to-child transmission: a narrative study" free of charge, should they need to or wish to be assisted.

HospiVision offices are situated on level 3 of the Out-patient Department Building at the Tshwane District Hospital.

Kind regards,

Dr. Andre De La Porte
CEO of HospiVision
Tshwane District Hospital (TDH)

APPENDIX F

RESEARCH STORAGE

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To whom this may concern,

STORAGE DECLARATION: RESEARCH DATA AND RELATED MATERIAL

Herewith the acknowledgement that I, **Ms. Danelle Stiglingh** is the principal researcher of the study, titled, **"Practical wisdom gained from journeying with HIV: Narrative therapeutic co-research".** As such, I declare that I will be storing all the research data and related material referring to the above-mentioned study in the **Department of Psychology** at the **University of Pretoria (UP).**

In line with the regulations for conducting research in the Human Sciences, the mentioned data and / or documents must be maintained for a **minimum of 15 years** from the commencement of this study.

Start date of study:	**2015**
End date of study:	**2016**
Year until which data will be stored:	**2031**

Name of Principal Researcher	Signature	Date
Ms. Danelle Stiglingh		

Name of Supervisor	Signature	Date
Prof. M. J. Visser		

Name of Head of Department	Signature	Date
Prof. D. Maree		