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**An Exploration of Roy's Adaptation Model and the Process of
Adapting to Life with HIV:
A Grounded Theory Study**

by

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PhD (Nursing)**

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Abstract

The aim of this research was to uncover the whole process of adapting to life with HIV. The research set out to consider the physical, psychological and social process of adapting to HIV and explore if stages of adaptation could be identified, presenting an up to date perspective of the HIV experience in light of new treatments and virus resistance.

Glaser's grounded theory method was chosen to gain a perspective on the whole process of adaptation and to develop a model reflecting this, useful to nurses and other professionals. The research was guided by the philosophical assumptions of Roy's Adaptation Model. A second component of this research involved testing Roy's Model of Adaptation by comparing it to the research results.

The resultant grounded theory unveiled the process of adapting to life with HIV as a process of adapting to uncertainty. 'Negotiating uncertainty' emerged as the core concept. This was demonstrated by seven subcategories representing movements between anticipating hopelessness and regaining optimism. The results affirm many propositions of Roy's Model whilst bringing new findings to the theoretical arena and highlighting areas for further clarification. The study concludes with recommendations for future theoretical and conceptual development to both the emergent grounded theory and Roy's Adaptation Model.

Contents

	Page
Abstract.....	3
Tables and Illustrations.....	8
Acknowledgements.....	9
Authors declaration.....	10
Chapter One: Introduction to the Study.....	11
1.1 A background to HIV/AIDS.....	12
1.2 The need to understand the HIV/AIDS experience.....	15
1.3 Aims and objectives of the research study.....	16
Chapter Two: Background to the Study.....	21
2.1 An introduction to the concept of adaptation.....	22
2.2 Early thoughts on adaptation.....	25
2.3 Adaptation as a sociological/psychological coping process.....	28
2.4 Adaptation to chronic illness.....	30
2.5 Adaptation to HIV/AIDS.....	31
2.6 Researching the theoretical perspective: selecting a framework.....	37
2.6.1 The Corbin & Strauss chronic illness trajectory.....	37
2.6.2 Radical Body Politics: women, body & illness.....	43
2.7 Nursing research: the call to be patient focused.....	47
2.8 Nursing models and theories.....	50
Chapter Three: Theoretical Perspective.....	59
3.1 Roy's Adaptation Model as a theoretical perspective.....	60
3.2 Development of the Roy Adaptation Model.....	62
3.3 Philosophical assumptions.....	63
3.4 Scientific assumptions.....	67

3.5	Roy's view of nursing.....	69
3.6	Roy's view of health.....	70
3.7	Roy's view of the environment.....	72
3.8	Roy's view of the person.....	73
3.9	Theoretical aspects of the person as an adaptive system.....	75
3.9.1	Stimuli.....	75
3.9.2	Adaptive response.....	76
3.9.3	The coping process.....	78
3.9.4	The adaptive modes.....	78
3.9.5	The nursing process in accordance with the adaptive modes.....	81
3.10	The use of Roy's Adaptation Model in research.....	84
3.11	Recommendations for research using Roy's Adaptation Model....	90
3.11.1	The concept of time.....	91
3.11.2	The role of perceptions.....	92
3.12	Qualitative research using Roy's Adaptation Model since 1995....	93
3.13	Implications of Roy's Adaptation Model based research review for this study.....	105
Chapter Four: Methodology.....		108
4.1	Grounded theory method.....	109
4.2	The emergence of grounded theory.....	111
4.3	The influence of symbolic interactionism on grounded theory.....	112
4.4	Quantitative influences on grounded theory.....	115
4.5	The emergence (or forcing) of grounded theory variations.....	117
4.6	Using the classic grounded theory method.....	122
4.6.1	The literature review.....	122
4.6.2	Data collection.....	125
4.6.3	Sampling.....	129
4.6.4	Data analysis.....	130
4.6.5	Ensuring credibility.....	134
4.7	Congruency of grounded theory and Roy's Adaptation Model.....	136

Chapter Five: Research Method.....	144
5.1 Aims of the research study.....	145
5.2 Focusing on the patient: selecting participants.....	148
5.3 Protecting the participant: ethical considerations.....	150
5.4 Listening to the patients story: interviewing and data collection.....	153
5.5 Understanding the patients story: data analysis.....	157
5.6 Other considerations: the accuracy of memories in recalling autobiographical events.....	162
5.7 Bringing together the research method and theoretical framework.....	164
 Chapter Six: Results – The Emergent Grounded Theory.....	 168
6.1 Introduction.....	169
6.2 Background to the data collected.....	171
6.2.1 Limitations.....	173
6.3 A brief synopsis of a grounded theory of adapting to life with HIV.....	176
6.4 The core category: negotiating uncertainty.....	178
6.5 Introduction to the seven sub-categories.....	195
6.5.1 Considering the risk: moving from denial to acceptance.....	196
6.5.2 Strengthening through hope: moving between vulnerability and empowerment.....	205
6.5.3 Assuming direction: moving from being controlled by HIV to controlling HIV.....	212
6.5.4 Seizing opportunities: moving from destroying life to saving life.....	223
6.5.5 Broadening vision: moving from self-focus to self-comparison.....	232
6.5.6 Planning for the future: moving from escaping to distracting.....	240
6.5.7 Existing as-was: moving from everything changing towards everything remaining the same.....	250

6.6	Concluding remarks.....	256
Chapter Seven: Theoretical Conclusions.....		261
7.1	Introduction.....	262
7.2	The theoretical concept of adaptation.....	263
7.3	The concept of stimuli.....	265
7.4	The coping process.....	268
7.5	Behavioural adaptive responses.....	272
7.6	Application of theoretical findings to Roy's definition of the nursing process.....	275
7.7	Theoretical advancements from the grounded theory towards Roy's Model of Adaptation.....	277
7.7.1	Advancements to the concept of time.....	279
7.7.2	Advancements to the role of perceptions.....	282
7.7.3	Advancements to Roy's scientific and philosophic assumptions..	286
7.8	Recommendations for future development of Roy's Model of Adaptation.....	287
7.9	Implications of the grounded theory for the wider nursing theoretical realm.....	290
7.10	Recommendations for future development to the grounded theory of adapting to uncertainty.....	292
7.11	Summary of recommendations for research and practice.....	293
7.12	Final summary and conclusions.....	295
References.....		299
Appendix 1	Typology of indicators of positive adaptation according to Roy & Andrew (1999).....	328
Appendix 2	Summary of qualitative research using Roy's Adaptation Model (1995-2005).....	330
Appendix 3	Advertisement for research recruitment.....	331
Appendix 4	Research study consent form for participants.....	332
Appendix 5	Information sheet for participants.....	333

Tables and Illustrations

Page

Tables

Table 1	Theoretical viewpoints of Parse, Roy and Newman.....	54
Table 2	Research areas covered by studies using Roy's Adaptation Model up until 2005.....	94
Table 3	Research objectives and questions.....	155
Table 4	Subcategories of the grounded theory and their categorical pairs.....	177
Table 5	Relationship of sub-categories to the core category.....	184

Illustrations

Figure 1	The chronic illness trajectory framework.....	39
Figure 2	Conceptual framework of women, body and illness.....	44
Figure 3	Representation of new cosmology.....	65
Figure 4	Roy's philosophic assumptions for the 21 st century.....	66
Figure 5	Roy's scientific assumptions for the 21 st century.....	68
Figure 6	The adaptive process according to Roy.....	74
Figure 7	Diagrammatic representation of humans as adaptive systems.....	79
Figure 8	Recommended foci for nursing research based on the Roy Adaptation Model.....	85
Figure 9	Outline of grounded theory according to Glaser & Strauss (1967) and Strauss & Corbin (1998).....	121
Figure 10	Data comparison points.....	160

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Author's Declaration

I certify that this thesis has not already been accepted, nor is it currently being submitted for any other degree.

This work is a result of my own investigation and all quotations and sources from other authors have been acknowledged.

Signed:.....

Stephanie E. Perrett

Date:.....

CHAPTER ONE

Introduction to the Study

“It is not enough simply to study. First one must determine what to study and what not to study; when to study and when not to study; and who to study under and who not to study with”

(Peck, 1995)

1.1 A background to HIV/AIDS

In 2009, at the time of completing this thesis, AIDS (acquired immune deficiency syndrome) has been knowingly present for almost 30 years. This long 30 years for those experiencing or affected by the human immunodeficiency virus (HIV) is a relatively short time in the history of medicine and disease.

The first cases of HIV were formally identified in 1981 through reports of *Pneumocystis carinii* pneumonia (PCP) in five previously fit and healthy young men in the USA (Pratt, 2003). The symptoms seen soon turned into a worldwide pandemic which could not have been predicted. There are now estimated to be 33 million people around the globe living with HIV/AIDS (Avert, 2008a). The majority of these are found with the developing world, mainly Africa, south-east Asia and Latin America (Pratt, 2003). The western world is still affected. Up until the end of June 2008 there had been a total of 97,423 diagnoses of HIV/AIDS within the UK (National Public Health Service Wales, 2007). In 2006, 884 Welsh residents were receiving treatment for HIV/AIDS (30 per 100,000 population) (National Public Health Service Wales, 2007). These figures are a drop in the ocean compared to worldwide cases, yet, each year, the number of UK individuals diagnosed continues to increase despite being a country of wealth, knowledge, education and healthcare that is free at the point of delivery to all.

Human immunodeficiency viruses belong to a family of retroviruses which, by infecting cells in the human immune system such as T-cells and macrophages (specifically CD4 T-cells), can lead to AIDS. AIDS is defined by the appearance of symptoms associated with late symptomatic disease such as pneumonia, candidiasis, toxoplasmosis, cytomegalovirus, herpes simplex, Kaposi's sarcoma and HIV encephalopathy. All are caused by progressive failure of the immune system (Pratt, 2003).

Since its initial discovery, medications have advanced although there remains no cure. Zidovudine, known also as AZT, was introduced in 1987 but proved to be of little benefit for those in the early stages of infection and came with significant side effects (Schmitz *et al*, 1994). By the mid 1990s complex combinations of antiretroviral medications known as highly active antiretroviral therapy (HAART) became available in developed countries (Sterne *et al*, 2005). Patients are treated with a combination (normally 3 or more types) of antiretroviral drugs (British National Formulary, 2009). HAART is started when patients become symptomatic or when monitored blood levels consistently fall or rise outside normal limits. Viral loads (an indication of viral replication) and CD4 (an indication of the body's immune system) are monitored frequently (Pratt, 2003).

Drug resistance to HAART is evident and monitored by prescribers (Cingolani *et al*, 2002; Clavel & Hance, 2004). Despite this, the advent of HAART has changed the history of HIV infection, suppressing viral loads, significantly delaying the onset of AIDS and most importantly increasing

life-span (Sterne *et al*, 2005; Crum *et al*, 2006). The drugs are expensive and rarely available for the majority of patients in the developing world (Avert, 2008b).

HIV is unlike any other disease as it does not occur randomly in populations. As a blood-borne virus it has been isolated from blood, semen, pre-ejaculatory fluid, saliva, tears, breast milk and cerebrospinal fluid. Its modes of transmission are through sexual activity, exposure to infected blood and perinatally from mother to child (Pratt, 2003). HIV is associated with various risk activities, sexual activity and intravenous drug use. Because of this the disease carries complex social and societal issues. Sufferers have experienced prejudice and stigma which is not seen in other conditions.

A plethora of studies, as exposed in Chapter 2, have investigated individual aspects of HIV but have not looked at the overall trajectory. Research has identified aspects of the HIV/AIDS experience such as stigma, coping with diagnosis, the affects on relationships with significant others, fear of the unknown, stress and coping during the disease course (Siegel & Krauss, 1991; Lesserman *et al*, 1992; Lamendola & Newman, 1994; Chidwick & Borril, 1996; Barroso, 1997; Crossley, 1998; Reeves *et al*, 1999; Siegel & Schrimshaw, 2000; Cote & Pepler, 2005; Jacobson *et al*, 2006). Understanding these aspects of the disease can help health professionals to tailor care, meeting the needs of the patients as identified by the patient. This research records the process of adjusting to a life as

HIV positive from a life that is HIV negative. The research uncovers paradoxes within the experience demonstrating that within a destructive illness, periods of joy maybe found.

1.2 The need to understand the HIV/AIDS experience

The importance of understanding a person's illness experience cannot be underestimated. Past research has clearly identified that patients are more likely to engage with services and follow treatment plans when they feel they are being listened to and understood (Cleary, 1988; Attree, 2001; Crawford *et al*, 2002). This is reflected in the uptake of holistic approaches amongst all health professions (Lowenberg, 1994; Ventegodt *et al*, 2003; Griffin, 2006). The benefits of being patient-focused have been recognised politically and suggested for practice in recent government papers (see section 2.7).

Within the field of HIV/AIDS it has been recognised that having an understanding of individual illness and treatment beliefs can strongly influence medication adherence (Holzemer *et al*, 1999; Procter *et al*, 1999; Gonzales *et al*, 2004; Schönnesson *et al*, 2007). Understanding the ways people adapt to HIV may positively affect the way health professionals encourage pharmacological compliance (Cardarelli *et al*, 2008). The need to understand influences on behaviours and processes has been made clear by Kemppainen *et al* (2008):

“Effective interventions to improve adherence can be developed only to the extent that the mechanisms underlying these behaviours are understood”
(Kemppainen, 2008; p127)

As the fourth decade of HIV infection approaches, research is need to constantly identify the changing complexities associated with the virus. Changes to the nature of the disease such as virus resistance, alongside introduction of new treatments means evidence needs to be continually re-evaluated and updated to present a contemporary and accurate perspective. Developments in understanding of the disease and increased life expectancy indicate that HIV is vastly different today to that previously comprehended (The Antiretroviral Therapy Cohort Collaboration, 2008). New therapies have changed HIV survival yet immunity to the commonly used therapies and the emergence of variant strains of HIV look set to challenge these trends. This presents repercussions for the treatment and care needed for those living with HIV/AIDS (Baillargeon *et al*, 1999; Jensen-Fangel *et al*, 2004; Vance, 2008). It is the changing discourse of HIV/AIDS today that provides the fundamental basis of this thesis.

1.3 Aims and objectives of the research study

Whereas previous research has investigating aspects of HIV as separate entities, this research uncovers the whole experience of adapting to HIV. It is hoped that adding further understanding to this area will help health professionals, in particularly nurses, to understand their patients more fully, improving the quality of care given. The majority of HIV positive

individuals will at some point seek medical help, establishing contact with nursing staff whether within a genitourinary-medicine clinic, hospital, out-patient, or community setting.

This thesis is concerned with adaptation to HIV/AIDS for individuals within the western world. The physical trajectory of the disease varies significantly between those who have access to treatment, knowledge and health promotion, and those who do not. Therefore discussions within this thesis, unless otherwise stated, refer to the portrayal of HIV/AIDS in the developed world – predominantly Europe and the USA where the majority of research has taken place.

The research question guiding the study is:

What are the processes of adaptation for those living with HIV/AIDS?

To answer this, unveiling any processes of adaptation and to further understanding of the HIV trajectory the following questions are asked:

- Firstly, what are the experiences (physically, psychologically and socially) of those living with HIV/AIDS today?
- Secondly, can adaptive stages be identified throughout the course of infection?
- Thirdly, to conclude the previous questions, what are the processes of adaptation within the HIV experience? How does the patient adjust to any changes experienced during the HIV discourse?

The study is primarily concerned with discursive formations of individual narratives describing the pandimensional experience of HIV/AIDS.

Glaser's grounded theory research method is used to outline the process of adaptation to HIV, the main aim being to develop a conceptual framework useful to nurses that maps the adaptive HIV discourse.

The study is unique in having a dual purpose, both creating theory but also testing theory. The central element of the thesis is concerned with the concept of adaptation throughout the course of the illness. The study is specific to nursing, based on the scientific and philosophical assumptions underlying Roy's Model of Adaptation (Roy & Andrews, 1999). Roy's model is based on the principle of humanism, recognising the person and their subjective dimensions of human experience as central to knowing and valuing. The assumptions of the model have been integrated in the way the study has been conducted as well as supporting the suppositions of grounded theory method. A critique of Roy's Model of Adaptation, grounded theory method and the role they play together in this research can be found in section 4.7. Roy's Model of Adaptation is tested through this research, the resultant grounded theory is brought back to Roy's model to compare for similarities and differences in the understanding of adaptation. The conclusions of testing Roy's model in this way can be seen in Chapter 7.

The objectives, stemming from the dual aspects of the study to both understand the adaptive process to HIV and test Roy's Model of Adaptation, are as follows:

- To identify the stages, if any, of adaptation throughout the course of HIV/AIDS
- To outline the process of adaptation to HIV/AIDS within a conceptual model or basic social process developed through grounded theory
- If stages of adaptation to HIV/AIDS exist, to test these against Roy's Model of Adaptation. Can stimuli, adaptive modes and their interactive relationships be determined throughout the stages of HIV/AIDS as in Roy's Model of Adaptation?

To establish a foundation for the research study, the following assumptions are made; these are based on the philosophical principles of the Roy Adaptation Model:

- The person is the primary domain concept of nursing, viewed as a system, a set of parts connected to function as a whole, for a purpose. Investigation into the way people adapt to situations places emphasis on the purposefulness of human existence.
- Description of life's journey through dialogical interviews and metaphoric representations will uncover the meanings of HIV to individuals, based on the assumption that humans act towards

events on the basis of the meanings that these things have to them, and that these meanings are modified and established through an interpretive process which will be described by the participant.

Having outlined the research question and objectives, an exploration follows uncovering why the issue of adaptation within HIV/AIDS deserves research attention. The subsequent section is an examination into the present understanding of adaptation as an individual concept and its place within the HIV/AIDS sphere. A discussion is presented of the issues considered whilst preparing for this research, including the process of selecting a theoretical framework for the study. The following text demonstrates the thought process behind the decisions made, showing what ideas were chosen (or eliminated) and why. It offers an understanding of how the preliminary ideas grew and the importance of nursing behind these decisions.

CHAPTER TWO

Background to the Study

“The Present is the moving Infinity, the legitimate sphere of the Relative. Relativity seeks Adjustment; Adjustment is Art. The art of life lies in a constant readjustment to our surroundings.”

Kakuzo Okakura (1906)

2.1 An introduction to the concept of adaptation

“Sometimes I guess in the emotional roller coaster that I’ve been going through the past couple of weeks, when...you’re down, its to the point of “I’m probably gonna get sick and I’m probably gonna die”...At other times its not “I’m probably”, it’s “I am going to get sick and I am going to die.”...On better days it’s “No I’m going to fight this tooth and nail. And I’m not going to let it get the better of me.” It’s been a hell of a roller coaster and the roller coaster is a tough ride.”

(Siegel & Krauss, 1991; p26)

Life is a journey. HIV/AIDS also *has* a journey. A journey consists of changes, adaptations and transitions. In 1984 the mean survival time following an AIDS diagnosis was 11 months, in 1995 the survival time was 47 months (Lee *et al*, 2001). New therapies have changed HIV/AIDS survival (The Antiretroviral Cohort Collaboration, 2008). The latest research shows that survival for people with HIV-1 has continued to increase since the introduction of HAART (Porter *et al*, 2003; Jensen-Fangal *et al*, 2004). Research has predicted those with access to antiretroviral therapies and who contracted HIV during 1996-1999 may now expect an average life expectancy of 20 years, if not longer (Tassie, 2002). In industrialised countries, those with HIV appear to have the same mortality rates as the general population during the first five years of infection (Bhaskaran *et al*, 2008). Conflictingly, manifestations of the virus alongside immunity to common antiretroviral therapies are occurring so quickly that only time will tell if these figures will remain optimistic (Little, 2000; Little *et al*, 2002; Bangsberg *et al*, 2003; Blower *et al*, 2003; Richman *et al*, 2004).

The rapid changes in the disease pattern since its discovery in the 1980's have implications for the treatment and care needed for those living with HIV/AIDS (Persson *et al*, 2003). People are living longer with the disease and new variants of HIV related symptoms are appearing (Perrin *et al*, 2003). Improved technology allows for earlier screening and diagnosis (Kassler, 1997), treatments can be started earlier and those living with HIV are increasingly aware of the choices in treatments and therapies available to them (Gustafson *et al*, 1999; Paterson *et al*, 2000). Those diagnosed in their twenties or thirties are aging and seem to be surviving the disease for longer. The rapid deterioration once seen in those with HIV is slowing as survival time's increase. Expectations of longevity for those living with HIV reflect the description of HIV as a 'chronic illness' (Nokes, 1991; Matic *et al*, 2006). AIDS is still the reality for patients living with HIV however its diagnosis is not as imminent *per se* as once expected (Detels *et al*, 1998).

The quote introducing this chapter, given by a patient describing his experience of HIV highlights the changes he experienced, the uncertainty of the illness, the emotions felt, the fear and the hope. Illness is a part of life and therefore has a part in each person's life history. For those with chronic illness, as HIV has been described (Nokes, 1991), this means considering how life existed in the past and how the experience of illness may alter the future. Chronic illness is life changing, permanent and progressive, often representing considerable vulnerability (Paterson, 2001). Each experience is unique but with common factors - changes in

lifestyle, adjusting to different social roles and sometimes facing pain. For some this may result in suffering and enduring (Ohman *et al*, 2003), others may see it as a time for gaining control (Micheal, 1996; Moch, 1998), achieving harmony (Delmar *et al*, 2005), or gaining life satisfaction (Heckman *et al*, 1997). One thing is certain: there is a need to adapt to this constantly changing discourse.

Adaptation is a broad term describing the response required when change occurs. The word 'adapt' stems from the Latin *adaptare*, meaning to adjust. Other definitions provided by the Oxford thesaurus include modification, change, accommodation, conversion and customisation. Adaptation can take many different forms, and as a concept it has been studied by a plethora of disciplines other than nursing: psychology, medicine and economics to name a few. Adaptation is a process experienced by all living things, varying from the study of evolution to industrial advancements in response to a changing society (Buss, 1984; Tooby & Cosmides, 1990). Adaptation is now a major concept within nursing science, focusing on the way people adapt to changes in health status. The nurse theorist Callista Roy defined adaptation as:

“the process and outcome whereby thinking and feeling persons, as individuals or in groups, use conscious awareness and choice to create human and environmental integration”
(Roy & Andrews, 1999; p33)

Within the many studies of adaptation, there is a general consensus that to adapt involves a consequence of coping efforts, denoting mastery and adjustment resulting from responses to problems or new challenges

(Monsen *et al*, 1992). A balance needs to be achieved between demands and resources, to achieve a state of reduced anxiety and enhanced well-being: positive adaptation to the situation. Adaptation takes into account the concepts of stress and coping (Lazarus, 1993) and occurs when an individual is able to affect a series of behaviours and mental processes (coping strategies) to neutralise the stress experience, re-establishing integrity of function. Failure to achieve this may result in negative adaptation, characterised by further perpetuation of the stress response (Monsen *et al*, 1992).

2.2 Early thoughts on adaptation

Studies into adaptation and coping formally began during the Freudian era of psychoanalysis (Joffe & Sandler, 1968; Sampson, 1990). At this time coping was viewed as a generic concept consisting of the ego-defences dealing with threats to an individual's psychological integrity. Coping was understood through associating each form of psychopathology with a defensive style, for example hysterical neuroses were linked to repression (Freud, 1949). The psychoanalytic school of thought, developed by Freud, consisted of three developmental variables, as follows, leading to the ability to cope with a given situation: a) psychosexual stage in childhood development; b) primary impulses (oral, anal, phallic and oedipal), and, c) cognitive characteristics shaping defensive style (Freud, 1949).

Researchers found it extremely difficult to observe and validate through research the characteristics of these stages (Lazarus, 1993). Freud's theories still hold historical prominence, and remain investigated and used

today. Conceptual and methodological difficulties in carrying out the research have led to many people abandoning this mechanical view of coping and instead they adopted the view of coping as a process. During the 1950-70s this new perspective became *en vogue* and took precedence within nursing and social science studies (Lazarus & Folkman, 1984; Lazarus, 1993).

Selye (1950), a Canadian endocrinologist, defined adaptation as a process and remains one of the main founders of the subject. His theoretical propositions and empirical findings still provide many of the principles used today for investigating adaptation, including within nursing (Selye, 1950; Roy & Andrews, 1999). Selye developed the General Adaptation Syndrome (GAS), a theoretical model for realising the physiological processes involved in the relationship between stress and acute illness, dividing adaptation into three stages: the alarm reaction, the stage of resistance and the stage of exhaustion (Selye, 1950; 1951). According to Selye, stress is a naturally occurring state, with the ability to enrich or damage, to which all living things are continually susceptible (Selye, 1950). Stress is viewed as a non specific induced biologic response of the body reacting to any demand (Leidy, 1989).

Selye's theories developed mainly from endocrinological experiments. His work focuses on biological and physiological adaptation, predominantly the pituitary/adrenal-cortical response to stress. This is recognised as a commonly experienced characteristic occurring regardless of the cause of

the stress yet each individual reacts differently depending on the amount of stress they can tolerate (Selye, 1950). This in itself may change for each person. Selye's model recognises the unique sensitivities influencing the intensity and progression of GAS resulting in different outcomes for each person. A situation which might normally be well tolerated for an individual can become pathogenic if the body system is weakened. Physiologically, some individuals may be genetically predisposed to certain conditions such as heart disease, pulmonary and gastrointestinal disorders. Individual differences in illness such as duration, intensity and recovery time also account for the variability in illness trajectories (Selye, 1976; Leidy, 1989). The GAS is seen as a coordinated physiologic defence mechanism of the body to adapt to illness. Although in some places Selye's biological view of stress is accused of being oversimplified due to its purely physiological nature, it provides a useful framework for discussing the processes of stress and its manifestations in illness (Sawatzky, 1998).

Influenced by Selye's work, researchers within psychophysics, such as the American psychologist Harry Helson (1964), developed the Adaptation Level Theory, its use extending to social and behavioural sciences. Adaptation was viewed as a dynamic two-way process between the function of the incoming stimulus and the individual's adaptive level. For example, a weight to be lifted would be considered alongside the fitness of the person doing the lifting and any other situational factors that may apply (Helson, 1964). The adaptive level was developed as a pooled effect of

three levels of stimulus which Helson labelled focal, contextual and residual. Depending on a person's adaptive level, their response will be negative or positive, adapting to the change or being maladaptive, unable to cope (Helson, 1964). Due to the complex nature of Helson's Adaptation Level Theory and its background in both physics and social science, Helson suggested that each discipline creates its own definitions guided by the science it follows (Helson, 1964; Pollock, 1993). Adaptation as a concept has been significantly developed within nursing and is described in depth in Chapter 3.

2.3 Adaptation as a sociological/psychological coping process

Many of the early investigations into adaptation focused purely on the human body's physiological response to change (Hamilton, 1964; Buss, 1984; Tooby & Cosmides, 1990). Theoretical development into stress and coping led predominantly by Lazarus & Folkman (1984) contended that studying perception and cognitive appraisal was the key to understanding the psychological response to stress and change leading to adaptation. They argued that regardless of intensity and duration of illness, responses vary between individuals due to their environmental-social situation and cognitive ability. Lazarus (1993) viewed stress as a psycho-physiological response brought about by a person/environment transaction. If the demands of a situation exceeded the individuals resources then well being would be endangered (Lazarus & Folkman, 1984; Monsen *et al*, 1992).

Lazarus viewed coping as a transactional conscious process that takes into account factors external to the individual such as support networks. The individual uses appraisal to assess a situation as either irrelevant (posing no threat), benign-positive (having a positive affect on health), or as stressful (Lazarus & Folkman, 1984). If a situation is seen as threatening health, Lazarus proposes two coping methods to be employed: problem focused coping, dealing with the individual's ability to solve or ward off problems, and emotion focused strategies, aiming to decrease negative emotions. Adaptive strategies employed maybe denial, distancing or making positive comparisons to other situations (Reeves *et al*, 1999). The prime importance of the appraisal and coping process, according to Lazarus, is that they affect three identified outcomes of adaptation: social functioning, morale and somatic health.

Lazarus stressed the importance of using a holistic viewpoint; this is particularly evident in his more recent work (Lazarus, 2006). When considering adaptation to threatening situations, stress should not be viewed as inherently maladaptive as some may gain strength and maturity through their situation. Stress should not be viewed as either good or bad, the amount of stress needs to be considered, at what point in life it is occurring and under what personal or social conditions (Lazarus & Folkman, 1984). Lazarus stated that the process of coping needs to be considered within "*the larger framework of a person's life and ways of relating to the world*" (Lazarus, 1993; p243). All of these aspects should

be considered when taking into account an individual's process of adaptation.

2.4 Adaptation to chronic illness

Looking specifically at coping with physical illness, Moos (1979), an American psychologist, developed a conceptual framework for understanding the adaptive behaviour encountered from diagnosis of a physical illness. Moos was intrigued by the fact that people remain able to function under what could be considered the most harrowing circumstances. Moos questioned why people don't give up under the stress of chronic illness. Through research and theory development, a framework for understanding physical illness as a 'life crisis' was developed. Moos claimed that through cognitive appraisal of a 'life crisis', coping skills could be applied to acquire basic adaptive tasks. He concluded that people respond differently due to personal characteristics, illness-related factors and their socio-cultural environment. These factors contribute to the overall perceived meaning of illness, the coping skills that are used, and the adaptive tasks employed. In some cases within crisis theory, life events such as physical illness may represent opportunities as well as hazards (Turner & Avison, 1992). Seven areas of adaptation within illness were identified:

- 1) Dealing with pain and incapacitation
- 2) Dealing with hospital environment and treatment procedures
- 3) Developing relationships with health professionals

- 4) Preserving emotional balance
- 5) Preserving satisfactory self image
- 6) Preserving relationships with family and friends
- 7) Preparing for an uncertain future

(Moos, 1979; p9)

Moos' development of 'crisis theory' maintains that individuals are more susceptible to external influences when experiencing a life crisis, than during periods of stable functioning. The model can be applied to health professionals aiming to help patients through critical periods in their life, promoting effective adaptive behaviour. This framework assumes that advice from health professionals is more likely to be taken when patients are experiencing a relapse in chronic illness or at a time when they are struggling to adapt (Moos, 1979). Health professionals may recognise the above areas of adaptation when assisting patients who are struggling to cope.

2.5 Adaptation to HIV/AIDS

Since the discovery of HIV/AIDS, studies have been conducted looking at various aspects of living with HIV. As previously stated in section 1.1, many of these focus on specific aspects of HIV such as uncertainty, dealing with stigma, loss, fear, mastery and grief. Three studies have been identified as looking more generally at coping within HIV/AIDS: Crossley (1998), Siegle & Krauss (1991) and Reeves *et al* (1999).

Crossley (1998), a lecturer in psychology and nursing, conducted semi-structured interviews with 38 individuals to investigate the ambiguities of living with HIV/AIDS. Crossley addressed the assumption that the increasing predominance of chronic illness changes the temporal structure of the experience of illness, therefore influencing the social expectation associated with the sick role. Parson's concept of the sick role was used to address HIV/AIDS as a chronic illness (Parsons, 1975). The results suggested that those with HIV/AIDS rejected the sick role, instead patients choose to view their illness as a form of empowerment. The paper exposes interesting insider views of HIV.

Within Crossley's study, many patients experienced 'breaking away' from family, friends and work circles, following diagnosis, whilst experiencing cycles of aloneness and searching, eventually leading to a turning point at which they began to find new meaning in their lives (Crossley, 1998). Crossley applied the results of her study to nursing theory. Changes in evolving interactive life patterns were seen as consistent with Newman's nursing theory of health as expanding consciousness (Newman, 1999). The patterns which unfolded during the testimonies were visualised as a spiral of expanding consciousness.

Karolynn Siegel, a professor of social science and Beatrice J. Krauss a psychologist conducted a similar study (Siegel & Krauss, 1991). Through conceptualisation of HIV/AIDS as a chronic illness their research provided insight into the challenges of daily living. Their research focused on the

adaptive tasks used to adjust to the daily changes inflicted by HIV. Through analysis of focused interviews with 55 HIV positive gay men, three major adaptive tasks were identified: dealing with the possibility of a curtailed life span, dealing with reactions to a stigmatising illness and developing strategies for maintaining physical and emotional health. The insights derived from the narratives highlight individual perspectives of HIV/AIDS as a threat to health. Each interpretation of HIV will have implications in the way someone is able to adapt to their disease (Siegel & Krauss, 1991).

Reeves *et al* (1999) conducted one of the few studies investigating adaptation specific to HIV infection focusing on the development of coping strategies over time. Purposeful sampling was used, all participants were under 45 years of age with a CD4 count of less than 500 (marking the point of medical intervention at the time of research). The authors stated that patients with this blood result would be unable to remain in denial about the virus, implying that by this point some type of 'adaptation' would take place (consideration of denial as a form of adapting was negated). Semi-structured interviews took place over 90 minutes. The necessity of ending an interview after a set time can be questioned when more 'rich' data might be acquired after this time which may contribute to the study. As this used grounded theory it would have been methodologically correct to continue until a point of data saturation was reached. Within this study the relevance of using grounded theory when there was "*no intention to gather theory*" (Reeves *et al*, 1999; p350) should be questioned.

Following diagnosis of HIV, participants used affective coping strategies such as anger, alongside behavioural coping strategies which included keeping busy, “just living life” and for some, self-destructive responses such as excessive use of drugs and alcohol. Looking to others for support was a method of adaptation used by most patients, although it was rarely used immediately after diagnosis. The development process following the initial diagnosis period ‘living with HIV’ included a period of transition which served as the testing ground for the use of the following adaptive strategies: humour, faith, altruism, seeking the support of others and balance. As time passed, a shift in attention and energy from self to others was observed as more proactive adaptive strategies were employed (Reeves *et al*, 1999).

Several other studies were found that explored aspects of sociological coping with HIV/AIDS. Lesserman *et al* (1992) investigating coping with the ‘threat’ of AIDS and interviewed 52 asymptomatic HIV patients. The resultant descriptive narratives revealed the use of four coping strategies: adopting a fighting spirit, reframing stress to maximise personal growth, planning a course of action and seeking social support (Lesserman *et al*, 1992). In a naturalistic study looking at long-term survivors with AIDS, survival strategies amongst patients were recorded as: focusing on living, normalising, being in relation to others, triumphing and taking care of oneself (Barroso, 1997).

Specific research on coping with HIV/AIDS suggests that coping strategies develop over time. Individuals stated that they coped more efficiently after two years since diagnosis had elapsed and they had been able to develop more effective social support (Chidwick & Borrill, 1996). Other studies have identified patients as developing adequate coping strategies as early as six months following diagnosis, whilst some patients took as long as five years (Courtenay *et al*, 1998).

The above studies that have been reviewed looking specifically at coping with HIV were published between 1991 and 1999. Together they demonstrate that coping with HIV is a complex and individualised process. Some common themes between the studies can be noted. Aspects of empowerment (Crossley, 1998) and maximising personal growth (Lesserman *et al*, 1992) demonstrate positive aspects emerging from the experience of being HIV positive. Strategies employed to cope with HIV included maintaining health (Siegel & Krauss, 1991), using humour and seeking the support of others (Reeves *et al*, 1999). These took place whilst facing issues such as stigma, death (Siegel & Krauss, 1991), broken relationships (Crossley, 1998), denial, anger and grief (Reeves *et al*, 1999). The length of time needed to develop adequate coping strategies, although somewhat subjective, varied individually, the research suggesting between six months to five years (Courtenay *et al*, 1998).

Such research provides a useful insight into the early effects of HIV/AIDS during its primary decade however they do not reflect the present changes

of the epidemic. Life span is increased; more effective anti-retroviral drugs are available changing the patterns of symptoms previously seen (Brodt *et al*, 1997; Palella *et al*, 2006). The characteristics of infected populations are changing, influenced by immigration, altered sexual practices and societal understanding (Feinberg, 1996; Hamers & Down, 2004). More women are being diagnosed that has been seen before (Quinn & Overbaugh, 2005). New research can provide an advanced understanding reflecting these changes.

Few of these studies employed a conceptual model or theoretical framework with which to guide the research, without this they are unable to prove or disprove the work of others done before them, or to build on a specific body of knowledge (Fawcett & Downs, 1992).

Through studying the work of those previously mentioned and analysing the initial ideas for this research, it became clear that further research was needed into the HIV disease of the twenty-first century and the changing nursing requirements of these patients. Greater substance was needed to develop the philosophical framework, enabling the research to stand as a credible piece, relevant to the advancement of nursing science. As selecting and developing the framework has been described as one of the most important steps in the research process (Burns & Grove, 2001), this stage was given significant consideration. Several models were reviewed in detail and are presented in the following section.

2.6 Researching the theoretical perspective: selecting a framework

Based on the research ideas around adaptation, coping and chronic illness, frameworks and theories were examined in the areas of ageing, HIV/AIDS, chronic illness, life changes, adaptation, transitions, lifespan development, grief and loss. Many models were searched including symbolic interactionist theory (Blumer, 1969; LaRossa & Reitzes, 1993), gerotranscendence (Tornstam, 1997; Jonson & Magnusson, 2001; Tornstam, 2005; Wadensten, 2007), activity theory (Engstrom *et al*, 1999), the model of healthy aging (Bryant *et al*, 2001), Levinson's lifespan development (Levinson, 1986; Rankin & Weeks, 1989), shifting perspectives model of chronic illness (Paterson, 2001, 2003), Neuman's system model (Neuman, 1990; Pierce & Hutton, 1992) and queer theory (Plummer, 2000).

From all the perspectives reviewed, two were selected and further scrutinised: The chronic illness trajectory model by Corbin & Strauss (1991) and the radical body politics model of women, body and illness by Moss & Dyck (2003). The following section explains these approaches and their influence on the formulation of this research.

2.6.1 The Corbin & Strauss chronic illness trajectory

The chronic illness trajectory framework was formulated as a result of 30 years of study into chronic illness and nursing practice and was developed using a grounded theory approach. The central concept of the framework is a trajectory: a course that is shaped by the combined efforts of an

individual, family, friends and health professionals (Corbin & Strauss, 1991; Corbin, 1998). This approach is based on individual trajectories that have been traced retrospectively in light of responses to illness. It is based on the overall values, beliefs, knowledge and experience of patients and the health professionals supporting them. The model exerts the premise that chronic illness can, to a degree, be shaped and managed over time even if the physiological course of the disease cannot be modified.

HIV is considered to be, and is now treated as, a 'chronic illness' (Reiter, 2000) hence this model was deemed suitable for review for this research. Nokes (1991) was one of the first nursing authors to describe HIV/AIDS as a chronic disease, claiming that it shared the characteristics of chronic illness: having a course which changes and fluctuates over time. Nokes claimed the transitions experienced by those with chronic illness mirrored those seen in patients living with HIV/AIDS. With this in mind it seemed appropriate to consider the frequently referenced model of chronic illness by Corbin & Strauss (1991).

The trajectory framework charts the stages of chronic disease from the beginning of illness until the final stage of death. The phases consist of: pre-trajectory, trajectory onset, stable, unstable, acute, crisis, comeback, downward and dying (see Figure 1). Although death may not be the final stage of the trajectory, the model implies the experience of illness will be present until death. The framework aims to reflect the diversity, multiplicity

and complexity of chronic illness, viewing it as a transitional process (Corbin & Strauss, 1991).

Figure 1 – The chronic illness trajectory framework

Pre-Trajectory	Factors/behaviours placing individual or community at risk of chronic condition.
Trajectory Onset	Appearance of notable symptoms. Diagnostic workup and announcement as person discovers and copes with implications of diagnosis.
Stable	Course and symptoms under control. Life activities managed within normal limitations.
Unstable	Inability to keep symptoms under control. Disruption and difficulty in life activities, adjustments made.
Acute	Severe and unrelieved symptoms. Complications may lead to hospitalisation. Life activities on hold.
Crisis	Critical situation – needs treatment and care.
Comeback	Return to acceptable way of life within limits imposed by illness.
Downward	Rapid or gradual physical decline, increased disability/difficulty in symptom control.
Dying	Rapid or gradual shutdown of body systems. Disengagement and closure leading to death.

(Corbin & Strauss, 1991; p156)

The authors of the framework state it is not intended to represent a rigid, linear approach to illness. Each phase may contain sub-phases, individuals may move in any direction along the trajectory, skipping phases or moving back and forth, reflecting the individual, dynamic and complex nature of chronic illness. The model allows room for the assumption that each individual will have a unique experience of chronic illness yet the trajectory emphasises common phases where changing health may require intervention from health professionals (Burton, 2000).

The theory was designed by those with sociology and nursing backgrounds but the authors believe it is applicable across disciplines. Due to its ease and simplicity of use, it has been frequently adopted by nurses caring for those with chronic illness (Robinson *et al*, 1993; Milliken & Northcott, 1996; Halcomb & Davidson, 2005). Using the model can help identify the patient's present trajectory phase, aiding the planning of appropriate goals of care. Illness takes place within a context including personal biography, activities of living and personal life choices of the patient (Burton, 2000). The framework is designed to allow individuals to actively make choices about how they wish to manage the course of their illness (Corbin, 1998; Burton, 2000).

Nokes (1991) tailored the chronic illness trajectory model for patients living with HIV/AIDS. The most significant alteration to the model was made within the pre-trajectory phase. As onset of symptoms cannot be used to determine the beginning of HIV the pre-trajectory phase was redefined as the phase before infection or illness begins, characterised by knowledge that participation in risk activities can lead to infection (Nokes, 1998). For some patients it may be years before symptoms are revealed, others may experience flu-like symptoms six weeks from infection. This adapted version of the illness trajectory model has yet to be tested through research with patients with HIV/AIDS (Nokes, 1998).

The trajectory framework provides one of the most useful models for mapping the illness process, aided by the ease and simplicity with which it can be used. It is research based (although the changed version by Nokes 1991 is yet to be thoroughly researched) and has been frequently tested within the health care setting amongst elderly patients (Robinson *et al*, 1993), in stroke rehabilitation (Burton, 2000), cardiac illness (Hawthorne, 1991), cancer care (Dorsett, 1991), diabetes (Walker, 1992) and multiple sclerosis (Miller, 1993) and elsewhere. The model considers the individual and their family as central to the illness management process; the nurse should assist the decisions made by the patient, encouraging self-management. This enables the nurse to look at illness from the patient's perspective, emphasising quality of life issues. It has the advantage of including functional ability and social responses to illness.

More recently ideas from the model have been adopted by the medical profession for use within palliative care (Murray *et al*, 2005) and critical care (Streat, 2005). Such frameworks have been used to help clinicians plan and deliver care with a greater understanding of the disease process.

The generic nature of the chronic illness trajectory has triggered discussion in previous papers (Ogden-Burke, 1999). Perrin *et al* (1993) point out that the idea of a chronic illness trajectory assumes that issues shared by individuals across a spectrum of diagnoses outweigh those issues that maybe unique. There is a risk, when using the chronic illness

trajectory, of presuming 'one size fits all'. As Ogden-Burke (1999) points out, researchers appear to have resisted the generalisation of chronic conditions, using the illness trajectory within diagnosis-specific fields of practice.

The chronic illness trajectory framework is well established and has proved useful to guide assessment and treatment within clinical practice. Yet within the model there is no opportunity to explicate the emotional or psychological stages of illness. The trajectory focuses purely on the physical changes as demonstrated through the descriptions of each phase. Pollock (1993) concluded that the greatest relationship between physiological and psychological adaptation within illness was due to the characteristic of hardiness not severity of illness. Therefore it cannot be assumed that when somebody is displaying physically-acute symptoms of illness they are at a low point psychologically. These correlations need further investigation. It has been stated by Corbin that the aim of the trajectory needs to be as follows:

“tailored to fit illness phases, biographical needs and interests, the care (hospital, home, school etc.) and cultural setting in which the care is to be carried out; it must be redesigned as necessary to reflect any changes that occur”
(Corbin, 1998; p37).

Corbin recognises the need for the trajectory to include more than just the physical changes of the illness but as yet no suggestions have been made as to how to do this.

2.6.2 Radical Body Politics: women, body and illness

The framework titled 'Radical Body Politics' by Moss & Dyck (2003) uses a feminist materialist analysis for understanding and explaining the body.

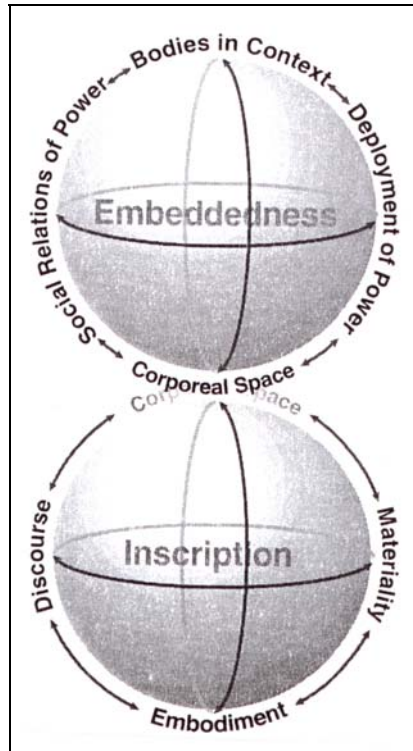
The context of their research took place amongst women suffering from chronic illness. The journey of chronic illness is traced through what they define as *radical body politics*, an approach for understanding power and identity, focusing on how discursive and material aspects of the body assist women in negotiating space (Moss & Dyck, 2003). The way illness inscribes the body with an 'ill identity' is developed through the framework to gain an insight into the experience of body and illness. The framework accounts for physical and social space, materiality of the body and its discursive construction, illness and disability (Sheach-Leith, 2003).

The conceptual framework (see Figure 2) was built around three sets of tensions: 'bodies in context', 'corporeal space' and 'embodiment'.

According to this perspective the body experiencing chronic illness is always viewed within a context, socially constructed and materially present, containing power. Bodies in context are conceived as embedded with social relations of power, citizenship, class, age, ethnicity, gender, health status etc, as well as existing in relation with other bodies, tangible and intangible things and processes. Corporeal space is considered an interim living space of the bodies in context giving rise to specific bodies in specific environments. The corporeal space is tension filled coalescing around bodies in context, linking power and identity. Embodiment is also seen as an interim space within spatiality, referring to the lived spaces

where bodies are located conceptually, metaphorically and concretely (Moss & Dyck, 2003).

Figure 2 - Conceptual framework of women, body & illness



(Moss & Dyck, 2003; p65)

The research conducted was framed using the conceptual model described above. In depth interviews took place with women who had either myalgic encephalomyelitis (ME) or rheumatoid arthritis (RA). Data from the interviews was transcribed and coded according to themes that included: symptoms, medications, treatments, friends, family, jobs, descriptions of the workplace, money, attitudes towards health, emotions, descriptions of self, well being and coping strategies. A second round of coding then took place and the categories of biomedicine, spirituality, social networks, employment and power were created. The themes of

materiality, identity and spatiality emerged from a third and final round of coding.

Results from the research were not presented directly in context with the framework however the following conclusions were drawn:

- Women with chronic illness come to embody the limits imposed on them by the illness as a way to redefine the parameters within which they exist as 'bodies in context'.
- Embodying the fluid borders of illness gives women room to negotiate their identity, reasserting themselves as women with chronic illness into the deployment of power/knowledge/space.
- Transition for women with chronic illness is about being as *is*, existing somewhere between how they will be in the future and what they use to be.

In summary it was suggested that women experiencing chronic illness:

“reconstitute their identity by relearning who they are with chronic illness, how they are replaced, repositioned and re-embedded, in social relations of power of a particular deployment of power/knowledge/space. Each woman relearns her body, redefining illness, reconnecting with matter and meaning and re-emerging as a specific body”
(Moss & Dyck, 2003; p163)

This complex, yet refreshing framework offers a new method for investigating the experience of chronic illness. The authors come to the framework with a background in feminist studies and social geography.

They offer the radical body politics framework using a poststructuralist philosophy of the body and its power relations. The model could be developed further by extending its use to chronic illness in men. It could make an interesting study into the experience of HIV/AIDS in relation to body, space, illness and overall self identity.

Upon scrutiny of this model, it appeared to offer a refreshing perspective from the many post-modern perspectives found behind nursing theory yet it still seemed to be deciding its own meaning. Correspondence with the authors of the study could not provide any other examples of research using this model.

Upon consideration of both models by Corbin & Strauss (1991) and Moss & Dyck (2003) both focusing on chronic illness, it was decided that although HIV is frequently viewed as a chronic illness, it also has stark differences from other chronic conditions which need to be acknowledged. HIV remains (at the time of writing) a terminal condition, following an initial asymptomatic period the illness eventually develops into AIDS. Secondly, the media speculation surrounding HIV/AIDS has presented it as a deadly epidemic separating it from any other chronic illness. Thirdly, the transmission routes for HIV have a profound affect on relationships, unlike any other chronic illness it does not occur randomly in isolated individuals. These significant differences call for development of a model unique to HIV, understanding the process of the illness without presuming the experience is the same as other chronic illnesses.

Both of the models reviewed have been designed from a sociological background which is heavily reflected in their perspectives. Using either of these frameworks may increase understanding of HIV/AIDS from a sociological perspective but would not advance nursing science. The use of nursing theory based research provides a stable, valid base for thinking, decision making and implementing. In this view it is of great advantage for the essence of this research, and for nursing as a discipline that the theory embraced is specific to nursing practice (Cody & Mitchell, 1992; Parse, 1992). With this in mind the idea of developing the concept of adaptation to HIV/AIDS has been taken back to nursing theory.

2.7 Nursing research: the call to be patient-focused

Nursing, since the time of Florence Nightingale, has prided itself on having 'caring' as the basis of the profession (Watson, 1988; McCance *et al*, 1999). Nursing is perceived as a 'caring profession' by nurses themselves and the general population (Momson, 1989; Watson *et al*, 1999; Triggler, 2008). The need for nurses to act with respect, promote the interest of patients, remain sensitive, respect wishes, treat fairly, seek patient wishes and be trustworthy is evident time and again throughout the nursing code of conduct (Nursing and Midwifery Council, 2008).

The majority of the nursing theories and frameworks are developed with the patient as the focus of the nurses care in order to promote health and well-being (Rogers, 1970; Orem, 1997; Newman, 1999; Parse, 1999; Roy,

2008). Despite these ideals, much of nursing practice has become heavily influenced and in some cases led, by the medical model (Allen & Hall, 1988). Changes in the ambition and role of nurses towards specialised 'doctors assistants' may contribute to this (Ewens, 2003). Although nursing has a long history of trying to keep its focus on the needs and wishes of the patient, policies are only beginning to recognise this – mainly through public pressure of patients themselves demanding their voice to be heard (Bridger, 1992; Cleary & Edgman-Levitan, 1997; Cleary, 2003).

The need to remain patient-focused is being echoed throughout various health professions. Indeed the most recent government documents demand this. 'The NHS Improvement Plan: Putting patients at the heart of public services' states patients have been found to expect '*staff who are even more attentive to patients needs*' (Department of Health, 2004; p22). With this in mind, the new patient-focused NHS aims to '*have greater readiness, nationally and locally, to seek and listen to the views of patients, and to act on them*' (Department of Health, 2004; p30). In order to do this it is suggested that 'patient surveys' and 'other systems' (presumably patient advisory groups although this is not stated) will be employed to gather more feedback on NHS services.

The NHS Improvement Plan focuses on exactly that – improving the NHS. Recognition is given to listening to the patient yet this is aimed at opinions of service delivery, waiting times, and clinic availability, not necessarily their experience of health/illness and what can be learnt from this

(Department of Health, 2004). The need to listen to the patient is echoed in the 2006 government document 'Our health, our care, our say: a new direction for community services'. Here strong promises are found "*We will give people a stronger voice so that they are the major drivers of service improvement*" (Department of Health, 2006; p7)

The Department of Health document, titled 'Creating a Patient-Led NHS: Delivering the NHS Improvement Plan' (Department of Health, 2005) goes somewhat further towards being patient-focused, in desiring a health service that is '*better at understanding patients and their needs*'. In order to do this there is a need to:

"respect people for their knowledge and understanding of their own experience, their own clinical condition, their experience of the illness and how it impacts on their life' and 'understand that the best judge of their experience is the individual"
(Department Of Health, 2005; p8)

Listening to patients needs involves more than analysing health statistics or the comments of advisory groups (although this is still an important medium for recognising need). Patients need to be listened to as individuals, ensuring the practitioners looking after them hear what their voice is saying (Baker & Streatfield, 1995; Entwistle *et al*, 2003).

Respecting individual wishes and desires ensures health professionals can respond more appropriately. This needs to take place at the most basic practice level, in every consultation between a patient and health professional (Bertakis *et al*, 1991; Webb & Hope, 1995). It also needs to happen within research – more specifically within nursing research, a

profession claiming to already be patient focused. Research which clearly documents and records the needs and experiences of individual situations can enable others to understand and be better equipped to provide tailored care and improved services. When this occurs, government surveys and stakeholder forums are more likely to report greater levels of patient satisfaction.

This research study highlights the way people adapt to living with HIV/AIDS, documenting individual accounts of this illness and wellness. Doing this practices the need to listen and recognise the patients experience as outlined in the most recent government publications. Results can be fed back to help tailor patient-focused services. This study also meets the government aims of looking specifically at those with long-term illnesses, a group of people which is steadily increasing in number (Department of Health, 2004).

2.8 Nursing models and theories

Science is the body of knowledge representing a group of people within a discipline. Research is a tool of science and theory is the product. Used together, theory and research will produce a science (McKenna, 1997b).

Science has been described as '*a unified body of knowledge about phenomena that is supported by agreed upon evidence*' (Meleis, 1997; p53). In this case nursing is the 'unified body of knowledge'. Research is essential to support, modify, develop or reject theories, just as theories are

essential to guide the study of the research in order to achieve outcomes advancing nursing science (Fawcett & Downs, 1992).

The results from research-based on theory can lead directly to the confirmation or rejection of previously founded hypotheses generated by that thesis. The relationship between theory and research is intricate and essential, and is described by Fawcett (1978) as 'a double helix'. The need for theory based research to develop knowledge is defined neatly by Fawcett (1978):

“Thus the body of knowledge of a science must rely on the repeated investigation of theoretically based problems that are redefined as research results accumulate. Theory should guide all phases of the research process, from choice of research issue to dissemination of results. All research, in turn, should be directed to one of two goals – theory building or theory testing.”
(Fawcett, 1978; p51)

To progress nursing science, nursing research needs to be conceptually based upon nursing theory. This in turn will build upon the body of evidence, developing nursing as a profession, science and art. Research by other professions contributes greatly to nursing but does not progress nursing as a science in its own right or promote nursing as a discipline. Members of a profession have a responsibility to participate in theory evaluation and production in order to develop and bring forward the theory base of their practising discipline (Cody, 1994; Prymachuk, 1996). Despite core members of the theoretical nursing community promoting the use of nursing theory-based research it has been seldom undertaken (Silva 1986; Acton *et al*, 1991; Silva *et al*, 1992, Jaarsma & Dassen,

1993). Nursing contains many conceptual models providing a useful guide for practice and education. Opportunities for empirically testing these models have not been exploited (Silva *et al*, 1992). Therefore concepts within nursing have not been developed to their full potential. This gap in the evidence is as visible, if not more so, than the need to explore adaptation within HIV. For this reason it was deemed appropriate and necessary to base this research on nursing theory, thus promoting the evidence of the concept of adaptation and the experience of HIV whilst furthering the scientific basis of nursing.

To begin investigating the models of nursing that might be appropriate for investigating how people adapt to living with HIV/AIDS, the following questions suggested by Young *et al* (2001; p55) were asked:

- What is the object or focus of nursing? Is it specific to the nursing discipline?
- Is the conceptualisation of the person consistent with my thought?
- What is the position of the person in context of their environment/the universe?
- Is there a central model representing the ontology?
- Does the theory provide guidelines for analysing a phenomenon?
- Does the theory reflect my phenomena of concern?
- Can questions that arise in practice be researched from this theoretical perspective?

Each model has been assessed according to its philosophical assumptions, phenomena of concern, and definition of the person, health and the environment. Each model was considered according to its approaches and goal of nursing. Using this approach, the choice of models was narrowed down to three: Parse's theory of human becoming, Roy's model of adaptation and Newman's theory of health as expanding consciousness. Table 1 presents the viewpoints of each of the three theories.

Each of the theories contained aspects that could be used within the research. The concepts of Parse's theory of human becoming, although previously criticised for their abstract nature (Edwards, 2000), fitted well with the aims of the research – to investigate the journey, or if used in context of Parse, the process of 'becoming' with HIV/AIDS. The research methodology, according to the theory of human becoming, is used specifically to uncover the essence of lived phenomena, gaining further understanding of universal human experiences (Parse, 1990; 1999). As HIV or AIDS is not a 'universal' human experience it would need to be researched from another perspective, one that can be related to by all, such as grief, sorrow, joy or laughter within HIV. The universal experiences of those with HIV need to be identified before this can take place, something which this research aims to achieve. The research method suggested by the theory of human becoming did not seem appropriate for investigating answers to the broad research questions

Table 1 – Theoretical viewpoints of Parse, Roy and Newman

Model	Person	Environment	Health	Nursing Approach	Philosophical Assumption
Parse	Humans are unitary beings, co creating becoming with the universe, freely choosing in each situation.	A dynamic context which is distinct yet inseparable from man.	A process of becoming and personal commitment lived by each individual.	Enhance quality of life from the perspective of the patient.	Existential phenomenology
Roy	As an adaptive system	All conditions, circumstances and influences affect the development of persons and groups.	A process and state of being and becoming whole and integrated in a way that reflects person and environment mutuality.	Promotion of adaptation for individuals and groups in each of the four adaptive modes, contributing to health, quality of life and dying with dignity	Humanism: Recognising person and subjective dimensions of experience as central to knowing and valuing. Veritivity: Principle of human nature affirming purpose in human existence
Newman	Pattern of consciousness expanding between various degrees of organisation	Unseen multidimensional pattern as ground or basis for all things and the explicate order, that periodically arise as temporary manifestations of the total pattern.	Expanding consciousness, pattern of the whole, encompassing disease and non-disease, regarded as the explication of the underlying pattern of the person and environment	Pattern identification and expanding consciousness through personal transformations and forming shared consciousness.	Based on the abstract conceptual system of the Science of Unitary Human Beings (Rogers, 1970)

initiating this study. It is possible that any universal human experiences identified from this research could go on to be investigated further by such a research method.

Margaret A. Newman based her theoretical ideas on the premise of health being a synthesis, the result of a fusion of disease and non-disease. These come together creating 'a pattern of the whole' (Newman, 1999). Newman's theory of health as expanding consciousness states that becoming ill does not diminish wholeness but changes wholeness to take on a different form. Nurses are seen as partners in the process of expanding consciousness, their aim being to facilitate pattern recognition through forming relationships with patients, rhythmically connecting with them as their experiences change. Through doing this the nurse can help patients recognise their own possibilities and allow for transformation to occur. This middle-range theory focuses on interactions between persons and environment with the assumption that all matter in the universe-environment possesses consciousness but at different levels. Disease is viewed as a manifestation of a unique pattern of person-environment interaction (Newman, 1999).

The Health as Expanding Consciousness research method, according to Newman, takes on the same role as nursing practice. The researcher embodies the theory, continuing in relationship with the participant in the same way the practitioner would continue in relationship with the patient. Bearing similarities to action research, the researcher becomes part of the patient experience, inviting participants to dialogue about meaningful events in their lives (Newman, 1990). The nurse then gains insight into the participants' experiences. Indeed both participant and researcher learn from the experience and from each other through rhythmically

coming together and moving apart. Newman has named a protocol for research using the method as 'hermeneutic dialectic'.

Newman's theory of health as expanding consciousness holds broad concepts making the theory feasible in relation to the proposed research ideas. Newman defines a person as 'consciousness' stating: "*The person does not possess consciousness – the person is consciousness*" (Newman, 1999; p33). Newman's conceptual definitions complement the ideas of this research by looking into a whole experience from an individual perspective. The journey of HIV would need to be mapped as a pattern of 'expanding consciousness', in keeping with the theory.

Roy's model of nursing focuses its inquiry on the person as an adaptive system. Adaptation is defined as:

"the process and outcome whereby the thinking and feeling person uses conscious awareness and choice to create human and environmental integration"
(Roy, 1997; p44).

The person is described as a holistic adaptive system, and is the main focus of nursing. Roy coined the term 'veritativity' as the belief in purpose, value and meaning in all human life.

Research using the Roy Adaptation Model is based on the adaptive processes in relation to the four adaptive modes: physiological, self-concept, role function and interdependence (Roy, 2008). Guidelines from Roy Adaptation Model state research must include basic life processes,

studied in relation to adaptation to constantly changing environmental stimuli (Roy & Andrews, 1999). The comparisons of HIV to chronic illness recognised the changing course of disease progression. It is known that HIV/AIDS is a constantly changing condition, or has the potential to constantly change. Investigation through the Roy Adaptation Model would build on this basic foundational knowledge, potentially revealing unidentified stages of adaptation throughout the course of the HIV/AIDS illness.

Investigation into the three models which has been briefly summarised here, led to the decision to use the Roy Adaptation Model to frame the research study. This decision was based on the following premises:

- HIV is a journey of uncertainty consisting of various feelings, emotions and physical affects. These have been previously identified in nursing research (Brashers *et al*, 1998; 1999; Thomas, 2007). Using research to online such stages, they could then be compared to back to Roy's model of adaptation for comparison of similarities or differences.
- HIV, no longer a 'new' disease, is ever changing (Hamers & Downs, 2004; Aberg, 2006). The introduction of pharmacological interventions and the increase in knowledge about the disease means the disease we see today is vastly different to that of the 1980's (Brodt *et al*, 1997; Tiamson, 2002; Palella *et al*, 2006; Wong

& Ussher, 2008). Using the Roy Adaptation Model would enable building a picture of the disease and its effects on the person, as it presents itself today. The Roy Adaptation Model allows this to be done whilst considering all aspects of the person (Roy, 2008).

- Roy's model is nursing based, designed by a nurse, for nursing. Its use aims to not only benefit the patient but to advance nursing theory and science.
- The Roy Adaptation Model does not promote any specific qualitative or quantitative research method, encouraging any approach to be chosen which may further development of the model (Roy & Andrews, 1999). This gives flexibility to this study in allowing selection of the most appropriate research method of unveiling a broad subject and leading to identification of a process.

The above summaries demonstrate the suitability of Roy's Model of Adaptation in framing a research study into the adaptive process of HIV. Having considered the theoretical background to adaptation and the importance of using nursing theory, the following chapter describes Roy's Adaptation Model in detail. The philosophic and scientific assumptions and the theoretical aspects of the model are discussed. The use of Roy's model within nursing research is reviewed. Previous research using Roy's work is presented alongside the implications of these studies for future research and how this may impact on the research.

CHAPTER THREE

Theoretical Perspective

“Knowledge of research methodology, no matter how extensive, is meaningless unless it can be utilised in the design and conduct of investigations that are grounded in theory”

(Fawcett, 1978; p52)

3.1 Roy's Adaptation Model as a theoretical perspective

The use of a theoretical perspective within research is essential to expand ideas, highlight flaws, strengthen, prove, disprove or suggest modifications of a specific body of knowledge. Implementing theory within research helps to build stronger and more reliable perspectives. Using a nursing model or theory to frame the study from beginning to end provides a stable base for exploration, guiding the research design, methodology, analysis and most importantly the perspective from which the results are viewed (Fawcett & Tulman, 1990).

Basing nursing research on a conceptual model or theory builds the body of evidence on which the nursing profession practices; developing theory helps predict or explain phenomena that are specific to nursing (Levesque *et al*, 1998). Advancing theoretical knowledge involves choosing the most appropriate theoretical base to produce a reliable and conclusive study. Analysis of several frameworks for their suitability within this study took place, as presented in the previous chapter. Each demonstrated valuable knowledge, even as they were eliminated for use within this study. The propositions and assumptions of a theory must be in keeping with the phenomenon of interest as well as accurately representing and proving informative to the nursing profession (Dunn, 2004).

Within this study, the Roy Adaptation Model was chosen to guide the research due to its focus on adaptation and relevant philosophical assumptions underpinning the ethos of the research. Its value as a

nursing theory enables the results to be applied directly back to the nursing profession, having direct implications upon practice and care for patients.

The Roy Adaptation Model was developed by Sister Callista Roy in 1968 and its framework was first published in 1970 (Roy, 1970). Roy's original work was motivated by her practice as a nurse which initiated her desire to create a theory that would demonstrate the impact of nursing on the health of a population. As previously mentioned in Chapter 2, the model is based around the concept of adaptation as defined by Roy as:

“the process and outcome whereby thinking and feeling persons, as individuals or in groups, use conscious awareness and choice to create human and environmental integration”
(Roy, 2008; p29)

The aim of the Roy Adaptation Model is to assist nurses in helping patients deal with the changes in their lives. The model outlines an assessment process to guide the nurse in helping their clients adjust to varying environmental circumstances. The model can be applied when working with individuals or groups.

Since its beginning in 1970 the Roy Adaptation Model has become widely recognised, being used globally to influence nursing practice, education and research. Research studies using the Roy Adaptation Model, both qualitative and quantitative, have led to development of middle-range theories (Woods & Isenberg, 2001; Whittemore & Roy, 2002; Tsai, 2003), a deeper understanding of the illness experience (Pollock, 1986; Pollock

et al, 1990; Gagliardi, 1991; 2003; Brydolf & Segesten, 1996; Gagliardi *et al*, 2002; Zeigler *et al*, 2004) and changes in nursing practice (Nyqvist & Sjoden, 1993; Raeside, 1997; Samarel *et al* 1998; Shyu, 2000; Modrcin-Talbott *et al* 2003; Shyu *et al* 2004). Studies have taken place that examine the nursing care of a wide range of medical conditions such as multiple sclerosis (Gagliardi, 2003), Duchenne muscular dystrophy (Gagliardi, 1991), ulcerative colitis (Brydolf & Segesten, 1996), breast cancer (Zeigler *et al*, 2004) and diabetes (Whittemore & Roy, 2002). The Roy Adaptation Model can be used in any nursing settings including the care of adults, children, the elderly and midwifery. The model is widely accepted across cultures, being used in Mexico, Japan, USA, UK, Sweden and Spain (Zungu, 1993; Chiou, 2000; Yeh 2001 & 2002; Lotus-Shyu *et al*, 2004).

3.2 Development of the Roy Adaptation Model

The Roy Adaptation Model originated from a psychophysics adaptation model first developed by Helson (1964). Helson viewed adaptive responses as a function of the incoming stimulus (any factor which provokes a response arising from internal or external environment), and the adaptive level. According to Helson the adaptive level consists of the combined effect of three levels of stimuli: focal (those immediately confronting the individual), contextual (those contributing to the effect of focal) or residual (unclear environmental factors). Helson defined adaptation as a process of responding positively to environmental changes. Roy combined Helson's theory with von Bartalanffy's (1968)

general system theory where each system consists of inputs, a central mechanism, outputs and a feedback loop. Roy included this within her theory in the form of inputs (stimuli), a control mechanism (regulator and cognator subsystems) and outputs (adaptive or ineffective responses). Theoretical concepts on coping theories were also borrowed from Lazarus and Folkman (1984), and Seyle (1951) and more recently, characteristics of creation spirituality from Swimme & Berry (1992). All contribute to the philosophical assumptions of the model. Expansion of these concepts and theories led Roy to theoretically depict the person as a biopsychosocial being adapting to constantly changing environmental stimuli. Adaptation is viewed as a component of parts (inputs, coping mechanisms and outputs) and can be viewed as a feedback loop as seen in Figure 6.

3.3 Philosophical assumptions

Both the philosophical and scientific assumptions made by the Roy adaptation model are clearly laid out and well defined. Ontologically, Roy believes nursing involves the care and well-being of persons stemming from the philosophy of humanism and veritivity, a term coined by Roy herself. Nurses demonstrate their belief in people through promoting the holistic well being of patients (Roy, 1997). The humanistic values underpinning the model assume that people, as individuals and groups:

- share in creative power
- behave purposefully, not in sequence of cause and effect
- possess intrinsic holism

- Strive to maintain integrity, realising the meaning of relationships.

(Taken from Fraser, 1996)

Humanistic principles recognise the person and subjective dimensions of human experience as central to knowing, valuing and understanding. The person is perceived as the primary domain concept of nursing within Roy's model. Roy's own term 'veritativity' stems from the Latin word *veritas* meaning truth. Following the logical positivist stance that the model has been associated with, veritativity asserts the existence of 'an absolute truth'. Within Roy's perspective, people are the discoverers of truth. Roy strongly believes that each person comes from, participates in and is destined to return to this absolute truth or source of creation. Roy therefore defines veritativity as "*the principle of human nature that affirms a common purposefulness of human existence*" (Roy, 2008; p28). Within veritativity the individual is regarded in the context of:

- the purposefulness of human existence
- unity of purpose of humankind
- activity and creativity for the common good
- value and meaning of life

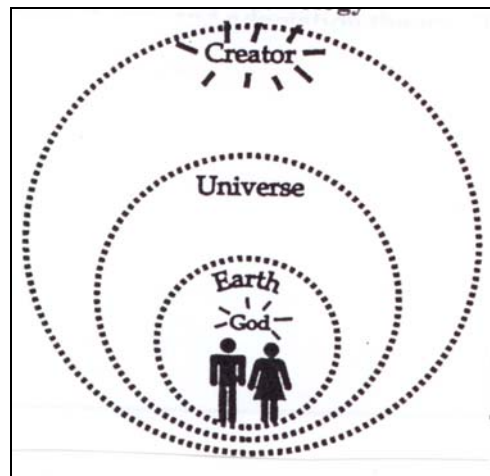
(Roy, 2008; p28)

The purposefulness of existence stems from Roy's belief that intelligent life form was formed through creative design and not by chance. This

conceptualisation gives the person a source and destiny providing purposefulness for their life (Roy & Andrews, 1999).

Roy addresses an individuals place in creation and the ultimate meaning of human existence in the form of cosmology (see Figure 3). The cosmology adhered to believes that *“God is intimately revealed in the diversity of creation and is the common destiny of creation”* (Roy & Andrews, 1999; p35). Roy developed these ideas from creation spirituality: that persons and the earth are one, and that they are in God and of God (Roy, 1997). The origins of this perspective have previously been described by the Christian palaeontologist de Chardin (1959) who explored the convergence of the universe and unity of being.

Figure 3 – Representation of new cosmology



Accepting this ontology and cosmology requires nurses to base their care on specific human values. Creation spirituality involves acting on behalf of the person, the well-being of the earth and creation. These characteristics

are combined with humanism and veritivity to produce Roy's philosophical assumptions, as presented in Figure 4.

Figure 4 – Roy's philosophic assumptions for the 21st century

- Persons have mutual relationships with the world and with a god-figure.
- Human meaning is rooted in an omega point convergence of the universe.
- God is intimately revealed in the diversity of creation and is the common destiny of creation.
- Persons use human creative abilities of awareness, enlightenment and faith.
- Persons are accountable for the processes of deriving, sustaining and transforming the universe.

(Roy, 2008; p31)

The philosophical assumptions of the Roy Adaptation Model have been supported through research. Dobratz (2004) conducted a secondary analysis into end-of-life spirituality. Content analysis was used to code transcribed responses from patients receiving hospice care, referencing them for the term 'spirituality'. The concept of spirituality was shaped by the core theme of believing, this was linked to six further themes: comforting, releasing, connecting, giving, reframing and re-questioning. These fully supported the philosophical foundations of the Roy Adaptation Model, for instance "*human meaning is rooted in an omega point convergence in the universe*" (Roy & Andrews, 1999; p35). Participants saw God or a 'higher power' as the omega point. Participants found sustenance through feeling connected with others. A belief in a 'supreme

being' or higher power supported the assumption that people have mutual relationships with the world and with a God figure. These findings uphold Roy's personal belief which has been weaved theoretically into the model here:

“foci of the assumptions are on mutual complex person and environment self-organisation and on a meaningful destiny of convergence of the universe, persons and environment in what can be considered a supreme being or God”
(Roy, 1997; p44)

3.4 Scientific assumptions

Formation of the scientific assumptions of the model was derived, as previously stated, from systems theory (von Bertalanffy, 1968) and adaptation theory (Helson, 1964). The basic assumptions that incorporate aspects of these two theories are summarised in Figure 5.

Helson's adaptation theory remains the parent theory of the Roy Adaptation Model. Roy has adapted the main notion of Helson's theory: adaptation is a pooled effect of multiple influences, labelled as focal, contextual and stimuli (Roy & Andrews, 1999). Humans are viewed as adaptive systems containing the ability to make adaptive and creative changes within and to the environment. Helson's original work was based on responses of the retina of the eye to environmental stimuli. Arguments exist regarding the generalisability of the theory to the social science and nursing arena and whether its credibility within the model can be supported (Fawcett, 1989). Roy does not use the theory in its original

form, but has chosen it as a basis for developing her theory of adaptation. The existing research supporting Roy's theory supports the integration and sharing of knowledge between disciplines.

Figure 5 – Roy's scientific assumptions for the 21st century

- Systems of matter and energy progress to higher levels of complex self-organisation.
- Consciousness and meaning are constitutive of person and environment integration.
- Awareness of self and environment is rooted in thinking and feeling.
- Humans by their decisions are accountable for the integration of creative processes.
- Thinking and feeling mediate human action.
- System relationships include acceptance, protection, and fostering of interdependence.
- Persons and the earth have common patterns and integral relationships.
- Persons and environment transformations are created in human consciousness.
- Integration of human and environment meanings results in adaptation.

(Roy, 2008; p35)

Roy describes humans as holistic adaptive systems, a mergence of systems theory with aspects of cosmology. This view provides a paradigm for the way nurses interact and relate with patients and their family. Emphasis is placed on the purposefulness of human existence in a universe which is creative. Swimme & Berry (1992) state the main processes of relationships between systems in the universe (for example

human-earth and human-human systems) rely on acceptance, protection and fostering. This is needed for systems to progress to higher levels of complexity.

3.5 Roy's view of nursing

The public and professional view of nursing has changed greatly over the past three decades since Roy's model was first published. Historically, nursing has been viewed as working to promote the health of individuals and society. Roy has refined this viewpoint in accordance with the view of humans as adaptive systems. The Roy Adaptation Model outlines the goal of nursing as:

“promotion of adaptation for individuals and groups in each of the four adaptive modes, contributing to health, quality of life and dying with dignity”
(Roy & Andrews, 1999; p55)

Nurses act as facilitators of adaptation through assessing behaviour and intervening to promote each individuals adaptive abilities by enhancing environmental interactions. Roy has developed her own version of the nursing process to help nurses promote adaptation through a sequence of stages:

- Assessment of behaviour
- Assessment of stimuli
- Nursing diagnosis
- Goal setting
- Intervention

- Evaluation

(Roy & Andrews, 1999; p64)

Although debates continue around the definition of optimal health, Roy recognises that complete physical, mental and social well-being is not possible for each person. Nurses should strive to promote personal and environmental transformations through fostering of independence, acceptance and protection for each person, thereby promoting adaptation which results in improved health (Roy & Andrews, 1999). It is within the scope of nurses to influence environmental factors occurring within the lives of people living with HIV/AIDS. The aim of this study lies in discovering how people adapt to environmental factors arising due to HIV/AIDS in their life.

3.6 Roy's view of health

Traditionally within nursing and medicine, health and illness have been viewed as separate entities, positioned at either end of the health-illness (Jones & Meleis, 1993). This perspective has been criticised as too simplistic, not explaining (or allowing) the coexistence of wellness and illness, an experience well documented amongst those with chronic illnesses (Moch 1989; 1998). A medical perspective leans towards a definition of health as the absence of disease, promoting cause and effect, diagnosis and cure, health and illness (Boorse, 1977).

Roy's perspective of health is again congruent with the view of humans as adaptive systems. Adaptation is viewed as a process of promoting physiological, psychological and social integrity: a condition leading to completeness or unity. Roy borrowed from Illich (1988) in moving away from the dichotomous health-illness perspective. Her thoughts assume:

“health is not the freedom from the inevitability of death, disease, unhappiness and stress but the ability to cope with them in a competent way”
(Roy & Andrews, 1999; p52)

Health and illness inevitably coexist and represent a dimension of the persons total life experiences. According to Roy, illness results when mechanisms for coping are ineffective, and health ensues when humans are able to continually adapt (Roy & Andrews, 1999).

Roy suggests health is viewed in light of the philosophical and scientific assumptions of the model; health is dependent on individuals reaching their goals and understanding the purposefulness of their life (Roy, 2008). Health is defined as *“a state and a process of being and becoming integrated and whole”* (Roy, 2008; p29). It is suggested that positive adaptive responses are viewed as wellness, whereby negative ineffective responses are viewed as illness or maladaptation (Fawcett, 1989). This viewpoint has not been confirmed by Roy. An elusive definition of health could cause problems when attempting to measure the attainment of health. Roy's holistic viewpoint goes against being able to put a 'measurement' or value on health (Roy & Andrews, 1999). With this in

mind research methodology using Roy's model must seek understanding of a whole and integrated human experience.

Roy's work does not offer a precise distinction as to whether attainment of health (or positive adaptation) is judged by the nurse or the individual themselves. Roy states that a competent qualified nurse should have the ability to judge maladaptation from a positive adaptive response. She emphasises the importance of the nurse-patient relationship stating that when making a judgement "*nurses should continually involve those for whom they are caring*" (Roy & Andrews, 1999; p70), emphasising the importance of the nurse-patient relationship.

3.7 Roy's view of the environment

At a simplistic level Roy understands the environment as the world within and around humans as adaptive systems. It is interaction with the changing environment that often leads to an adaptive response.

Environmental influences often provide the input to the adaptive system.

The environment is considered inclusive of:

"all conditions, circumstances and influences that surround and affect the development and behaviour of humans as adaptive systems, with particular consideration of person and earth resources"
(Roy & Andrews, 1999; p52)

Roy's definition of the environment consists of internal and external factors; these are further sub-divided into focal, contextual and residual stimuli (see section 3.9.1). Roy explains these three areas in detail but

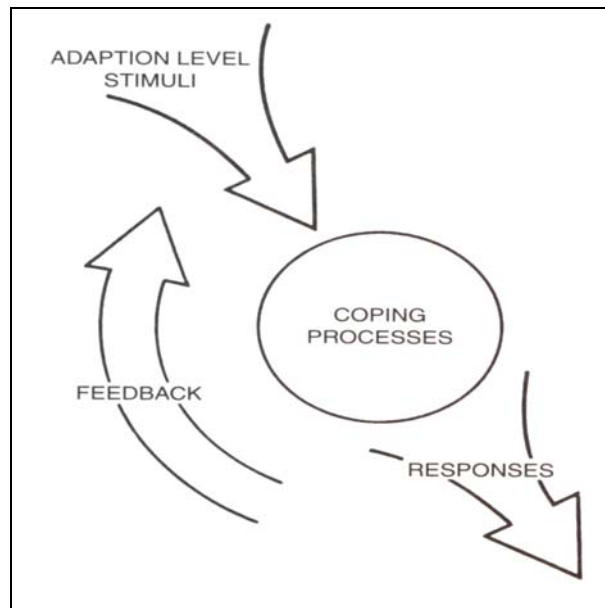
does not distinguish between the internal and external environment. External appears to represent those factors outside the person, and internal the environmental influences created within the self (Fitzpatrick & Whall, 1996). Internal aspects of the environment are not distinguished from the person as an adaptive system. As highlighted by Fitzpatrick & Whall (1996), this may create controversy as nursing care is based on management of stimuli from the environment.

3.8 Roy's view of the person

Humans, within the Roy Adaptation Model, are viewed holistically: functioning as a whole and more than the sum of their parts. Persons are seen as striving towards homeostasis, attempting to balance the continuing interaction between internal and external environments. Roy sees people as representing unity amongst diversity, all being united in a common destiny (Roy & Andrews, 1999).

The diagrammatic representation of Roy's model in Figure 6 demonstrates the person as a feedback system. Within this, Roy describes three levels of adaptation: integrated, compensatory and compromised. It is these fluctuations in adaptation level which pre-empt a person's output – an adaptive or ineffective behavioural response. The input for humans is defined as the stimulus which itself evokes a response in the form of an output. The output as either an ineffective or adaptive response can then be fed back into the system.

Figure 6 – The adaptive process according to Roy



(Roy & Andrews, 1999; p37)

Each individual's adaptation level affects their ability to respond positively in a situation. Some writers have referred to Roy's portrayal of the person as a 'biopsychosocial' being, a conclusion drawn from the four adaptive modes (Fawcett & Tulman, 1990). Roy herself has never used the term biopsychosocial.

Roy's description of a person as a 'set of parts' has been previously criticised as reductionistic, going against the holistic perspective (Benner & Wrubel, 1989). Roy has defended her description of the adaptive system by claiming this perspective is for descriptive purposes only and that a persons behaviour is purposeful not just resulting from cause and effect.

3.9 Theoretical aspects of the person as an adaptive system

Understanding Roy's Adaptation Model is built around comprehending the complexity of the person as an adaptive system: with an input (stimuli), adaptive level, method of coping and output (behaviour). The following section details the process of adaptation according to Roy's model. To begin, it is necessary to understand the stimuli evoking a human response or call for adaptation.

3.9.1 Stimuli

Three categories of stimuli initiate the adaptation process: focal, contextual and residual. These are based on the work of Helson (1964), previously mentioned.

Focal stimuli refer to that causing the most awareness in the human consciousness, requiring the person's focus and energy to deal with it. The focal stimuli may be internal or external, positive or negative but always requires a response from the person undergoing the experience. Pain may be an example of a focal stimulus, focusing the patient's energy despite other symptoms or stimuli (Roy & Andrews, 1999).

Contextual stimuli consist of factors which contribute to the effect of the focal stimulus. These may include other environmental factors which exist but are not the centre of attention or energy for the person concerned. The contextual stimuli contribute to the way a person copes with the focal

stimulus. A patient's pain (focal stimulus) may be affected by anxiety over the cause of pain being unknown (contextual stimuli).

Residual stimuli encompass factors where their effects are unknown but still contribute to the changing situation. A person would be unaware of their existence or effect. Roy provides an example of a distant memory as a residual stimulus (Roy & Andrews, 1999).

Stimuli are constantly changing as the situation alters. A residual stimulus may become focal and vice versa. Stimuli are viewed as fluid in nature and their change may be rapid (Roy & Andrews, 1999).

3.9.2 Adaptive response

The adaptation level is representative of the range of stimuli which evoke an ordinary adaptive response. The adaptive level is seen as a standard unique to each person, consisting of focal, conceptual and residual stimuli and its position is constantly changing. Roy has identified three levels of adaptation: integrated, compensatory and compromised (Roy, 2008).

When using the Roy Adaptation Model, life processes are discussed in relation to each adaptive mode. Nurses can use assessment of a person's adaptive level as part of the process of monitoring stimuli to develop awareness of the strengths and weaknesses of the person they are working with. The level of adaptation can help determine an individual's range of coping (Roy & Andrews, 1999).

An integrated level of adaptation describes specific structures and functions of the body's mechanism that are working to meet its needs. Roy gives a specific example of intact skin protecting against infections (Roy & Andrews, 1999). The second, 'compensatory' level is reached when the integrated level is challenged. Both cognitive and regulatory body systems act to compensate for the disturbance. Thirdly, the 'compromised' and most vulnerable level of adaptation represents the occurrence of difficulty in adaptation through inadequacy of both the compensatory and integrated processes (Roy & Andrews, 1999).

Theoretically the levels of adaptation portray the human system as active amongst the environment. The human system and environment are constantly integrating with each other. The varying adaptation levels reflect the strengths and challenges of the external and internal environment of the person and demonstrate the activity of the human system in responding to changes in these environmental factors (Roy, 2008).

Behaviours resulting from the adaptation level may present themselves as ineffective responses (neither promoting nor contributing to the goals of adaptation), or as adaptive responses (promoting the integrity of the human system). Adaptive responses can take place in terms of survival, growth, mastery, reproduction and person/environment transformations. Determining adaptive or ineffective responses takes place through

recognising the regulator and cognator subsystems of the coping process (Roy & Andrews, 1999).

3.9.3 The coping process

Coping processes, defined as innate or acquired ways of interacting with the changing environment, are considered in light of the human as an adaptive system. The coping processes have been broken down into cognator and regulator subsystems, these responses control the adaptation levels (Roy, 2008).

The regulator subsystem refers to the body's automatic and unconscious response through endocrine, neural or chemical channels. Stimuli through the senses pass an input to the nervous system, this information is then processed as appropriate, resulting in an unconscious automatic response.

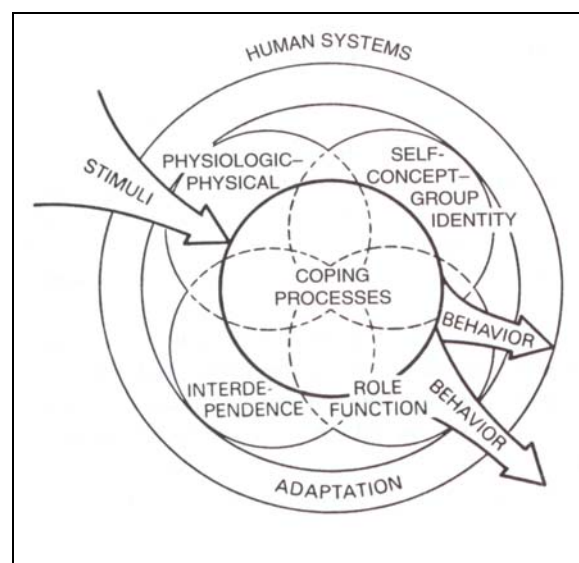
The cognator subsystem responds through cognitive and emotive channels consisting of learning, judgement, emotion, perceptual and information processing. Many stimuli including social, physical and psychological factors act as inputs to the cognator subsystem. Information is processed producing a learned response (Roy & Andrews, 1999).

3.9.4 The adaptive modes

The responses of the regulator and cognator subsystem can be directly observed yet it may not always be possible to observe the way they are

functioning. In order for nurses to carry out a more effective evaluation Roy has devised four adaptive modes to act as a framework guiding assessment. It is through these four modes that responses to interaction with the environment are carried out (see Figure 7) (Roy & Andrews, 1999).

Figure 7 – Diagrammatic representation of humans as adaptive systems



(Roy & Andrews, 1999; p50)

Physiologic-physical mode

This first mode represents the way humans interact as physical beings with the environment. Behaviour is manifested through physiologic activities of the cells, body and systems comprising the human body.

The five basic human needs are included within this category:

oxygenation, nutrition, protection, elimination, activity and rest. Also included are the four process of physiologic adaptation: the senses, fluid, electrolyte and acid base balance, neurological function, endocrine function.

Self-concept and group identity

Psychic and spiritual integrity is identified as the basic need for the individual's self concept. This is understood as the beliefs and thoughts one holds about oneself at any given time. This category represents the need to know who one is and to exist with a sense of unity amongst others. Components of the self-concept mode consist of body sensation and body image, self-consistency, self-ideal and moral-ethical-spiritual self. Group identity refers to interpersonal relationships, self image and culture.

Role function

The role function mode identifies the role an individual holds within society. It has also been defined as "*a set of expectations about how a person occupying one position behaves towards a person occupying another position*" (Roy & Andrews, 2008; p44). The role function represents the underlying need of social integrity, knowing who one is in relation to others, knowing how to act and how one is expected to act among their own social group.

Interdependence

The final mode, interdependence, describes perhaps the most basic mode: interactions and emotions related to the giving and receiving of love, respect and value, representing the feeling of security within relationships. For groups, this represents the context of how the group relates to contacts both within and outside the group. It looks at

relationships between people (collectively and individually), focusing on aspects such as their purpose, structure and personal development. Roy believes people who possess a balance in relationships, feeling valued and supporting by others and offering the same, will be more able to adapt to changes in the environment (Roy & Andrews, 1999). This has been supported through research by Gagliardi *et al* (2002) who demonstrated the effect of relationships and feeling valued on the health and psychological well being of those with multiple sclerosis.

Although described as four separate entities, within the Roy Adaptation Model conceptual framework the four modes are depicted as overlapping circles representing the person as a whole (see Figure 7). Behaviours within one adaptive mode can affect or act as a stimulus for the other modes; these complex relationships demonstrate the holistic nature of humans as adaptive systems (Hedberg & Sjoden, 1993). A valuable factor in the models design is that it does not limit patient assessment to only the physiological needs and symptoms. The overlapping nature of the adaptive modes (which has recently been viewed as a criticism of the model), confirms the complexity of each patients situation and could be said to illustrate the need to move away from nursing assessments in the form of a list of needs or simplistic protocol (Nyquist & Sjoden, 1993).

3.9.5 The nursing process in accordance with the adaptive modes

The nursing process according to Roy consists of six stages:

a) assessment of behaviour, b) assessment of stimuli, c) nursing

diagnosis, d) goal setting, e) intervention and f) evaluation (Roy & Andrews, 1999). This process provides steps to help nurses reach the goal of promoting adaptation.

Assessment of behaviour is used to evaluate behaviours that maybe detrimental to adaptation, disrupting the human system (Piazza *et al*, 1992). Assessment (whether for clinical practice or research) can be undertaken through observation, measurement and interviewing all of which should be done purposefully and sensitively (Roy & Andrews, 1999). Interviewing skills should be honed enabling attentive listening and purposeful questioning in order to obtain behavioural data. The verbal response can then be taken as documentation of behavioural data and tentative judgements can be made on whether the behaviour is adaptive or ineffective.

Assessment of stimuli is undertaken by the same methods of observation, measurement and interviewing. Stimuli should be assessed into the categories of focal, contextual and residual, depending on their impact and level of disruption for the person involved. The most immediate cause of disruptions would be the focal stimuli (Roy, 2008).

Each observation should be validated to strengthen its interpretation. Validation may occur through an individual's confirmation that something is having an effect or through the nurse using experiential or theoretical knowledge to establish a confirmation (Roy & Andrews, 1999).

Assessment of behaviour and stimuli should be a continuous process as evolving circumstances may bring about further changes.

Once data has been collected regarding the behaviour and level of stimuli affecting adaptation, an interpreted nursing diagnosis can take place in the form of statements linking behaviour and stimuli. Roy has developed a typology of indicators of positive adaptation and a classification of commonly occurring adaptation problems according to each adaptive mode (see Appendix 1). Their aim is to aid the process of nursing diagnosis. From these diagnostic statements the nurse can then work with the patient in setting goals: *“establishing clear statements of the behavioural outcomes of nursing care”* (Roy & Andrews, 1999; p81). Goals should state the aimed behavioural response, the change that is expected and an ideal timeframe.

Intervention, as laid out in the planned goals should aim to manage the focal stimuli (when this is not possible the contextual stimuli), bringing them within the manageability of the coping process, eventually leading to positive adaptive behaviour. The sixth and final step involves evaluating the impact of the intervention, reflecting on goal planning and the changes in the stimuli, judging whether an adaptive behaviour has been reached (Roy & Andrews, 1999). Each step of the nursing process is in line with the assumptions of the Roy Adaptation Model. Communication should be maintained with persons throughout the process. The nurse and patient

should work alongside each other ensuring close collaboration. An open, trustworthy nurse-patient relationship will aid adaptation (Roy, 2008).

3.10 The use of Roy's Adaptation Model in research

When using a model to guide research it is imperative that it is fully integrated into the study from beginning to end, allowing the reader to identify and evaluate the framework throughout the research process.

Roy's model of adaptation is one of the most frequently used conceptual frameworks within nursing research (Frederickson, 2000). The model has been chosen to guide the study as it enables identification of the constructs considered essential to adaptation leading to discovery of how these interact into the process of adaptation (Roy, 2008).

Roy's model calls researchers to investigate problems in adaptation to constantly changing environmental stimuli, the purpose being to understand how people adapt to changing stimuli, how this affects health and how nursing can enhance this process. Tolson & McIntosh (1996) warn that the broad perspectives offered by the Roy Adaptation Model may cause researchers to be diverted, leading to loss of direction and focus, however the majority of researchers using the Roy Adaptation Model have found it provides a wide unrestrictive framework to examine complex and holistic health needs of the client as they continually adapt to constantly changing stimuli (Roy & Andrews, 1999).

Figure 8 - Recommended foci for nursing research based on the Roy Adaptation Model

<p>Basic nursing science</p> <ol style="list-style-type: none">1) Groups as adaptive systems2) Age and gender as part of pooled effect on adaptation3) Levels of adaptation as integrated, compensatory and compromised4) Dynamics of evolving adaptive patterns5) Reciprocal relationships of adaptive modes and processes6) Factors influencing adaptive mode development, particularly the effect of culture7) Extension of major concepts to all age groups and commonly occurring situations of health and illness8) Interdependence mode adaptation in children9) Relationship of adaptation to health10) Conceptual, theoretical and empirical basis of perception in integrating the adaptive modes. <p>Clinical nursing science</p> <ol style="list-style-type: none">11) Protocols to identify patient and family perceptions in commonly occurring clinical situations12) Appropriate timing for effectiveness of given nursing interventions13) Appropriate time interval to measure adaptation as an outcome in differing situations14) Specific stimuli to managed for effectiveness of given nursing situations15) Programs of research to design and test interventions to promote adaptive processes in given patient populations16) Intervention studies that deal directly with cognator and regulator processes.
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(Roy & Andrews, 1999; p553)

The focus of any research which follows the crux of the conceptual model should be on 'adaptation' as a concept or phenomenon. Knowledge, according to the Roy Adaptation Model, is described as "*understanding people as adapting within their various life situations*" (Roy & Andrews, 1999; p537). Research using the Roy Adaptation Model should therefore aim to advance knowledge in this way, focusing on human life patterns which emerge from adaptive life processes, advancing the understanding of people as adaptive systems (Roy & Andrews, 1999). Roy has

recommended specific areas for research in order to constantly refine the model (see Figure 8).

Roy has not specified the use of any particular data collection techniques. Both quantitative and qualitative methods may be used. The chosen method must reflect the perspective of the theory. Data collection should take place in relation to the four adaptive modes. Through observation, measurement and interview, internal and external stimuli are first identified then classified according to focal, contextual or residual. Research can be used to establish goals or behavioural outcomes of nursing care, developing conceptual models or middle range theories.

Fawcett & Tulman (1990) outlined a set of research rules for using the Roy Adaptation Model, within these they stated enquiry should be focused on focal, contextual and residual stimuli, regulator and cognator coping processes, and on adaptive responses according to the physiological, self-concept, role function and interdependence modes. Studies examining clinical nursing science have been noted to focus on changes in cognator-regulator and stabilizer-innovator effectiveness, changes within the adaptive modes and effectiveness of nursing care to promote adaptive processes (Roy & Andrews, 1999).

The Boston Based Adaptation in Nursing Research Society (BBARNS) was established to review 25 years worth of research studies using the Roy Adaptation Model, examining the categories under study and the

contributions made to both nursing theory and practice. The aim of the review was not just to reflect on the previous work but to look to the future in identifying new directions for theoretical advancement. The purpose of the review was to:

- Critically analyse research based on the Roy Adaptation Model.
- Evaluate relationships of research to Roy Adaptation Model.
- Synthesise contributions of research findings to nursing, including implications for nursing practice and for future research and theory development.

(BBARNS, 1999; p13)

Criteria for inclusion into the review required research studies to have identified Roy's Adaptation Model as the conceptual framework underpinning the study. The research needed to be a primary research piece, published in the form of a journal article, thesis or dissertation. Each study was critiqued according to its method, strengths and weaknesses of the design, and the affiliation to Roy Adaptation Model. Despite the increased uptake in qualitative studies within nursing, out of 163 studies reviewed, just 16 (9.8%) used qualitative methods (BBARNS, 1999). This reflects not only the flexibility of the model in allowing a wide scope of methods to be used, but the fashion in studies over the last three decades, the majority of which have used a quantitative perspective. The choice of qualitative methods varied although content analysis, descriptive and exploratory studies were predominant.

A quantitative approach enables the deductive testing of hypotheses and middle range theories derived from the Roy Adaptation Model. Areas investigated included responses to chronic illness (Pollock *et al*, 1990); testing a theory of chronic pain (Tsai *et al*, 2003), quality of life in cancer patients (Nuamah *et al*, 1999; Yeh, 2002), biobehavioural effects of human touch (Modrcin-Talbott, 2003) and testing hypotheses from the Roy Adaptation Model (Fredrickson *et al*, 1991; Hamner, 1996)

Although the majority of studies using the Roy Adaptation Model have been quantitative, qualitative enquiry is an appropriate method, congruent with the philosophical perspectives, viewing people as purposeful in their decision making. Roy's model addresses the meaning of existence and the place of people in creation; qualitative methods can be used to gather rich descriptions uncovering the perspectives of this cosmology.

Qualitative enquiry is a means of understanding what is happening and revealing phenomena, enabling the study of changing situations over time (Speziale & Carpenter, 2003). For this reason it is suited to looking at issues such as coping, adaptation and adjustment.

Qualitative studies reviewed by the BBARNS were critiqued according to their descriptive vividness, methodological congruence, analytic preciseness, theoretic correctness and heuristic relevance. Reliability of the qualitative studies was judged according to the position of the research, the participant selection, the contextual conditions and

procedural stages (BBARNS, 1995). Further links between the research findings and Roy's Model of Adaptation were classified as either explicit, implicit or absent.

Each study was grouped according to its subject and area of focus within the Roy Adaptation Model. Studies varied from looking at specific modes: self-concept (Lamb & Sheldon, 1994), role function (Legault, 1991; Nyqvist & Sjoden, 1993), interdependence (Smith *et al*, 1993) and physiologic mode (Zungu, 1993). Several focused on stimuli triggering the need for adaptation (Munn & Tichy, 1987), others took into account all of the adaptive modes (Florence *et al*, 1994; Gagliardi, 1991; Smith *et al*, 1993). Subject matters varied from exploring the needs of parents (Fawcett, 1981; Smith *et al*, 1983), families (Gagliardi, 1991; Smith *et al*, 1993), mothers (Nyqvist & Sjoden, 1993; Gibson, 1995), and women (Lamb, 1991; Legault, 1991; Florence *et al*, 1994). The effect of different environments was explored including intensive care (Munn & Tichy, 1987; Nyqvist & Sjoden, 1993) and the home (Smith *et al*, 1983). One study investigated the single concept of empowerment as affecting adaptation (Gibson, 1995); others such as Lamb & Sheldon (1994) looked at a specific area of adaptation: sexual adaptation in those treated with endometrial cancer.

Of all the qualitative studies reviewed by BBARNS, all but one applied the results back to the conceptual model (implicitly or explicitly). Of those that drew their results back to Roy's Adaptation Model, all supported the

propositions of the model in some way. Roy makes the premise that the characteristics of the focal, contextual and residual stimuli influence adaptive responses (Roy & Andrews, 1999). This statement was supported through the results of several studies (Legault, 1991; Florence *et al*, 1994; Lamb & Sheldon, 1994). Gibson (1995) verified this by indicating that focal stimuli affecting a significant other within a relationship may affect adaptation within the interdependence mode. Smith *et al* (1993) supported this recognising that the role of care giving can place demands upon the interdependence mode. Pollock (1982) concluded that external stimuli might place greater demands on the adaptive system.

Results from the qualitative studies provided intriguing links between adaptation related to cognator and regulator processes. Gagliardi (1991) and Florence *et al* (1994) identified patterns of cognator processing within specific groups of patients and related this to influencing innate and acquired ways of adapting. Smith *et al* (1993) supported fluctuating adaptation levels linked to cognator and regulator responses. From these findings, and those of other studies reviewed by BBARNS, recommendations were made for further investigation into understanding the relationships of cognator and regulator processes, particularly within the self-concept mode.

3.11 Recommendations for research using Roy's Adaptation Model

The quarter-century review led to many recommendations for future research interest, stemming from both the quantitative and qualitative

studies. Specifically, attention was given to the need for further understanding of the relationships of cognator and regulator processes most noticeably within the self-concept mode. The usefulness of qualitative methods was noted in their ability to provide detailed descriptions of adaptive processes that could then be used as frameworks within other populations (BBARNS, 1999).

The total BBARNS review led to two major recommendations for expanding and clarifying the concepts of the Roy Adaptation Model: the notion of 'time' relating to the process of adapting, and the role of 'perceptions'.

3.11.1 The concept of time

Lamb & Sheldon (1994) identified that sexual adaptation in those living with endometrial cancer is a process continually evolving over time. Changes in adaptation levels over varying periods of time were also identified in quantitative studies (Artinian, 1990). From the intriguing results of these studies, the BBARNS reviewers called for further research into the effect of the passing of time on the adaptive modes (in particular the interdependence mode). They also suggested research investigating the concept of time as a variable. This could lead to pinpointing the most appropriate period for providing nursing interventions in a variety of different situations (BBARNS, 1999). The BBARNS voice support for various research methods to investigate the concept of time. Qualitative methods are well suited to open enquiries gathering detailed descriptions

of events over duration of time and hence maybe well placed to investigate the concept of time within the Roy Adaptation Model.

3.11.2 The role of perceptions

Roy & Andrews (1999) define 'perception' as *"the interpretation of a sensory stimulus and the conscious appreciation of it"* (Roy & Andrews, 1999; p259). Perception is viewed as a process of the cognator subsystems within the model. The need to explore this concept has largely been identified through quantitative studies (Leech, 1982; Holcombe, 1986; Shaffer, 1989). Interestingly, Armer (1989) and Dahlen (1980) proposed through their research that the perception of an event is a stronger indicator of adaptation than the focal stimuli triggering the event itself. This reinforces Roy's viewpoint that the focal stimuli needs to be considered in light of the residual and contextual stimuli in order to acquire perception over a situation (Roy & Andrews, 1999). Directions for future research include developing understanding of the role of perception within clinical situations, and the role perception plays in connecting regulator and cognator processes (BBARNS, 1999). Roy & Andrews (1999) also describe perception as *"providing meaning to what is sensed"* (Roy & Andrews, 1999; p260). Qualitative methods may be particularly useful in uncovering the meaning of patient situations, as they perceive them. It is recommended that the exploration into time and perception takes place amongst a cross-section of communities, including patients and families, those of different ages and social situations, those in periods of health, acute or chronic illness (BBARNS, 1999).

3.12 Qualitative research using Roy's Adaptation Model since 1995

In order to consider the way in which Roy's Adaptation Model has recently been used alongside qualitative methods, a review was performed of qualitative studies using Roy's Adaptation Model as a conceptual framework between 1995 and 2005. Databases such as British Nursing Index, CINAHL, Swetswise and Ingenta were used as well as a hand search of the journals.

To maintain continuity, the inclusion criteria for studies remained the same as that of the BBARNS review. Nine qualitative studies were identified from the ten year period 1995-2005, compared to 16 over the previous 25 year period. The numbers suggest support for the rise in popularity of qualitative methods. The categories of research reviewed by BBARNS and those reviewed since can be seen in Table 2.

Four of the studies from this time span looked at the self-concept mode (Brydolf & Segesten, 1996; Dobratz, 2002; Gagliardi, 2003; Dobratz, 2004), one study focused on role-function (Lotus-Shyu 2000), two on adaptive modes and processes (Yeh, 2001; Gagliardi *et al*, 2002), one study focused on stimuli (Raeside, 1997) and one study looked at nursing interventions (Zeigler *et al*, 2004). A summary of the aim and findings of each study can be seen in Appendix 2.

Table 2 – Research areas covered by studies using Roy’s Adaptation Model up until 2005

Research area of focus within RAM	Total no of studies reviewed by BBARNS	No of qualitative studies reviewed by BBARNS according to area of research	No of qualitative studies reviewed between 1995-2005, according to area of research
Physiologic mode	(n=21)	1	0
Self-concept mode	(n=19)	1	4
Role-function mode	(n=10)	6	1
Interdependence mode	(n=21)	2	0
Adaptive mode and processes	(n=36)	4	2
Stimuli	(n=19)	2	1
Nursing intervention	(n=28)	0	1
TOTAL STUDIES	(n=163)	16	9

Each of the nine studies demonstrated unique use of Roy’s Model. All studies (to varying degrees) explicitly related their findings back to Roy’s Adaptation Model. Raeside (1997) studied the role of ‘perception’, highlighted as needing further investigation from the BBARNS review. The research was directed at differences in perception of stressors between nurses and mothers within the neonatal intensive care unit. Results were related back to the physiologic, self-concept and interdependence adaptive modes. Mothers rated perceptions of stressors as lower than nurses.

Recommendations for practice were drawn from the results, including controlling room temperature, noise and illumination levels and providing

quieter areas to promote mother and baby bonding and aiding women in their experience of adapting to motherhood (Raeside, 1997). This supports the proposition of Roy's Adaptation Model that the characteristics of internal and external stimuli influence both cognitive and regulator processes, which in turn influence the adaptive response. The research demonstrated that tours for parents around the NICU department were helpful to their adaptation despite being stressful. This supports the proposition of Roy Adaptation Model that 'adaptation is influenced by the integration of the person with the environment', and provides a rationale for carrying out the tours (Raeside, 1997).

The above study furthered understanding around the concept of 'perception' but did not explicitly relate any connection between regulator and cognator subsystems and their role in perception. The presentation of the results would indicate that parent's perceptions of their baby's response to environmental stressors heavily influenced their own cognitive adaptation. The research builds on previous investigations into nurse's perceptions of stressors within intensive care environments as conducted by Munn & Tichy (1987). Interestingly Raeside (1997) does not draw on or mention this study in her review.

The second major recommendation from the BBARNS review was investigation into 'time' as a variable in the process of adaptation. Although this has not been explicit within any of the latest qualitative studies using Roy's Adaptation Model, three studies focus on the

experience of illnesses from onset until the time of study completion (Brydolf & Segesten, 1996; Yeh, 2001; Gagliardi *et al*, 2002). Each provides an insight into the whole experience of illness over time, highlighting changes and fluctuations. Research into the experience of illness allows for the unmasking of individual perceptions. The following three studies inadvertently look at both the concepts of time and perception.

Brydolf & Segesten (1996) explored the experience of living with ulcerative colitis in adolescents. Interviews were conducted amongst 28 participants focusing on the personal experience of diagnosis, discovery of symptoms and their feelings at the time of interview. Grounded theory was employed to analyse the data and create a model outlining the process of disease over time. Throughout the participant's experience, two phases were identified 'living in a state of transition' proceeded by 'a subsequent altered lifestyle'. Sub-categories representing the experience were labelled as alienation, reduced living space, support and lack of support, confidence in self, role identification as a child and as an adult. The idea of living space was linked to Roy's definition of 'environment' within the model, highlighting the need to create a supportive environment for the adolescent, providing them with independence to make their own decisions, thus aiding adaptation.

Roy's definition of adaptation was supported throughout the study, particularly within the phase 'living in a state of transition'. Themes such

as alienation and lack of support highlight the need for health promotion within the interdependence mode and recognise how these needs may change throughout adolescence (Brydolf & Segesten, 1996). The research supports previous studies looking at the self-concept mode by verifying that both time and perception influence the process of adaptation, supporting the propositions of Roy's Adaptation Model (see sections 3.11.1 & 3.11.2). The results demonstrate the changing nature of the trajectory of chronic illness. The study provides important insights into the changes that occur not just over time but also with age through their focus on adolescents and young adults. This backs up the previous work of Bertch (1994) and Shaffer (1989) in identifying fluctuations in perceptions according to age. Additional insight could be gained through examining the experiences of older adults, identifying changes and differences from that of adolescents. Further qualitative work could explore the role of parents/guardians caring for adolescents with ulcerative colitis. This could advance Roy's work on the role-function and interdependence mode, helping nurses understand how best to support the family as well as the child undergoing this transition.

Yeh (2001) also focused on the younger population in a study of adaptation amongst Taiwanese children with cancer. Adaptation was viewed as "*a coping mechanism used by participants to achieve an underlying goal of getting back to normal life after the cancer was identified*" (Yeh, 2001; p143), a definition similar to that of Roy. Recorded interviews were analysed in a process that combined open coding and

comparison. Although the method was similar to that of grounded theory, the comparison was not made within the paper. Results were coded according to the Roy Adaptation Model's four adaptive modes. Links were made to previous studies as well as to the Roy Adaptation Model. Differences in adaptation within age groups were noticeable, reinforcing the results of Brydolf & Segesten's (1996) study. The concept of 'the future' was not identified in any children younger than 10 years of age but was found more frequently as age increased. The impact of time on perception can be associated within this. Within the propositions of Roy Adaptation Model, time is seen as a variable that influences the process of adaptation. This research indicates that for young children, who have no or little concept of time, this was not a factor for them in their process of adapting. However, nurses or parents may see time as even more significant to their process of adaptation as their ability to understand increases over time (Yeh, 2001).

Additional findings highlighted the role function and interdependence modes as mixed and interrelated whereas the physiological and psychological aspects were found to be independent. The authors suggested that future studies should focus on this relationship. The study offers an international perspective, demonstrating the itinerant constitution of the Roy Adaptation Model. Similar studies conducted in different countries could seek to identify differences or similarities in the way cultures affect children's adaptation to cancer.

Gagliardi *et al* (2002) conducted the third qualitative study considering the experience of illness over time amongst adults living with multiple sclerosis (MS). Case study content analysis was used in interviews with nine men and nine women all of whom had been living with MS for a minimum of two years. Results were coded according to themes and each theme linked to the four modes of Roy's Adaptation Model. Five themes were uncovered: "*we're not completely the same, how I view my future, let me tell you my feelings, how I see my work, and let me tell you about my life*" (Gagliardi *et al*, 2002; p233). Each depicted Roy's definition of adaptation. Although the data was categorised according to Roy's adaptive modes, specific links regarding ways in which research strengthens the theoretical foundations of the model were not made. Observation of the results suggests support for Roy's proposition that '*adaptation is influenced by integration of the person with the environment*' (BBARNS, 1999; p202). The descriptions used to develop each theme also demonstrate that cognitive processes have more influence on coping with adaptation than regulator body processes. Individual perceptions of role function, interdependence and self concept have a stronger influence over achieving a positive adaptive response than physical health. This enables those with chronic, physically degenerative conditions such as MS, to develop positive adaptive responses despite their physical condition. The research as a whole achieves the aims from the BBARNS review by uncovering the 'perceptions' of those with MS. No previous studies could be found using the Roy Adaptation Model to investigate MS so this

research makes headway providing valuable insight into the impact of chronic illness on daily life.

Gagliardi (2003) furthered understanding of the MS experience in her qualitative study that uncovered the meaning of sexuality for those with MS. The naturalistic case study framed by the Roy Adaptation Model identified three themes: *“How I feel about my appearance”*, *“I have feelings about my sexuality”*, and *“sexuality for me has both negative and positive emotions”* (Gagliardi, 2003; p575). All reflect the four modes of the Roy Adaptation Model and demonstrate their interrelatedness. Sexuality was raised as an important issue to nearly all the participants ($n=8$). The need for nurses and health professionals to recognise this and provide opportunities for patients to discuss sexuality was emphasised. The research builds on the work of Lamb & Sheldon (1994) who looked at the sexual adaptation of women with endometrial cancer. Both research studies took different angles on the subject and therefore came up with different findings. Both studies agree that the onset of illness can have a profound effect on the way a person feels about their sexuality, affecting them in their self-concept, role function, interdependent and physiologic mode.

The three remaining qualitative studies published within 1995-2005 introduce new areas of interest. Lotus-Shyu (2000) emphasised role-function through looking at the relationships between caregiver and care receiver during discharge transition. The Taiwanese study used grounded

theory to uncover *'role-tuning'* as the transitional means in which to achieve a harmonious discharge from the hospital to home. Both the care receiver and caregiver adjusted behaviours and expectations in order to meet the needs of each other and the new situation in which they found themselves. *'Role-tuning'* was seen as containing three phases: *'role engaging, role negotiating and role settling'* (Lotus-Shyu, 2000; p325). Role tuning was seen as consistent with the Roy Adaptation Model concept of role function. Each phase was identified as supporting the concepts of role transition. The study suggests support for Roy's proposition that adaptation is influenced by integration within the environment. Integration is achieved through the caregiver and care receiver developing understanding of their role function, self-concept, and *'group identity'* in the way they perceive themselves within the family. These ideas are fully consistent with the concepts of Roy's Adaptation Model.

The author highlighted the importance of interaction in coping with transition – a premise supported by Roy's concept of role-function. Lotus-Shyu (2000) also took two nursing approaches suggested by Roy in promoting role transition (the introduction of role cues and role supplementation) as aiding the participant in role-tuning and therefore in adapting. Links of results within the Roy Adaptation Model allow for further clarification of the concepts, strengthening the model. The research demonstrated the flexibility of Roy's Adaptive Model – an American model – through its application within the Taiwanese nursing arena.

All studies within the BBARNs review focusing on nursing interventions were undertaken using quantitative methodology. Zeigler *et al* (2004) have broken new ground in using open ended survey questions (reflecting the four adaptive modes) and a qualitative content analysis to evaluate the experiences of a breast cancer support group, therefore being the first study using the Roy Adaptation Model to look at nursing interventions using qualitative methodology. This study is also unique in including the voice of both participants and facilitators from the support group.

Questions were asked in accordance with the four adaptive modes, answers to the open-ended questions were rated as describing either an adaptive or ineffective response. Adaptive responses were found most frequently within the role function and interdependence mode. These addressed issues such as support systems and daily activities. The research indicates that the role of the support group may have assisted this, demonstrating that once again, adaptation is indeed influenced by the integration of the person with the environment and those around them.

Ineffective responses were found more frequently within the physiological and self-concept mode. Issues such as body image and physical distress were found as being the most significant to overcome when living with breast cancer – these are issues that nurses need to be conscious of when dealing with patients. The responses differed over the course of the year, some from adaptive to ineffective, and others from ineffective to

adaptive. This displays the varying trajectory of breast cancer and shows the influence of time on affective and ineffective adaptation. The research study testified the strengths of the Roy Adaptation Model in being able to use all four adaptive modes to guide evaluation of the total experience of the support group. The usefulness of using qualitative research alongside Roy's Adaptation Model to evaluate nursing interventions as exhibited here.

The final two studies to be reviewed were both conducted by Dobratz (2002, 2004). Grounded theory was used in the first study to investigate the psychological adaptation amongst home hospice patients. Results generated a theoretical framework of seven process-patterns occurring individually and at once. The patterns were labelled as:

“the becoming-self; interpreting meaning; connecting others; weighing expectations; sustaining acts; adjusting expectations; bodily feelings”
(Dobratz, 2002; p138)

The research was supportive of the philosophical and theoretical aspects of the Roy Adaptation Model, and added to the previous research looking at 'perception'. Dobratz (2002) related the findings back to the Roy Adaptation Model in the following areas:

- The pattern of becoming-self in death and dying was found to support the adaptation process as defined by Roy & Andrews (1999).

- Dying individuals found purpose in their existence through connecting with others and to a spiritual force – supporting Roy’s philosophical assumptions of cosmology, veritativity and humanism.
- The cognitive-emotive channel, as described by Roy as handling perception, was activated by those within the study seeking a sense of purpose.

(Roy & Andrews, 1999; Dobratz, 2002)

Dobratz (2004) continued her work from this study in a secondary analysis, coding previously transcribed data for the theme ‘spirituality’. All 44 participants were undergoing hospice care at the time of being interviewed. A core theme of ‘believing’ was identified, underlined by six other themes: comforting, releasing, connecting, giving, reframing and requesting. These reflect Roy’s spiritual assumptions that people have, and need, a mutual relationship with God and the world as well as recognising the importance of awareness and faith in daily living – particularly when living with illness (Roy & Andrews, 1999; Dobratz, 2004). The need to connect and be comforted reflects the need to maintain relationships as described in the interdependence mode. This also has an impact on the individual’s self-concept, needing to give and to release. The overlapping nature of the adaptive modes is evident in these aspects of spirituality (Dobratz, 2004).

The fact that the research study was a secondary analysis must be taken into account when looking at the overwhelmingly supportive nature of the

results towards Roy's Adaptation Model. Out of the 97 participants interviewed in the original study, 44 who gave reference to 'spirituality' were included in the secondary review. The interesting results from this study and the unique subject area add credibility to the philosophic assumptions of the Roy Adaptation Model. Further studies investigating spirituality, across wide, perhaps cross-cultural populations are needed to verify the philosophic assumptions.

3.13 Implications of Roy Adaptation Model based research review for this study

This review of the past 35 years worth of research studies using the Roy Adaptation Model demonstrates the ability of the framework in mapping processes of adaptation for those in varying states of health. The model is flexible in its application to both qualitative and quantitative methods. The purpose of this piece of research is to map the process of adaptation for those living with HIV/AIDS, a topic in concordance with Roy's work. The research is both theory-guided and theory testing. The philosophical assumptions of Roy's Adaptation Model are used to guide the research process. The research results are applied back to the model, examining similarities or differences to Roy's description of the adaptive process.

The compatibility of this process is described in more detail in section 4.7

The research aims to reveal stages in the course of HIV, looking at how the patient adjusts to changes throughout the discourse. The focus is on the dynamics of evolving adaptive patterns and on the relationships of

adaptive modes and processes, both areas in which Roy suggests as the foci for research (see Figure 8) (Roy & Andrews, 1999). The research aims to further the theoretical basis of Roy's model by covering the issues of 'time' and 'perception', and the role these play, if at all, in the adaptive process to HIV. The research, primarily focused on the concept of adaptation, relies on patient's perceptions of how they adapt, and how time affects this process, from diagnosis to the participants present day.

The objectives of the study, as previously stated, are:

- To identify the stages, if any, of adaptation throughout the course of HIV/AIDS
- To outline the process of adaptation to HIV/AIDS within a conceptual model or basic social process developed through grounded theory
- If stages of adaptation to HIV/AIDS exist, to test these against Roy's Model of Adaptation. Can stimuli, adaptive modes and their interactive relationships be determined throughout the stages of HIV/AIDS as in Roy's Model of Adaptation?

To uncover the objectives, a sound research method is needed to allow flexibility in discovering a process, a systematic method of data collection and the ability to lead to theory development. Qualitative methods are deemed the most appropriate in gaining descriptive accounts of the adaptive process. Grounded theory has been chosen as the research

method, allowing exposition of the process of adapting to HIV/AIDS, whilst building this into a basic social process framework. The following chapter presents a detailed background to the history of grounded theory method and details its suitability with a study of this type. A discussion is offered on the compatibility of grounded theory and Roy's Adaptation Model.

CHAPTER FOUR

Methodology

4.1 Grounded theory method

“Grounded theory is a qualitative research approach used to explore the social processes that present within human interactions”
(Speziale & Carpenter, 2003; p107)

The original publication of grounded theory (GT) research “Awareness of Dying” (Glaser & Strauss, 1965) outlined the use of a method of using qualitative data to develop understanding of a basic social process. The study was conducted by two sociologists: Barney G. Glaser (born 1930) and Anselm Strauss (1916-1996). Since their first publication of grounded theory, many derivations of the method have emerged through ongoing theoretical discussion. Wide uptake of the method has furthered scholarly debate, particularly around paradigmatic and theoretical issues as this chapter will unravel.

Amongst the contents list of any book on qualitative research methods, grounded theory can be found cited as a qualitative method of analysis, designed from, and for the use in qualitative research. However, the founders of the method state that GT is not exclusively a qualitative method as it can be used as a method of analysis for both qualitative and quantitative data (Glaser & Strauss, 1967). Amongst published research, it has been used predominantly for analysis of qualitative data, when exploring social processes. Glaser (2005), one of the founders of GT claims that it should not be classified as either qualitative or quantitative as it is applicable to both qualitative and quantitative data. This enables it to

be used throughout multiple disciplines such as medicine, education, nursing and economics to name a few.

The strong links between grounded theory and qualitative research have led to the majority of published literature linking it with the philosophical ideology of symbolic interactionism, a school of thought developed and studied at the University of Chicago. Although symbolic interactionism has had a significant influence on grounded theory development, it is by no means the primary philosophical focus of the method. Nursing has been particularly criticised about its recurrent adoption of symbolic interactionism within GT studies. Glaser (2005) has published his concerns about the lack of understanding nurses have for the theoretical aspects of GT, leading to questioning of the credibility of research results. Glaser specifically describes the way in which nurses have confused and misused GT, when he stated that:

“Researchers, especially in nursing, just want a theoretical perspective. SI institutionalises GT as its own! Researchers like it because it gives them an ontology (what is data) and an epistemology (a philosophy of research). The takeover becomes structurally induced by researchers, especially nursing, in their research, since they want a theoretical perspective in advance” (Glaser, 2005; p141)

According to Glaser (2005) GT is a ‘general method’, free from any specific ontology or epistemology. This makes it versatile in application to a wide range of subjects, areas and perspectives. The relentless affiliation of grounded theory with symbolic interactionism has led to careless omission of the many other influences that helped develop grounded

theory, as well as leading to presumptions of grounded theory as a purely qualitative method with post-positivist underpinnings, losing sight of its inductive aspects.

This chapter aims to explain the roots of grounded theory and the theoretical influences on its development. Debates surrounding both methodological and philosophical issues are addressed, as well as an examination of the applicability of grounded theory to this research study and its congruency with Roy's Adaptation Model.

4.2 The emergence of grounded theory

Glaser & Strauss, the founders of grounded theory method, came from differing academic backgrounds. Strauss' background was predominantly in qualitative research where he gained his PhD from the University of Chicago, taught and heavily influenced by Herbert Blumer and Robert E. Park in the field of symbolic interactionism. Glaser was trained in quantitative research and theory generation gaining his BA at Stanford in 1952 and going on to study contemporary literature at the University of Paris, France. Glaser received his PhD at Columbia University in New York before beginning his post-doctoral work at the University of San Francisco, California where he was introduced to and worked with Anselm Strauss. The influence of their contrasting backgrounds is evident in what they each bring to the formation of grounded theory.

At the time of developing grounded theory, both Glaser & Strauss were working within the field of sociology; their aims emanated from an awareness of the need to accurately comprehend human interactions; they approached the human experience as a process of continually evolving change and complexity. Glaser & Strauss realised that there was an absence of research methods enabling the depiction of relationships between conditions, meaning and actions within a given situation. Strauss & Glaser wanted to develop a method allowing the evolution of theories directly from the data collected in social science research. They developed grounded theory method from the following objectives:

- To use data to ground theory regardless of the way data was collected or presented.
- To conceptualise patterns in the data by way of 'concepts'.
- To relate conceptualised patterns, generating a theory through the use of theoretical codes.

(Glaser, 2005)

4.3 The influence of symbolic interactionism on grounded theory

Strauss's qualitative background was heavily influenced by the pragmatics in the form of symbolic interactionism, most notably the work of John Dewey (1859-1952), George Herbert Mead (1934) and Herbert Blumer (1969), also from the same Chicago school of thought as Strauss. Blumer (1969) had perhaps the most notable influence on GT through his work on symbolic interactionism. This is based on the principle that human

behaviour and actions stem from the meaning people hold towards each other and the objects around them. Symbolic interactionism, according to Blumer, rests on three premises:

- Human beings act towards physical objects and other beings in their environment on the basis of the meanings that these things have for them.
- Meanings derive from the social interaction between and among individuals.
- Meanings are modified and established through an interpretive process

(Blumer, 1969; p2).

When using the symbolic interactionist perspective with GT, researchers attempt to determine the symbolic meanings used as people interact with each other and the world around them. The focus is on change, emergence and social process, developing understanding related to actions and attempting to see objects as the individual would themselves see them. The sociologic perspective views humans as active creators of their world. From Blumer's perspective, as noted above, research attempts to determine the symbolic meanings of a group of people as they attempt to interact with each other and the world around them. Symbolic interactionism (SI) views life as a continuous and active process of defining and interpreting (Blumer, 1969). Grounded theory reflects this through attempting to unveil fluctuating social processes. It is this that

Glaser & Strauss uncovered in their first renowned study, *Awareness of Dying* (1965). Grounded theory can be one way of uncovering meaning and understanding of the way in which people interact. Human action is viewed as purposeful, based on meanings the individual holds; this is parallel with the philosophical perspective of Roy's Adaptation Model (Roy & Andrews, 1999; Priest *et al*, 2002).

Symbolic interactionism is sympathetic to the humanistic nature of nursing and this may partly explain the popularity of this approach in nursing. Many nursing theorists including Parse (1999), Rogers (1970) and Roy (1997) follow similar philosophies, desiring to understand people, their interaction and how they define their own health. Although it is not necessarily wrong for nurses to use SI in grounded theory research, the hazard is in choosing SI just because many texts claim it to be part of the GT process. It is important to make explicit the reasons for using SI (Robrecht, 1995; Sheldon, 1998; Cutcliffe, 2000; Eaves, 2001; McCann & Clark, 2003 & Jeon, 2004).

Strict adherence to SI, or any other theoretical perspective when using GT, may risk forcing the data to fit the approach rather than allowing theory to emerge, untarnished by other influences this then contradicts the GT process. Within GT "*all is data*", regardless of the theoretical framework (Glaser, 1998). Glaser (2005) recognises the risk of forcing data around discipline-specific theory in order to gain recognition and legitimacy. This is contrary to the ethos of GT in which the data should be

allowed to emerge, proving its own legitimacy through the grounded theory which results. Remaining open to varying codes and patterns is the key to allowing free emergence of data.

4.4 Quantitative influences on grounded theory

Glaser's background in quantitative methods holds as much influence on grounded theory as does symbolic interactionism. Glaser was a student of Paul F. Lazarsfeld (1901-1976), a distinguished mathematician who went on to become a prominent American sociologist. Lazarsfeld taught at Columbia University where he introduced Glaser to the techniques of survey analysis, latent structure analysis and contextual comparison (Eid, 2004).

Lazarsfeld used qualitative mathematics, believing there was no qualitative hypothesis or concept that could not be represented by a mathematical formula, and that most mathematical formulas could be stated qualitatively. This influence is prominent in grounded theory in the way that probability statements can represent a pattern or behaviour. Glaser claims it is the choice of the researcher (influenced by the type of data) as to whether theoretical statements are reduced to mathematical formulas or qualitative assertions (Glaser, 2005). Despite Glaser advocating the use of quantitative data within grounded theory, very few examples of this exist within research to demonstrate the success and appropriateness of this variation. The paucity of quantitative grounded theory has been noted by other researchers (Duchscher & Morgan, 2004).

No examples of GT using quantitative data could be found within the nursing literature, indicating that this approach may be poorly understood. Glaser's own PhD, completed in 1961, remains one of the only examples of GT research using a quantitative approach.

Despite the lack of GT studies using quantitative data, the mathematical influence can be seen clearly when delving into the background of GT development. Constant comparison was partly inspired by Lazarsfeld's use of 'concept indicators' to generate categories from his data. Within this mathematical approach, indicators are given a value (degree of recognition), of high, medium or low. Glaser used this method, introducing the comparison of indicator to indicator, thereby producing an index, grounded with a meaning behind it. Glaser claims that continual comparison of indicators brings forth categories with meaningful properties (Glaser, 2005).

The idea of theoretical saturation was originally proven quantitatively through demonstration that indicators of the same pattern will yield different indexes but all with the same meaning. Taking this on board through constant comparison led to a way of maximising full use of the data collection process, leading to rich abundant results whilst delimiting, preventing waste, and bringing forth the emergent theory. The idea of 'coding' as a way to identify the categories and indicators was initiated by the work of social scientist Robert K. Merton (1910-2003), also from the Chicago School.

Glaser's training at the Sorbonne, University of Paris in 'explication de text' (text analysis) helped inspire the 'line by line' analysis evident in GT. This approach of closely reading each line to understand meaning without interpretation or manipulation completes the constant comparison process (Glaser, 2005).

Although Strauss enriched grounded theory through the influence of symbolic interactionism, quantitative aspects such as concept-indicator model should not be forgotten. Quantitative theory and qualitative symbolic interactionism should not be viewed as separate entities when considering grounded theory. Both areas add unique and essential qualities to understanding and using the method. As outlined, the combined backgrounds of both Glaser & Strauss have led to the development of a widely used general method, applicable to varying types of data within any discipline, enabling the discovery of new patterns, processes and theories (Cutcliffe, 2000).

4.5 The emergence (or forcing) of grounded theory variations

Glaser & Strauss eventually moved from the social science department in Chicago to join the faculty of nursing at the University of California, San Francisco. Here their influence led to the uptake of grounded theory, specifically in nursing research. The ease of using rich, descriptive data, mostly detailing the patient's experience, made grounded theory popular in qualitative nursing research – a popularity which has continued to grow.

Nurse researchers became interested in studying social processes over a selected period of time, looking at patterns of action, interaction or adaptation among various types of social situations (Allen, 1995; Benoliel, 1996).

Grounded theory within nursing is most frequently based on the supposition that a group of people share an unarticulated social problem which needs to be discovered through research. The focus of the researcher commonly includes investigation of social context, focus on experience and basic social processes, consideration of conscious choice and investigation into the conscious construction of meaning (Benoliel, 1996; Annells, 1997). Grounded theory can uncover the discovery of phases or stages in the social process or phenomenon under study leading to conceptualisation of what might/should occur under certain conditions, this allows the emergence of new theories (Glaser, 1978).

The classic and original method of grounded theory, led by Glaser & Strauss (1967), and continued by Glaser (1978), assumes there is a 'reality' waiting to be discovered through the research process. The grounded theory researcher focuses on the main area of concern for subjects in a specific area. The researcher keeps an open mind to the problems that may occur in an area, asking neutral questions of the data such as: what is this data a study of? What is actually happening in the data? And what category does this incident indicate? Concepts are generated, through emergence, focusing on relationships, explaining and

accounting for variations in behaviour (Glaser, 1998). The feature distinguishing this classic method from more recent modifications of GT is the *emergence* of concepts discovered through constant comparative analysis and substantive and theoretical coding. The use of coding enables the analyst to see research data and emergence of concepts in new ways that subsequently may generate theory (Glaser, 1998). The result of this method is discovery of grounded theory hypotheses, basic social processes, or other theoretical codes.

The popular uptake of grounded theory has inevitably led to modifications as researchers add their own knowledge and findings, adjusting the theory according to the discoveries they have made. Individual researchers have made changes to the original 'classic' design to suit their studies and complement their theoretical background. As Annells (1997) wisely points out:

“Grounded theory method should be sustained and developed by the very researchers, worldwide, who apply the method and have a responsibility to enter into methodological debate, giving justification for their contribution to, and variations of, the method.”
(Annells, 1997; p179)

Three versions of GT currently dominate the paradigmatic debate: the classic version (Glaser & Strauss, 1967; Glaser, 1998); Strauss & Corbin (1998), who point their work to positivist roots, and Charmaz (1983) who furthered the debate by adopting a constructivist approach. GT is perceived from the perspective of varying philosophical approaches such as the postpositivist era (Charmaz, 1983; Denzin & Lincoln 2000). Others

claim that GT follows an interpretivist constructivist approach (Annells, 1997), a perspective developed further by Charmaz (2000). Glaser himself criticises Strauss & Corbin for reverting to positivism due to their increased emphasis on verification and maintains that grounded theory should be intentionally free from any particular philosophical perspective enabling it to be applied to any discipline (Glaser, 1998; 2005). Charmaz opposes Glaser, considering his approach as closer to traditional positivism and Strauss & Corbin as closer to postpositivism (Charmaz, 2000).

Strauss & Corbin (1998) vary from the classic method through their focus on phenomena already identified by the researcher prior to commencing the investigation (see Figure 9). Grounded theory hypotheses are developed and tested against the data. Steps labelled open, axial and selective coding, lead to the intended outcome of an inductive grounded theory which can be used for direct application to explain and manage the phenomenon under question. Strauss & Corbin advocate asking further detailed questions of the data, prising for categories and continually verifying these categories in the data they collect. Glaser (1998) criticised this process claiming that it forces the data into preconceived categories, suffocating the process of emergence and leading only to conceptual description and not a grounded theory (Glaser, 1998). Johnson (1999) claimed that more prescriptive method of grounded theory developed by Corbin & Strauss moves into a positivist domain, striving towards the objectification of knowledge.

Figure 9 – Outline of grounded theory according to Glaser & Strauss (1967) and Strauss & Corbin (1998)

	Glaser & Strauss (1967)	Strauss & Corbin (1998)
Focusing on:	A substantive area.	A phenomenon.
Aiming to:	Generate an inductive grounded theory.	Develop an inductive grounded theory.
Commencing with:	A general area of interest.	A pre-identified problem or sensitising question.
Through use of method:	Grounded basic problem/question and social problem emerges.	Development of grounded theory questions and testing hypotheses regarding social process.
Underpinned by:	Symbolic interactionism.	Strauss' theory of continual permutations of action.
Resulting in:	Generated grounded hypotheses.	Some degree of verified grounded theory.
Leading to:	Experimental or survey research resulting in a verified grounded theory.	An understanding with direct pragmatic application – problem management.
Ontology:	Critical realist	Realist
Epistemology:	Modified objectivist	Subjectivist

(Annells, 1997; p124)

The constructivist approach developed by Charmaz (2000), argues that concepts and categories emerge not just from the participant but from constructions made by the researcher and their interactions within the field. Glaser believes constructivism is searching to determine accuracy of the data through a degree of mutual interpretation, dismissing the pure emergence of theory. Glaser insists that although there will always be a

degree of bias on the side of the researcher, this is not interwoven with the data but revealed through the process of constant comparison (Glaser, 2003).

4.6 Using the classic grounded theory method

Within this study, use of the classic method of grounded theory has been chosen. This method enables the development of theory through constant comparison. It has a philosophical background similar to Roy's Adaptation Model complementing this chosen theoretical framework. Through employing this method, ways of adapting to HIV can emerge leading to a theoretically sensitive 'grounded' theory. The resultant theory can be traced back to the original data, is rooted in the data and not in another existing theory. The following section will detail the method to be used according to the classic grounded theory method, based on the work of Glaser & Strauss (1967) and continued by Glaser (1998).

4.6.1 The literature review

Grounded theory is used primarily to present findings in the form of new theories, a framework or conceptual model such as the basic social process (BSP) as previously mentioned. For this reason it is used to investigate subjects where little is known. A researcher with little insight into the subject under investigation is less likely to be influenced by previous or subconscious experience or knowledge. It is acknowledged that approaching the research study with 'minimal' understanding of the subject area may not always be realistic (McGhee *et al*, 2007). A certain

amount of background knowledge is needed to discover gaps in a subject area appropriate for research. Smith & Biley (1997) state that general reading of the literature will help to identify gaps for further conceptual clarification. They suggest reading should take place but not be too 'extensive'. As Cutcliffe (2000) rightly questions, how extensive is extensive? Glaser & Strauss go some way towards clarifying this blurred area by stating that the researcher should not read beyond understanding a partial framework of the concepts under study. Cormack (2000) follows this opinion, recommending that the literature be consulted but not analysed or critiqued too extensively. Morse & Field (1996) argue that an extensive content analysis should be carried out prior to commencing the research in order to accurately identify the relevant gap in the research. They go on to explain that the researcher should present their understanding of the subject prior to the research to highlight and prevent areas of bias (O'Reilly, 1995)

Glaser advocates that grounded theorists should not carry out a literature review prior to conducting a research study and by using this approach they would therefore prevent the occurrence of coding with preconceived ideas and being influenced by prior expectations of the resulting hypotheses (Glaser, 1998). Lincoln & Guba (1985) suggest prior acknowledgement of previous ideas will widen the researcher's ability to distinguish between those ideas originating from the research and those from their own previous experience. Acknowledgment of ideas and thoughts at the beginning of the research process will help the researcher

gain awareness of their own preconceptions, in turn helping the research gain credibility by decreasing the chance of personal bias. Hutchinson (1993) suggests a literature review should be carried out following the research in order to help identify any further gaps in knowledge. This should be acknowledged when presenting the results of the research, particularly if the review contributes to development of a theory.

Glaser (1998) argued that a pre-research literature review is inappropriate as the researcher does not know which concepts will emerge and therefore which substantive area should be covered in the literature review (Glaser, 1998). Instead whilst the research is taking place, the researcher should be reading widely around areas other than the subject under study. Reading of the literature should only take place once the developing theory has been sufficiently grounded in a core variable. It is at this point that the researcher should be confident enough in the development of a grounded theory not to be swayed by what is read in the literature (Glaser, 1992). McGhee *et al* (2007) suggest that their interpretation of Glaser's stance on the literature review is that:

“he does not reject the need for the researcher to be reflexive in the sense of being self-aware, but rather rejects the self-destructive introspective compulsion to locate their work within a particular theoretical concern.”
(McGhee *et al*, 2007; p335)

The researcher should always remember the aim of the research is to generate theory, not to verify existing theories. The purpose of a grounded theory literature review is to integrate newly generated theory

with existing literature to demonstrate its contribution to the field.

Questions arising from the literature review can then be woven back into the research through constant comparison or by influencing theoretical sampling (Glaser, 1992).

4.6.2 Data collection

“*All is data*” is a point continually emphasised by Glaser (Glaser, 1998; p8). Interviews, observation, document collection, casual comments, reports and articles can all be used as grounded theory data (Pope *et al*, 2000). Interviews are the most commonly used data collection method within grounded theory, taking place in a variety of settings. Benoliel (1996) carried out a study of nursing research using grounded theory and found the majority of studies failed to use data collection methods other than interviews, many focused on the lived experience, incorrectly using a phenomenological interview approach with a grounded theory method. When used appropriately, interviews provide a flexible method of gathering a comprehensive account from the participant whilst giving the opportunity to observe non verbal responses. They allow the researcher to clarify meaning and explore more complex areas, hence making them a popular method to use (O’Reilly, 1995).

Research interviews enable the researcher to probe into the necessary areas that are required to uncover the phenomenon, yet should not be carried out without negating the philosophical perspective, as encouraged by Silva (1986). Although philosophy alone does not provide a specific

research method, it has a significant bearing on the conditions for knowledge of the person's situation. Applications of philosophy within research can aid conceptualisation of the whole process, influencing the way research (and therefore interviews) are conducted. The increased use of open interviews within qualitative research could be contributed to the shifting trends in current philosophy, moving away from positivist thought towards a growing amount of phenomenological description and hermeneutical interpretation (Speziale & Carpenter, 2003). Uncovering experience and meaning has become a priority and the open interview is seen as an effective way of doing this (Kvale, 1996). The philosophical perspective is often overlooked within research reports, particularly during data analysis yet it has an impact on the results that will be discovered (Geanollos, 1998), and in the case of grounded theory, the birth of the conceptual framework (Wimpenny & Gass, 2000).

Glaser (1992; 2001) provides guidance on carrying out interviews for grounded theory studies, guarding against the use of the many structured interview guides and protocols which may stifle emergence and hinder theoretical sampling. As interview questions should be based on emerging categories and themes, researchers need the freedom to interview in whichever style fits best at the time. Glaser suggests that grounded theory researchers should read around developing an awareness of the many different interview styles in order to have the resources of using different techniques as maybe appropriate. As interview questions are based on emergent themes it is not necessarily

appropriate to use the same questions with each participant. Questioning should be varied according to theoretical sampling (Glaser, 2001).

Many grounded theory research interviews may begin with formal or structured questioning however questions should become looser as the enquiry continues, leading to more open ended conversational interviews. Questions are not asked to gain repetitions, positive or negative responses but to generate concepts (Glaser, 2001). As data is gathered, the researcher should be asking neutral questions of the data such as:

- What is this data a study of?
- What category or what property of what category does this incident indicate?
- What is actually happening in the data?
- What is the basic social process that processes the main problem that makes life viable in the action scene?

(Glaser, 1992; p51)

The answers to these questions should then guide all following interviews, striving towards theory generation and data saturation (Glaser, 1992).

The meaning of responses in interviews is dependant on the questions which precede them yet frequently responses are analysed purely on a stand alone basis without considering the researcher's questions. The researcher should be viewed as a co-constructor of the final discourse, not

just an instrument for data collection. Preparation is vital to ensure the relevant questions are posed. A balance needs to be achieved in ensuring the interview stays on track establishing a rapport with the participant and paying attention to non-verbal cues. Achieving this balance requires precision, sensitivity and organisation (Kvale, 1983; 1996).

Miczo (2003) notes that recalling past stories may offer an opportunity for the participant to manipulate the data, in some cases being seen as a means of acquiring social status through the ownership of special knowledge required by the researcher. Glaser acknowledges that many factors may influence participants responses but stresses that *“all is data”* leading to emergent theory (Glaser, 1992). Data collection interviews can benefit both researcher and participant. The researcher can obtain the required data whilst the participant is able to share their perspective, projecting their desired identities and ideas (Hutchinson *et al*, 1994). It is undoubtable that interview responses will be influenced by the participant’s perspective of what the researcher wants to hear, as well as societal influences. Society is seen as intolerant of those who make demands or possess negativity in their thought processes (Miczo, 2003). This could be an influencing factor when patients talk about a negative aspect of health as a ‘positive experience’. The presentation of the researcher as a ‘positive’ healthy person, with expertise in an area of health could influence the narratives. Unmentioned rules of social conduct should be considered when analysing data (Miczo, 2003).

Observational data should not be overlooked. Field notes should contain thoughts from the researcher such as the participant's body language and tone of voice. First impressions should be recorded as they may extend insights into the participant's descriptions. Photos, paintings, music or other media can also be used by the participant (Mulhall, 2003). Using other mediums can help create comprehensive descriptions, focusing the observations and guiding the researcher to produce more credible data. Field notes should be written immediately after observation to ensure precision (Cohen *et al*, 2000).

4.6.3 Sampling

Debates regarding sampling methods exist amongst grounded theorists. Traditionally, purposeful sampling has been abandoned in favour of theoretical sampling, thus ensuring that data collection is driven by the emerging theory (Cutcliffe, 2000). Sandelowski *et al* (1992) and Cutcliffe (2000) believe purposeful sampling should be used followed by theoretical sampling as participants need to be chosen according the relevant detail they can contribute to the study. Recommendations vary on the size of the sample used. Lincoln & Guba (1995) advocate the use of large studies using diverse sampling to ensure an extensive collection of data. Morse & Field (1995) differs in opinion preferring that the sample is smaller, focusing on those who have the most experience in the subject under investigation. Glaser & Strauss (1967) suggest sample size is decided by the individual researcher based on the intended depth of the study and aspired level of theory. Sample size is deemed satisfactory

when a point of saturation has been reached, clearly identifying all key concepts. One participant should be investigated at any one time and data analysis completed before the next investigation occurs. This way gaps in the required research can be identified and re-examined with the next participant (Smith & Biley, 1997; Glaser, 1998)

Glaser (1998) recommends the use of theoretical sampling to guide data collection throughout the whole study. Glaser argued that theoretical sampling is the only way to direct the emergence of grounded theory and is therefore critical to the study, being the prime method of moving the coding, collecting and analysing of data forward. Although grounded theory is considered an inductive method, theoretical sampling is a deductive approach; the focus of questions depends on the requirements of the emerging theory. By using this method, codes can be elicited from the data at the beginning of the study, and through the use of constant comparison and theoretical sampling, these can be used to direct further collection of data. This process continues until saturation of data occurs. Glaser (1998) states that in doing this the researcher is able to check on the emerging conceptual framework. Strauss & Corbin (1998) use this method to verify preconceived hypotheses. This is viewed by Glaser as forcing the data and is not advocated in his own method.

4.6.4 Data analysis

Constant comparative data analysis is the central feature of developing a grounded theory. As field notes and interview transcripts are collected

they are continually compared for similarities and differences. From the beginning of the research process data is coded and compared. Strauss & Corbin (1998) designed analysis to take place in three stages: open, axial and selective coding, each consisting of specific steps leading towards theory development. Glaser (1992) has criticised the high level of 'forcing' the data that these stages entail, preventing the emergence of concepts and later grounded hypotheses.

Analysis of data according to Glaser takes place in two stages: substantive and theoretical coding, constant comparison being the key feature to both of these phases (Glaser, 1992). Substantive coding involves the beginning of the journey of conceptualising from the data in hand, through constant comparison and use of memos. Theoretical coding then conceptualises how the substantive codes relate to each other through formulation of hypotheses which are integrated into the emerging grounded theory (Glaser, 1992).

By analysing the data the researcher is looking for emerging categories and their properties (a category being a higher level concept than a property). Categories also contain levels – the core category being the highest and accounting for most of the coping behaviour in the substantive area being researched. Theory generation, the aim of grounded theory method, occurs through establishing hypothetical relationships between the conceptual codes and categories (Boeije, 2002).

To begin substantive coding the data is read line-by-line making immediate comparisons. The goal of substantive open coding is to generate an emergent set of categories and their properties which will be relevant for integrating within the grounded theory. Incidents to incidents are compared enabling categories and properties to emerge. Glaser (1998) has outlined four purposes to constant comparison:

- It verifies the concept as a category denoting a pattern in the data
- It verifies the fit of the category nomenclature to the pattern
- It generates properties of the category
- It saturates the category and its properties by the interchangeability of indicators

(Glaser, 1998; p139)

Throughout coding neutral questions are asked of the data to develop categories: what category does this incident indicate?, what property of what category does this incident indicate?, what is the participants main concern here?, what is actually happening in the data?, what are the basic psychological problems faced by participants here? As categories are coded, memos are made to note their grounded meaning into the theory, their relationship to each other and how they emerge. Memos aid the researcher to capture meaning and ideas for the developing theory at the moment they occur (Glaser, 1998). Memos help raise the data to a level of conceptualisation and integrate groups of categories to generate theory. As more and more categories emerge the researcher begins to reach

saturation and theoretical completeness, a stage that occurs when different incidents point towards the same concept.

Once the researcher believes the emergence of a core variable has been discovered, substantive selective coding can take place. The core variable becomes the guide for further data collection and theoretical sampling. Memos increase their focus and may show gaps to lead theoretical sampling.

The process of comparing enables the researcher to confront degrees of consistency, similarities and differences, all building towards the emerging category. Concepts earn their way into the grounded theory through systematic generation from the data because they are relevant and they fit, as opposed to being used *a priori*. As more indicators are found to fit, the concept becomes saturated until nothing new is revealed in the data (Glaser, 1978). At this point the 'core category' should be compared to the following criteria to determine its position:

- It must be central
- It must reoccur frequently
- It must relate meaningfully and easily with other categories
- It must have clear grabbing indications for formal theory development
- It must be completely variable due to its relations to other categories

- It must be a dimension of the problem under study
(Glaser, 1978; p95-6)

Studies collecting fieldwork over a period of time may be more suited to look beyond core category development, emerging a basic social process (Glaser, 1998). A basic social process highlights the emergence of process, change and movement over time. The stages within a process should differentiate accounting for changes in behavioural patterns. The stages can be considered theoretical units with their own unique conditions, consequences and properties, functioning together to map and account for change over time. An example of a basic social process developed through grounded theory method is the Chronic Illness Trajectory developed by Corbin & Strauss (1991).

Basic social processes are discovered in the same way as conceptual categories. Constant comparison leads to emergent fit, a process is discovered accounting for variations in behaviour, the focus of the research is then directed towards investigating the process, using constant comparisons to generate a substantive theory (Glaser, 1998).

4.6.5 Ensuring credibility

Strauss & Corbin (1998) claim that exact replication of a grounded theory study is impossible although similar results may be obtained in similar situations which use identical theoretical perspectives and conditions. Research is legitimated through elaboration of the research method and

constant comparison. Grounded theorists do not claim generalisability of the grounded theory or have concern for degrees of probability (Glaser, 1978). A truth value is not found through looking for proof of the grounded theory but instead ensuring the theory has been developed through a rigorous research process that can be evaluated for trustworthiness. Verification involves searching for evidence within the data that backs up the statements and relationships that have been made. The end product of grounded theory should provide understanding of the phenomena but does not have to be generalised for purposes of control (Annells, 1996).

Atwood & Hinds (1986) recommend a panel procedure to evaluate the collected data. They suggest internal consistency within grounded theory depends on the accuracy of the coding process. A panel review from experienced researchers may help examine similarities within codes.

To ensure validity, Glaser & Strauss (1967) suggest sharing the collected data with participants enabling them to judge the work on face value. This provides researchers with the challenge of letting the voice of the participant resound strongly in the text. Creativity is required to develop the voice which is being represented (Annells, 1996). Participants can evaluate the representation of their world and perception of reality, clarifying that a true description has been made (Ashworth, 1993; Parahoo, 1997).

4.7 Congruency of grounded theory and Roy's Adaptation Model

The previous section has provided detail into the various schools of thought on GT and differing theoretical perspectives, namely the debates between Glaser & Strauss (1967), Strauss & Corbin (1998), Annel (1997), Glaser (1998) and Charmaz (2000) whose discussion continues to advance paradigmatic perspectives.

The purpose of this section is to outline the use of Glaserian grounded theory method alongside Roy's Adaptation Model as a theoretical framework as proposed for this study. The compatibility and scope of using grounded theory and Roy's Adaptation Model will be discussed, demonstrating the strength and practicality of the study. Discussion will be focused around Roy's Adaptation Model and symbolic interactionism – the social behaviourist theoretical basis of grounded theory which sets the stage for the examining process, identifying phases and stages within the experience. The discussion will begin by looking at the three main principles on which symbolic interactionism is founded and will then move on to look at its role within research affecting the compatibility of Roy's Model of Adaptation and grounded theory within this study.

Grounded theory was deemed the most appropriate research method for investigating the process of adapting to HIV/AIDS, providing the means to closely examine data in uncharted areas whilst offering exploration of social processes and interaction. Grounded theory is a means of understanding what is happening through revealing phenomena. It

bridges the gap between practice and theory, allowing for theory development (Sheldon, 1998). Roy's Adaptation Model was selected as a theoretical background due to its focus on the process of adaptation and the nurse's role in gaining understanding of this process to promote the patient's adaptation.

As previously mentioned, the philosophy behind symbolic interactionism was led by the pragmatists, most notably John Dewey (1859-1952). Later work leading to its development as a social theory took place by George Herbert Mead (1934) and Herbert Blumer (1969), both, as Glaser & Strauss, from the Chicago school of thought. There are many similarities in the theoretical aspects of Roy's Adaptation Model and symbolic interactionism enabling them to work neatly together within research. Although few authors have made reference to the compatibility of Roy's model and symbolic interactionism (only one could be found to do this, Raeside, 1997), Roy herself acknowledges the influence of Mead (1967), Sullivan (1953), Cooley (1964) and Goffman (1959, 1967). Their interactionist theories influence the characteristics of the self-concept and group identity mode of the Adaptation Model (Roy & Andrews, 1999, p108).

Glaserian grounded theory is influenced by the work of Blumer (1969). The underlying principle being based upon the way in which humans interact with each other and the environment and the meaning they derive from this interaction. Symbolic interactionism, according to Blumer, rests

on three premises. These will now be explored in more detail and compared to the theoretical basis of the Roy Adaptation Model.

1) *“Human beings act towards physical objects and other beings in their environment on the basis of the meanings that these things have for them.”*

(Blumer, 1969; p2)

Blumer proposes that all human behaviour and actions are based on the meaning that people have towards objects and the people around them. Blumer sees humans as actively defining this meaning, not merely responding to environmental stimuli (Blumer, 1969). This perspective could be seen as conflicting with Roy’s model of adaptation and her focus on human reaction to stimuli in eliciting an adaptive response. Roy conveys that although the “stimuli” in her model represent objects or situations triggering change, the degree of change would depend on the value or meaning of these change/stimuli to the person concerned.

Humans react to environmental stimuli based on the value these hold for them. The level and significance of this value, according to Roy, can be seen as represented in three levels of stimuli – focal, contextual and residual (Roy & Andrews, 1999). A problem or object identified as focal stimuli may trigger a change in adaptation level as the person may attach a strong meaning to it. Residual stimuli may remain unnoticed to the

person as they view it as having a largely insignificant value (at the present time).

The basis of meaning to humans can be identified in Roy's work through looking deeper into the philosophical and scientific assumptions of the model. Here Roy acknowledges that humans use creative abilities and are accountable for their actions (Roy, 2008). Roy recognises the complexity of consciousness and that each person has an awareness self rooted in thinking and feeling responses which are based on people's values (Roy, 1988).

2) *"Meanings derive from the social interaction between and among individuals."*

(Blumer, 1969; p2)

The second premise of symbolic interactionism focuses on social interaction and the meaning that develops from this. The ideology that Blumer presents is echoed in Roy's creation of the self concept/group identity mode. Roy recognises the importance of social interaction with others in order to develop meaning and value to oneself and the things around. Within the self-concept mode Roy states that beliefs and feelings about oneself stem from both internal and external perceptions. The value of these perceptions reflects on ones sense of self and is then used to direct future behaviour (Roy & Andrews, 1999). When looking at specific populations Roy suggests that groups perceive themselves as based on

environmental feedback. Group members use social interaction, sharing identity and goals in striving for identity integrity.

3) *“Meanings are modified and established through an interpretive process.”*

(Blumer, 1969; p5)

Blumer’s work focuses on the way in which meaning is interpreted, developed, modified and established. Although Roy does not outwardly detail humans ‘interpretive response’ it is addressed throughout the model of adaptation. Roy suggests that people interpret the environmental stimulus which eventually leads to behaviour as either an adaptive or ineffective response. Roy suggests human interpretation is formed through *“awareness of self and environment rooted in thinking and feeling”* and later that *“thinking and feeling mediate human action”* (Roy & Andrews, 1999; p35)

Through close examination of the premises of symbolic interactionism similarities can be seen with the scientific and philosophic assumptions of the Roy Adaptation Model. Symbolic interactionism is concerned with how the self develops; Roy is concerned with human development through adaptation. Symbolic interactionism states humans are active creators in their world. Roy recognises the active part that people play in creating the world around them when stating that:

“persons and the earth have common patterns and integral relationships” and that “humans by their decisions are accountable for the integration of creative processes”
(Roy & Andrews, 1999; p35)

The similarities in ontological and epistemological approaches between symbolic interactionism and Roy’s Adaptation Model continue when considering the research arena. This is manifested when answering two main questions considered by any researcher:

- What is to be the focus of the research?
- What is the role of the researcher in undertaking the research?

The underlying principles of symbolic interactionism are evident, although not essential, in grounded theory method, calling for investigation to depict relationships between conditions, meaning and action in given situations. The focus is on change, emergence and social processes, developing understanding around people’s actions – seeing objects as the participant themselves would see them (Glaser, 1998). The use of Roy in framing this helps focus the investigation around the concept of adaptation, the affect of environmental stimuli on coping levels, taking on board relationships, meanings and values inherent to the person within the social process of adaptation. Roy stresses that nurses should seek to understand stimuli from the person’s perspective in order to promote adaptation. Basic knowledge according to Roy is “*understanding people adapting within their various life situations*” (Roy & Andrews, 1999; p537)

Symbolic interactionism views life as a moving, formative process where participants are defining and interpreting each others acts (Blumer, 1969). Grounded theory reflects this in seeking to uncover fluctuating social processes (Glaser, 1998). Roy views adaptation as a fluid, continual process of using conscious awareness and choice to create human and environmental integration (Roy, 2008). Grounded theory can be used to uncover this process appropriately.

To unearth this complex social process of adaptation, gaining understanding of people's situation from the way in which they see them, researchers need to go directly to the empirical world of the participant (Blumer, 1969). This can be done through an ethnographical, phenomenological or grounded theory approach depending on the specific aims of the study. Roy's model of adaptation is open to the use of both qualitative and quantitative methodologies offering scope for researchers developing their ideas (Roy & Andrews, 1999). Roy's model focuses on adaptation, a concept that grounded theory is designed for and can therefore provide the means to openly investigate this process leading to development of new frameworks (Benoliel,1996). Roy advocates the development of conceptual models through research guided by the model; grounded theory is ideally placed to produce this. Roy's model also addresses the meaning of existence and the place of people in creation, grounded theory can be used to uncover perspectives of this cosmology (Roy, 2008).

In using the Roy Adaptation Model alongside grounded theory in this way the focus of the study remains on the process of adaptation for those with HIV/AIDS. The philosophical assumptions of Roy's model will guide the investigation, remaining true to the grounded theory process. It is not the aim to 'force' the collected data into the theoretical framework of Roy's model but instead the results will be used to test Roy's Model of Adaptation, bringing the final results alongside Roy's work to compare for similarities and differences. The method of grounded theory must be adhered to ensuring the research provides accurate, credible results which are able to stand up to vigorous analysis. Having outlined the background of the study and established the theoretical perspective, Chapter 5 explains how this is practically brought together, describing in detail the research method, addressing issues such as participant selection, ethical considerations, data collection and data analysis.

CHAPTER FIVE

Research Method

5.1 Aims of the research study

The previous chapter has outlined the development and background of grounded theory methodology. Within this chapter an account of the research is presented including method, questions and objectives. Ethical aspects will be addressed ensuring the design is rigorous and able to withstand critical analysis.

A preliminary review of the literature on HIV revealed a lack of understanding relating to the way people adapt to HIV/AIDS in their daily lives. HIV is a heavily researched area yet the process of adaptation has not been thoroughly investigated. There is minimal research investigating those with HIV/AIDS in Wales (Blakey & Frankland, 1995). To shed light on this, the research has been developed to focus on the process of adaptation for those living with HIV/AIDS in Wales. Roy's Model of Adaptation has been chosen as the theoretical basis, recognising the person as an adaptive system, making decisions in response to a changing environment. This nursing-based theory follows a humanistic approach, viewing persons as purposeful in the changes they make, allowing for in-depth study into adaptation. As one of the most frequently used nursing theories its usefulness has been proved within previous qualitative studies investigating adaptation to chronic and acute health, as reviewed in Chapter 2.

The research uses Glaser's grounded theory method allowing a rich description from the participants of their journey of HIV/AIDS and the way

in which they have adapted to each stage. The method has been chosen for its compatibility with the Roy Model of Adaptation, as outlined in the previous chapter. It allows for investigation of a process over time, and more specifically, leads to the development of a conceptual model outlining the stages of adaptation in those with HIV/AIDS.

The research question guiding this study was:

“What are the processes of adaptation for those living with HIV/AIDS?”

The objectives of the study were as follows:

- To identify, stages, if any, of adaptation throughout the course of HIV/AIDS.
- To outline the process of adaptation to HIV/AIDS within a conceptual model or basic social process developed through grounded theory.
- If stages of adaptation to HIV/AIDS exist, to test these against Roy’s Model of Adaptation. Can stimuli, adaptive modes and their interactive relationships be determined throughout the stages of HIV/AIDS as in Roy’s Model of Adaptation?

The assumptions underlying the research study were based on the philosophical orientation of Roy's Adaptation Model and symbolic interactionism:

- The person is the primary domain concept of nursing, viewed as a system, a set of parts connected to function as a whole for a purpose. Investigation into the way they adapt to situations places emphasis on the purposefulness of human existence.
- Description of life's journey through dialogical interviews and metaphoric representations will uncover the meanings of HIV to individuals, based on the assumption that humans act towards events on the basis of the meanings that these things have to them, and that these meanings are modified and established through an interpretive process which will be described by the participant.

Undertaking the research was founded on the philosophical principles of Roy's Adaptation Model. Grounded theory method was used to unveil the process of adaptation. Narrative and metaphoric descriptions were used by participants to illustrate this process. The results of the research have both societal significance in further understanding the journey of those with HIV, and professional significance, increasing the knowledge base of nursing and furthering development of the Roy Adaptation Model through testing of its main assumptions.

5.2 Focusing on the patient: selecting participants

Due to the large amount of data collected from qualitative research it was anticipated that only a small number of participants would be needed for the study. Under traditional grounded theory, the sample population is determined to examine the phenomena under study, not based on pre-chosen variables. Participants were chosen because they have knowledge or experience of the subject under scrutiny. The social process under study needs to have been experienced by the participants (Smith & Biley, 1997). Data was collected according to theoretical sampling and gathered until a point of saturation had been reached (the emergence of new data ended), therefore the number of participants could not have been stated beforehand (Chenitz & Swanson, 1986).

Based on the principles of theoretical sampling, participants were chosen according to the following inclusion criteria. The participant had to be:

- Over 18 years of age.
- Diagnosed with HIV/AIDS for a minimum of 3 years.
- Able to communicate clear English with no significant speaking or hearing impairment which could affect accuracy of the data collected.
- Resident or receiving care within South Wales.

As a local study, that aimed to reflect the experiences of those in South Wales (although not claiming that the resultant experiences are unique to

only those in this area), participants needed to be resident or receiving care within this location. Recruitment took place at two settings: the local genito-urinary medical (GUM) clinic, where the majority of HIV testing and treatment for the local area take place, and, the Terrence Higgins Trust Cymru (THT), the main non-governmental organisation providing support for those with HIV. Posters and postcards advertising the study were placed within the clinic and THT centre, (see Appendix 3). Potential participants were informed of the study by clinic staff; however participants had to make direct contact with the researcher if they wished to take part. To maintain confidentiality, no names of patients were taken from staff members. Full permission and support from clinic staff was obtained in order to obtain access to the site.

Participant recruitment took place over a period of approximately eighteen months. Due to recruitment difficulties consideration was given to expanding the area of recruitment and increasing the number of participating venues, as suggested by Faugier (1997). Snowball sampling was also kept in mind in case there were found to be further difficulties in recruitment. This would involve asking existing participants if they knew of anyone who would be interested in taking part in the research. It should be emphasised that using this approach the researcher would have no idea who the potential participant might be unless they contacted the researcher directly themselves (Kylma *et al*, 1999).

5.3 Protecting the participant: ethical considerations

HIV/AIDS is surrounded by an ethical minefield, particularly regarding issues of confidentiality. Those with HIV/AIDS are viewed as a vulnerable group due to the delicate nature of the illness, the stage of illness they may be experiencing, and the strong connections of HIV/AIDS with sexual behaviour and drug use (Parker & Aggleton, 2003). The nature of such a grounded theory study focuses on inner feelings and thoughts, requiring sensitivity, organisation and assurance that participants are protected from harm. Recognising the ethical implications of a grounded theory study, particularly amongst participants who may be considered vulnerable is imperative to ensure a fair, harm-free investigation, safe-guarding the participants and researcher (Parahoo, 1997).

Nursing is concerned with compassion, commitment, confidence and competence and the research should reflect these qualities (Kylma *et al*, 1999). As a piece of nursing research, ethical aspects cannot be considered without looking to the Nursing and Midwifery Council code of professional conduct. This instructs all nurses to:

“make the care of people your first concern, treating them as individuals and respecting their dignity...be open and honest, act with integrity and uphold the reputation of your profession”
(Nursing and Midwifery Council, 2008; p1)

Ethically sound research should guarantee the protection of basic human rights: the right to self determination, privacy, anonymity, confidentiality, fair treatment and protection from harm and discomfort (Munhall, 1988; James & Platzer, 1999).

The process of the study and outline of the interviews was explained to each participant. Grounded theory presents immediate problems for consent as questions during the interview emerge from the dialogue and therefore it is impossible for the participant to have knowledge of exactly what will be asked. Participants were made aware of this and it was pointed out to them that whilst the researcher was asking questions, they would be able to regulate the interview through the dialogue which they give. Participants could refrain from answering any questions and were encouraged to inform the interviewer if they became uncomfortable at any point. Participants were able to withdraw from the study at any time without prior notice with no implications on the care they received.

Full consent was obtained from participants before taking part in the research (see Appendix 4). This took place on commencement of the study and remained ongoing throughout the research process. Gaining consent was seen as a communication process enabling time to explain the aim of the study, what was involved and any implications. Information was given to potential participants in the form of an information sheet, presenting the details of the study (see Appendix 5). Each participant had access to the researchers' phone number to contact with any queries about the study. Discussion took place with participants prior to agreeing to take part in the study to ensure the participant met the criteria and fully understood their role in the research.

Risks and benefits of the study were explained enabling the participant to give full informed consent. Risks included the participant becoming distressed when talking about sensitive issues or reliving past emotions. This had the possibility of threatening the participants feeling of self control and integrity. The research was undertaken in an empathic and understanding manner at all times, ensuring the participant did not feel threatened or forced to keep discussing sensitive issues. Consideration was given to the length of the interview, this was determined largely on the participants desire to keep talking.

Benefits of the research included allowing the participant to talk about an experience which he or she was not often able to express. Previous qualitative studies have documented this as having a therapeutic effect, helping the participant to gain empowerment and self awareness (Hutchinson *et al*, 1994). Benefits to future nursing science have already been discussed, enabling a fuller understanding of the process of adapting to life with HIV/AIDS, and theoretical development to the concept of adaptation. This can be used to help nurses provide increase care, support and have more understanding.

Written consent forms were kept within the patients medical notes at the GUM clinic, to ensure full confidentiality. The consent form was the only evidence of the participant's identification, either as a name or clinic number. Numbers and letters represented the participant on all tape-

recorded and written documentation. All recordings were kept locked in the researchers possession on University premises.

Full ethical approval was granted from the Co-ordinators of NHS Research Ethics Committee (COREC) in April 2004, giving permission for the study to take place. Permission to recruit participants was granted from the consultants and nursing staff at the GUM clinic, and staff at the THT.

5.4 Listening to the patient's story: interviewing and data collection

Interviews provide an ideal medium in which to obtain deep descriptions of life events (Crabtree & Miller, 1991). They also enable the researcher flexibility in being able to guide the topic of conversation, checking the reliability of the interview, confirming responses and verifying the interviewers own interpretation. A semi-structured interview enables the researcher to see the participant in person and provides the opportunity of gathering data in the form of field notes, noting details such as facial expressions and posture (Mulhall, 2003).

The relationship between the researcher and participant can strongly influence the data acquired. A relationship of trust and good rapport is more likely to place the participant at ease, leading to more open and honest replies. Miczo (2003) has established a set of interactional requirements for the researcher when conducting interviews on illness: reassurance, encouragement, alleviation of blame, confidentiality,

understanding, sympathy, expression of feeling and validation. Issues such as alleviating the participants feelings of guilt or validating their feelings are often left out when scrutinising the data. Using these methods within interviews can help give assurance to the participant yet must be acknowledged in data analysis (Miczo, 2003).

The conduct of the interview was based on the philosophical perspective of the Roy Adaptation Model, recognising the person and the subjective dimension of their experience as central to knowing and valuing. Roy bases nursing ontology on the need for human meaning and articulation of person's values (Roy, 2008). Formal unstructured interviews are the most common method used in grounded theory; these are congruent with Roy's theoretical basis and were the method chosen for this research study.

Roy refers to the use of interviewing as part of the nursing process in assessment of a persons behaviour and environmental stimuli. Roy suggests the use of purposeful questioning using the person's verbal response as behavioural data. Skilful observation and sensitivity are needed to uphold the scientific and philosophic assumptions of the Roy Adaptation Model advocating acceptance, protection and fostering of independence within all relationships (Roy & Andrews, 1999).

Interview questions stemmed from the aims and objectives of the research. Each interview began by asking open questions about the experience of adapting to HIV/AIDS. It was viewed as important to allow

the participant to articulate their values and express the meaning of their experience, as encouraged by Miczo (2003). Questions sought to uncover the experience of adapting to life with HIV/AIDS, identifying stimuli and adaptive modes in accordance with Roy's Adaptation Model. Further questions emerged from the dialogue. Examples of initial questions posed are seen in Table 3:

Table 3 – Research objectives and questions

Research objectives	Initial research questions
<ul style="list-style-type: none"> - To identify processes of adaptation for those living with HIV/AIDS. - To identify stages (if any) throughout the course of HIV - To determine (if any) the stimuli, adaptive modes and their relationships throughout the stages of HIV. 	<ul style="list-style-type: none"> - Tell me about your experience of adapting to HIV/AIDS - Has HIV changed anything in your life? - What have these changes meant for you? - Have there been significant points in your life in which HIV has forced adjustments? - What aspects of HIV have led you to make adaptations?

To gain an impression of changes in adaptation over time, participants were interviewed twice over a six month period. Three advantages were identified in conducting a second interview. Firstly, a second interview provided the opportunity to clarify points from the first interview and determine these meanings. Some participants were recalling experiences of HIV as far back as 25 years. If diagnosis of HIV is assumed to be a 'traumatic' event, research indicates traumatic memories are extraordinarily persistent over long periods of time (Berntsen, 2001). Traumatic incidences have been found to be recalled by the memory more

reliably than other emotional experiences (Peace & Porter, 2004). This implies that the stronger the stimuli affecting the need for adaptation, the more accurately it is likely to be recalled during an interview reflecting on past life events. Conducting a second interview with participants enabled clarification of these memories, providing a means of continually checking the emerging conceptual model.

Secondly, subsequent interviews enabled investigation into issues brought up by other participants since the initial interview. This provided a way of checking the emerging conceptual framework against each participant, developing stronger categories and heightening theoretical sensitivity.

Thirdly, as a study investigating adaptation over time, the second interview enabled opportunity to identify any issues that may have caused changes or a need to adapt since the original interview. For example, some participants had commenced anti-retroviral therapies during this time; such changes could then be picked up and themes woven into the grounded theory.

Following recording of interviews, each was transcribed. Transcriptions served as a reminder for the researcher of the interview conducted.

Glaser (1998) warns against the traditional method of transcribing claiming it ignores the theoretical saturation of categories and can delimit the production of theory. Glaser claims the researcher should use field notes and memory only, trusting in emergence of categories. The use of

transcriptions have been debated within the field of linguistics which recognises that all transcriptions take sides, enabling interpretation in the interests of the transcriber (Bucholtz, 2000). Indeed the reader of the transcription will bring to it their own interpretation.

Due to the length of this study, participants being recruited over an eighteen month period and interviews taking place over a two year period, transcriptions were essential to serve as a reminder of the topics covered within the interviews. Observational data was collected through note-taking immediately after the interview. (Notes were not made during the interview to prevent distracting the participant). Notes were collated alongside the transcript and used during the coding process of data analysis.

5.5 Understanding the patients story: data analysis

Data analysis included open, substantive coding and theoretical coding, as outlined by Glaser (1998). Analysis started immediately during data collection. The researcher during interviewing continually breaks down ideas, seeking emergent categories from the responses of the participants.

Following transcription of the interviews, open coding took place, its goal being to generate a set of properties and categories which fit towards integrating into a theory (Glaser, 1998). Two analytic methods were the key to this stage: asking questions and constant comparison – both form

the method of constant comparative analysis. Questions were asked of the data such as “what is this data a study of?”, “what category does this incident indicate?”, and “what is actually happening in the data?” (Glaser, 1978). Such questions enable the breakdown of data through “categorising”, enhancing theoretical sensitivity. A line by line analysis of the text took place with each category being labelled and then placed on index cards giving the name of the category and area from which it emerged. Each identified category was given a name representing the concept to which it referred, a process known as substantive coding.

The process of constant comparison, as described in section 4.6.4, was used to guide theoretical sampling around the gradually emerging categories. Sampling in this way provides a basis to continually check on the emerging conceptual framework. Constant comparison and theoretical sampling go hand in hand leading to the development of grounded theory. Although grounded theory is described as an inductive process – the theory is induced after data collection starts – there are deductive aspects such as theoretical sampling, which are vital to the process. The following comparisons were made of the data:

- Comparing incident to incident
- Comparing concepts to more incidents
- Comparing concepts to concepts.

The above comparisons took place on four different levels within the research:

- Making data comparisons within each interview
- Making data comparisons amongst all first interviews
- Making data comparisons amongst all second interviews
- Making comparisons between all data of first and second interviews

(Developed from Boeije, 2002)

Further questioning of the data was used to aid the comparison process. Examples of such questions can be seen in Figure 10. This rigorous process led to the development of theory directly traceably from the data.

Selective coding, the second stage in the process took place following open coding although these stages had considerable overlap. Selective coding involved searching for 'core variables' – delimiting the coding process to only those categories that related to the core variables. The core variables then became the guide for further theoretical sampling. Selective coding aims to lift the data to a higher level of analysis. The focus is on providing conceptual specification – being able to visualise the categories, the concepts they have led to and the core variables that then emerge (Glaser, 2002). Through doing this, categories are not just developed because they appear relevant but because they have earned their way into the theory through continual emergence (Glaser, 1978).

Figure 10 – Data comparison points

1. Comparison of single interviews
<ul style="list-style-type: none"> • Which codes are used to label the categories in this particular interview? • What characteristics do fragments with the same code have in common? • What is the core message of this interview? • Is the storyline consistent? • Are there any expressions with are contradictory? • How are all the fragments related?
2. Comparison between interviews in the same group (eg. all first interviews)
<ul style="list-style-type: none"> • Is interview A talking about the same category as B? • What do both interviews tell us about the category? • What are the similarities and differences between interviews A, B and C? • What are the criteria underlying this comparison? • What combination of codes/concepts occurs? • What interpretations exist for this?
3. Comparison between interviews of different groups (eg. between first and second interviews)
<ul style="list-style-type: none"> • What does group 1 say about certain themes? • What does group 2 say about the same themes? • Which themes appear in one group and not in the others (and vice versa) • Do both groups view any issues similarly or differently? Why? • What additional detail/new information does one group supply about another group?

(Taken from Boeije, 2002; p397-9)

The third stage, and often the stage described as the most taxing for the researcher, is that of theoretical coding (Glaser, 2005). Theoretical coding differs to that of previous substantive coding, although in many papers the unique and essential qualities of each stage are not differentiated.

Substantive codes are described as:

“the categories and properties of the theory which emerge from and conceptually image the substantive area being researched”
(Glaser, 2005; p11)

Theoretical codes are emergent and work to weave the substantive concepts back towards an organised theory. Theoretical codes conceptualise how the substantive codes will relate to each other as interrelated hypotheses which explain the main aim of the research. Glaser explains that theoretical codes without the basis of substantive codes would just be empty abstractions (Glaser, 2005).

Glaser describes many of the theoretical codes that may emerge (and have emerged through previous research). These may be basic social processes (BSP's), social worlds, micro-macro, binary, autopoiesis etc (Glaser, 1978, 1998, 2005). The variety of outcomes all consider the different disciplines that may use grounded theory. Outcomes will also depend on whether qualitative or quantitative data is used. Theoretical codes should stem purely from emergence. It is necessary to consider preconceptions which may develop from discipline backgrounds.

Theoretical coding needs to be used with care, ensuring the data and substantive codes are not forced through anticipation of pre-existent frameworks. This process is vital to the development of a sound grounded theory.

As mentioned in the previous chapter, Glaser warns against the influence of external theoretical perspectives of specific disciplines when using grounded theory, in particularly during the stage of theoretical coding.

Glaser is adamant that grounded theory should not be “hand maiden” to specific schools of thought. He states this could lead to conducting the research with a prerequisite theoretical code in mind (Glaser, 1978). Theoretical or philosophical perspectives can be used provided this is clarified from the beginning and the researcher remains open to other perspectives which may naturally emerge from the data. This research study is influenced by the epistemology of symbolic interactionism which affects the approach to interviewing and the whole study overall. Roy’s Adaptation Model has guided the aims and objectives of the study to further understanding into the concept of adaptation. Grounded theory has been chosen as the method to unveil this process of adaptation (be it a basic social process or other theoretical codes). The emergent theory is taken back to the discipline of nursing and compared to Roy’s Adaptation Model but not forced into the structure of the model.

5.6 Other considerations: the accuracy of memories in recalling autobiographical events

“We have to depend on memory in order to gain knowledge of the past, indeed any knowledge at all”
(Hamilton, 1998; p290)

It is well established that due to treatment developments patients with HIV are living longer and healthier lives. Many patients have been living with HIV for up to 20 years, sometimes longer. This research looks at the overall experience of HIV, from diagnosis up until the time of interview. Some participants are reflecting on experiences that happened quite some

time ago. The possibility of time altering perspectives of memory may have implications for the accuracy of the study, for instance, a participant may give a very different account of his diagnosis which took place 15 years ago than if he was to recall the situation at the time it occurred.

The accuracy of memories is well researched within psychology yet results remain inconsistent. The results from research into this area are found to be either inconclusive or contradictory. Some studies have revealed that depressed mood is inaccurately recalled (Christianson & Engleberg, 1999) others state it depends on the individual as some may use repression of memories as a form of coping more than others (Newman & Hedberg, 1999). Hamilton (1998) argues that there can be no empirical justification of memory as this could only be achieved through the resources of memory itself. The subjectivity of memory is both acknowledged and accepted within this study. Confabulation, from the perspective of the Roy Adaptation Model, can be seen as part of the creative changes made in the process of adaptation. Roy accepts that to understand and value human experience is founded on subjectivity.

Despite accepting the subjective nature of narratives, evidence suggests that the way in which questions are asked will determine the nature of the answer given. Therefore in an interview situation (be it structured or semi-structured) measures can be taken to obtain accurate descriptions. Recall may be improved through prompts. For instance, using clues about an incident such as who was involved and where the event took place may

trigger more accurate memories. Using clues about location have been found to improve recall above asking the date of an event (Bradburn *et al*, 1987).

Experiments on autobiographical recall suggest events are often recalled in a sequence. Research has demonstrated that beginning with the most recent memory and working backwards can be more effective than starting 'at the beginning' and working forwards (Bradburn *et al*, 1987). Using semi-structured interviews to obtain narratives can be useful in gaining insight into a sequence of autobiographical events, as anticipated through this research.

5.7 Bringing together the research method and theoretical framework

A preliminary review of the literature (Chapter 1) revealed a lack of knowledge of how individuals adapt to living with HIV. The paucity of recent research was particularly evident given the changing nature of the disease and treatments now available. The research aim to investigate the process of adapting to life with HIV stemmed from this exploration.

A qualitative research method seemed the most appropriate given the desire to understand subjective human experience. Grounded theory method was chosen for its qualities in outlining previously unexplored areas and developing the data into a theory or basic social process. Using

grounded theory allows for exploring the nature of adapting to HIV, outlining this process as it naturally emerges from the data.

As a nursing project, with results that are particularly applicable to nursing practice (among other professions) it was decided to explore existing nursing theories and philosophies that might be appropriate for framing the study. This was approached with caution given the nature of grounded theory method – the need to ensure research data is not biased by or forced into pre-existing frameworks.

Roy's Model of Adaptation was reviewed (Chapter 3), the nature of which naturally fitted into a study of adaptation. The philosophical nature of the model was examined and fitted neatly alongside the philosophical background of grounded theory method (see section 4.7). Both the philosophical assumptions of Roy's model and the philosophical background of grounded theory are concerned with human development, both recognising that humans are active creators within their world. Grounded theory calls for investigation to depict relationships between conditions, meanings and actions. Roy calls for investigation into relationships, meanings and values within the social process of adaptation. Grounded theory looks to uncover fluctuating social processes. Roy calls for investigation into the fluctuating processes of human and environment integration. Such similarities allow both grounded theory and Roy's Model of Adaptation to work well together,

however to prevent forcing of data or bias, this needed to be done sensitively.

The research method, as outlined in this chapter, was conducted according to Glaser's method of grounded theory. The philosophical assumptions of Roy's Model of Adaptation (see section 3.3) were used to ground and conduct the study, and form a platform on which to view the data. Roy sees people as having creative abilities of awareness, enlightenment and faith (Roy, 2008). Persons are viewed as accountable for their own processes of sustaining and transforming. It is these aspects that are explored by the grounded theory method, investigating how people adapt to living with HIV. Through using grounded theory, the data emerged freely and was eventually used to contrast with Roy's Model of Adaptation (see Chapter 7). The data was not gathered to 'fit' into Roy's Model of Adaptation.

As well as being philosophically guided by the theory, this research has the dual purpose of testing Roy's Model. Once the data emerged, having reached a point of saturation, and the final process had been written up, the resultant grounded theory was taken back to Roy's Model of Adaptation to contrast for similarities and differences. Consideration is given as to whether any of the resultant processes of adaptation resembles those laid out within Roy's Model. This tests Roy's model, strengthening its existing framework where similarities are found, or suggesting further areas for development where differences are noted. It

was anticipated that the concepts of 'time' and 'perception' would be explored, as recommended by Roy (see section 3.11). The nature of examining changes made in order to adapt to HIV over time naturally uncovers aspects of these concepts.

This chapter has outlined the details of the whole research process, considering recruitment, interviewing, ethical considerations and data analysis. The chapter has concluded with a synthesis of how the research process is brought together using Roy's Model of Adaptation, explaining the impact of this model on the whole research study.

The following chapter presents the results of the grounded theory that. An introduction is made to the data collected, considering limitations to the study. The core-category and seven subcategories are described in detail. Theoretical conclusions and the application of Roy's Model of Adaptation relating to the grounded theory are made in Chapter 7.

CHAPTER SIX

Results: The Emergent Grounded Theory

“Before scientific theory comes the story.

When the scientific theory is able to explain and predict, individual narratives are no longer required as a starting point. They become merely exemplars of the theory that they are informed.”

(Mooney, 2005; p72)

6.1 Introduction

This research was established with a dual purpose to develop an outline of the process of adapting to life with HIV whilst testing this process against Roy's Model of Adaptation, an established nursing model. There are therefore two components to the results of this research. Firstly the results of the grounded theory, the process of adaptation that emerged directly from the data. This is presented here, in Chapter 6.

Secondly, having established the grounded theory, it is able to be tested by, and to itself test, Roy's Model of Adaptation. The theoretical element of the results is presented in Chapter 7. The dual aspects of these conclusions are brought together at the end of Chapter 7 in future recommendations.

The data resulting from this study demonstrates clearly and uniquely the way in which a group of individuals have adapted (and are adapting) to being HIV positive. All participants recalled a point of diagnosis. It was clear from the voices of the participants that this process involved adapting from an HIV negative life to an HIV positive life.

At a conceptual level, the resultant grounded theory revealed a process of adapting to uncertainty. 'Negotiating uncertainty' was established as the core concept. Seven subcategories underpin this process as explained later in this chapter. The theory of adapting to uncertainty could and

should be applied, tried and tested among uncertainties experienced within different disciplines, to strengthen and develop it further.

The resultant grounded theory not only furthers the conceptual meaning of uncertainty but demonstrates the way uncertainty is perceived and managed in order to adapt to the unknown. The results illustrate the role of uncertainty in life-course planning and the relational search for certainties to balance this as a way of moving forward. The grounded theory demonstrates the significance of the passing of time on the way uncertainties are perceived and adapted to.

A grounded theory does not simply present itself as findings but instead as an integrated set of conceptual hypotheses accounting for behaviour in a given area. What follows in this chapter is a conceptual outline of the process of adapting to life with HIV as emerged conceptually from the data. The following data analysis is not intended to be descriptive; discussion takes place amongst the concepts themselves rather than the participants as individuals; thus the grounded theory is placed into a theoretical realm, increasing its transferability between disciplines. Description taken directly from the data is used to demonstrate the emergence of concepts.

The following section provides a background to the data collected, leading into a brief synopsis of the grounded theory. The chapter then explains the core concept of 'negotiating uncertainty', leading into further

exploration of the seven subcategories, and their subsequent categorical pairs, outlining the whole process of adapting to an HIV positive life.

The literature has been reviewed in light of the emergent results, and is presented within each of the following sections alongside explanation of the data. Literature searches were conducted of journal publications, databases used were ASSIA, BNI, CINAHL, Cochrane Library, Ingenta Connect, Internurse, Medline, PsychInfo and Science Direct. A hand search of journals also took place to locate the most recent publications. Google Scholar was used to locate papers by specific authors. Internet searches were used to access up to date statistics, policies and government documents. The literature adds substantial weight to aspects of the emergent theory, and in other places is challenged by it. The theory provides new information and highlights gaps for further investigation.

Reflections of the results in light of Roy's Adaptation Model and the place of the theoretical findings within the nursing realm, is presented in chapter seven.

6.2 Background to the data collected

Fifteen interviews took place with eight HIV positive participants. All were recruited from a GU clinic in South Wales where they were receiving regular check-ups or attending for treatment. All participants were of British origin but came from a variety of backgrounds and cultures. Although this research was based in Wales, participants were not

necessarily of Welsh origin and therefore this study does not claim to be representative of a specific cultural group. All participants were male (there were no female respondents to the research recruitment) and had been living with HIV for between three and twenty years.

Four participants were on anti-retroviral medications. Three were either symptomatic of HIV at the time of interview or had experienced symptoms in the past. The remaining five participants had remained asymptomatic since diagnosis. None of the participants had been formally diagnosed with AIDS. Participants were not asked to disclose their mode of transmission however most chose to reveal this of their own persuasion. Of those having contracted HIV through sexual intercourse, six identified themselves as homosexual and one as heterosexual, one participant chose not to disclose his mode of transmission or sexuality.

Each participant was interviewed twice. Fifteen interviews were conducted, one participant choosing not to take part in a second interview. All interviews were transcribed for ease of data analysis, taking into account the long period of time over which the interviews were conducted. Interviews were analysed in the chronological order in which they took place, regardless of whether they were the participants first or second interview. Second interviews had the advantage of retesting emerging themes, aiding the elaboration of concepts.

Data collection, as previously stated in Chapter's 4 and 5, was based on constant comparison; the findings from one interview led onto inform the next. The first interview started with very open questions: "tell me about how HIV has affected your life", "has HIV enforced any changes to your life?" and "have anticipations of your future changed since being diagnosed with HIV?". This helped to establish open dialogue about the effect of HIV on daily life. Data was coded immediately after each interview (open-coding). Subsequent interviews were influenced by the coded categories from the previous interviews. In some instances concepts continued to be grounded throughout the interviews, other themes did not reappear. These were coded but later disregarded. Interviews moved forward according to themes which continued to occur (theoretical coding). The final interview confirmed the subcategories and core category that led to the grounded theory.

6.2.1 Limitations

HIV/AIDS is a sensitive area of healthcare to work within, issues of confidentiality proved challenging to the recruitment of participants. Recruitment, as described in section 5.2 took place using poster advertising and through the assistance of the staff at the GU clinic. The sample of participants was small, as often found within qualitative studies, yet the amount of data collected was large and rich, with some interviews lasting 2 hours or more.

Saturation of data was reached within 15 interviews, the core concepts clearly emerged. Constant comparison led to the elimination of some coded memos, for example: medication choices, service availability, stigma, religious faith, gay community. Coded notes that emerged from one interview but did not compare and continue emerging in other interviews were eliminated. The data collected was rich allowing the strong emergence of the categories outlined in this grounded theory.

Participation was open to patients diagnosed with HIV whether male or female, from any ethnic background or nationality, symptomatic or asymptomatic. Specific patient groups were not targeted. This had the advantage of increasing the number of patients eligible to take part. This also meant that patients could not be picked for any other reason than having 'HIV'. There were no patients with AIDS that volunteered to take part. The results therefore present a process of adapting to 'HIV' and not 'AIDS'. This has been made explicit. Although recruitment took place in a local clinic, the data is not representative of a specific area or culture group. Some patients travel long distances from their home to the clinic. Cultural issues were not specifically sought out or emergent.

Disappointingly no women volunteered to take part in the study. The results therefore do not claim to represent how women with HIV might adapt. Future application of the findings to a group of women with HIV gives scope to strengthen and develop the grounded theory.

The grounded theory, as will be elaborated, described a detailed process of adapting, whilst acknowledging that HIV did not bring any great changes to life. 'Existing as-was' (section 6.5.7) demonstrates that a large part of adaptation involved adapting to the fact that nothing changed when expecting everything would change. It is acknowledged that this overriding positive theme may be due to participants volunteering for the study that feel positive, motivated and well. Patients who do not feel well (physically, mentally or emotionally), and who feel as if they are not coping with their diagnosis may be unlikely to volunteer to talk about their experience. The recruitment method, necessary due to confidentiality issues, may have put-off or prevented such patients taking part. This possibility is acknowledged. The grounded theory is open to modification if further developed amongst a greater number of patients in different stages of the HIV process.

The following sections outline the grounded theory and in describing the concepts, demonstrate how it emerged. Relationships between subcategories and the core concept are explained. A brief synopsis of the grounded theory acts as introduction followed by an exploration of the core concept, leading onto explain the seven sub-categories that outline the process of adapting to HIV.

6.3 A brief synopsis of a grounded theory of adapting to life with HIV.

Adaptation was established as a necessary process to adjust to an HIV positive life from an HIV negative one. Adaptation took place as a process of negotiating uncertainties, moving away from an initial anticipation of hopelessness towards a regaining of optimism for life. The core concept of 'negotiating uncertainty' formed the backbone of the grounded theory and was the action responsible for the constant shifting between hopelessness and optimism.

Seven areas emerged in which uncertainties were most prominent, and required significant negotiation and deliberation:

- when considering risks
- when seizing opportunities
- when making plans for the future
- when attempting to assume direction
- when finding hope to strengthen
- when expanding vision
- when attempting to exist as before.

These areas formed the seven subcategories of the grounded theory and demonstrated how uncertainty was adapted to. The active process by which adaptation took place is explained within a pair of categories contained within each subcategory. Continual movement between

categories and subcategories established adaptation as an active and often proactive process.

Each subcategory contained a pair of categories, suggestive of bi-polar opposites, one representing an anticipation of hopelessness, the other of the pair representing a point of being able to regain optimism. Movement between these categories explicitly shows how participants actively adapted to the uncertainties faced. Perhaps more importantly, they show how uncertainties could not be adapted to without a conscious decisive movement resulting in change (of thought or action). Each subcategory and its pair of categories are outlined in Table 4.

Table 4 – Subcategories of the grounded theory and their categorical pairs

	Movement of negotiating uncertainty	
Subcategory	Anticipating hopelessness	Regaining optimism
Considering risk	Denial of risk	Acceptance of risk
Seizing opportunity	Destroying life	Saving life
Planning for future	Escaping	Distracting
Assuming direction	Controlled by HIV	Controlling HIV
Strengthening through hope	Vulnerability	Empowerment
Broadening vision	Self-focusing	Self-comparing
Existing as-was	Changing everything	Staying the same

Movements between categories were continually fluctuating, moving back and forth as the perspective and relevance of uncertainties changed.

Movements between categories could take place at any time and often

simultaneously. Fluctuations between pairs occurred as uncertainties were negotiated and certainties sought in order to strive towards an adaptive state of regaining optimism. Adapting to HIV, or uncertainties, was never static, movements between categories occurred too-and-fro as situations changed. Movements could not occur without negotiating uncertainty, the concept central to the whole process.

The forthcoming sections of this chapter describe in depth the grounded theory, outlining each sub-category and category, demonstrating the complex relationships within these and with the core concept. The order in which the categories are described does not necessarily represent the order in which they were experienced. Each participant experienced shifting movements through the categories, retreating from and revisiting categories as fluctuations transpired. Categories often overlapped, being experienced simultaneously as will be seen more clearly in the following analysis. Extracts from the interviews are presented to demonstrate the emergence of categories through constant comparison. What follows immediately is an analysis of the core concept, 'negotiating uncertainty', demonstrating its position as central to the process of adaptation.

6.4 The core category: 'negotiating uncertainty'

When reflecting on life pre-diagnosis it emerged that life appeared stable and secure, plans for the future were tangible and realistic. An HIV diagnosis changed these existing plans, once perceived as certainties, into uncertainties, casting a question mark over the present, future and

past. The data described the life of those with HIV as having two definite stages, that before diagnosis and that after. As data was gathered it became apparent that the process of adapting to a life with HIV was indeed a process of adapting to uncertainty; the idea of 'negotiating uncertainty' formed the core category, becoming stronger and more evident in each interview. Constant comparison ensured that as each interview progressed, the concept of uncertainty within HIV was pressed further.

Negotiating uncertainty was an active process involving consideration and reflection over many situations unique to the participant whereby they identified an uncertainty, or in some cases something they perceived as a risk. The emergent active process of negotiating over an uncertainty involved:

- Considering possible positive (desired) outcomes.
- Considering possible negative (undesired) outcomes.
- Negotiating the potential certainty of each outcome and ways in which the preferred outcome could be achieved or influenced.
- Choosing a desired outcome and striving towards achieving its certainty.
- Continually negotiating uncertainties whilst striving towards the desired outcome.

Negotiating uncertainties was a continual process as situations in life changed. Adapting did not happen automatically over time but involved conscious thought and subsequent action. The passing of time did however influence the ability to take on board these conscious decisions (this is discussed further in section 7.7.1). New uncertainties arose for participants that changed the original outcomes they were striving towards; this could be triggered by any number of situations such as starting antiretroviral medication, changes in family situation, relationship status or a change in ambition.

Negotiating uncertainties took place on a day to day basis of living as HIV positive. This theory describes the process of adapting to an HIV positive life, starting at transmission of the virus, leading to diagnosis and life beyond. When a risk of transmission was undertaken and later recognised, participants began negotiating the uncertainty of whether they may have contracted the virus. Deciding on testing involved mulling over ideas of whether they were likely to be sero-negative or positive, weighing up their perceived chances of each outcome by considering the number of episodes of exposure and using their own perception of transmission risks. The data demonstrated a period of negotiating these uncertainties which lead to the decision to undergo HIV testing in order to establish a certainty.

Uncertainties did not end after receiving the scientific certainty of an HIV positive sero-status. Diagnosis created a multitude of uncertainties over the present, what the future would hold, and of how certainties had been

perceived in the past. Continual questions over transmission risks in light of the diagnosis lead to reflection of past theories of transmission, casting uncertainties over past decisions. Many participants felt they had been acting safely and considered taking 'minimal' transmission risks as being something that would be certain enough to remain sero-negative. Thus an HIV positive status cast uncertainties over past perspectives of being certain participants were not at risk. This was demonstrated through participants reflections on their past:

“why did this happen, how can this have affected me when I have done my utmost to protect myself in the past?”
(Interview 5)

“but I usually practice safe sex so I did think about it but I never thought about what life would be like with it because I thought I would never need to”
(Interview 3)

“I was regularly, every six months going and getting tested, although I thought I was practicing safe sex, I wasn't obviously otherwise I wouldn't have caught”
(Interview 4)

“I really didn't think I was ever going to become HIV positive ever because I thought I was always the one that never took risks”
(Interview 10)

“I didn't reduce it to a percentage but I would have said it was less than 10% chance because it seemed to me that it would require extraordinary bad luck to be infected on that one occasion...so I wasn't prepared by anybody in advance of a positive result”
(Interview 11)

Uncertainties after diagnosis were centred around the questionable impact that HIV might have on the future. Would physical ill-health be imminent

and how would this impact on daily life? Participants revealed great uncertainties over not knowing how shortened, if at all, their life would be. In light of this participants debated whether existing ambitions (once certainties) were still realistic:

“I didn’t expect to live longer than four years anyway...there may be long periods where I am sick and I might face discrimination and quite a lot of prejudice”
(Interview 1)

“I mean rightly or wrongly for the first two or three weeks I thought I was going to die, so I was thinking of all the things I wanted to do before I die”
(Interview 3)

“because at the beginning I thought you haven’t got long to live – potentially you’ve only got five to ten years to live, just cram it all in”
(Interview 4)

“I was scared because I didn’t know what was going to happen in my life, if anything was going to change”
(Interview 10)

“Suddenly the road ahead appears very uncertain and I knew enough about AIDS and HIV to know that this was a big problem but I didn’t know exactly what it meant, what the prognosis was...if I had been told I had a year to live I would respond differently to if I had been told I had ten years to live or twenty years”
(Interview 11)

Uncertainty arose through the unpredictable nature of an HIV-future, which formed the backbone of this grounded theory. As this governing uncertainty could not be reversed, removed or immediately solved, it had, at some point, to be adapted to.

The negative impact of the uncertainties imposed by HIV created a clear anticipation of hopelessness within the data. Emergence of categories such as vulnerability, destruction of life, escapism, denial and self-focusing describe this stage of hopelessness. Descriptions such as *“the rug had been pulled from beneath my feet”*, *“the stuffing had been knocked out of me”* (Interview 1), *“I was devastated”* (Interview 5), *“it came as a complete shock”* (Interview 2), *“it depresses you, brings you down”* (Interview 6), *“it’s a bit of a smack in the face”* (Interview 10), *“it was the proverbial being punched in the gut”* (Interview 11), provide evidence of the shock and despair felt when faced with HIV.

The data revealed that the uncertain future of the virus was blamed for these feelings. It also highlighted a desire to overcome this way of feeling and where possible, to regain a perception of control back from the virus. An attempt to regain optimism was made by creating achievable goals, or potential certainties amongst the uncertainties. The data showed it was possible to reach a point of ‘regaining optimism’. Feelings between anticipating hopelessness and regaining optimism fluctuated daily, or even hourly but remained universal. All experienced these feelings with some being able to maintain a state of optimism for longer periods. Each individual was unique yet the process of adapting they shared was the same.

For each category within the subcategory of anticipating hopelessness, a method of adapting was established through regaining optimism over a

situation. This took place, as outlined by the emergent subcategories, through seizing opportunities, assuming life's direction, broadening vision, making plans for the future and using hope to strengthen self. The link of each subcategory to the core concept of 'negotiating uncertainty' can be seen in Table 5. Applying these adaptive strategies enabled optimism to be regained, leading to a sense of empowerment and the feeling that HIV had in many ways not actually changed a thing.

Table 5 – Relationship of sub-categories to the core category

Sub-category	Link to core category 'negotiating uncertainty'
Considering risk	Negotiating the modes of transmission, considering the possibility of being HIV positive and establishing this uncertainty through testing. Reconsidering transmission risks in light of results.
Seizing opportunity	Moving from the negative uncertainties that HIV brings to establishing new opportunities that would not be experienced without HIV.
Planning for the future	Overcoming uncertainties by moving from escapism strategies of ignoring HIV to developing positive plans for the future that encompass an HIV diagnosis.
Assuming direction	Minimalising the uncertainties of HIV by taking practical steps to control the uncertainties of HIV.
Strengthening through hope	Moving from the vulnerabilities caused by the uncertainties of HIV to establishing hope leading to empowerment.
Broadening vision	Moving from focusing on the uncertainties of oneself, widening vision towards others for encouragement and hope.
Expecting as-was	Negotiating the impact of the uncertainties of HIV on the past, present and future. Establishing ways in which life need not change due to diagnosis.

Adapting to uncertainty was a gradual active process, almost circular in motion as new uncertainties arose. The concept of 'regaining optimism'

came from being able to reach or strive to reach a desired goal, identifying new opportunities along the way. The desired goal for each participant was to get rid of the HIV virus, hoping for a cure. As this is presently impossible, the data revealed ways of dealing with uncertainty by establishing other achievable certainties and actively making positive life changes.

“I am feeling less stressed, I’m managing my time better and I’m training and my diets better...my relationships with family members, my intimate relationships have taken on a new meaning, I have become more empathic”
(Interview 1)

“There is things I want to do, I want to travel, do all sorts of things. Initially I thought I couldn’t do any of that but now I am thinking I can do all of that”
(Interview 3)

“you need to have some sort of distant goal, even if it is only a distant one, you know you get there the long way round but now I can make long-term goals, I feel confident making them”
(Interview 7)

“you just have to kick yourself in the butt and get out of there, carry on in life and that is what I have done and how I have survived it”
(Interview 6)

“I would rather just give myself the best chance ever and keep healthy and fit because I want children and I want grandchildren as well, I want to see my grandchildren and children grow up”
(Interview 12)

When a feeling of optimism was gained towards their existing life and future, it emerged that in hindsight, HIV had not brought about the life changes that were first anticipated. Indeed the initial expectations of illness and death which were felt on diagnosis had not materialised. This

emerged as participants stated the small day to day changes HIV had on their lives:

“All I need to do is take some tablets each day and attend an appointment every three months”
(Interview 2)

“I expected to be like Tom Hanks walking around with a drip listening to opera, but it hasn't really been like that, I've just been taking it a day at a time and here I am and I am still alive”
(Interview 3)

“It doesn't have to be that big a trauma, you can get out there and do stuff, I don't want to die, I'm having a ball”
(Interview 4)

“I just don't think about it...You think about it on the moments or times when you have to really think about it or remember it, for a particular reason and then I switch off and forget about it again until next time”
(Interview 12)

“On the one hand, I feel like a death sentence has been passed on me. On the other hand, I feel just like I did before physically. This discrepancy is odd and unexpected”
(Interview 14)

Through emergent adaptive strategies of developing goals and making small lifestyle changes, uncertainties appeared lessened, physical health and longevity were perceived as having a greater certainty, becoming not just something to aspire to but a graspable reality. By negotiating the uncertainties in this way and using the adaptive strategies which are explained in more depth in the forthcoming sections, participants expressed a sense of gratefulness towards the virus. The virus was described as giving opportunities that would not have been, and steering

life (often positively) in a direction they would not otherwise have taken. These emotions evolved as part of the process of regaining optimism over uncertainties.

The concept of uncertainty has been widely investigated within every academic discipline. Arrays of attempts to define uncertainty appear to share similar qualities, including the need to balance probabilities in order to influence expectations or outcomes of the future.

Within the nursing literature, uncertainty has been investigated as a concept experienced within illness. Nurse led studies into uncertainty have taken place in clinical areas such as atrial fibrillation (Kang, 2006), prostate cancer (Gannon *et al*, 2004; Bailey *et al*, 2007) and endometriosis (Schoen-Lemaire, 2004). Mishel (1981, 1984, 1988, 1990) has produced some of the most prominent work on the concept of uncertainty within illness. He defines the concept as:

“A cognitive state created when the person cannot adequately structure or categorise an event because of the lack of sufficient cues”
(Mishel, 1990; p257)

Mishel (1990) suggests uncertainty is increased in illnesses which have ambiguous symptom patterns and which are unfamiliar to the patient. Mishel states those with chronic illness may have increased uncertainty due to the long-term nature of chronic disease. The potentially unknown course of HIV and the discovery of uncertainty as the core concept in adapting to the virus would back up Mishel's theoretical claims.

McCormick (2002) claims uncertainty consists of qualities such as ambiguity, unpredictability, vagueness, inconsistency, unfamiliarity and lack of information. Interestingly, all the attributes of uncertainty within the literature are based on negative connotations. Uncertainty is described as something to be avoided or eliminated. Several nursing research papers have focused on or suggested the need for nurses to help reduce uncertainty in patients (Brashers *et al*, 1998; Cochrane, 2003; Heinrich, 2003). Results from this research point towards the need to adapt alongside the uncertainty rather than avoid or eliminate it. Indeed, avoiding uncertainty can be clearly seen within the subcategory 'planning for the future'. Within this subcategory, uncertainty was avoided or ignored whilst anticipating hopelessness. Yet in order to positively adapt participants faced up to the uncertainties, adapting alongside them. Thus this research suggests uncertainty must be faced in order to establish degrees of certainty. Mishel's (1990) work also suggests that patients may prefer the experience of uncertainty in chronic illness instead of the certainty of a purely negative outcome.

Many of the negative qualities of uncertainty suggested by McCormick (2002) were echoed by participants in the despair and fear they felt when facing an HIV positive future. Existing research fails to make reference to positive aspects of uncertainty – developing acceptance, developing empowerment, finding hope, assuming a new direction – as were revealed in this research study. Zinn (2004) makes reference to the observation

that existing research has suggested illness can be a positive life experience for a patient. Zinn (2004) suggests this may take place when degrees of certainty can be incorporated into future illness expectations which may also open up new opportunities. Responses from this research take Zinn's suggestions a step further, confirming that within this study uncertainties were adapted to by creating new certainties or increasing the probability of something towards certainty. Participants moved from anticipating hopelessness towards regaining optimism by acknowledging the uncertainties and creating new goals which could be cognitively perceived as certainties, as a means of adaptation. Zinn (2004) calls for further examination into the different ways of relating certainty and uncertainty to each other within life course planning. The data from this study clearly demonstrates ways in which the concepts of certainty and uncertainty are related, and frequently bargained.

Experiencing uncertainty when living with HIV has been mentioned in several qualitative studies; those investigating the general experience of HIV and those focusing on concepts such as stigma, hope, grief and identity (Siegel & Krauss, 1991; Lesserman, 1992; Lamendola & Newman, 1994; Chidwick & Borril, 1996; Barroso, 1997; Crossley, 1998; Reeves *et al*, 1999; Siegel & Schrimshaw, 2000; Cote & Pepler, 2005; Jacobson *et al*, 2006). Uncertainty as a concept specific to those with HIV/AIDS has undergone limited investigation.

In 1989 Weitz undertook a qualitative study amongst 23 gay and bisexual men investigating uncertainty in the lives of persons with AIDS. Her original work took place at a time when very little was known about the virus and life spans with HIV/AIDS appeared drastically shortened. Weitz (1989) highlighted the theme of uncertainty for those with AIDS at a time when an HIV/AIDS diagnosis came with the certainty of an imminent death. Her results show uncertainty was experienced by patients through questioning why they had become ill, how they had contracted HIV, whether they would be able to beat AIDS and whether they would die with dignity. Uncertainty was centred on the final stage of life. Participants in Weitz's study faced uncertainty in their prognosis and in trusting the knowledge of the medical profession, knowing the virus was relatively new and little understood.

Although the study focused predominantly on the different areas in which uncertainty was experienced within AIDS, Weitz does make some suggestions as to how participants coped with this uncertainty, highlighting the role of attempting to gain control in order to make situations comprehensible. Where control could not be gained, participants attempted to gain a sense of control, helping to reduce the stress felt from living with uncertainty. Weitz advises that in light of the results of her study, health professionals should be striving to help patients achieve a sense of control over the uncertainties, not just attempting to eliminate them (Weitz, 1989).

Although 20 years old since its publication, the results from Weitz's study are ever-relevant as they record the first reports of uncertainty in the experience of the virus. Areas of uncertainty highlighted by Weitz's study differ to those outlined within this grounded theory study, demonstrating the changed nature of the virus and altered expectations of living with the virus which has occurred through the passing of time.

The emergency of the subcategory regaining optimism from the results of this study provide further depth to Weitz's suggestions of the need to regain a sense of control. Regaining optimism was found to take place despite being unable to assume any certainty and thus took place as a significant method of adapting to uncertainty.

The consequences of uncertainty due to HIV infection were explored in a later paper by Katz (1996). The qualitative study investigated both the experiences of and consequences of uncertainty, revealing five core experiences: *"surviving the HIV diagnosis, taking care, living in the present, seeking support and appreciating the positive"* (Katz, 1996; p51). Within each core experience, methods of dealing with uncertainty were unveiled such as changing expectations, embracing spiritual beliefs, making lifestyle changes, seeking support, asking for help, enjoying relationships and contributing to society to name a few.

Although not explicitly stated by Katz, each method of dealing with uncertainty involved a proactive decision, reaching out to take hold of a

degree of control. This suggests that adapting to uncertainty is not a passive transition simply occurring by itself over the passing of time. Instead time appears to provide the opportunity to make changes and see these unfold.

The results from this grounded theory study support the theory of adaptation to uncertainty being a proactive process as it appears in Katz's study. In her discussion of the results, Katz also stated that:

“Individuals with HIV infection seem to grow as a result of the uncertainty inherent in living with HIV infection, and this growth is seen as positive”
(Katz, 1996; p59)

Katz makes one of the first links of positivity to the HIV experience, distinguishing clearly that although the virus itself is negative and destructive, the experience of having the virus may provide opportunities for growth or change of life events for the better that might not have been experienced without the virus. Indeed, the data revealed that being able to identify positive aspects of the experience can be a way of creating control, albeit psychologically, over the virus.

Overall, in Katz's study, uncertainty was dealt with by forming a new perspective on life. Although the virus forced participants to take a new (or altered) direction in life, personal certainties were created to balance the uncertainties. Katz describes this as probabilistic thinking to focus on multiple alternatives and probabilities. Creating small certainties appears to offset the anxiety created by so many certainties.

In 1998 Brashers *et al* reviewed the concept of uncertainty within the four phases of the biopsychosocial HIV/AIDS trajectory: at risk, diagnosis, latent and manifest. Despite claiming to be based on a biopsychosocial model, the review focused on physical changes within each phase and their impact on uncertainty. Raised uncertainty was dependant on the number of physical risks taken to contract HIV. Following diagnosis, uncertainty was increased with a raised CD4 count or viral load. Uncertainty about disease progression was particularly evident in the latent and manifest phases and was exacerbated by ambiguous symptoms or side-effects from medication. Although new treatments now exist, participants in the grounded theory study explained that anxiety was felt to be related to potential side effects of combination therapy and changes of daily routine enforced by medication. Although the review by Brashers *et al* (1998) points out important physical changes which may increase uncertainty, it does not discuss or suggest how this uncertainty may be dealt with or adjusted to. In the ten years following the publication of this paper, the physical pattern of HIV has changed dramatically although uncertainties related to diagnosis, changing blood levels and symptom management remains.

The three main studies from the nursing arena examining uncertainty in HIV have been reviewed: Weitz (1989) revealed areas of uncertainty in HIV; Katz (1996) suggested methods used to deal with uncertainty, and Brashers *et al* (1998) highlighted physical changes which may cause

uncertainty. Some surprising differences and similarities exist between the results of these publications and this grounded theory study, adding new information to the field and reinforcing existing research. Physical changes such as medication side effects or raised viral loads have continued to cause varying levels of uncertainty in all studies. Participants in Weitz's (1989) study questioned how they had contracted HIV, why they were becoming ill and if they could fight off the virus, all at a time when transmission risks were not widely known, many myths existed and treatments were experimental. Similar issues emerged in this grounded theory study despite transmission risks being understood by all the participants and wide availability of sophisticated treatments. Nearly two decades since Weitz's study, the grounded theory research highlighted that participants still felt uncertain about their future and questioned why they had contracted HIV when attempting to remain 'safe' to protect themselves.

The grounded theory study presents a more detailed and complex description of the way HIV is adapted to, adding to the work of the three above studies. The grounded theory suggests both causes of uncertainty, areas of uncertainty and ways in which participants adapted to uncertainty, providing an up to date perspective of HIV as seen by those living with the disease today.

The following sections will explore and explain in greater depth the seven subcategories which emerged from the data. Each subcategory is

underpinned by the theme of 'negotiating uncertainty' and demonstrates the process of developing small goals and changes, moving towards optimism as outlined in the previous pages. Thus, each subcategory was employed as a significant adaptive strategy for adjusting to a life with HIV.

6.5 Introduction to the seven sub-categories

Seven subcategories emerged that were underpinned by the core category of negotiating uncertainty. These were: considering risk, strengthening through hope, assuming direction, seizing opportunity, broadening vision, planning for the future and existing as-was. As previously described, each of these was divided into two categories, one denoting an anticipation of hopelessness and another representing regaining optimism. Adapting to HIV consisted of movements between these points. These movements were frequent and fluid taking place on a 'to and fro' fashion depending on the emotional state of mind and physical situation. Overlaps between categories were frequent. One could feel vulnerability whilst controlling HIV or be working through plans for the future whilst existing as-was. This demonstrates the complexity of the process of adapting to a life with HIV.

Moving between anticipating hopelessness towards regaining optimism could take place on an hourly, daily, monthly or yearly basis depending on the individual and their unique circumstances. Interviews with participants about changes over their lifetime of living with HIV revealed these constant fluctuations.

Difficulties in moving from anticipating hopelessness to regaining optimism centred on the core category of 'negotiating uncertainty'. Being unable to know the time span ahead or what level of fitness might be expected along the way. Reaching the 'regaining optimism' stage of each category signifies the point reached where participants were able to negotiate the uncertainties experienced of HIV, gaining an optimistic outlook of the future and eventually the ability to make plans for a future they intend to experience. Moving into the regaining optimism phase took place when participants were able to look further ahead than before and make plans in accordance with this new anticipated outlook. This is evident in the following sections offering a more detailed description of movements within the seven subcategories.

6.5.1 Considering the risk: moving from denial to acceptance

Adaptation only takes place when there is a new event triggering change which requires adapting to. In this research, the possibility of and subsequent diagnosis of an HIV positive future emerged as the first hurdle of adaptation for each participant. Doubt over their HIV negative status was the first uncertainty faced. On diagnosis, denial of a sero-positive status was experienced, adapting to this involved gradually accepting it.

Seeking clarification of HIV status took place following reflection of transmission risks, desiring to know the outcome of the chosen risk and therefore wanting to be tested. The stage of diagnosis emerged as a vivid

and memorable event, a time when things came to a standstill with the expectation of dramatic life changes.

The desire to seek diagnosis demonstrates an underlying desire, in a situation where there could be an unknown, to seek out what can be known, where a risk has been taken, to know the result of that risk. The core category of uncertainty can be seen as running through the need to seek clarification – wanting to eliminate the uncertainty that exists.

Seeking clarification through testing followed an underlying concern that risk of contraction may have been misjudged. For those participants who did not believe they would be HIV positive, the need to be tested represents an underlying recognition of the possibility of being positive, again something that some were unconsciously aware of.

Receiving clarification meant life could go in one of two directions, either a new path of being HIV positive or continuing life as HIV negative.

Descriptions from the data of being diagnosed as HIV positive were indicative of physical violence, damage and threat:

“the rug was pulled from beneath my feet, and I’m using cliché after cliché but the stuffing had been knocked out of me”
(Interview 1)

“I felt as though everything had been swept from under my feet when I was diagnosed...the worst blow for me”
(Interview 1)

“It came as a complete shock, out of the blue; it was so hard to deal with”
(Interview 2)

“It was the proverbial being punched in the gut as it was completely unexpected and I was sufficiently well aware of what it meant”
(Interview 11)

Such data strongly expresses the shock factor and distressing impact that facing such an unexpected uncertainty can bring. Confirmation of diagnosis involved a vast mix of emotions, feelings and expectations, all unique to the individual whether expectant of a diagnosis or not. Those expectant of a positive diagnosis expressed distress if only acknowledged on reflection:

“my reaction to being positive is totally relaxed compared to a lot of other people. To me it is a part of life, um yes I blotted it out for the first couple of years after I found out I was positive.”
(Interview 1)

Participants varied in their ability to comprehend receiving an HIV diagnosis. The ability to accept a diagnosis depended on the participants original expectations of being HIV positive, and in some cases their belief in fate. Some expected that they were HIV positive due to having frequently taken part in high risk behaviour – this group were able to accept the diagnosis more easily.

“So I wasn’t surprised because I went for the test and thought if I’m not positive then I’ll be surprised because I had led such a hectic sex life, I would have been more surprised to find out I was negative than positive”
(Interview 9)

Others believed they had protected themselves from the risks of transmission and therefore the shock of diagnosis was greater:

“I thought well for twenty years I have engaged in safe sex, I have been HIV negative since I was twenty till I was forty, and I managed to not get infected, I was prudent and played safe, you figure right, I have had two lapses, but really if you put two lapses in the context of God knows how many sexual encounters it’s a very tiny percentage, what are the odds? What are the odds?”
(Interview 11)

Adapting to diagnosis could only happen through reconsidering the risk of contraction. This led to fluctuations between being in denial over the risks of HIV to accepting the transmission risks. For those who believed there was originally very little or no risk, adapting involved re-evaluation of this. Prior to diagnosis the degree of risk of contracting HIV was viewed by the number of times the risk was taken. In hindsight, following transmission, participants expressed being in denial over the transmission risks at the time of contracting the virus. Perceptions of transmission risks changed when diagnosed through re-evaluating the risks that had been taken. Reflection over the risks of transmission helped participants regain optimism, examining their role in preventing further transmission.

Constant comparison of the data demonstrated that seeking and receiving clarification over HIV status was a physical event taking place as a result of risk negotiation. Adapting to having HIV involved giving a significant amount of time to reflecting over individual risk-taking. Throughout the interview process this emerged as quintessential in positively adapting to having HIV. The data clearly demonstrated a need to recognise the risk that had taken place, re-examining individual actions and choices that were made. Both expressions of regret and destiny emerged. The first

stages of adaptive behaviour can clearly be seen as risk-negotiating with self before taking the risk and then later revisiting that risk-negotiation in reflective form, adapting to the implications of the risk that was taken and the reasons behind why it was chosen.

All participants from this research study had a prior awareness and understanding of the modes of transmission before entertaining a risk of infection. Despite knowledge of transmission the risk had still been chosen. Therefore before choosing to undergo testing, each participant evaluated that a significant risk was posed which may change HIV status from negative to positive.

Literature and research exploring 'risky' decision making often excludes consideration of the context in which the risk was taken. Researchers have attempted to explore why, despite knowledge of risk and health promotion strategies, a risk is still taken to the scientific detriment of health. Zinn (2005) argues that:

“risk perception and risk-taking are constructed against the backdrop of local knowledge and are quite different to expert assessment grounded in scientific knowledge”
(Zinn, 2005; p3)

Participants within this research have highlighted multiple reasons why risks were justified or chosen, either planned or as a momentary decision. As Rhodes & Cusick (2002) suggest, previous research has predominantly focused on risk calculus, not taking into account the context or risk acceptability or the decision making process. Although it may be

impossible to scientifically demonstrate contextual, knowledge base and personal factors in analysing the choice to take a risk, the strong emergence of risk consideration from the data of this study demonstrates the significance of this subject in coping with diagnosis and the further uncertainties posed by an HIV positive status.

The data suggested that individual calculation of transmission risk, at point of transmission, deduced a negligible or non-existent risk. Risk consideration in light of an HIV positive status changed this previous perception of the risks involved. Previous research suggests that those with knowledge of transmission who acquire HIV by unprotected sex often display a thought process justifying actions and demonstrating an underestimation of the risks involved (Mikolajczak *et al*, 2006). Risks can be underestimated or justified for a number of reasons. In a study by Rhodes & Cusick (2002), participants gave examples of risk justification by means of experiencing pleasure, trusting a sexual partner (or demonstrating trust to a sexual partner), distancing oneself from believing there was a risk, dissolving responsibility, or trusting in fate for the future.

Various research studies have individually noted some of these concepts (Kalichman, 2000; Crepaz & Marks, 2002; Eaton & Kalichman, 2009). The complexity of emotions involved in sexual relationships makes the willingness to risk health in this area a complex one. Participant's spoke of the difference using barrier contraception can make to a relationship. Some stated that using a condom took away the pleasure of sex and

therefore taking the risk of unprotected sex was worth it for the experience of sexual pleasure. Other studies have described the condom as providing a physical barrier which creates a feeling of distance from another person. Rhodes & Cusick (2000) describe fluctuations in the perception of sexual risk as a relationship changes. Moving from protected to unprotected sex can silently signify a deeper aspect of trust and faith in the relationship, representing commitment to the other person.

Lauby *et al* (2006) suggests that strong emotional ties to another person can lead to minimising the perceived risk of HIV transmission. This assumption is reinforced by the data from this grounded theory study which demonstrates such ideas. Feelings of rejection on diagnosis of HIV were expressed when trust had been placed in a partner believed to be HIV negative. Working through these emotions, away from denial to a point of recognising the transmission risks emerged as a key feature in adapting to HIV.

Recognition and reflection of transmission risks stirred an uncertainty over HIV status which could only be resolved through HIV testing. Emergent ideas indicate HIV testing can be viewed as a frequent, routine check-up, indicating a prior knowledge of and involvement in 'at-risk' behaviour. The data also indicated testing can be a one-off significant event due to a single episode of at-risk behaviour which led to immediate uncertainty.

Mikolajczak *et al* (2006) claim that in some instances receiving repeated negative HIV test results can reinforce risk behaviour, leading individuals to the perception of risks as low or creating the impression they are immune to transmission. Within this study, one participant believed previous negative results had assisted a belief in immunity and a decreased probability that he would be infected. Following diagnosis this perception was altered as transmission risks were re-evaluated. This poses an interesting dilemma to health professionals providing pre and post test counselling advice, demonstrating that individuals do not calculate risks in the same manner as experts (Zinn, 2005).

The concept of fate strongly emerged from the data. Risk taking was translated into fate as a way of accepting that a diagnosis was meant to be. Although the idea of fate has been briefly touched upon by some published research (Fryback & Reinert, 1999; Gauthier & Forsyth, 1999; Rhodes & Cusick, 2002; Kemppainen *et al*, 2008), it has not been developed as a stand-alone concept within HIV research. Rhodes & Cusick (2002) describe fate as a method of placing control of HIV transmission into the hands of nature, presenting the self as passive and lacking agency. In researching beliefs about HIV disease and medication, the results from a study by Kemppainen *et al* (2008) suggest the importance of fatalism or spirituality on beliefs of the cause of HIV transmission. Responses to questions about what people believed to be the cause of their HIV included being 'God's will' or down to 'human nature'. Of those who believed they were HIV positive due to God's will or

'chance', they were also more likely to believe their own disease progression would be due to the same reasons.

The data from this grounded theory study clearly displays that a belief in fate was highly significant in adapting to HIV, moving from denial to acceptance of the risks that were taken. A belief in fate gave an HIV diagnosis a sense of purpose and destiny, enabling it to be incorporated into future plans as something that was 'meant to be'. According to Moch (1998) fate can be incorporated to increase meaningfulness when needing to reconsider an un-anticipated future.

The concept of fate within the literature is explored in a select few papers focusing on a small population of individuals labelled as 'bug chasers', those who seek to acquire HIV infection, believing it to be integral to their destiny (Gauthier & Forsyth, 1999; Hill, 2000). Although none of the participants within this study expressed an explicit desire to be HIV positive, in accepting the risks of transmission some reflected that transmission was inevitable and used this to weave HIV into their future, as fate that they should have such a diagnosis. Some research suggests identity can be found in acquiring HIV in the context of a developing gay movement (Carricaburu & Pierret, 1995). This idea however, did not emerge from the research study. Jacobson *et al* (2006) suggest that finding meaning in adversity can be an indication of fatalism. Their research discussed the role of fate in the context of religious beliefs such as "*God allows things to happen for a reason*" (Jacobson *et al*, 2006; p45).

Although the concept of fate surrounding risk taking emerged strongly from this grounded theory research, religious or spiritual ideas for the experience of fate did not emerge.

Data emergent from this study demonstrates that a risk proposed by health professionals can have a very different interpretation when individual and contextual factors are taken into account. The data displayed an acknowledgement of risks that had been taken, for many in hindsight as the risks were not tangible at the time of transmission. Considerable time was given to considering these risks in order to process individual chances of having acquired HIV. The use of fate as a way of acceptance enabled HIV to be viewed as a form of destiny. Others chose to accept an individual responsibility for acquiring HIV. All participants despite having knowledge of transmission risks had justifiable reasons why they did not consider themselves to be at risk at the time of risk-taking. Adaptation involved an initial denial of risks which then changed into risk acceptance as a way of accepting the diagnosis.

6.5.2 Strengthening through hope: moving between vulnerability and empowerment.

The uncertainty of how HIV might affect daily life caused an obvious vulnerability: a feeling of lack of control over the future interspersed by the fear that HIV may take an even greater hold over life, going on to cause experiences of prejudice and disability. The data clearly revealed that vulnerability was not experienced in isolation but was interspersed with

feelings of empowerment. Vulnerability and empowerment mirrored closely the categories of fear and hope – vulnerability when experiencing fear yet developing empowerment through evolving hope. Both categories of fear and hope fluctuated as situations in life changed. One participant stated that:

“Subjectively I would say it [HIV] increased my vulnerability but made me more determined to become empowered eventually, I had to go through huge dips in my mood and mental health to get to that stage where I felt I was starting to become empowered and I was empowering myself... I think vulnerability and empowerment go hand in hand, we are feeling vulnerable one moment and empowered in another moment, its like that peaks and troughs, you experience one before you experience another”
(Interview 5)

Vulnerability was felt automatically in response to an HIV diagnosis. Fear of the unknown effect of the virus on future health and relationships. Following diagnosis, feelings of vulnerability continually fluctuated as physical situations changed. Emergent examples of this were raised viral loads, clinic appointments, appearance of symptoms, commencing treatment or a need to disclose, as expressed by one participant:

“My fear was of the unknown and I think that is a big fear factor for anybody, the fear of the unknown and knowing what is going to happen, because my fears were, what is going to happen when I first get ill, what is going to happen when I first take medication, and what is going to happen when I tell people, and those were probably the biggest fears that I had. When I think about it, when I look back, its fine because I got through it alright”
(Interview 10)

HIV acted as a reminder of human fragility and vulnerability, particularly for those who were not expectant of receiving an HIV positive diagnosis.

Vulnerability reiterated the lack of control over life, reinforcing the risk of contracting HIV.

“If anything I suppose my own experience has reinforced in my own mind just how anyone is vulnerable unless you are absolutely safe in every respect, and I suspect there are people who play safe in every respect but I played it safe in almost every respect, I had two lapses, one of which led to my current dilemma, that is reinforced to me just how vulnerable the overwhelming majority of people are who are sexually active are to contracting this.”
(Interview 11)

A sense of vulnerability, as previously stated, was automatic, experienced immediately from diagnosis and yet emerged to be quintessential in prompting conscious adaptation to HIV. Vulnerability acted as a trigger for change, promoting movement forward to confidently take control of future decisions. Participants used empowerment to prevent living in a continual state of vulnerability. The vulnerability experienced when diagnosed led to an altered view of transmission risks as the fragility of human existence was realised. This initial vulnerability gave birth to a new dimension of hope to prevent others from contracting HIV. Working actively to prevent others from being infected with HIV was an active method of demonstrating empowerment. Developing empowerment demonstrated a useful coping mechanism to move towards regaining optimism, using the experience of HIV as something positive.

Fear was caused by the core concept of uncertainty yet was never experienced in isolation but always alongside an aspect of hope. Fear and hope emerged as a balancing act over the core concept of uncertainty. Hope was described in relation to overcoming the fear of uncertainties

ahead, and led to empowerment. Developing empowerment and overcoming fear involved finding something in which to have hope. One such example emerged such as maintaining fitness and placing hope in their body's ability to fight the virus. Hope was also maintained through the support of friends and family, fear was exacerbated if this support was lacking. Hope was placed in medical technology or in the possibility of a future cure for HIV:

“medical advances have made it a lot less threatening”
(Interview 2)

“I hope that one day, touch wood, they will find a cure for it but there's hope, hope on the horizon with new medication”
(Interview 10)

“science is always evolving so it may be that by the time I am 60...there may be breakthroughs that may prolong me yet further”
(Interview 11)

If a physically negative situation could not be reversed (i.e. living daily with a chronic illness aspect of the disease) then hope was found through acceptance of the present situation, and fear conquered through the hope of using a negative situation to make a positive difference in the lives of others. Hope was often found through turning a negative experience into something positive, often something that would benefit the lives of others or help prevent others from a negative experience; this created a feeling of empowerment and control.

“I certainly feel that I have a sense of accomplishment and I’ve become empowered in empowering other people, if that makes sense...I’m driven to keep going and keep providing the services, in that privileged position of empowering others which empowers me”
(Interview 1)

“I’ve been told on a couple of occasions now that I am going to make a difference to lots of peoples lives and a couple of people have said medically, I don’t know how or what that can be and I just think, maybe one day I am going to do something, I don’t know, maybe that’s just hope in my mind as well, a little bit of hope going perhaps that is going to happen”
(Interview 10)

If hope could not be found in ones own situation then hope was found within the lives of others. Hope was offered through the stories of those surviving with HIV, living healthy and active lives. This inspired the expectations for individuals to also keep believing in the optimum health they aspired to reach despite the virus.

“I have a friend who was diagnosed with HIV a long time ago, back in the mid-eighties who was quite ill at the time but is now very healthy, has more energy than me and is easily 10 years older than me and is leading a really full active life, drinks, smokes like a fish, doesn’t worry about anything, goes out virtually every night of the week and really isn’t suffering at all from any ill effects of anything that I can see, and has been diagnosed nearly 20 years, so there is reassurance in that sense”
(Interview 15)

Fear and hope are theoretical concepts identified in this study and framed by the core concept of uncertainty. Fear represents an anticipation of hopelessness; strength can be gained through the development of hope, which leads to being empowered. Fear was overcome by various strategies, each developing the strength to face up to an unknown and uncertain future. If the object of hope was disturbed in some way,

uncertainties arose and feelings fluctuated towards fear. In some cases having hope can be seen as a 'risk', striving towards something that cannot always be grasped and having no guarantee that what is hoped for may be gained. Finding strength through hope was one strategy to help adapt to the uncertainty found in HIV.

Hope has been discussed as a resultant concept in many previous pieces of research examining aspects of living with a chronic illness (Baker & Stern 1993; Delmar *et al* 2005; Greenstreet 2006; Bernays *et al* 2007). Within this study hope emerged to turn vulnerability into empowerment, subsequently developing strength. Empowerment enabled optimism to be regained, aiding positive adaptation. This research is not the first time that uncertainty has been positively related to hope. Previous suggestions from published research have posited that opportunities to create hope can be created by the experience of uncertainty in illness. Heinrich (2003) looked at relationships between hope, social support and uncertainty in illness amongst 125 HIV seropositive men in America. Hope was found to have a positive effect on perceived health, being viewed as necessary to develop a 'survivor attitude' in order to maintain health in times of ill-health. Persons with HIV turned uncertainties into an opportunity to create hope as a coping strategy. Similarly to this grounded theory study, hope aided positive adaptation although this was not always consciously employed amongst participants but instead was noticed on reflection.

Delmar *et al* (2005) researched the need to achieve 'harmony with oneself' as a way of accepting chronic disease. Similarly this could only be achieved by the existence of hope amongst the pressure of doubts – a balance sought by participants that mirrors the movements between vulnerability and empowerment unearthed within this study.

Existing literature exploring hope within HIV has highlighted ways in which hope has been found such as, through religious faith (Jacobson *et al*, 2006), extended social support (Turner-Cobb *et al*, 2002) and cognitive counselling (Creuss *et al*, 2002). Participants within this grounded theory touched upon similar themes but more unusually participants revealed hope in lesser-explored areas such as through comparison with others. Participants looked to others who had survived longer than themselves with HIV, or who responded well to treatment and this inspired hope. Comparison to individuals who were in a worse state of physical health to themselves also helped build confidence in their own ability to fight the virus. The use of comparison is discussed further in section 6.5.5.

Comparison with others was used as a mechanism to help process individual experiences and to gain perspective over vulnerabilities. Comparison with others was then transformed into a way of empowering others, encouraging others through focusing on areas of good health, or through pointing out comparison as a useful method of adaptation. Through helping to empower others, each individual felt empowered in themselves, producing a sense of personal strength and hope.

Having hope was also described as taking a 'risk' when there was no certainty in what was hoped for. Although it emerged that individuals used comparison with others as a form of encouragement, it was also described as 'risky' to put hope in something that was not necessarily tangible. Therefore it took personal strength to use hope as a form of adaptation. Previous research has demonstrated that social support can help increase hope (Cruess *et al* 2002; Greene *et al*, 2002; Turner-Cobb *et al* 2002; Heinrich 2003; Kylma *et al* 2001, 2003). A sense of close relationship with others can increase personal strength at times when this feels lacking, encouraging others to take the 'risk' in having hope for the future. Hope emerged from the data as integral to adaptation. Low moments were described as lacking in hope and strongest moments as being full of hope for the future. These moments did not necessarily coincide with medical determinants of health (i.e. viral load or T-cell counts) but instead on a personal feeling of wellbeing. This supports the suggestion by Moch (1998) that health can be found within medical diagnoses of illness and that hope does not necessarily correlate with degree of disease progression.

6.5.3 Assuming direction: moving from being controlled by HIV to controlling HIV

The despair experienced at diagnosis was caused largely by feeling the virus had stolen all previous expectations for future life, causing plans to be rewritten in the direction of the virus's choosing. The process of

reassuming direction became a determined decision that was exercised as a daily choice. Assuming direction involved power negotiations, working from the belief that HIV had ownership of the body, towards taking ownership of the HIV, gaining control back from the virus. Regaining control involved creating certainties amongst uncertainties.

When recalling the time of diagnosis, the data showed a clear disassociation of the person from the disease; HIV was described by participants in an abstract form. As the interviews moved onto talking about living with HIV in the present, descriptions changed towards an attitude of ownership over HIV. Owning HIV became a certainty and thereby a clear starting point in the process of adaptation. Descriptions of “my HIV”, demonstrate ownership of HIV. Control over the disease was also displayed by practical actions taken to maximise health:

“I just kind of realised that whatever happens now is down to me, its my responsibility, it was my responsibility before and it is still my responsibility, and I cant, I’m not just going to turn up at the clinic and say here I am, you fix it, because that’s not their job, that’s my job so that’s what I’m doing...its all down to me I have to decide what I can and cant do and it’s a bit overwhelming...maybe I was expecting the clinic to say do this, take these and do that, come back in two weeks and that hasn’t happened, that’s all misconceptions in my head”
(Interview 3)

Adapting to HIV involved working through the misconceptions that life had been stolen by the virus. Participants used practical methods to claim back control of their life from HIV. Direction was assumed in order to prolong life, maintaining health for as long as possible with the aim of

continuing as things were before diagnosis. Methods of control include:
changing diet, giving up smoking and taking regular exercise.

“I’m on top of things, I don’t take anti-depressants, my recreational drug use is down to a minimum and I train, I train regularly. I’ve never trained before. When I was diagnosed I realised that I had to do something. That thought was always at the back of my mind...I guess me taking control of my health over the last year has been a preparation really for optimum health and optimum response to anti-retroviral drugs, so yeah, I think I am taking the ownership of my health to a different level”
(Interview 1)

“I’m very health conscious because I know I am HIV positive I have become more sort of in tune with what I eat and when I eat and how I eat it and not overdoing it and not burning the candle at both ends because I find I have found that I do get more tired easier and I know that’s because my body is trying to fight off an infection constantly”
(Interview 10)

In some instances reclaiming direction emerged as taking place directly from diagnosis, wanting immediately to have control over the future. In other cases the data indicated that taking control of HIV was triggered by an additional significant event such as a low CD4 count, a raised viral load or appearance of symptoms. The introduction of combination therapy marked a new era in HIV treatment providing a new hope and method of taking control over the virus. Amongst the scientific community this new group of medications promised improved health, control of the virus and longevity – these expectations filtered down to patients as seen in interview 4:

“Once things like triple therapy came in I thought, no hang on a minute you’ve got a good chance of living as long as anyone else here so you’d better not mess it up, you’ve messed it up once potentially so if you’ve been given another chance then well you may as well go for it. So I gave up smoking, stopped taking recreational drugs, started taking triple therapy, I’d moved to Spain by that time so full on Mediterranean diet, all healthy the whole lot, loads of swimming”
(Interview 4)

For the above participant, taking anti-retrovirals was a significant way of taking control of the virus. Other participants chose to maximise their own independent control of the virus, leaving medications as a back-up plan:

“I thought I should be on treatment, not just sitting back and waiting for things to deteriorate, but then after a while I started to think I’m not on treatment because my body is doing it for me already, and it is only when I can’t manage it myself that I will need to go on treatment”
(Interview 3)

Maintaining mental and emotional health was viewed as equally important as keeping physical health. Psychological well-being was viewed as having an active role in maintaining physical health, suggesting a ‘mind-over-matter’ perspective. Strong mental stability was viewed as being able to control the physical effects of HIV and therefore hold back the onset of AIDS. Each participant’s view of their relationship to the virus differed and this influenced ways in which they claimed control over it. Some viewed themselves as a separate entity from the virus; others had a general acceptance of being co-joined with the virus:

“OK well I have HIV but I don’t have AIDS, I’ve never had an illness so I can separate myself really well”
(Interview 4)

“Yes I am not defined by my diagnosis, that is one thing that has helped. I refuse to be a PWA or a PWHIV. Even though I have the virus and I have antibodies to it...I don't want to be waiting there observing it because the more I think you stare at it and look at it the more it is going to jump up at you. No I've refused so no I don't see myself as ill, I don't have an illness, I have something that can be passed on and cause an illness but I am not ill”
(Interview 7)

Participant four adopted the mindset that HIV had the potential to cause ill health but was not an illness itself. This viewpoint helped form an identity away from the virus, giving a positive mindset from the beginning. Strategies to reassume direction involved moving on as a healthy person and continuing as before. Others viewed themselves as one with the virus and could only move on alongside it.

“unfortunately you can't separate the two now because I am connected to HIV now”
(Interview 10)

Realising that it was impossible to get rid of the virus from the body led to a choice – to ignore the virus, sitting back and letting it run its course or to take ownership of the virus, regaining control of the life that originally surrendered to it. The shock of diagnosis created a period of ignoring the virus – a part of adapting to being HIV positive. Whatever perspective a participant held of their relationship to the virus the need to take back control from the virus was paramount to successful adapting. Regaining control was triggered by a personally significant event such as raised viral load or social situation prompting change. To adapt to HIV, the uncertainties of the future were negotiated – such as the potential of reduced health. A decision was then made to personally control the virus

by whatever means possible. Having a sense of gaining control or losing control to the virus fluctuated as situations changed. Retaining mental and emotional positivism was viewed as a way of controlling the virus regardless of the physical circumstances, thus creating a positive adaptive response.

Asbring & Narvanen (2004) explored the role of power and control amongst women with illnesses considered to have an uncertain trajectory. They describe taking control within chronic illness as:

“having opportunity to use power, namely making choices, implementing intentions, taking action and affecting the actions of others”
(Asbring & Narvanen, 2004; p228)

In their research amongst women with either chronic fatigue syndrome or fibromyalgia, participants gained control by acquiring information. Although this research was not HIV specific, the illnesses under inspection share an uncertain trajectory in the same way as HIV. The women spoke of gaining knowledge in order to influence the medical health consultations (Asbring & Narvanen, 2004). In the results gained from the grounded theory study into adaptation to HIV, participants also acquired information to help gain control but tended to do this in association with health professionals, using medical expertise as a precious resource. Seeking diagnosis was perhaps the first stage of taking control of HIV, alleviating an uncertainty even though, in the case of the participants interviewed, positive diagnoses lead to further uncertainties.

The above responses by participants demonstrate the way individuals choose to view their relationship with the virus, influencing the control they feel and subsequent actions taken towards overcoming uncertainties. Crossley (1997) suggests that those who construct a more robust meaning of their diagnosis and the way they view themselves, adjust more easily to having HIV. Participants indicated two different viewpoints of their own relationship with the virus: either being attached or separate from it. Each viewpoint employed varying strategies towards adapting; neither viewpoint offered an easier or better method of adaptation. What appeared to matter most was that each individual had determined the way they viewed the virus and employed strategies of control accordingly. Those viewing the virus as separate from themselves took control by attempting to continue with life as it was pre-diagnosis. This involved living a life with a determination not to let the virus change the way their life was led. Those viewing themselves as co-joined with the virus talked about a future that incorporated the virus, integrating it into future life events in a positive fashion.

In most instances it took a physical event aside from diagnosis, to trigger the ability or desire to regain control of the virus. Examples include a breakdown in relationship or formation of new relationship, learning of a raised viral load, or commencing antiretroviral treatment. Deciding to take control of the virus did not occur automatically from diagnosis or just due to the passing of time. Existing research has explored methods of control over the virus but there is no evidence to suggest an optimal time at which

these should be encouraged or introduced (DiClemente & Peterson, 1994; Fitch *et al*, 2006). Each individual within this study had a certain 'moment' or reason acting as a trigger enabling them to take control and move on, successfully adapting.

Thorne *et al* (2003) investigated the process of self-care decision making amongst those with chronic illness, namely multiple-sclerosis, HIV and Type 2 diabetes. Participants within their study similarly recalled a precise moment in their illness trajectory when they felt able to make decisions to control the disease. Disease management was not assumed on diagnosis but instead through occurrences such as facing a disease complication or a realisation that gaining control may actually be possible. Thorne *et al* (2003) describe this as a noticeable philosophical shift in the experience of those with chronic illness. A sense of being in control is described as:

“being able to mediate the effects of the disease so that they could live as normally as possible”
(Thorne *et al*, 2003; p1314)

The results by Thorne *et al* (2003) show a degree of consistency with the results from this grounded theory study. Participants exercised methods of taking control as a means of adapting to present and future uncertainty. Their study acknowledged that despite strategies of control, aspects of uncertainty remain, the study states that methods of control were:

“never sufficient to ensure that the effects of the disease would be controlled perfectly”
(Thorne *et al*, 2003; p1348).

This grounded theory demonstrates that regaining control of the virus involves taking practical strategies to maximise health (or the potential for health). Maintenance of emotional and psychological well-being was viewed as vitally important in controlling the physical progression of the virus. Feeling in control within the mind enabled a feeling of being physically in control in the body. Existing evidence appears to support this assumption (Taylor & Brown, 1994; Folkman, 1997; Taylor *et al*, 2000). Cote & Pepler (2004) state that emotional and psychological distress are likely to increase HIV related physical symptoms, weighting evidence to participants own methods of choosing to control physical aspects of the disease by psychological means. Their research focused on enabling symptomatic HIV patients to increase their perception of control in order to reduce anxiety and other physical symptoms.

Previous research has strongly suggested that an increased perception of control over illness reduces depressive symptoms and anxiety. Bower *et al* (1998) suggest that thinking about, and gaining control of an event can lead to a sense of mastery and re-gaining of self-esteem instead of depression or despair. A study by Griffin and Rabkin (1998) looked at perceptions of illness control amongst 42 patients with late-stage AIDS. Those with a greater sense of control displayed fewer symptoms of depression and anxiety whilst maintaining a realistic acceptance of the possibility of death. Recent research has developed this indicating strongly that the effects of depressive symptoms, stress and social support

can influence the physical progression of disease (Cohen & Williamson, 1991; Cohen & Herber, 1996).

Lesserman *et al* (1999) researched 82 HIV positive gay men over a 5 year period, monitoring CD4 counts (for disease status) alongside assessments of depression, stressful life events and social support. Results indicated an association of faster progression to AIDS with more cumulative stressful life events and depressive symptoms, and less cumulative social support. Although this grounded theory study focused on the concept of adaptation and did not undertake any clinical measurement of participants disease progression, results are consistent with Lesserman's study.

Participants felt most physically well when feeling a psychological sense of control over HIV. Feelings of health did not necessarily tally with medical analysis of blood results which may indicate a disease status contrary to their feelings. Anxiety was also less when participants felt supported by family and friends or when personal relationships felt stronger.

Physical strategies such as adjusting diet, exercise and sleep patterns were initiated by most participants as they adjusted to their diagnosis.

These strategies were implemented as participants altered their perspective of living with the virus. At diagnosis such strategies were not employed, instead thinking was focused on the short-term, getting through each day. As participants developed a sense of regaining control they focused on optimum long-term health in an effort to maximise their body's ability to fight the virus and maintain good physical health. This coincides

with the findings of Thorne *et al* (2003) whereby practical strategies to assume control of a disease took place once the ability to develop psychological control of health was enabled. Adopting healthier living practices were taken on board for the primary reason of gaining control over the disease. In turn such actions, Thorne states, reflect individual life priorities and self-confidence in ones own future. Such results suggest physical health promotion strategies should not be introduced prior to working with patients towards comprehending what a diagnosis of HIV means to them as individuals. This suggests working towards cognitive control of the diagnosis maybe more helpful in promoting successful adaptation.

The benefits of maintaining an overall healthy lifestyle, improving diet and exercise, have been well documented within studies of various chronic illnesses (Wannamethee *et al*, 1998; Astrup, 2001). Results have demonstrated physical and psychological benefits for those who are HIV positive (Wagner *et al*,1998; Neideg *et al*, 2003). Exercise gained an elevated priority within the lives of participants within this grounded theory study. The scientific evidence of the benefits of aerobic exercise on HIV disease progression are limited due to the small number of studies existing in this area. A recent Cochrane paper (Nixon *et al*, 2005) reviewing the benefits of aerobic exercise in those with HIV/AIDS identified only one study demonstrating a non-significant improvement in CD4 counts for those taking part in interval aerobic exercise compared to a non-exercising control group (Perna, 1999). There is greater evidence to

support direct benefits of exercise on improving mental and psychological well-being, which in turn may help improve physical health.

Eller *et al* (2005) found that exercise benefited psychological coping of HIV. Exercise was viewed as a strategy for overcoming depressive symptoms in those with HIV.

From the evidence collected, conclusions can be drawn supporting the importance of regaining a sense of control back from the virus in aiding successful adaptation, helping participants to retain a positive mindset amongst the uncertainties, maintaining both mental and physical health.

6.5.4 Seizing opportunities: moving from destroying life to saving life

Despite the negative descriptions of living with HIV, such as fear, vulnerability and loosing control (Laryea & Gian, 1993; Riskind & Maddux, 1994; Trussler *et al*, 2000; Kylma *et al*, 2001), living with HIV offered new opportunities which participants felt they would not have gained without their diagnosis. The concept of seizing new opportunities emerged as participants moved away from viewing HIV as something purely destructive. Upon diagnosis the virus was seen as destined to destroy life. Adapting to life with HIV involved reassuming control and inevitably this meant seizing new opportunities presented by the disease. Participants moved away from viewing HIV as all-destroying towards seeing aspects

which had 'saved' their life. A movement in attitudes emerged: from being diagnosed as 'HIV positive' to being 'positive about an HIV diagnosis'.

On reflection of an HIV diagnosis, participants expressed recognition that lifestyle choices once deemed beneficial had perhaps played a part in HIV transmission. Hindsight of diagnosis initiated the decision to alter risk-taking activities, and indeed to prevent others from taking the same risks.

An HIV diagnosis was viewed as a unique opportunity, using the experience to prevent others going through the same thing. The grounded theory describes the role of finding meaning in HIV, perceiving hidden blessings which present new opportunities that would never have been without the diagnosis.

"I just wonder sometimes if I hadn't been HIV positive I would have probably carried on taking recreational drugs and probably wouldn't be a nurse right now and I'd be in a right mess. I'm not saying HIV saved my life but it suddenly its been there as a deciding factor in the background of big decisions I have to make"
(Interview 4)

Becoming 'positive about HIV' was an ongoing process throughout life. In some cases it became a daily decision to hold onto this perspective. The expectation of imminent death following diagnosis triggered a complete re-evaluation of life. HIV provided the impetus to reconsider life's priorities, something participants would not have considered without diagnosis. This re-evaluation inevitably triggered changes, particularly amongst relationships with friends and family. A realisation of the vulnerability of life led to re-establishing previously broken relationships. In adapting to

the uncertainty of life with HIV, an increased awareness of the value of strong friendships and relationships was apparent.

“It has had quite a detrimental affect on things but it has had a very positive effect...I have this sort of heightened awareness of other things that I overlooked for a long time, particularly my platonic relationships, my relationships with family members, my intimate relationships have taken on a new meaning, I have become more empathic I suppose, more keen to understand the plight of other people, I have more time for people on a daily basis, I have also become more assertive and less likely to tolerate things that I dislike...so I certainly feel that has changed, for the better.”
(Interview 1)

In turn, the re-establishment of relationships with friends and family led to further support in dealing with the uncertainties associated with diagnosis. Re-establishing relationships was seen as a new positive opportunity stemming from something that was previously seen as so negative. Many felt this enriched life and without HIV these relationships would never have been re-built.

Adapting to HIV was found to be easier when others understood the experience. Involving family and friends on the HIV journey aided positive adaptation. Experiences of disclosure enabled the journey of HIV to be made easier:

“I even told a couple of people at work because I got really close to a couple of people and they are alright and sometimes I think do I really need to tell somebody but when you are getting close to somebody and you build up that friendship, one of trust and obviously it's a way of showing how much you trust somebody...my life has a completely different meaning now as well, I am living to share my experience with somebody else”.
(Interview 12)

Concerns over HIV disclosure have been well documented (Pettrak *et al*, 2001; Klitzman *et al*, 2007; McDowell & Serovich 2007; Arnold *et al*, 2008; Rutledge 2008). Indeed the data demonstrated of a fear of receiving prejudice when informing people of their status, yet this appeared unfounded as experiences of prejudice did not emerge from the data. Surprise was expressed when receiving heightened emotional responses from others when disclosing an HIV status:

“she was so emotionally charged over that she balled her eyes out and this time I was quite calm and was like oh by the way I’m HIV positive and she was like you are going to die and I was like I’m not stop telling me I am going to die. So they were probably the two worst experiences I could have had from a family member and a best friend but in hindsight I think it probably helped me deal to get over it better”
(Interview 10)

The emotive reactions encountered when telling someone of an HIV status meant that disclosure involved more than simply making others aware of HIV. Consideration needed to be given to the reversion of roles – looking for support but becoming the supporter; looking for information but becoming the educator. The data revealed the role of the patient in being a supporter of others when disclosing his or her diagnosis. This presented a situation forcing participants to focus on others and not just on their own situation. Strength to continue adapting was gained from this potentially negative situation.

As the data was collected it became clear that HIV significantly impacted life’s direction, yet rarely prevented any original plans (those made pre-

diagnosis) from going ahead. Uncertainty over the remaining length of life provided impetus to strive to achieve the things that were previously desired. Despite the fears, HIV played no hindrance in life choices or career. HIV emerged as changing life's direction for the better, positive situations took place which would not have been experiencing without an HIV diagnosis. This was clearly demonstrated early on in interview 5:

“It was the best thing that ever happened to me, HIV was the best thing that ever happened to me, it gave me a kick up the ass...I've achieved so much since being diagnosed that this has been the best thing that has ever happened to me because I find it difficult to talk hypothetically on where I could be pre-diagnosis or if I hadn't been diagnosed because I just would have been probably in a mundane job not enjoying myself.”
(Interview 5)

When looking back at the overall experience of HIV, a new perspective was gained, this being a positive aspect of the virus. Experiencing HIV improved understanding of others and built strength of character. The experience of working through initial emotions of fear and despair helped develop courage, wisdom and strength. Strength of character grew from the experience. This was something that could then be used to benefit others going through a similar situation, helping them to adapt and 'regain optimism'.

“It has made me a better person I think, a wiser person and a stronger person to deal with it as well...I am very sort of happy, so yeah its been a massive eye-opener, it really has but in a good way and I am glad of the experience, I really am.”
(Interview 10)

Adapting to an HIV diagnosis through gaining perspectives of the positive outcomes of having been diagnosed was a huge step in moving towards

regaining optimism. In order to achieve this stage of adaptation, participants actively seized the new opportunities they felt HIV presented to them – finding new opportunities from potentially negative circumstances. Viewing HIV as something that almost saved life occurred through the development of empowerment, hope and a sense of control over HIV, or if not over HIV then over the way one can choose to live their life with HIV. Successfully adapting to a negative event involved finding positive aspects within that could bring new opportunities.

Although the concept of benefits within illness is not undiscovered, neither has it been adequately investigated in light of existing findings. In 1994, Lamendola & Newman published a paper discussing the paradoxical nature of living and dying in HIV. They stated that new meanings could be found within distressing experiences of illness. They described this experience as a ‘manifestation of expanding consciousness’. New meanings amongst the nine male participants living with HIV included, appreciating life, finding new friends and reconnecting with family. These were experienced after reaching a ‘turning point’ following experiences of alienation, breaking away, loneliness and searching. Each turning point for the participants in the study was difficult and often painful. This mirrors the experience of participants within this grounded theory study of adaptation, whereby triggers enabling them to view HIV as ‘life saving’ were sometimes difficult such as a raised viral load or immediate threat of ill-health. In addition to the results by Lamendola & Newman (1994), this study reveals that such a change in perspective may also be triggered by

positive opportunities such as a new relationship or medication regime. The study strongly supports the view that a definite 'turning point' is experienced before participants are able to move from seeing HIV as 'destroying life' to something that may 'save life'. It adds weight to the view that living with HIV/AIDS contains many paradoxes which keep unfolding, not just over the passing of time, but through the occurrence of physical events acting as turning points.

An HIV diagnosis triggered a re-evaluation of relationships. In the example of these results relationships were renewed and strengthened in light of the diagnosis. Brashers *et al* (2004) found that support from others can help manage uncertainty whilst acknowledging the burden that can stem from managing others' uncertainty levels. Within this grounded theory study, social support was not necessarily sought as a means of overcoming uncertainty but the new and strengthened relationships triggered by diagnosis had a significant role in the overall process of adapting to uncertainty, emerging as something positive from diagnosis.

As the focus of HIV has moved away from a terminal disease towards chronic illness, research has taken place looking at quality of life changes in those with HIV. Sarna *et al* (1999) looked at the quality of life in women who were symptomatic of HIV or AIDS over a period of four months and found that quality of life significantly improved. Improvements were seen in physical and psycho-social aspects and factors influencing this change included being single and younger. Older age was associated with

declines in physical quality of life and participants married or living with a partner also showed a slight decline in quality of life. Interestingly, in comparison with the results from participants in this study on adaptation, time since diagnosis did not appear to be related to changes in quality of life. Sarna *et al* (1999) surmise in their results that expectations for health and quality of life may instead be recalibrated, leaving actual quality of life as stagnant or decreased. Aspects of quality of life were improved for the women interviewed through personal re-prioritising and re-evaluation of life in the face of threatening illness. The reprioritising that took place suggests it was initiated by a trigger or turning point although the research paper does not explicitly discuss this.

Siegel & Schrimshaw (2000) investigated whether benefits existed in the adversity experienced by women living with HIV/AIDS. Eighty-three percent of their sample reported at least one positive change which was directly attributed to their illness experience. Areas of growth included: health behaviour, spirituality, interpersonal relationships, view of self, and value of life or career goals.

Fryback & Reinert (1999) conducted a qualitative study amongst patients with cancer and unveiled that those who were able to find meaning in their disease believed they had a better quality of life than before their diagnosis, going against the negative perceptions associated with disease and chronic illness.

Siegel & Schrimshaw (2000) noted that it was the need to cope with negative consequences that gave birth to opportunities to experience positive changes. These positive aspects were often described as 'mixed-blessings' or 'silver-linings', perhaps denoting acknowledgement of a higher spiritual authority which ultimately controls life's destiny. Jacobson *et al* (2006) attempted to better understand religious-spiritual biographies of those with HIV/AIDS. Participants spiritual views helped them positively adapt to uncertainty believing 'God allows things to happen for a reason'. Participants within Siegel & Schrimshaw's study described HIV as a catalyst for spiritual growth and a strengthening of religious beliefs. As an HIV diagnosis appeared to trigger spiritual strength, so spiritual strength helped adaptation to HIV.

Although such direct links to spirituality did not emerge within this grounded theory study, similarities were found in the view of negative consequences of HIV providing the opportunity of positive changes which would never have been experienced without HIV. This indicates that despite the continual uncertainty exerted by the disease, positive growth in other areas may still occur alongside. Physical health may deteriorate but still relationships can take new positive meanings and personal strength can still develop. All of these positive opportunities took place amongst fluctuations of low moments and uncertainty.

Within the literature many of the positive aspects to come out of an HIV diagnosis are described when using hindsight and reflecting on past

moments. Participants from the grounded theory study used this reflection as well as consciously looking for ways in which their diagnosis could be used to produce something positive within the present and future. This was then actively manipulated to take place, creating something beneficial from the illness. This also impacted on a feeling of control over the virus, a feeling of determination to prevent the virus from destroying. Such examples include the desire to use the experience of HIV to warn others against the virus, to use experiences as a way of health promotion or to come alongside, to share and support others. Such experience helped to give a sense of purpose to life. Katz (1996) revealed similar findings in her study into new perspectives as a result of uncertainty in HIV infection. 'Appreciating the positive' emerged as a strong theme whereby patients actively made changes to improve their future such as, changing personal attitudes, enjoying relationships and contributing to society. Such actions demonstrate the ability, amongst uncertainty, to seize opportunities stemming from past events, creating from this, opportunities for the present and future.

6.5.5 Broadening vision: moving from self-focus and self-comparison.

Adaptation to HIV involved significant changes to ones view of themselves and others, some becoming at one with the virus, others seeing the virus as invasive, unattached to themselves as a person. Some chose to allow the virus to become part of them, others disowned it. The virus created a heightened awareness of the vulnerability of life, something that was

gradually used as a form of empowerment, as outlined in the previous section.

Adapting to diagnosis led to a period of self-awareness. The bombardment of uncertainty meant participants needed to focus on their own transition to move themselves forward. Self-focus took place through emotions of despair and panic whilst anticipating total hopelessness and being unable to look beyond ones own situation. The data demonstrated a feeling of consumption by the uncertainty of the diagnosis, preventing participants from being able to take on board the situations of others around them. Self-comparison was noted from the data as a significant transitional behaviour in order to regain optimism. Comparison to others created both positive and negative adaptation depending on the measure the comparisons were made against and the purpose to which they were used.

Two forms of comparison took place – comparing self to those without HIV, and comparing self to others also HIV positive. Initially a longing was felt to get rid of the virus thus immediate comparisons were made to those free from HIV. The virus caused participants to see themselves as positioned within a minority in comparison to the majority population who do not have HIV. This isolating perspective ran hand in hand with the vulnerability and fear experienced when anticipating a hopeless situation. The label and potential stigma of an HIV diagnosis created the feeling of experiencing something which no-one else could feel or understand. The

data spoke of a strong desire from individuals to be included in the same situation as others. This involved each person searching to try and place oneself with a majority group despite the diagnosis. This was indicated in the way participants negotiated that they were no different to anyone else as 'everyone dies eventually'.

By comparing self to those without HIV, participants expressed a preference to suffer with something considered socially acceptable such as heart disease, an illness which would place them back within an accepted majority. To overcome the impossibility of trading one sufferance with another, participants developed common ground between aspects of HIV and other complaints which they perceived as common amongst a majority.

"I now realise, if I end up like that with lesions and all those things, I think well I'm fine now because I know it is not such a bad thing, and this woman explains that, its just cancer, its nothing bad, you have cancer like millions of other people in the world. I thought yeah that's right it's not associated with AIDS but it's the words that you use, they are just words at the end of the day. And its nice because it puts everything into perspective and it helped me get over any fear factor that I have"

(Interview 10 - talking in regards to Kaposi's Sarcoma)

Despite differing perspectives of what was considered 'normal', comparison to others took place with the aim of placing oneself within ones own chosen majority. This was reflected in the way one participant identified himself as still the same as others within his own local geographical area:

“I see me, living like any other person in South Wales and probably dying like any other person in South Wales, at the age of 85 with blocked arteries and you know (laughing), my main concern at the moment health wise is not the HIV its coronary heart disease and getting my cholesterol level down and taking exercise, so that is my, HIV is unimportant to me to such an extent that other risk factors of living in this part of the world I think are more or a priority. So I see myself as living a perfectly normal life.”
(Interview 7)

Acknowledging that death is a certainty for everyone helped dissolve the uniqueness of feeling alone in facing death and placed those with HIV back within the majority.

“I’ve always had the attitude that the only certain thing in life is that you are going to die, it doesn’t matter how or when, when your time is up, your time is up...in society we’re all going to die, it doesn’t matter how or when. You can fall off a pavement and break your neck, you can be run over by a double decker bus, if you dwell on anything like that what is the point of living?”
(Interview 6)

“Its natural, I am going to die whether it be in 25 years or 40 years time. Its going to happen but probably the chances are that at the moment, the way things are that I may die of an AIDS related illness, I don’t know, I may just die of old age”
(Interview 10)

Assuming the self as part of a minority was indicative of feelings of isolation and increased uncertainty, feeding an anticipation of hopelessness. Moving towards regaining optimism involved developing a changed mindset, finding similarities that one shared with others. Realising that life is no more certain for those without HIV than for those who are HIV positive helped to decrease feelings of isolation.

Comparison to others with HIV appeared inevitable yet this method enabled successful adaptation through being able to find a majority within a minority. Placing self within a majority helped to relieve loneliness, gaining a broader perspective beyond the boundaries of an HIV status. A sense of belonging to a majority helped relieve fear, instead gaining hope. As one participant concluded:

“I mean millions of people have HIV, I am not so unique”
(Interview 10).

Placing the self amongst an average within HIV helped to gain certainty amongst the reoccurring theme of ‘uncertainty’ running throughout the whole adaptive process.

“I have had trouble finding these statistics, particularly of survival rates, I’ve done HIV survival rates but I’ve yet to find out what statistically my prospects are. As I said I could succumb to it in a year or 5 years or 25 there must be a statistical norm, a distribution curve or whatever the distribution curve looks like of people with the disease, and am I normal?”
(Interview 11)

Self-comparison to others with HIV enabled participants to see if they were coping in similar ways to others, comparing their own reactions to diagnosis or appearance of symptoms. One participant spoke of his experience of attending a support group for people with HIV/AIDS, although he found it a negative experience, it enabled self-comparison to a positive effect:

“it was lots of people sitting round chain smoking, oh my chests bad, I’ve just had another bout of PCP and thinking about it all the time, that just makes me drink, I drink to forget and that’s lowering my CD4, and I just thought well stop thinking about it which I suppose is easy for me, its obviously a massive trauma in their life. But I think to myself it doesn’t have to be that big a trauma, you can get out there and do stuff, I found a lot of people, I felt the room was full of people just waiting to die, I don’t want to be involved in that. I don’t want to die, I’m having a ball, I really don’t want to die, I thought I’m not going to sit here”.

(Interview 4)

Another participant spoke of his desire to attend a support group, if only to enable him to meet others also adapting to HIV and see how their experiences compared to his own:

“My main interest in a support group isn’t really for emotional support because I am quite an emotionally contained person but I was interested to meet people further along in this process than I am, who have been diagnosed longer than I have, to query them for precisely those reasons, to do my own research as it were”

(Interview 11)

Comparing self to others was used as a tool to deal with uncertainty.

Witnessing others with HIV helped participants develop a better impression of their expectations for the future, relieving some of the uncertainties they felt. The ability to compare self to others helped participants move forward in planning their own lives. Interview 11 outlined the need to make comparisons with others in order to prepare for the future:

“What is the average T-cell count on first diagnosis? Is it 400? Is it 450?...I kept pressing them and getting answers like ‘not too bad’ or ‘normalish’ things like that. I wanted facts, and the same as the viral load, the doctors said well sometimes patients have viral loads in the millions, well of course you do but what stage are they? Have they been infected for 10 years? That doesn’t really help me to know...I used to sail a lot and in navigation you chart your

position on a chart and then you do what is known as an EP, an estimated position, you interpret your current course and speed where you will be so you don't run aground. So you need accurate information at that one point, in order to make this estimated position you draw a line into the future, my ship will be there unless something disastrous happens. This is what I have been trying to do but you need that information but I didn't get it"
(Interview 11)

Comparison to others with HIV who appeared to be in a more difficult situation, or a worse state of health, helped participants to regain optimism over their own situation, particularly at times when they felt vulnerable or fearful over their health. This comparison often took place alongside those symptomatic of HIV or AIDS.

"I have done voluntary work and I have looked after people who are really end stage...you learn to deal with it so it doesn't matter what the illness is, I feel I can stand away from it because its not me, I'm able to say that's not me I'm not that ill, I'm not saying I won't ever become that ill but at the moment that's not me so I just have to get on"
(Interview 4)

"Like I said I have to take medication everyday but then I could be having to take an aspirin everyday to thin my blood. It's when I compare it to something else. I mean I'm not having chemotherapy, when I look back I don't have cancer or something, I know there is light at the end of the tunnel"
(Interview 10)

In some cases comparison to others had the potential to lead to further isolation. Through making comparisons participants began to question themselves over whether they were reacting in the 'correct' manner compared to the reactions of others. Comparing oneself to those symptomatic of HIV or living with AIDS risked causing increased fear about what the future might hold.

“Sometimes its quite difficult because I see my friends on treatment and becoming quite ill and you know like any other people I draw comparisons on what I have seen, what I am experiencing, is this going to happen to me? Is it going to happen to somebody else I know? Um so yeah, I mean they are usually when I have bad days”
(Interview 1)

“I’ve had a look at the UK coalition website message boards, there is quite a lot of messages from people who have just been diagnosed who are completely freaked out by it and cant leave the house and can’t speak and can barely get out of bed. I’m not like that at all, so what, I must be missing something, I think should I be like that?
(Interview 3)

Comparisons which had the potential to aid uncertainties were generally avoided or turned into positive comparisons to rebalance the uncertainty and begin working towards regaining optimism. This was a continual pattern, fluctuating throughout the experience of HIV, participants appeared to move back and forth between self-focus and self-comparison whilst adapting to the uncertainty. Making comparisons helped adaptation by broadening vision to encompass other people’s situations. Considering the situation of others offered an overall sense of perspective, reducing the negativities over ones own situation.

The use of comparison to aid adaptation emerged strongly from the data of this study. Little evidence was found in the literature indicating previous recognition of the role of self-comparison in adapting. Mayers *et al* (2005) touches on this briefly in their qualitative research into low income women coping with HIV. Results from this study suggested that a:

“coping strategy employed by many women was to universalise their predicament, by placing it in the context of other possible illnesses, and life’s struggles in general”
(Mayers *et al*, 2005; p105)

Comparing health progress was seen as necessary to plan for the future. Participants spoke about having questioned health professionals about how their own health compared to others at similar stages of the illness. Comparison to the general HIV population enabled a wider vision of their own illness, lessening the isolation sometimes described. No research studies were found that focused on the use of comparison in coping with HIV, yet it seemed to be a universal method used in some form by each participant interviewed. The significance of this emerging from this grounded theory study is great and unique and needs to be taken forward to be examined as an individual concept.

6.5.6 Planning for the future: moving from escaping to distracting.

Whether anticipated or not, receiving an HIV diagnosis caused an immediate shift in focus and future outlook for all participants. The clinical advice given to participants diagnosed during the 1980s was to expect and make plans for AIDS: inevitable sickness and imminent death. A significantly curtailed life-span was to be expected. Participants reacted by living for the moment, experiencing everything possible in the remaining time left. For some this was a method of planning for the immediate future, for others a way of escaping to cope with the drastic news that was uncomprehending.

Contrary to the 1980s, those diagnosed during the late 1990s and early millennium recounted experiences of being informed by health professionals to expect life and be encouraged by developments in treatments (Tiamson, 2002; Westburg & Guindon, 2004; Matic *et al*, 2006). Despite the positive messages, health promotion images of those dying from AIDS that were used during the 1980s held fast and are difficult to dispel. Expectations of a life lived with HIV have evolved alongside medical advances and the demands of those living with HIV (Davies, 1997; Barroso, 1999; Clinton, 2002; Siegel & Schrimshaw, 2005; Wong & Ussher, 2008). Each individual's future expectations depended on when they were diagnosed, their level of infection, physical health and their hopes and dreams. Uncertainty of the future paved the way for fear of being let down by future expectations.

Methods of escapism to avoid the potential damage of what HIV might bring emerged strongly from the data, occurring most commonly around the time of diagnosis. Escapist behaviour was used to shift the focus of life away from HIV, attempting to forget the diagnosis and its possible implications; this became obvious in the first interview:

“I turned to drugs to help me get through, to get through what I was experiencing. Um I actually went back to university, didn't learn a bloody thing whilst I was there I was so high off my face constantly but I got into a cycle of taking amphetamine based drugs in the day and benzodiazepines in the night so the constant sort of like rollercoaster of ups and downs not really absorbing any information, just trying to deal with a bad situation I suppose and my immediate escape to cope with it”
(Interview 1)

Escapism strategies emerged to be temporary; taking place in a state of panic at diagnosis, the concept of escapism is thus initiated through an emotional state of despair, panic or a need for temporary release from the situation in hand. This escapism later shifted towards a longer outlook once the initial shock of being HIV positive subsided.

Movement from short-term escapism towards long-term goals paralleled a movement towards expectations of good health and longevity. Those believing they had a short time to live employed immediate escapist strategies which were used until a longer term focus developed.

Participants who believed they had a longer lifespan adapted more quickly by creating long term goals. Initial escapism strategies were all of the aim to put HIV out of mind, pretending it was not there, refusing to acknowledge or ignoring its existence.

“so I just went in for the test, got the results, said alright thanks and walked out. Um I remember I didn’t have sex for 12 months, I pushed myself into work, I remember I just pushed everything into work and it just went out of my mind completely. I can remember having the test but I couldn’t remember what the results were.”
(Interview 6)

Expecting a curtailed life span led to the feeling of needing to make the most of every moment, in some cases this involved an increase of health-risk activities. If health was damaged already it was seen to be a futile situation that could not be changed. An example of not wanting to waste the little time left is seen in the following quote:

“so you were looking at a 5-10 year lifespan and I remember thinking oh well I may as well have a bloody good time while I’m here, if that’s all you’ve got left, and then friends started dying and I was thinking oh my God I’ve only just started, I was determined to go out and have a bloody good time, and carry on living the life that I was living at the time”.

(Interview 4)

As time passed a degree of acceptance towards diagnosis was felt along with an increased hope of health. Initially participants existed on a day-to-day basis, waiting for symptoms of illness. As this did not materialise, the realisation that there may be a longer term future ahead began to dawn. This shift in focus led to the gradual formation of longer term plans, developing long term goals that proved a useful distraction from the ever-lingering label of being HIV positive. Participant one, in his second interview, described shifting his focus to the longer term as he gradually adapted to the changes in his life:

“I have put myself through education so that I could get a greater sense of self worth and you know achievement, when that happened to me”

(Interview 5)

Hope in science and the evolution of new treatments also helped participants to be confident in expecting a long future:

“There is things I want to do, I want to travel, do all sorts of things. Initially I thought I couldn’t do any of that but now I am thinking I can do all of that I just have to make sure that HIV doesn’t get in the way...after diagnosis I thought there was going to be so many things that I cant do anymore, I cant go off to China for three months, but actually I can and even if I was on treatment I could probably still do it, I could post on the pills somewhere I think so I guess its kind of initially you think that’s the end of it and then you think I can still do that type of thing, so I will.”

(Interview 3)

“Before combination therapy I didn’t look much beyond six months to a year. Which is no way of living for a long period of time, fair enough if you only have four or five years to live I mean that is quite useful, you don’t make plans too far ahead, you enjoy life, but now you cant keep living that erratically forever. I think as human beings you need some sort of distant goal, even if it is only a distant one, you know you get there the long way round but now I can make long term goals, I feel confident making them and that is supported by friends and family so I can make a goal...whereas before I would have thought it is pointless”
(Interview 7)

“I realised that you had a reasonable life expectancy but didn’t realise it was sort of infinite as such, nobody can put a figure on it, whereas I suppose nobody could put a figure on your natural life anyway.”
(Interview 15)

HIV affected changes in future planning not just in the form of fluctuations between short and long term goals but in the type of goals. Through a gradual adaptation to being able to expect a future, participants were able to move from self-focusing towards considering the lives of others. HIV was weaved back into future plans, using it to empower and make a difference to others.

“The focus wasn’t on what I was experiencing it was what other people are experiencing and how I can help other people, how I can guide other people based on my experience and understanding from the information I had acquired you know the novice that I had. I’m able to help people now”
(Interview 1)

“I really want to make a difference. I would like to make a difference to people’s lives and go into schools”
(Interview 10)

Future plans moved towards taking ownership of HIV, bringing it into the future (and present) and using it as something positive amongst the

negative. Planning for the future enabled finding the freedom to live in the present without viewing HIV as a preventative to life.

Whether planning on the short or long-term, the uncertainty of what might lay ahead was central to the challenge of future planning, attempting to plan without knowing what impact HIV might bring. The core concept of uncertainty led to the fluctuations between escapism and long term planning:

I might live 40 years or 10, who knows? It is the uncertainty of knowing when you are going to die was a consequence of the illness that makes it hard to readjust your priorities as your priorities may be entirely appropriate for the long term if you live long.”
(Interview 11)

It can be hypothesised that uncertainty towards future life enforced by a diagnosis of HIV leads to a shifting-focus. This takes place in two stages, firstly use of escapist strategies normally lasting on a short-term basis. Secondly the emergence of long-term goals to provide a longer term distraction. All this takes place within the context of adapting to the uncertainty created by HIV. This noticeable movement overlaps with the subcategories of constant shifting between dichotomous points of ‘anticipating hopelessness’ and ‘regaining optimism’.

Accounts from the 1980s document the use of escapism strategies in those recently diagnosed with HIV (Shilts, 1988; McKirnan *et al*, 1996). The need to make the most of every moment as if it is the last is vividly described in many accounts from those indulging in a party lifestyle as a

chosen way of using up final moments. Extracts from the voice of those with HIV during the 1980s demonstrate that long-term plans were not made, and neither were they encouraged to be made by those in the medical profession (Reeves *et al*, 1999; Westburg & Guindon, 2004). As individuals watched friends and partners die of AIDS, no one believed the situation could be any different.

Since the introduction of anti-retrovirals, the medically predicted future of those with HIV has altered greatly (Cardarelli *et al*, 2008). Health professionals now encourage the view of HIV as a manageable chronic disease where quality of life can potentially be maintained to a high standard.

As participants expressed within this study, difficulties were encompassed in adjusting to new roles and identities in light of an altered life-span. An extended life brought about further uncertainties in comparison to preparing for the certainty of an early death. Participants described this transition as one of the most difficult points of adaptation in their life with HIV.

'Encouraging perspective shifts' was identified as a category in research by Brashers *et al* (2004) when dealing with the management of uncertainty in HIV/AIDS. Their research focused on the use of social support in order to help reappraise situations, in particularly uncertainty, to bring about a perspective shift. The identification of the need for a 'perspective-shift'

bears some similarity with the 'shifting-focus' emergent from this grounded theory study. Adaptation clearly involves a constant movement of perspectives over time, constantly reappraising the present in order to plan for the future.

Pierret (2001) conducted one of the only research studies that explored personal meaning of *long-term* life with HIV. Interviews were conducted amongst 30 participants who had all lived with HIV for at least 10 years. Participants described lessening uncertainty as time passed by, due to acquiring confidence in the stability of their health. This confidence gave participants the ability to imagine a relatively stable future having experienced a relatively stable past. The research however focused predominantly on the participants reconstruction of their past and therefore did not describe in what ways they looked to the future. Both the study by Pierret (2001) and this grounded theory study involved participants who had experienced good health and had not yet gone onto develop AIDS. Those experiencing bouts of illness may approach future planning in an entirely different way. The research does demonstrate the role of self-confidence in managing health as increasing the ability to plan for the future.

Nixon & Renwick (2003) conducted qualitative research that explored the experiences of those with HIV contemplating returning to work. In working out their future plans participants struggled over the notion of whether they were 'ill', and therefore exempt from the societal norms of working, or

whether they were 'well' and therefore expected to have a working future regardless of the uncertainty of their future health. The participant's perspectives of whether they viewed themselves as ill or well influenced their ability to make plans. The participants in this grounded theory study faced similar negotiations. Only after acceptance of diagnosis and developing a degree of expectation for future life could they begin to make plans. Participants in the study viewed themselves as 'well' and were therefore more easily placed to do this. As they developed confidence in their ability to stay well – alongside seizing opportunities, assuming their own direction and finding strength in hope – they were able to remain focused on the future, developing confidence in plans whilst retaining the comprehension that plans may have to change due to the uncertainty of the illness.

Planning for a long-term future consisted of strategies that distracted the individual away from HIV as an all-consuming focus, towards giving thought and time to other chosen plans whilst not ignoring the virus and the uncertainties it brings. Kuijer & Ridder (2003) suggest that having future plans helps to give meaning and purpose to life, aiding adaptation. Their research uses the term 'self-efficacy' to explain the belief in oneself to achieve a desired outcome. They suggest a low level of self-efficacy maybe linked with depression and helplessness whereas higher levels may improve the ability to make attainable future plans. Their study stated that in making future plans both goal importance and goal attainability were significant in maintaining self efficacy. Their results emphasise the

importance of ensuring future plans are attainable if adaptation is to be positive. Data from this grounded theory study showed the need to continually evaluate the attainability of future plans alongside negotiations over the uncertainty of HIV on the future. When feeling confident in the future life plans reflected this. Plans changed when feelings fluctuated between anticipating hopelessness and regaining optimism.

Cote & Pepler (2005) designed and tested a nursing intervention tool encouraging HIV patients to take control of emotions where medical facts were beyond their control. Patients were encouraged to make plans, living these out day by day, gaining an increased feeling of control. Their research concluded that encouraging patients to make plans helps improve their cognitive coping strategies, helping them to adapt. The results that emerged from this grounded theory study support this. Participants regained optimism by making plans and in turn making and living out plans helped them regain optimism amongst the daily uncertainties faced.

As seen in the above papers that were reviewed, previous research acknowledges the benefits of future planning and goal setting in dealing with uncertainty and therefore coping with HIV. No research studies could be found that specifically examined the process of adjusting from believing one is going to die (imminently) to believing one can live. Published studies have uncovered certain aspects impacting on future planning yet have not described the difficulties in recognising ones own identity as

being either ill and expecting death or well and expecting life. Establishing this personal self-perspective has emerged as key to making plans of any sort.

The participants in the studies by Pierret (2001) and Nixon & Renwick (2003) took time reconstructing their past identities before making plans for the future. In recalling their experience of HIV, participants in this grounded theory study spoke directly about the past in relation to plans for the future. This process of recognising and deciding on ones own identity both in the past and for the future governs if and how plans will be made. Decisions included whether one is ill or well. The results from the grounded theory study and the implication of conclusions from the above studies indicate that the ability to make future plans is not a sudden event but a gradual development, indicating a movement of thought as self-efficacy brings confidence amongst uncertainty. Once again this process is continually fluctuating as perspectives of uncertainty change following movements between anticipating hopelessness and regaining optimism.

6.5.7 Existing as-was: moving from everything changing towards everything remaining the same.

One of the most significant and perhaps revealing categories to emerge was the phenomenon of 'existing as-was', expecting everything to change, yet nothing changing. The theory demonstrates difficulty in adapting to the fact that things need not necessarily change because of HIV, despite original fears.

“No it changed things before that. It changed things in an instant. In some ways it changed everything and it changed nothing”
(Interview 11)

Diagnosis created an expectation of immediate life changes such as development of symptoms or severe illness, anything synonymous with receiving a diagnosis of a terminal disease. This changed as participants remained asymptomatic for prolonged periods. Participants realised they need not necessarily face illness or symptoms, at least not as immediately as they first anticipated. Once again, the theme of uncertainty ran throughout this subcategory – being uncertain of the changes which HIV may enforce on lifestyle. As lives were adjusted to living with HIV it was established that in reality a diagnosis of HIV led to very few changes:

“All I need do is take some tablets each day and attend an appointment every three months”
(Interview 2)

“No, the only time it becomes an issue in my life is when I have my clinic appointments, when I am forced to think about it, its not that I avoid thinking about it, its just I have other things to think about”
(Interview 4)

“No there hasn’t been a huge dramatic change really. Just slight alterations, just a little divert into the way that I eat, how many times I should exercise, I know that I have to be really protective about sex”
(Interview 10)

Further questioning of participants in this area revealed that HIV involved small adjustments to life which were easily adapted to and indeed became routine such as taking medications. The adaptive stage proving to be the most challenging emerged as adapting to the fact that there was nothing

to adapt to; nothing significant had changed and in some ways this made the process more difficult to face. Deceptive, was the nature in which one participant chose to describe HIV:

“Its not hard to deal with in the short term like I said because nothing changes but that is misleading in a way, you can walk out of the clinic feeling exactly like you did before and continue to feel that way for months and years and I can see how that is misleading because the worst is yet to come and it will eventually come”
(Interview 11)

The good health experienced whilst living with HIV was viewed by this participant as giving false hope. The interviews revealed the ongoing daily struggle of adapting to being healthy when a diagnosis of HIV implied sickness. Regular clinic appointments and blood taking were a constant reminder of the uncertain anticipation of ill-health, waiting for the body to surrender to the virus. Participants saw this as taking a greater deal of mental adjustment than facing tangible ill-health which is seen as normal and expected when receiving a diagnosis.

The feeling of everything changing was felt most profoundly at diagnosis, going hand in hand with fear and vulnerability. An overriding sense of anticipating hopelessness seemed like the ‘right’ reaction when diagnosed with a potentially terminally illness. Adjusting to the realisation that ‘nothing changed’ appeared to go against social norms of disease, something associated with ill-health. Allowing oneself to exist as-was, adapting to ‘nothing changing’ meant a bold move away from the crutch of a diagnosis, risking hope in an uncertain future.

Allowing oneself to accept that nothing had significantly altered in life also meant demonstrating to others that life could continue as before – going against the stereotypes of HIV/AIDS and the way the virus had been viewed in the past, both medically and socially. Overcoming this point of adaptation enabled movement towards regaining optimism of the future and the ability to make future plans.

Much of the qualitative research that has been conducted into living with HIV starts with the initial assumption that HIV is an adverse condition, bringing about significant emotional, physical and social demands (Servellen *et al*, 1998; Schmitz & Crystal, 2000). This assumption is grounded from the results of research that took place during the 1980s where the emergence of HIV caused fear throughout communities and uncertainties stemmed from the lack of knowledge of this new illness (Barroso & Powell-Cope, 2000; Kylma, 2005).

As HIV approaches the end of its third decade much more is understood about the virus, by both health professionals, patients and the general public. This is not to say that stigmas no longer exist but the results from this grounded theory study indicate that those with HIV exist post-diagnosis as they did pre-diagnosis with relatively small changes to their lives. The largest hurdle of adaptation, once over the crisis of diagnosis, appears to be mentally adjusting to the fact that little has changed, that life can go on as before.

Following a review of the literature, very little research exists surrounding the idea that those with HIV may continue with life as before. Research is predominantly focused on the changes enforced by HIV and personal reactions to these. Several studies contain results which hint that existing as-before is entirely feasible but the idea is left for others to explore further.

Fleishman *et al* (2003) conducted a cluster analysis of longitudinal data looking at patterns of coping amongst those with HIV infection. They discovered a high number of 'passive copers' who infrequently used any of the coping strategies under study (blame-withdrawal, distancing and active-approach). These passive copers were found to have high emotional well-being, good health and supportive relationships. This contradicted their original assumption at the beginning of the research that HIV was an adverse situation requiring continual efforts to adjust. They conclude that successful adaptation to chronic illness may result in an emotional equilibrium where continued coping strategies are minimal. The idea of 'existing as-was' emergent from this grounded theory study complements their findings that HIV may not bring about huge changes to all its carriers.

In the study by Pierret (2001), previously discussed in section 6.5.6, five out of thirty qualitative interviews contained the category 'keeping things the same'. Participants attempted to maintain life as before within an 'identical present'. The attitude of maintaining continuity was more

noticeable amongst women and those who were older. Although no further discussion was given to the significance of this category it demonstrates that indeed not all persons with HIV undergo huge changes in their lives, or desire to make huge changes to their lives.

Although it may first appear advantageous to be able to continue life with HIV as it was before diagnosis, for many adjusting to life with a potentially terminal diagnosis whilst remaining in a state of well being brought confusion and in some cases turmoil. Nixon & Renwick (2003) investigated the feelings of those with HIV returning to work. Participants in their study felt that improvements in health led to an increase in stressors when trying to renegotiate the process of dying alongside re-engaging with living. Participants felt that continuing as if nothing had changed went against the societal norms that if they had HIV they should be 'ill' and not working. This led to a struggle of identity.

An exploration of an HIV narrative by Mooney (2005) reveals that images often associated with HIV such as unemployment, transgression, drug use, being gay and stigma are often not found within those with HIV. Therefore there appears an element of surprise in the grounded theory extracts that offer an alternative view of the disease away from the stereotypes.

Within this grounded theory study it emerged that continuing life in full health was one of the most significant points of adaptation. The data

showed that having HIV created few physical alterations to life, 'changing everything yet changing nothing'. Adapting to HIV also involved adapting also to the fact that things may not necessarily have changed and therefore the future maybe able to exist as it was planned before. The uncertainty associated with HIV continually exists in the background of 'existing as-was', as quoted by Pierret (2001):

"life had to go on as it had before the infection except for one thing: keeping a watch on HIV"
(Pierret, 2001; p172)

6.6 Concluding remarks

The core concept of uncertainty emerged strongly to underline the entire process of adapting from being HIV negative to being HIV positive and continuing to live with this diagnosis. Uncertainty was caused by the unpredictable nature of the virus.

The process of grounded theory revealed seven subcategories, each gathered depth and significance throughout the interview process, earning their place as a subcategory through constant comparison. Adaptation is a process whereby a new event triggers change. Each subcategory consisted of an active process, movements between two bi-polar categories demonstrating the action taken to achieve the subcategory. Each category represented either an anticipation of hopelessness or regaining of optimism.

The process of adapting proved to be continually moving between subcategories and categories but all focused around the core category of uncertainty. A significant overlap between subcategories can be noted despite each strongly emerging from the data in its own right. This overlap demonstrates the complexity of the process of adaptation as a whole.

The grounded theory significantly contributes to previous work on uncertainty as a concept. It draws attention to areas of uncertainty, causes of this and ways of adapting. The research provides an insight into the role of uncertainty in those with HIV, adding an up to date perspective to existing research which although still significant, has dated in light of the rapidly changing nature of the disease. Conceptually it provides further understanding into the role of uncertainty with regards to life course planning, self-identity and the passing of time. The role of uncertainty is closely examined within each of the subcategories and categories, uncovering its influence on considering risk, seizing opportunity, future planning, assuming direction, strengthening through hope, broadening vision and expecting as-was. Each subcategory demonstrates an active process of dealing with uncertainty, within this categories demonstrate the practical steps taken to battle under the shadow of uncertainty in order to regain optimism and move forward positively adapting.

It was felt positive adaptation had been achieved when optimism had been regained. Optimism could be felt in one area whilst retaining feelings of

hopelessness in another. An anticipation of hopelessness was caused when uncertainty was increased leading to a sense of vulnerability and fear. Regaining optimism emerged through the development of feelings of acceptance and empowerment. These feelings were reached by active processes to gain a sense of control, making plans for the future that distract away from the virus, and making comparisons with others. Through these actions participants were able to view positive 'saving' opportunities stemming from their diagnosis, and could continue with life as it once was, retaining a constant awareness of uncertainty but regaining optimism over this.

Negative adaptation emerged as an anticipation of hopelessness, caused by an overwhelming sense of uncertainty. Vulnerability and fear led to denial, escapism and a sense of being out of control. Everything changed, in a destructive way. The surge of hopelessness meant being unable to look beyond oneself.

Overcoming uncertainty and positively adapting emerged as a constant, fluctuating, balancing act between an anticipation of hopelessness and regaining optimism. Positive adaptation did not occur automatically but was a conscious process involving choice and subsequent action.

Adaptation did not occur simply due to the passing of time, although the passing of time did bear influence on the ability to adapt and also gave time for reflection. The active process of positively adapting to HIV became a decision, for some being hourly, daily, weekly or monthly. In

some ways regaining optimism was a mindset decided daily despite uncertainty. The passing of time influenced this as mindsets and perceptions of self-identity perspectives settled.

The concept of uncertainty remained constant and unchanging throughout the process. Adapting to uncertainty did not involve changing the nature of the uncertainty. At the present time the virus cannot be removed or cured from the body so the uncertainty remains. What is significant is that positive adaptation can still take place despite a constant uncertainty. Steps can be taken to achieve, focus, plan, hope and develop expectations despite the looming uncertainty.

Due to the grounded theory process and emergent nature of the data, the results from this study demonstrate not just findings but relationships between concepts. The data has been constantly verified throughout the research by the process of constant comparison. The emergent process shows how a group of people are currently adapting to their diagnosis of HIV and going on to live with the constant fluctuations this implies. The sample of participants taking part in the study were all male, white and predominantly asymptomatic. None of the participants had progressed to AIDS. The grounded theory does not claim to demonstrate a universal experience for all, for it can be used again, in similar and different fields, and modified accordingly. It does however claim to demonstrate the experience of the participants that took part. This provides a significant insight into a small group of people living out their diagnosis day by day.

The following chapter offers perhaps the most significant section of the thesis: the theoretical conclusions from the grounded theory. The results are brought alongside Roy's Model of Adaptation for comparison.

Advancements to the concept and process of adaptation are offered.

Advancements are also made to the concept of time and role of perceptions, as called for by Roy (Roy & Andrews, 1999). Implications of the grounded theory are suggested for advancements to Roy's work, the wider theoretical nursing realm and nursing practice. Future challenges for research and theory are recommended.

CHAPTER SEVEN

Theoretical Conclusions

“And most importantly, a well done grounded theory will usually, if not invariably, transcend diverse previous works while integrating them into a new theory of greater scope than extant ones.

This is a useful contribution”

(Glaser, 1998; p10)

7.1 Introduction

This grounded theory study sought to gain understanding of the effect of an HIV diagnosis on an individual's life; to look at how individuals adjusted their behaviour (if at all) in light of their diagnosis. The research has unveiled the whole, previously unknown, adaptive process, starting from scratch, allowing the free emergence of data from the voices of the participants themselves and using grounded theory to raise this to a theoretical realm. The resultant grounded theory, as outlined in Chapter 6, clearly demonstrates the process of 'negotiating uncertainty' in order to adapt to life with an HIV positive diagnosis. The results can stand alone in their own right, the conclusions having been demonstrated through constant comparison. In isolation the results demonstrate the struggle of wrestling with hopelessness whilst attempting to adapt by regaining optimism. Such knowledge of the patients experience can be used by nurses to assist patients along the journey, helping to encourage and enhance adaptive coping.

The selection of Roy's Adaptation Model to philosophically guide the study was a natural choice given its focus on adaptation and compatibility with the philosophical aspects of grounded theory. Roy's Adaptation Model was not used as a theory to frame the research, for grounded theory research is dedicated to the unbiased discovery of theory. Instead the philosophical assumptions underpinning Roy's model were used to guide the conduct of the research study, with the aim of bringing the resultant grounded theory back alongside Roy's model, scrutinising for similarities

and differences in the adaptive process. The research is used to add knowledge to the theoretical basis of nursing, through testing Roy's Adaptation Model.

It is what follows in this chapter that gathers the results, bringing them back to the realm of nursing theory, using them to enhance, disprove or suggest modifications within the nursing theoretical arena. It is here that the results can be used to forward theoretical knowledge specifically for clinical nursing practice.

This chapter relates the results of the grounded theory to testing each aspect of Roy's Model of Adaptation including the theoretical definition of adaptation, the concept of stimuli, the coping process, adaptive responses and Roy's definition of the nursing process. This chapter goes onto discuss the contributions of the grounded theory to developing Roy's work including the philosophic and scientific assumptions, and the concepts of time and perceptions. A conclusion offers future challenges for research development around the concept of adaptation, Roy's Model of Adaptation and theoretical development for the wider nursing realm.

7.2 The theoretical concept of adaptation

According to Roy's model, adaptation is defined as:

“The process and outcome whereby thinking and feeling persons, as individuals or in groups, use conscious awareness and choice to create human and environmental integration”
(Roy & Andrews, 1999; p30)

The conclusions drawn from the grounded theory outlined in Chapter 6 fully support this definition. Adapting to uncertainty took place as a continual process, the concept of 'negotiation' emphasising its active nature. Adaptation was not automatic but required the conscious thought and subsequent action of the individuals involved. As is elaborated in section 7.7.1, adaptation did not happen automatically over time but the passing of time impacted significantly on the ability to make conscious decisions. Roy does not elaborate on her choice of wording "*to create human and environmental integration*" as the aim of adaptation, however it is fair to state that the theoretical model itself sufficiently elaborates this process.

The grounded theory results revealed the aim of adaptation was to reach a point of regaining optimism and, as the seven subcategories demonstrate, this took place through integration with others, the self and aspects of the physical environment surrounding the self. Thus it is clear that the emergent grounded theory supports Roy's conceptual view and definition of adaptation.

Roy elaborates her definition of adaptation with a complex theoretical process of how this takes place. At its most basic level Roy's Adaptation Model is described as a feedback loop: a stimulus initiates a coping process, leading to a response which is fed back into the cycle (see Chapter 3). The grounded theory developed from this research appeared to mirror a similar process. The process of adapting to uncertainty was

continual and active with too and fro movements between categories and subcategories. An HIV diagnosis triggered a level of uncertainty, this lead to a coping process as described within the seven subcategories. The behaviour resulting from this produced one of two responses: an anticipation of hopelessness or the regaining of optimism.

Roy significantly expands upon the basic description of a feedback loop. Three types of stimuli are described: focal, contextual and residual. The adaptive process consists of four areas in which adaptation may take place, through changes in role function, interdependence, self-concept or the physical. Coping can take place in these areas through regulator responses (body systems) or cognitive methods. Action through this process leads to either an adaptive or ineffective response.

The forthcoming sections present the emergent theory of adapting to uncertainty in relation to each area of Roy's Adaptation Model. Analysis takes place to see if the theory of adapting to uncertainty can support the suppositions of Roy's Model.

7.3 The concept of stimuli

Roy describes a stimulus as something that provokes a response, in this case, that which triggers a need for adaptation. Theoretically Roy takes into consideration stimuli internal to the body system and those externally from the surrounding environment, categorising these, as mentioned, into focal, contextual and residual.

The emergent core concept of uncertainty can be interpreted, according to Roy, as the focal stimulus, that causing the most prominent need for adaptation. Participants struggled to deal with the uncertainty faced by the virus and it was this that each felt needed to be dealt with. Great uncertainty caused an anticipation of hopelessness and this triggered the need to activate change in order to regain optimism over life. Constant comparison revealed uncertainty, time and time again, as being the most difficult aspect of living with HIV. Life situations may change but still uncertainty over the future remained the factor most significant to those with HIV.

Whilst uncertainty can be revealed as the focal stimulus, the research led to the emergence of other factors significant to participants also triggering a change or move towards adaptation of a specific circumstance. Starting antiretroviral medication was seen as a new chance, an opportunity to regain optimism, extending lifespan. Changes to relationships (starting a new relationship or finishing an old) also provided a trigger to move forward striving to regain optimism. Such factors, according to Roy can be considered contextual stimuli, defined as "*other internal or external stimuli evident in a situation*" (Roy & Andrews, 1999; p73). These factors contributed to the focal stimulus of uncertainty.

Roy describes a third group of stimuli, residual. These are factors unknown to the individual but still influencing behaviour. As the theory

stemmed directly from dialogue with individuals such stimuli cannot be identified from the research and therefore the concept of residual stimuli is not necessarily supported, nor refuted, by this research. Roy states that residual stimuli *“have an undetermined effect on the behaviour of the human adaptive system”* (Roy & Andrews, 1999; p66). If stimuli have an undetermined effect then it is questionable as to how they can be researched, or if indeed they can exist at all. For Roy clarifies that as soon as residual stimuli are identified as affecting a situation they become contextual. It can be argued that if residual factors are unknown (and therefore potentially do not exist) perhaps the category is not needed. Further clarification is needed from Roy regarding how residual stimuli can be researched if they are unknown; for once they become known they are labelled as contextual.

The research clearly supports the existence of stimuli, factors which initiate adaptation or a process of change. As stated, uncertainty was such a significant factor, emerging as the core concept that it can be clearly identified, according to Roy, as the focal stimuli. This was influenced by contextual changes occurring in life situations. The type of contextual stimuli differed for each participant however was consistently identifiable from the research. The study brings into question the need for residual stimuli, and indeed how their existence can be proven through research.

7.4 The coping process

As dictated by Roy, the existence of a focal stimulus produces a reaction in the form of a coping process. The grounded theory results demonstrated that great uncertainty caused an overwhelming experience of anticipating hopelessness. A coping process emerged consisting of the seven subcategories describing the way participants adapted to this uncertainty, attempting to regain optimism. In Roy's viewpoint a coping process takes place in four overlapping areas of adaptation: self concept, physical, interdependence and role function. Coping mechanisms are deemed to be either cognitive or regulator (internal body responses).

When reviewed in light of Roy's Adaptation Model, the seven subcategories from the grounded theory fall predominantly within the self-concept, role function and interdependence modes. Physical elements such as taking anti-retrovirals, CD4 or viral load results were mentioned by participants but not measured *per se* as part of the research. Participants were asymptomatic, therefore adaptation emerged as focusing around cognitive aspects of the coping process rather than regulator body responses. Physical aspects could be evaluated in future research as their existence is recognisable but did not become the focus of this research. Physical aspects did not emerge as specific concepts however the fear of physical aspects becoming more prominent did cause uncertainty. Maintaining physical health was an important part of regaining optimism. If categorised according to Roy, an individual's self-

concept of being physically well was of a higher priority than biochemical measurements indicating physical deterioration.

The coping process outlined in the grounded theory explains specifically methods used by participants to adapt to uncertainty. Each subcategory demonstrates an area in which adaptation took place. The pair of concepts within each category show the changes made in order to adapt, regaining optimism over uncertainty. Each subcategory can be represented within the adaptive modes of Roy's Adaptation Model, in some cases the subcategories represent more than one adaptive mode, this supports Roy's notion that adaptive modes are overlapping and in some cases cannot be separated.

The subcategory 'seizing opportunity' signifies aspects of an individual's role function and self-concept, where they see themselves in the future and how they might achieve ambitions. In this instance a view of self and ones role within society overlap. 'Planning for the future', consisting of the categories escaping and distracting, gives consideration to both role function and interdependence. Plans are made in relation to changing ones role function within the family or working environment whilst also making plans to maintain or develop new relationships.

'Considering risk' was judged to lie within the self-concept mode of adaptation. Perceptions of risk varied from individual to individual, and changed according to experience and knowledge. Denial and acceptance

of risks were individual personal experiences. Choosing to take a risk may have physical implications but what emerged from the study was the importance of risk judgement. The implications of risk taking emerged as secondary to perception of the risk itself.

'Assuming direction' and 'strengthening through hope' also lie within the self concept mode when applied to Roy's Adaptation Model. Perceiving oneself as being controlled by HIV or being able to control HIV depends heavily on one's own self-perception. Movements between vulnerability and empowerment, categories dependent on emotion, also proved reliant on one's view of the self. As self-perception altered, individuals experienced adaptation.

'Broadening vision' fell concisely amongst the notion of self-concept yet contained aspects of role function and interdependence. Moving from self focus to self comparison involved looking to oneself and the way one felt, gradually moving to look to others, making comparisons to the role of others in society, in some cases developing relationships with others in order to take the focus away from oneself. This process involved making cognitive judgements of others' situations and applying this back to one's own life.

The category 'existing as-was' provides an example of all four adaptive modes. Believing that everything had changed due to the great uncertainty looming over life impacted both one's concept of self, role

function, ones relationship with others and physical health. Regaining optimism of this subcategory and acknowledging that things perhaps had not changed involved realising that relationships could be the same (interdependence), careers could remain unchanged or improved (role-function), wellness could coexist with diagnosis (physical) and ones self perception could be unaffected (self-concept).

Evaluation of the subcategories in relation to Roy's Adaptation Model provides support for the adaptive modes described within the theory. The subcategories which emerged from the grounded theory demonstrate specific and applicable methods of adapting. Roy's adaptive modes provide a strong theory which is applicable to the grounded theory. Indeed the adaptive modes support the grounded theory in the same way in which the grounded theory provides support for the adaptive modes.

Adaptation within each subcategory required cognitive behaviour, in order to alter ones perception of the uncertainty. Roy recognises the ways in which individuals apply cognitive functioning to adaptation; she labels these the cognitive-emotive channels: perceptual, learning, judgement and emotion. All of these were employed and can be identified within the grounded theory. Participants altered their perception of events in order to change the degree of uncertainty they felt. Learning took place as participants sought information that altered their perception of risk. Judgements were used when comparing self to others or making steps towards saving ones own life. Emotion ran strongly through all the

subcategories being resonant in the form of feelings of hopelessness and optimism. These feelings were never static, emotions continually changed, each individual kept learning new things, perceptions of uncertainty were negotiated and re-negotiated. Judgements, feeling and emotions could change, in some cases being re-fed into the process as contextual stimuli.

The data from the study strongly reinforces Roy's portrayal of adaptation as highly active, always moving and constantly changing. These cognitive changes were not dependant on physical changes, indeed most participants were asymptomatic. Therefore cognitive coping processes took place regardless of physical changes to the body.

7.5 Behavioural adaptive responses

As part of the feedback loop system, Roy views behaviour as the adaptive response. Roy states that behaviour "*shows how well the system is adapting in interaction with the environment*" (Roy & Andrews, 1999; p43).

Behaviour can be judged as either adaptive or ineffective. Positive adaptive responses are those which:

"promote the integrity of the human system in terms of the goals of adaptation: survival, growth, reproduction, mastery and person and environment transformations"
(Roy & Andrews, 1999; p44)

On the contrary, ineffective responses are those that do not contribute to the goals of adaptation. Roy states that if these are not addressed such responses may:

“threaten the human system’s survival, growth, reproduction, mastery or person and environment transformations”
(Roy & Andrews, 1999; p44)

Emergence from the grounded theory study highlighted two similar behavioural responses: anticipating hopelessness and regaining optimism. Participants strove to regain optimism; this emerged as the theoretical aim for all participants and represented a positive adaptive response.

Anticipating hopelessness over a situation was viewed as letting uncertainty take hold; such responses (ineffective) were fed back into the feedback loop as contextual stimuli in order to strive to achieve or maintain a positive adaptive response. The seven subcategories, as discussed within the coping process, demonstrated the ways in which participants strove to achieve an adaptive response.

It is evident from the grounded theory that achieving a positive adaptive response by regaining optimism, involved various person and environment transformations, the strong emergence of the subcategories demonstrate this. Movements towards positive adaptation involved aspects of mastery, such as developing control over HIV, as described in the subcategory ‘assuming direction’. Survival was evident in the determination displayed by participants to keep on living, indeed altering their viewpoint of HIV to see it as something which has ‘saved their life’ (seizing opportunity subcategory). Many personal transformations are visible in the way optimism was regained, through developing a personal sense of empowerment and acceptance. Self comparison was used as a practical

means in which to personally transform ones own view of self. From this it is clear that many of the qualities Roy describes as acting to produce a positive adaptive response are evident in the grounded theory as the same qualities used to regain optimism.

In the same way, the characteristics of anticipating hopelessness also mirror Roy's description of an ineffective response. The descriptions by Roy of ineffective responses appear to be opposite of those used to describe positive adaptive responses. This is similar to the categories of bi-polar opposites used to describe the subcategories of the grounded theory, i.e., destroying life and saving life, vulnerability and empowerment. Roy sees adaptive responses as promoting the integrity of the human system and ineffective responses as those which do not. Anticipating hopelessness, emergent as an ineffective response contained negative characteristics that could indeed threaten the human system.

Vulnerability, destroying life and being controlled by HIV are examples of ways which may threaten human survival, increasing or exacerbating levels of uncertainty. Roy uses similar descriptions leading to ineffective adaptation in her typology of commonly occurring adaptation problems: *"anxiety, powerlessness, role-conflict, separation and loneliness"* (Roy & Andrews, 1999; p84).

According to the grounded theory, facing uncertainty resulted in an anticipation of hopelessness, in the words of Roy, an ineffective adaptive response. A process of negotiation, similar to Roy's description of the

adaptation process, was employed by participants to regain optimism, developing an adaptive response. Responses from the grounded theory were manifest as behaviours, as in Roy's work. Anticipating hopelessness and regaining optimism hold similar qualities to Roy's descriptions of ineffective and positive adaptive responses. Thus the results of the grounded theory support the adaptive responses described in Roy's model.

7.6 Application of theoretical findings to Roy's definition of the nursing process

Roy's model is designed from Roy's own experience in nursing practice. It is a tool to assist nurses in the nursing process: clinical assessment, diagnosis, goal setting, intervention and evaluation. Nurses are encouraged to use the model to identify ways in which patients are struggling to cope through the assessment of behaviour and stimuli that influence adaptation, the overall aim of nurses being to promote positive adaptation.

With an understanding of Roy's Adaptation Model, nurses can use this as a template to identify stimuli, establish behavioural goals, set interventions and evaluate the outcome of these, judging the effectiveness of the nursing intervention. This process takes place by the nurse making statements about behaviour through observation, measurement or subjective recordings. Research can also be used to identify behaviour,

indeed Roy actively encourages the use of research contributing to the understanding of life processes and adaptive coping (Roy, 2008).

The theory of adapting to uncertainty which has emerged through the grounded theory study can be applied to Roy's model, identifying stimuli and methods of coping as previously discussed. It may also be applied to the nursing process as it helps identify areas in which participants struggled to adapt, as emerged from the voices of the participants themselves. The emergence of uncertainty as the core category, or in the language of Roy's model, as the focal stimuli, can help inform nurses of the impact of this feeling on all areas of life as identified through the subcategories.

Constant comparison of themes emerging from the dialogue identified the theme of uncertainty as the core category. The use of grounded theory method ensures that results uncover processes which already exist but have not previously been formally identified. Roy's model differs slightly in its approach as it relies on nursing judgements to make a nursing diagnosis. The 'diagnosis' of uncertainty as the core category emerged from the data and was not an assumption of the researcher or nurse. Roy does not explicitly state whether the judgement of a behaviour being either ineffective or leading to positive adaptation is the construct of the nurse or participant. The technique of grounded theory ensured the identified process of adapting to uncertainty was theoretically constructed directly from the participants. Anticipating hopelessness was seen by participants

as an ineffective response, hence the desire to negotiate uncertainty, striving to regain optimism. Roy indicates that when using her model in nursing practice, it is the nurse's decision of whether a behavioural response is adaptive or ineffective. The involvement of patients in the nursing process is however recommended:

“The individuals involved in the situation are actively involved in the formulation of behavioural goals whenever possible. This involvement provides the nurse with the opportunity to explore the rationale behind certain goals and gives the participants, as individuals or a group, the chance to suggest goals and evaluate whether other goals are realistic. Those who are actively involved in the formulation of goals are likely to be committed to achieving the goal”
(Roy & Andrews, 1999; p85)

The results of the grounded theory have been developed through rigorous constant comparison from the voice of the participants themselves. The grounded theory results are not a nursing judgement or diagnosis. Nursing practice is complex, nursing judgements are needed in the decision making process. However, as Roy acknowledges, the involvement of patients is paramount to providing patient-centred care. The results from the grounded theory provide, at a theoretical level, the voice of participants. This can be used to inform nursing practice when making judgements and diagnoses.

7.7 Theoretical advancements from the grounded theory towards Roy's Model of Adaptation

The previous sections have outlined the ways in which the results of the research have affirmed many of the propositions of Roy's model such as

the definition of adaptation, concept of stimuli and overall coping process. The research also brings new findings to Roy's theoretical arena, expanding areas which had previously been highlighted as needing more conceptual and theoretical development. As described in section 3.11, a published review of research using Roy's Model flagged two recommended areas for future research: the concept of time and the concept of perception. Steps towards unearthing these concepts have been made within this research as will be described. Roy also published a set of specific *'Recommended Foci for Nursing Research Based on the Roy Adaptation Model'* (Roy & Andrews, 1999; p553 – see Figure 8). These sixteen areas fell within either the categories of basic nursing science or clinical nursing science. Three of these foci have been further uncovered within this research:

- Dynamics of evolving adaptive patterns
- Relationship of adaptation to health
- Conceptual, theoretical and empiric basis of perception in integrating the adaptive modes.

The following section offers an in depth exploration of the conceptual advancements to Roy's Model and nursing theory from the research that has been conducted.

7.7.1 Advancements to the concept of time

As mentioned, Roy has called for further development through research into the concept of time and its influence on the adaptive process. As a qualitative study, the concept of time in this research was not quantitatively measured however the influence of time has emerged strongly, providing steps towards its theoretical advancement.

The whole adaptive process was influenced by, and if not to some degree, controlled by, time. This is perhaps seemingly obvious, without time the adaptive process could not exist. The focal stimulus of uncertainty was in many ways controlled by time, or the perception of it. The uncertainty created when diagnosed with HIV was brought on not only by the uncertainty of illness but by the sudden uncertainty of how much time might be left. The remaining lifespan perceived by each participant influenced their coping process and thus the whole process of adaptation.

As one participant stated:

“If I had been told I had a year to live I would respond differently to if I had been told I had ten to twenty years to live”
Interview 11

This statement demonstrates the value and reliance on time to make decisions and choose a way of adapting. Without a certainty of how much time was left, participants were left to draw their own conclusions; each had an anticipation of how long he might live, with the hope that he might live longer, especially if a cure was found. Thus it can be proposed that the perception of time had a greater influence on the adaptive response

and coping process than the reality of time present. A positive adaptive response was dependant on the existence of an anticipation of time for the future. The amount of time could vary from individual to individual but in this research hope for time had to exist for a positive adaptive response to take place.

It was clear that adaptation was not an automatic process occurring over the passing of time. As already stated, adaptation emerged as a process requiring conscious thought and reflection, decisions and plans. However the effect of time passing influenced these plans as it provided further opportunities for thought and reflection. Time enabled the opportunity to search for certainties, giving more opportunity for cognitive processing. As time passed plans were made with more confidence and participants gained more time to make decisions. Sarna *et al* (1999) touched upon this point in their study whereby quality of life for women with HIV appeared to improve over time. The results from this grounded theory have built upon this point demonstrating that the passing of time provides an automatic confidence in ones own ability to survive, reinforcing hope for continual survival into the future, furthering the likelihood of a positive adaptive response.

Time passing provided the opportunity for further reflection and the realisation that many uncertainties and fears had not materialised and things had indeed stayed the same. Each participant's description of their present was already further along in time than they had anticipated at

diagnosis, this gave participants confidence in hoping for more time. In this way, the concept of time significantly influenced the self-concept mode. Participants developed confidence in their own self concept of their life-span, this had positive repercussions on the role function and interdependence mode, assisting them to make plans, moving towards regaining optimism and a positive adaptive response. Thus in this way, the passing of time strongly influenced the self-concept mode, and it was this in turn that influenced the role-function and interdependence mode.

In developing the concept of time, Roy has called for examination into the most appropriate time for nursing interventions (see Figure 8). The emergent grounded theory outlined stages individuals went through when adapting to HIV whilst noting that each participant reached these stages at a different time. Such movements could take place on an hourly, daily, monthly or yearly basis. For some individuals reaching a point of positive adaptation may take a year, for others a day. The research provides nurses with an awareness of the stages that patients may go through, but encourages nurses to work holistically with each patient, with the awareness that each person will reach these stages at a variable time. Nurses should be aware that the passing of time can provide the impetus for patients to strive towards positive adaptation. As time passes, adaptive strategies and plans may become more tangible and desirable as ones confidence in time grows.

Nurses should be encouraged that ineffective responses can often act as a focal stimulus triggering an adaptive process in which the nurse can encourage a positive adaptive response. Therefore the negative uncertainty associated with anticipating a curtailed life-span can be challenged by the cognitive subsystem. If perceptions of time can be altered, the research demonstrates that the adaptive response is more likely to be positive.

7.7.2 Advancements to the role of perceptions

Roy defines perception as “*the integration of a sensory stimulus and the conscious appreciation of it*” (Roy & Andrews, 1999; p259). Within the Roy Adaptation Model, the role of perception is outlined as a component of the cognitive subsystem, a cognitive tool for adaptive change. The way one perceives oneself takes place through cognitive processing. Roy also acknowledges the role of perception in the self-concept mode in the development of *self schema* – cognitive generalisations about the self. The significance of perception within the model demonstrates the need for the nurse to be attentive to the patient’s perspective, their perception of themselves and their environmental factors will be paramount to how they adapt. Roy believes nurses need an awareness of this and prompts the use of questions and observations to gain further understanding of a persons self schema during the nursing assessment (Roy & Andrews, 1999; p393).

The research into adaptation to uncertainty has demonstrated that perception has a role in almost every aspect of the adaptation model influencing the whole adaptive process. The way a stimulus is perceived will depend on whether it is deemed focal or contextual. Responses are based on individual perceptions of a situation. A situation demanding an adaptive response for one person may not be perceived as requiring any response for another. As described in the previous section, perception has a strong role to play in the concept of time – the perception of time being a stronger stimulus than time itself. This supports previous research by Dahlen (1980) who proposed that the perception of an event is a stronger indicator of adaptation than the focal stimulus triggering the event itself.

Individual perceptions play an active part in each adaptive mode, ones perception of their role function within society, ones perception of their physical health, and ones perception of their relationships with others (interdependence). Perceptions within these areas affect adaptive responses. When several responses are required, the order in which these take place demonstrates their perceived significance to the individual. The focal stimuli can identify ones perception of environmental factors and demonstrates and the value placed on them by the individual. Within this grounded theory uncertainty as the focal stimuli demonstrated the high value placed on time and health for each individual. When these were threatened, uncertainty arose.

The research has highlighted the importance of seeking the patient's point of view, enquiring into what they consider to be their focal stimulus. It is possible that nurses and patients may differ considerably in their perception of events. The research demonstrated that blood results, i.e., viral load and CD4 count, were not as significant an indicator of health to the individual as their feeling of well-being at the time. A patient's perception of their physical health may have greater influence on adaptation than physical indicators. Research by Gagliardi *et al* (2002) concluded that cognitive processes had more influence on adaptation than regulator body processes. Within the grounded theory results uncertainty was not hinged on viral counts but instead on how one felt, a combination of ones own perception of each of the adaptive modes. The importance and significance of cognitive processing is highlighted here. If, as revealed from this research, an individual's perception of their situation has a greater impact on their adaptive ability than the situation itself, then nursing interventions should be focused on the cognitive subsystem, not just attempting to medically balance the patient's regulator system.

Understanding the way a patient perceives their situation is paramount to providing good nursing care. The patient's perception may determine where, and at what point, nursing interventions are required. The results from the emergent grounded theory demonstrate the need to look beyond the immediate presentation of the regulator body system, or medical diagnosis. The patient's perception of what their diagnosis means to them will have a greater effect on their adaptation than the diagnosis itself. A

nurse's perception of a positive adaptive response may differ from that of the patient. This is particularly significant as the way an adaptive response is perceived by a patient will influence the way it is fed back into the feedback loop.

Roy's explicit description of perception within the cognitive subsystem is of particular significance to this study. Perceptual processing is labelled as one of the four cognitive-emotive channels within the cognitive subsystem, the remaining three being learning, judgement and emotion. Roy discusses these as having equal significance. The results of this research however strongly indicate that the role of perceptual processing is needed before other responses can be activated. This research proposes that the cognitive-emotive channels of learning, judgement and emotion are dependant on perceptual processing. The research showed that emotions were felt dependant on the way something was perceived. One's perception of events indicated how judgements would be passed on a situation. Equally learning took place in response to perception. Some participants wanted to learn more about HIV, gathering as much knowledge as possible in order to adapt. Others did not want to know anymore information, content with the understanding they already had. Each response was right for the individual concerned and they adapted depending on their own perception of their needs. This point, raised from the research results, is particularly significant as Roy has called for further understanding into the role of perception within the regulator and cognitive processes.

7.7.3 Advancements to Roy's scientific and philosophic assumptions

Roy's philosophic assumptions were used to base the conduct of the research enquiry, providing a starting point on which to build the grounded theory. The study did not intend to prove or disprove the assumptions underlying the model. Nevertheless discussion of the scientific and philosophic assumptions in light of the grounded theory is valid.

The emergent grounded theory does not necessarily support or reject the philosophic assumptions. Concepts did not emerge from the dialogue regarding creation, spirituality or God. With regards to Roy's assumption "*Persons use human creative abilities of awareness, enlightenment and faith*" (Roy & Andrews, 1999; p35), each account of an experience of adapting to HIV demonstrated the use of creative abilities, particularly through awareness and perception. Enlightenment and faith did not emerge as concepts although the idea of 'fate' demonstrated some belief in destiny.

Roy's scientific assumptions were supported by the grounded theory. The overall theme of the scientific assumptions emphasises the role of individuals using consciousness, thinking, and feeling to integrate with the environment, progress to higher levels of self-organisation and develop meaningful relationships (Roy & Andrews, 1999). These ideas came through strongly in the grounded theory. The role of an individual's perception in determining the focal stimuli and adaptive experience

demonstrates the level of consciousness involved in adapting. The fact that adaptation came through very strongly as requiring conscious thought and not being an automatic process resonates with the scientific assumptions. The need for acceptance, protection and fostering of independence was also evident in individual methods of striving to regain optimism

7.8 Recommendations for future development of Roy's Model of Adaptation

The results of this research can stand alone in their own right as a newly evolved grounded theory of adapting through negotiating uncertainty. Yet it is also the nature of this study that makes it so unique: applying the grounded theory back to the nursing theoretical arena. Section 3.10 reviewed previous research incorporating Roy's Adaptation Model and demonstrated that only one research study had applied the results back to Roy's theory of nursing. It is this final application that provides sustenance to the work, using it to strengthen the backbone of nursing, building on the theory and research of others before, helping nursing to maintain a solid framework on which to base practice.

The previous sections within this chapter have discussed the results of the grounded theory in relation to the many aspects of Roy's Model of Adaptation, providing a specific focus on developments to the concept of time and role of perception, as recommended by Roy. It can be

summarised that the grounded theory supports the propositions of Roy's Model of Adaptation in the following ways:

- The grounded theory fully supports Roy's definition of adaptation.
- The grounded theory supports the idea of focal and contextual stimuli.
- The grounded theory supported Roy's idea of a coping process consisting of adaptive modes (indeed all emergent subcategories in the grounded theory were classifiable according to Roy's Adaptive Model).
- The research supports the notion that adaptive responses (adaptive outcomes) can be positive or ineffective.
- The grounded theory concludes that adaptive modes are overlapping and sometimes inseparable.

A theory is only as good as the research that can support and develop it. Roy's model is only a useful tool if continually updated so that it can be used in practice. In effect, the emergent grounded theory has tested Roy's Model of Adaptation and demonstrated the strength in its core concepts. Roy's Model of Adaptation is well established and therefore it is not surprising that the results of the grounded theory were transferable to the model. However, new ideas from the grounded theory offer some areas that require further clarification, either through development of the concepts or through further research. Those ideas challenged by, or not supported by the grounded theory were:

- Residual stimuli did not emerge and indeed the research cast questions over how these can ever be determined. Are they identifiable and if not, are they necessary?
- The internal subsystems of regulator responses and cognitive processing did not emerge as equal. Cognitive processing appeared to have a much stronger impact on adaptation than regulator responses.
- Within the idea of cognitive processing, the role of perception held more significance than learning, judgement or emotion. Indeed these latter categories appeared to depend on perception itself.

In relation to the above points, several areas emerged from the grounded theory which did not oppose Roy's Model of Adaptation but required further elaboration to demonstrate their consistency are:

- Focal stimuli appeared to be controlled by time – or the perception of time.
- A positive adaptive response appeared to be dependant on an anticipation of future time.
- The passing of time was positively linked to the self-concept mode.
- Of all the adaptive modes, 'physiologic-physical' did not significantly emerge from the study. Furthermore perception of self-concept, interdependence and role function appeared to have more

importance to individuals than the physical. Further research is needed to establish if the other modes take a higher priority.

The above challenges provide an opportunity for future research studies to develop Roy's Adaptation Model, enhancing the theoretical basis of the model, eventually making it stronger. The grounded theory has demonstrated the strength already existent in Roy's work yet provided opportunities to continue refining it. These should always be viewed positively.

The established grounded theory needs to be taken to other communities or situations to see if similar themes emerge or are experienced.

Conducting a similar study amongst those in the end-stages of their illness may reveal that adaptation can take place without an anticipation of future time. Research amongst those who are symptomatic of their illness may reveal a stronger emergence of the 'physiologic-physical' mode. The grounded theory presents a true conceptual picture of the experience of those interviewed. It can be lifted and applied to other audiences to see if the same experiences occur.

7.9 Implications of the grounded theory for the wider nursing theoretical realm

As a grounded theory of adapting to uncertainty the results resonated with Roy's Model of Adaptation. The grounded theory is supported by the

concepts of Roy's work, and Roy's Model has also been strengthened by the grounded theory.

Research can produce and modify theory. Research can continually test and develop theory (Fawcett & Downs, 1992). Theory can also be tested and developed through its application to practice; it is here that its usefulness is revealed. Research using any chosen theory of nursing helps to advance the theoretical realm, encouraging open debate and conceptual development/advancement (Cody, 1994). Research taking place in a nursing context but using a theoretical base from a different discipline (i.e. social science), helps build the theory of that specific discipline only. The results may be useful to nurses but will not build up the disciplines own background.

It is possible that the results from this grounded theory study may be applicable to other nursing theories, challenging or complementing them. Newman's theory of health as expanding consciousness (briefly reviewed in section 2.8) recognises health as a fusion of disease and non-disease. Illness is not viewed negatively and does not take away from the person but instead causes the wholeness of the person to take on a different form. This echoes aspects of the grounded theory; HIV was not viewed as wholly negative. Newman views people as a 'consciousness' consisting of a pattern which is continually evolving as time passes and situations change. Similarities from this perspective can be found in the grounded theory as perception and conscious choice was used as a means to

continually adapt. An in depth synthesis of the grounded theory to other nursing theories could highlight similarities, differences, strengths and weakness, both in and between existing nursing frameworks. Further application to nursing will provide necessary challenges to a theoretical debate which needs expanding and continuing. The developed grounded theory has tested Roy's model, strengthened it and found areas to challenge. These areas need to be researched further in order to continually refine and develop concepts.

7.10 Recommendations for future development to the grounded theory of adapting to uncertainty

Through exploring the process of adapting to life with HIV, a grounded theory of adapting to uncertainty emerged. This has been compared to Roy's Adaptation Model as a way of testing and developing a pre-established theory. The developed grounded theory is however, able to stand independent of any other work, in its own right, as a theory of negotiating uncertainty. According to Glaser (1998) the process of constant comparison constantly verifies the fit of the data. The proof of the research is in the outcome of the grounded theory. What has been produced in this study is an explanation of how a group of individuals negotiate uncertainty in order to adapt to life with HIV. The grounded theory has conceptually produced this process as outlined in Chapter 6.

To build and strengthen any theory it needs to be modifiable as new data emerges. A unique aspect of grounded theory is the use of 'modifiability'

where other methods may use verification. Grounded theories should be used and applied to different areas or used amongst different data in order to continually modify them.

To further research from this study, it is recommended that the grounded theory of negotiating uncertainty is taken to other areas within nursing, and the wider field for modification, strengthening the process that has originally emerged. The research took place among a group of asymptomatic patients diagnosed with HIV. Future research could use the outcomes of the grounded theory amongst symptomatic HIV patients, or those with AIDS. The development of the data into concepts enables the grounded theory to be transferable across disciplines. The grounded theory can therefore be used (and subsequently modified) in any area where uncertainties maybe negotiated, be this in business, marketing, healthcare, politics or environmental science. This flexibility demonstrates the usefulness of grounded theories. Taking this theory forward within other areas will continue to demonstrate its contribution to knowledge within nursing and the wider world.

7.11 Summary of recommendations for research and practice

In summary, the recommendations for future research to develop and refine Roy's Adaptation Model are:

- To investigate further the need for and significance of residual stimuli.
- To take further the idea that cognitive processing has a stronger influence on adaptation than regulator responses.
- To further establish if, within cognitive processing, perception has more significance than learning, judgement or emotion.
- To establish if focal stimuli are predominantly controlled by the perception of time rather than time itself.
- To further establish links between the passing of time and the self-concept mode.
- To establish if each adaptive mode plays an equal role in adaptation and to establish the impact of the physical-physiological mode on the other adaptive modes.

Recommendations for developing the grounded theory of negotiating uncertainty are:

- To use the grounded theory amongst patients with HIV who are symptomatic and/or female – such participants did not take part in this study – and modify the grounded theory accordingly.
- To use the grounded theory in other areas (or disciplines) where uncertainty is present and adaptation takes place, modifying the theory accordingly.
- To apply the grounded theory to other nursing theories, such as Newman for comparison and critique.

The summary of recommendations for forwarding nursing practice is to:

- Encourage application of theory to practice through distribution of knowledge from the theory of negotiating uncertainty, enabling nurses to be aware of situations their patients may experience.
- Develop awareness that for patients grappling with uncertainty, the passing of time may provide an impetus to strive towards adaptation.
- The grounded theory suggests that if the perception of time can be altered, the adaptive response is more likely to be positive; it may be beneficial for the nurse to be aware of this when encouraging positive adaptation.
- Develop awareness that ineffective responses may act as a focal stimulus triggering an adaptive process in which the nurse can encourage a positive adaptive response.
- To forward the work of Roy's Adaptation Model as suggested by the above recommendations and apply this to nursing practice.

7.12 Final summary and conclusions

This thesis began with the aim of exploring the process of adapting to life with HIV as it is currently experienced in a climate with available drug therapies and increased life expectancy but where virus resistance is also apparent. Glaser's grounded theory method was used to gather and analyse the data, answering the research question and meeting the objectives originally outlined (see section 1.1). The research has revealed

a new perspective of adapting to HIV that involves a constant process of negotiating uncertainty. Uncertainties were outlined within seven subcategories; negotiations of these took place by trying to move from anticipating hopelessness towards regaining optimism. New aspects of adaptation which were identified which have not been previously researched such as the use of self-comparison as an adaptive strategy. The theory provides a basis for future evaluation and exploration of the HIV experience. This work advances understanding of the HIV experiences which can be applied and used in nursing practice. Theoretically this work progresses the concept of adaptation, adding new information to this field.

Recruitment took place from the local genitor-urinary clinic. Fifteen interviews took place amongst HIV positive (but asymptomatic) males. Data saturation was reached amongst these participants however it would be useful to repeat the research amongst women and/or those symptomatic with HIV or having been diagnosed with AIDS who were invisible in this study.

The philosophical assumptions of Roy's Adaptation Model were used to ground the study from beginning to end. The results of the theory of negotiating uncertainties were compared to Roy's Model of Adaptation. This theoretical comparison proved useful in supporting the majority of the main concepts of Roy's Model. Correspondingly, this comparison also strengthened the results of the grounded theory. This research has

pushed forward the boundaries of theoretical nursing development, uniquely using new research to develop a well established nursing theory. Few 'theory based' research studies have been found to actually apply their results back to the theoretical starting point. This research has furthered knowledge of the concept of time and role of perceptions as called for by Callista Roy herself. The research has highlighted areas of Roy's model which may need further development or clarification to update and refine the concepts such as the idea of residual stimuli, the significance of cognitive processing over regulator responses and the role of perception over learning, judgement and emotion.

Nursing science and theory is developed with the ultimate aim of being filtered down to practice level to improve patient care. What has been uncovered by this research is the strategies employed by a group of patients to cope with their diagnosis in their everyday lives. Through understanding the everyday effect of a diagnosis nurses can be better equipped to provide support, more informed to understand at which stage the support might be most beneficial, and perhaps most importantly, more sensitive in listening to their patients, hearing how HIV is affecting them whilst retaining the background knowledge from this research of how it has affected others.

Theoretically this study is unique in having created a theory relevant to practice whilst testing and suggesting areas for refinement of a well established nursing theory. The research itself has been successful in

developing these aspects. The challenge for the future is to build on these, modifying and pushing them forward, integrating new information into practice so the care of patients might be more expertly met, improving their adaptive experience.

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Appendix 1 – Typology of indicators of positive adaptation according to Roy & Andrews (1999)

Physiologic / Physical Mode	
Individuals	Groups
Oxygenation Stable processes of ventilation Stable pattern of gas exchange Adequate transport of gas Adequate processes of compensation	Adequate fiscal resources Member capability Availability of physical facilities
Nutrition Stable digestive processes Adequate nutritional pattern for body requirements Metabolic and other nutritive needs met during altered means of ingestion	
Elimination Effective homeostatic bowel processes Stable pattern of bowel elimination Effective processes of urine formation Stable pattern of urine elimination Effective coping strategies for altered elimination	
Activity and Rest Integrated processes of mobility Adequate recruitment of compensatory movement processes during inactivity Effective pattern of activity and rest Effective sleep pattern Effective environmental changes for altered sleep conditions	
Protection Intact skin Effective healing response Adequate secondary protection for changes in integrity and immune status Effective processes of immunity Effective temperature regulation	
Senses Effective processes of sensation Effective integration of sensory input to information Stable patterns of perception, interpretation and appreciation of input Effective coping strategies for altered sensation	
Fluid, Electrolyte, and Acid-Base Balance Stable processes of water balance Stability of electrolytes in body fluids Balance of acid-base system Effective chemical buffer regulation	
Neurologic Function Effective processes of arousal and attention;	

<p>sensation and perception; coding, concept formation, memory, language; planning, motor response Integrated thinking and feeling processes Plasticity and functional effectiveness of developing aging and altered nervous system.</p>	
<p>Endocrine Function Effective hormonal regulation of metabolic and body processes Effective hormonal regulation of reproductive development Stable patterns of closed loop negative feedback hormone symptoms Stable patterns of cyclical hormone rhythms Effective coping strategies for stress</p>	
<p>Self Concept – Group Identity Mode</p>	
<p>Physical Self Positive body image Effective sexual function Psychic integrity with physical growth Adequate compensation for bodily changes Effective coping strategies for loss Effective processes of life closure</p>	<p>Effective interpersonal relationships Supportive culture Positive morale Group acceptance Principle-based relationships Value-driven relationships</p>
<p>Personal Self Stable pattern of self-consistency Effective integration of self-ideal Effective processes of moral-ethical-spiritual growth Functional self-esteem Effective coping strategies for threats to self</p>	
<p>Role Function Mode for Individuals and Groups</p>	
<p>Role clarity Effective processes of role transition Integration of instrumental and expressive role behaviours Integration of primary, secondary and tertiary roles Effective patterns of role performance Effective processes for coping with role changes Role performance accountability Effective group role integration Stable pattern of role mastery</p>	
<p>Interdependence Mode for Individuals and Groups</p>	
<p>Affectional adequacy Stable pattern of giving and receiving Effective pattern of dependency and independency Effective coping strategies for separation and loneliness Developmental adequacy Resource adequacy</p>	

(Roy & Andrews, 1999, p79-81)

Appendix 2 – Summary of qualitative studies using
Roy's Adaptation Model (1995-2005)

Author, date and area of investigation according to RAM	Purpose	Sample	Design	Findings
Brydolf & Segesten (1996) (Self-concept)	To describe adolescents experience of living with ulcerative colitis	Adolescents with ulcerative colitis (n=28)	Descriptive, grounded theory analysis	Eight identified categories formed a model of the disease process from onset to present time. The main variable was reduced living space, a strategy to manage the new situation.
Raeside (1997) (Stimuli)	To assess and compare mothers perceptions of stressors related to the NICU environment with nurses perceptions of environmental stressors experienced by mother and neonate	Mothers (n=12); nurses (n=12)	Descriptive	Stress caused by the NICU environment was less than expected. Stress caused to the neonate by the environment was rated lower by mothers than nurses
Lotus Shyu (2000) (Role-Function)	To develop a conceptual framework explaining interaction between care give and receiver during the discharge transition	Caregivers (n=16); care-receivers (n=12)	Grounded theory	Role tuning was used by both caregivers and receivers to achieve harmonious adaptation during the transition from hospital to home
Yeh (2001) (Adaptive modes and processes)	To establish a conceptual framework for the adaptation process of Taiwanese children with cancer	Paediatric cancer patients: boys (n=23); girls (n=11)	Content analysis	Five aspects of adaptation were identified as physiological, psychological, cognitive, interdependence and future orientation.
Dobratz (2002) (Self-concept)	Psychological adaptation in home hospice patients	Home hospice patients (n=15)	Grounded theory	Emergence of seven process patterns, including that of 'becoming-self'
Gagliardi, Frederickson & Shanley (2002) (Adaptive modes and processes)	To examine how people make sense of the experience of living with multiple sclerosis	Multiple sclerosis patients (n=18)	Content analysis	Five themes were identified: we are not completely the same, how I view my future, let me tell you about my feelings, how I see work and let me tell you about my life.
Gagliardi (2003) (Self-concept)	To identify the experiences of sexuality as experienced by those living with multiple sclerosis	Multiple sclerosis patients (n=8)	Naturalistic case study	Three themes conceptualised the experience: how I feel about my appearance, I have feelings about my sexuality, and sexuality for me has both positive and negative emotions.
Zeigler, Smith & Fawcett (2004) (Intervention)	To identify the experiences of participants and facilitators of a community breast cancer support group	Women with breast cancer (n=10); registered nurse facilitators (n=2)	Content analysis	A combination of information, emotional and social support was effective in the breast cancer support group
Dobratz (2004) (Self-concept)	To describe perceptions of spirituality in home hospice patients	Persons receiving home-hospice palliative care (n=44)	Secondary analysis coding for 'spirituality'	Core theme of believing, followed by six other themes: comforting, releasing, connecting, giving, reframing and requesting

Research volunteers needed!

- **A nurse conducting research is seeking volunteers to participate in a study investigating people’s experience of adapting to HIV/AIDS.**
- **Taking part would involve meeting with the researcher to “tell your story”.**
- **Full confidentiality and anonymity is guaranteed.**
- **The research aims to help nurses understand more about HIV/AIDS and may improve the services we provide. You can help!**
- **For more information see the leaflets below or contact Stephanie Perrett on **** * or **** * (mobile)**

Appendix 4 – Research study consent form for participants

CONSENT TO PARTICIPATE FORM

Title of Project: An Investigation into the process of adaptation for those living with HIV/AIDS

Researcher: Stephanie E Perrett

- I confirm the purpose and procedure of the study have been fully explained to me and I have read and understand the information sheet for the above study. I confirm I have had the opportunity to ask questions about the study.
- I understand I will be asked to describe my experience of living with HIV/AIDS and the ways in which I have had to adapt. I understand I will be asked to take part in three open, tape recorded interviews. I understand I will be granted full anonymity and my name will not appear on the written transcripts, reports or any published papers. I understand I may choose not to give my name but to give my clinic number instead.
- I understand that for security and to protect my anonymity, consent forms will be kept locked within the GU Clinic, *****, within my medical notes.
- I understand my participation is voluntary and I may withdraw from the study at any time without giving any reason and without my medical or legal rights being affected.
- I understand I may call Stephanie Perrett to talk about any concerns or questions I may have about my participation in the study.
- I agree to take part in the above study

NAME OR CLINIC NUMBER (Block Capitals):.....

ADDRESS.....

TELEPHONE:.....

In order to arrange times for the second and third interviews, please state how you would like to be contacted (ie, telephone, please give number):

.....

Signature of Participant:.....

Date:.....

Signature of Researcher:.....

Date:.....

PARTICIPANT INFORMATION SHEET

A RESEARCH STUDY ON ADAPTING TO HIV/AIDS

You are being asked to consider taking part in a research study led by Stephanie Perrett, a staff nurse at the *****. Please take time to think about the following information and discuss it with others if you wish. Please contact us (numbers below) if there is anything unclear or if you need more information. Please take time to decide whether or not you wish to take part.

What is the purpose of the study?

The study is investigating the way people adapt to living with HIV/AIDS. It is hoped results from the study will help nurses understand more about what it is like to live with HIV/AIDS. A better understanding will help us to improve services and be better equipped to meet the needs of you, the patient.

Can anyone take part?

To take part you must be over 21 years of age and have received a diagnosis of HIV or AIDS at least two years ago. You need to be able to speak English as this is the language of the researcher.

What will happen if I choose to take part?

Taking part will involve meeting with the researcher three times over a year. You will be asked to describe your story and experience of HIV/AIDS. Each interview will be tape-recorded. The interviews will take place six months and one year from the initial interview. Each interview will take place in an agreed setting. The length of the interview will depend on how much you want to share! Interviews will begin by the researcher asking open questions leading to discussion about your experience of HIV/AIDS. You may talk as much or as little as you like! You may refuse to answer any of the questions.

What will happen to the information that I give?

All information you share will be strictly confidential and full anonymity will be assured. Your name (or clinic number if you prefer) will appear ONLY on the signed consent form. Your name will not appear on any other written documents used in the study or in any published results.

What will happen to the results of the study?

Results from the study will be shared with staff at the GU clinic in *****. Results will be published in a medical/nursing journal and presented at relevant conferences. However, confidentiality is guaranteed and no names will be published or presented. Your identity will NOT be identifiable from any of the published work.

Are there any risks to me in the study?

There are no known risks or real benefits to taking part. You may find it helpful to discuss your experience and know you are contributing to nursing knowledge and service development. You are free to talk with Stephanie Perrett (***** *****) at any time, about any concerns or questions you may have regarding the study. If you become uncomfortable at any point of the research you may stop and withdraw from the study or stop and reschedule the interview to another time.

What if I start the research and later change my mind?

You can refuse to answer any of the questions and may stop the discussion and withdraw from the study at any time without explanation. This will have no impact on the health services that you receive or on your legal rights.

What do I do if I want more information or to take part in this study?

For more information or to take part please contact Stephanie Perrett. You can call her at any time on **** ***** or ***** (mobile). You may also contact Dr F Biley, research supervisor at ***** on **** ***** for more information.

Thank you for considering participating in this study