

**HIV positive and treated for cancer: the social context and  
lived experiences of dual diagnosis and its treatment**

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## **Declaration**

I, Emma Georgina Hainsworth, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Date:

## **Abstract**

**Background** As the number of people living with HIV increases due to the combination of effective treatment and continued HIV incidence, a growing number will experience a cancer diagnosis. This thesis explores patients' experiences of a dual diagnosis of HIV and cancer.

**Methods** Three studies were conducted comprising: (i) an analysis of popular discourse about HIV and cancer in free London newspapers from 2012-2017 (ii) semi-structured longitudinal interviews with 17 patients with a dual diagnosis (iii) a focused ethnography of seven participant observations and seven informal interviews with healthcare professionals.

**Findings** Popular representations of cancer from the newspaper analysis depict it as a condition that could happen to anyone and deserving of sympathy whilst HIV retains negative and stigmatising connotations linking it to social deviance, blame and shame. The interview data revealed two conditions both with a powerful impact. Although HIV could be well managed on simple treatment it wielded an enormous influence over people's lives in the form of felt stigma which meant that individuals were engaged in constant work to manage information and avoid blame and rejection. Cancer could provide an opportunity to share and get support for the first time but its physically debilitating treatment and uncertain outcome caused fear and anxiety which was exacerbated by people's lack of fit with the cancer services. The deeply personal nature of a HIV diagnosis was not well understood by oncology healthcare professionals and not always accommodated within cancer care.

**Conclusions** Patients with this dual diagnosis are uniquely vulnerable; a better understanding of their experiences is essential for cancer services to provide good patient centred care.

## Impact Statement

A primary motivation for exploring the experiences of people with a dual diagnosis of HIV and cancer was to collect evidence in the form of experiences which could then be used to improve those experiences and inform more tailored healthcare services for this group of patients. There are very clear ways in which this work can be put to beneficial use, both inside and outside academia.

In terms of academic impact, the lived experiences of people with a dual diagnosis have been largely unexplored in the published literature. The findings of this study add an important new dimension to existing biomedical knowledge about the medical treatment and management of this group.

For those affected by a dual diagnosis, wide dissemination of the findings via accessible sources of information is likely to be of benefit in recognising the particular needs of this group. Patient involvement was an important and continuous component throughout the conduct of the research. Key patient representative advisors who are active members of HIV advocacy groups were involved at all stages and will be invaluable in disseminating the study findings to the people who are most affected. Findings from this thesis could be put to beneficial use to improve experiences for patients by helping to tailor and improve information about cancer produced for people with HIV by advocacy groups and charities. Following the publication of the systematic literature review an HIV charity known for providing trusted high-quality information approached me for input into some of their introductory factsheets covering a general overview of cancer and information about specific cancer types. Some of the study findings have therefore already been put to beneficial use by contributing to widely available patient information. Given some of the shared experiences that study participants related and the fact that social isolation was often a feature of these experiences, there may be potential for exploring and establishing a system of support, either online or face to face, which is tailored specifically to the needs of those people with a dual diagnosis of HIV and cancer some of which have been identified by this research.

Another important area where insights gained from this study can provide benefit is in the promotion of a better understanding of the needs of this group of patients amongst healthcare professionals. The study findings have indicated a number of areas of service provision that could be better tailored for patients in order to improve their experiences of cancer care. Dissemination of these findings via

journal publication and conference presentation would reach some of the relevant audience. There is also scope for the development of a learning tool, either online or face to face, which could have wider reach for relevant oncology staff and members of the support services, the aim of which would be to provide accessible, useful and appropriate information to help improve practice.

## Acknowledgements

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*I would like to dedicate this thesis to the memory of the six participants who died during the course of the project: I will never forget their stories*

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## List of Abbreviations

<b>Abbreviation</b>	<b>Definition</b>
AIDS	Acquired Immunodeficiency Syndrome
GP	General Practitioner
HAART	Highly Active AntiRetroviral Therapy
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
NIHR	National Institute for Health Research
PrEP	Pre-exposure Prophylaxis
TB	Tuberculosis
MSM	Men who have sex with men
KS	Kaposi's Sarcoma
HPV	Human Papilloma Virus
CAM	Complementary and Alternative Medicine
NCIN	National Cancer Intelligence Network
CD4	Type of T cell in the blood. Measuring the CD4 count by a blood test indicates how well the immune system is functioning
GCSF	Granulocyte Colony Stimulating Factor. A treatment given as an injection under the skin which helps the body make more white blood cells
NRES	National Research Ethics Service
REC	Research Ethics Committee
U = U	Undetectable = Untransmittable. People living with HIV who are on antiretroviral therapy and have an undetectable viral load in their blood for at least six months cannot infect others with HIV through sexual transmission

# **Chapter 1 Motivation for the Study and Setting the Scene**

## **1.1 Introduction**

The number of people living with HIV has been increasing due to the combination of effective HIV treatment and continued HIV incidence. Cancer remains a significant co morbidity for people living with HIV and this is likely to increase as the population ages. This thesis explores patients' experiences of a dual diagnosis of HIV and cancer and the implications for experiences of treatment. The research seeks to reveal the social, personal and health-systems contexts within which people with a dual diagnosis live, work and access treatment. This opening chapter provides an overview of my personal motivation for choosing this as an area of research. It then describes the rationale and aims of the study and the overarching principle of patient involvement throughout. It concludes with an outline of the work presented in the thesis.

## **1.2 Biography of the Researcher and Motivation for the Study**

I have worked as a nurse in both HIV and cancer over the course of a 23 year career, starting out caring for HIV positive patients in hospital in the mid 1990's at a time when antiretroviral therapies were first being introduced. HIV services were specialist and it felt as though there was a shared culture amongst healthcare professionals and patients alike. This culture was characterised by a tolerance of different lifestyles and an expectation that patients would be vocal and involved in decisions regarding their care and treatment, which was evolving and improving rapidly. Moving into cancer nursing in 2006 I perceived a different culture with a greater emphasis on a hierarchical structure where patients were more deferential and were accepting of the decisions made by healthcare professionals. My own perception of this difference stimulated my interest in exploring the experience of individuals coming into contact with both services.

The contrast in the two types of service appeared striking to me based on my own experience. However, in the time I had moved away from working in HIV care effective antiretroviral treatment had become established. Medical, policy and institutional discourses started to operate so as to reframe HIV as a chronic disease with a routine and biomedical underpinning provided by reference to biomarkers in the blood such as CD4 counts and viral loads. This idea of HIV being turned into an

everyday rather than an exceptional condition is one that has continued to develop since I worked in the field. However, it is clear that tensions and challenges such as stigma and marginalisation by sexuality and ethnicity still exist in today's society which make this more recent 'normalisation' discourse problematic for people living with HIV and makes it difficult for them to have the same experience of illness as people without HIV.

HIV and cancer are associated in society with commonly used metaphors; warfare and positive thinking for cancer; deviance and danger for HIV. Both have stigmatising features and it feels important to explore how they interplay within a dual diagnosis. I am particularly interested in how people interpret illness and assign meaning to it in the context of their own particular biography, cultural values and social relations and specifically how this happens within HIV and cancer. This area of inquiry falls into a broadly interpretivist approach which aims to explore people's worlds within the context of their life as a whole, incorporating social and personal influences as well as the biomedical, healthcare arena in which they receive their treatments. A better understanding of how people frame their experiences will help to inform improvements in services for this group of people and this has been my primary motivation in choosing this area of enquiry.

The study's central locus is patients' journeys through cancer treatment. This journey, although it is idealised and in practice is not always experienced as linear, includes recognisable stages such as diagnosis, treatment and follow up. The research methods, focused ethnography and patient interviews, are situated within the notional time-points of this journey and are chosen to produce knowledge which explores and understands the life context of the participants. A focus on their meanings and interpretations forms a key part of the interpretivist approach which is adopted.

## **1.3 HIV and Cancer: Rationale for the Study**

### **1.3.1 The burden of disease**

Globally there were approximately 38.8 million people living worldwide with HIV in 2015, and from 2005 – 2015 the global incidence was around 2.5 million per year (Wang et al, 2015). From a UK perspective an estimated 101,200 people were

living with HIV in the UK in 2015, with 6,095 new diagnoses in that year. London accounted for almost half of these (Kirwan et al, 2016). For cancer, the global incidence is approximately 17 million per year. In the UK there were an estimated 2.5 million people living with cancer in 2015, with almost 360,000 people diagnosed in that year (Cancer Research UK Statistics viewed 15 February 2019). Cancer incidence is highest in the north of England and lowest in London (Office for National Statistics, 2014). This provides a broad overview of the relative burden of disease in the two conditions, with almost 60 times more new cancer diagnoses in the UK in one year than HIV diagnoses and key differences in the geographical spread.

It is clear there is a growing population of people diagnosed with HIV who are increasingly experiencing co-morbidities including cancer. Three cancers are known as AIDS-defining cancers: Kaposi Sarcoma, high grade B-cell Non-Hodgkin Lymphoma and invasive Cervical Cancer. Cohort studies have suggested that those AIDS defining cancers which were common before the introduction of effective highly active anti-retroviral therapy (HAART) for HIV have declined over time (see Table 1-1). The incidence of all other cancers combined is similar in early and late HAART periods and approximately double that of the general population (Franceschi et al 2010). It particularly features those cancers associated with viruses, examples being the human papilloma virus (anal cancer) and the Epstein Barr virus (Hodgkins lymphoma). It seems clear that cancer remains a significant co morbidity for people living with HIV. This is likely to increase as the population ages, particularly as there is also a high prevalence of traditional cancer risk factors such as smoking amongst people living with HIV (Lifson and Lando, 2012). The recent START trial indicated that viral driven cancers such as Kaposi's sarcoma and lymphoma occurred more often in those people who started HAART later, so late treatment and poor adherence may be a feature of certain affected groups (INSIGHT START Study Group 2015). Those who are diagnosed late and/or who have disengaged with treatment are likely to be a particularly vulnerable group. They may also be a member of marginalised populations experiencing stigma from more than one social category such as being gay and/or a migrant. Both HIV and cancer are illnesses with stigmatising features and the presence of felt stigma (a sense of shame and fear of encountering discrimination leading to secrecy) or enacted stigma (actual discrimination on the grounds of social unacceptability) is likely to be relevant to patient experiences. This group may pose a particular

challenge to the provision of dual care in two conditions which are both serious and in which diagnosis can be distressing and frightening.

**Table 1-1 Incidence of cancers over time amongst people living with HIV**

Time period	AIDS related cancers	Non-AIDS Defining Cancers NADC
Pre-HAART 1985-1996		NADC significantly higher than general population in Hodgkins, anal cancers (concomitant oncogenic viruses)
Early HAART 1997-2001	Incidence of AIDS related cancers (KS, NHL) decreased	
Late HAART 2002-onwards	AIDS related cancers further declined	Cohort studies vary, some show stable incidence of all NADC combined, others show an increase.  Several highlight an increase over time of specific cancers such as Hodgkins, anus, liver and lung cancer  All show higher incidence than general population

D.A.D study Worm et al 2013; Swiss HIV Cohort Study Franceschi et al 2010; Patel et al 2008; Reekie et al 2010; BHIVA Conference presentation 2013 Manchester; Lifson & Lando 2012

### 1.3.2 Why look at patient experiences?

As people living with HIV increasingly engage with cancer services their experiences are important to inform healthcare provision. Outcomes for both conditions rely on engagement and trust in the health system and this will be influenced by experiences. The National Cancer Patient Experience Survey of 2014 showed that patient groups with an existing chronic condition, or from an ethnic or sexual minority, were less likely to be positive about their experiences of cancer

care and treatment (Quality Health 2014). Investigation into the views, attitudes and experiences of people living with HIV who are often from marginalised communities provides insights with the potential to tailor care which can improve outcomes. Literature which looks specifically at patients' experiences is an important addition to the body of knowledge previously used as a means to improve care in other disease areas such as diabetes self-management and adherence to breast cancer treatment (Heisler et al, 2002, Kahn et al, 2007). An understanding of patients' experiences can help to provide a context and explanation for issues such as later presentation with symptoms of HIV or cancer; information requirements around diagnosis and treatment, and adherence to treatment for both conditions. There are strong links between being involved in decision-making and feeling information is communicated effectively and improved safety and better clinical outcomes (Doyle, 2013). For this particular group of patients it is important to identify the common drivers of good experience in order to inform improvements in services offered. Ziebland and colleagues (2013) present patient experience as a key component of healthcare quality and this is reinforced by NHS policy drivers such as the NHS Constitution of 2015 and the responses to the Francis Report of the Mid-Staffordshire NHS Foundation Trust Public Enquiry. (Department of Health 2015; Mid Staffordshire NHS Foundation Trust 2013). For HIV services, data on patient experiences are vital for raising awareness around the experience of cancer and collaborative working with cancer services. This information may be particularly valuable at a time when HIV support services across England and Wales are being cut or decommissioned.

Recent changes within the landscape of cancer service provision means that experiences may differ according to the types of cancer with which HIV positive people are diagnosed. There has been a move to reorganise specialist services for rare and complex cancers and focus services in fewer centres that treat a large number of patients with an aim of producing better patient outcomes. This has implications for people with a dual diagnosis of HIV and cancer. The number of people with HIV with a normal life expectancy has increased (The Antiretroviral Therapy Cohort Collaboration 2017) and so we expect to see more of the common cancers which are associated with getting older such as breast and prostate: these will continue to be treated in a more general setting which may not be as well informed or adapted to meeting more complex needs. Haematological malignancies such as lymphoma will be treated in centralised specialist centres where provision may be different. It is therefore important and timely to explore the differences in

experiences of this growing group of patients presenting to either general or specialist cancer services with a pre-existing condition.

In the wider social context the study is conducted at a time when the impact of austerity has resulted in HIV support services being cut or decommissioned and there are an increasing number of accounts in the media of people with cancer finding it difficult to access financial support through Personal Independence Payments (PIP) (Roulstone, 2015). An exploration of dual diagnosis experiences at this time may provide some insight into the impact of these structural influences on peoples' lives.

Having looked at the motivation behind the work and the reasons for its relevance the next section will present the study's aims which are described within three areas: the social, the personal and the healthcare contexts.

## **1.4 Aims**

**To explore the views and experiences of HIV positive patients being treated for cancer and to gain an understanding of their experience in the context of healthcare systems and wider society.**

### **1.4.1 The social context: an analysis of popular discourse within articles in free newspapers in London**

- i) To understand how HIV and cancer are represented in popular discourse and society and to examine any links between these discourses and patient accounts

### **1.4.2 The personal context: patient stories**

- i) To consider the meanings and understandings that people associate with a diagnosis of HIV
- ii) To consider the meanings and understandings that people associate with a diagnosis of cancer
- iii) To consider the meanings and understandings that people associate with a dual diagnosis of HIV and cancer

- iv) To understand how patients negotiate access to medical treatment and navigate healthcare services
- v) To consider the expression of links between meanings and illness and the mobilisation of wider social support

#### **1.4.3 The health systems context**

- i) To consider the features of the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis

### **1.5 Patient Representative Involvement**

There is some evidence in the literature that patient and public involvement can have a positive impact on health and social care research ensuring its appropriateness and relevance (Brett et al 2014). I felt it was very important to involve patients in the development and design of my study. Although I have clinical experience of caring for patients with HIV and Cancer, in framing the question I was conscious of my own position and associated perspective as a female, middle class, white British healthcare professional. Engaging with people who have had first-hand experience of both cancer and HIV has helped to reassure me of the importance of my research question. Patient involvement has been an important and continuous component throughout the entire progress of the study from initial planning to dissemination of findings. For a project that explores patient experiences it is essential that the patient voice is represented at all stages to ensure the research is conducted in an acceptable way for participants and that it is relevant to their concerns. Patient involvement is also intended to promote reflexivity on my part and provide an alternative view on my own position and perspective within the research. Based on their understanding and experience, patient representatives have highlighted priorities that I had not previously considered and helped to ensure that the design was workable and acceptable.

In response to an advert placed on the Bloomsbury Patient Network six HIV positive patient representatives with experience of cancer treatment were recruited to form the study's patient representative group. They were initially consulted on the validity of the research question and the acceptability of the research methods used. Their views on the timings and content of proposed interviews, the acceptability of the diary methods and the organisation of the dissemination workshops were collected

and compiled. This feedback informed the development of an initial protocol. All patient information for the study was developed with patient representative input and representatives have been kept informed of the progress of the study by newsletter.

Two patient representatives were recruited to be members of the advisory group for this study (further described in section 0). They are both active members of HIV advocacy groups and are well placed to provide representation of a range of views from within the HIV community as well as being key advisors for the dissemination of the study findings at the end of the project.

A successful application was made to the NIHR University College London Hospitals Biomedical Research Centre/Wellcome Trust Patient and Public Involvement Bursary Fund to support the patient representatives' involvement and reimburse them for appropriate expenses during the study.

To summarise the rationale, motivation and background for the study: the idea originated from the first hand clinical observations of the researcher. It takes place in the context of an increasing number of HIV patients who are ageing and who are engaging with healthcare services, specifically cancer services, in addition to HIV services. The work is particularly mindful of a vulnerable group of patients who may have been diagnosed late or who are poorly adherent to treatment.

As well as being a research area of current relevance the approach of exploring patient experience is one that is viewed as increasingly important.

Finally, as it is a study exploring patient experience, patient involvement has been determined as a key component in both the planning and undertaking and underpins all aspects.

Having described the motivation and rationale for the study, the next section of this chapter will provide an outline of the programme of work presented within this thesis.

## **1.6 Overview of Thesis**

This thesis is divided into eleven chapters.

Chapter one, an introductory chapter, has provided an overview of the researcher's motivation to perform the study, the rationale for the work and its aims and an outline of the role of patient involvement.

Chapter two presents a systematic review of the literature to establish what is already known about patient experiences of a dual diagnosis of HIV and cancer

Chapter three presents the theoretical underpinnings: those wider themes in the literature which are relevant to an exploration of patient experiences of dual diagnosis. These include the social context of HIV and cancer with the cultural construction of both illnesses forming part of this; literature on patient story telling (the personal, life course with narrative); and the patient/doctor relationship (the health systems context in which the patient receives treatment).

Chapter four describes my own epistemological interpretivist position and three different methodological approaches adopted: thematic analysis of discourse within newspaper articles; a narrative approach with a focus on individuals' stories provided in their own language through semi-structured interviews and diaries; and focused ethnography used to explore the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis.

Chapter five provides insight into the social context of HIV and Cancer by presenting the methods and findings of a thematic analysis of representations of both conditions in two free London newspapers, the Metro and the Evening Standard, over the past five years.

Chapter six presents the methods used to collect and analyse participant narratives from longitudinal, semi-structured interviews and diaries of people who have a dual diagnosis of HIV and cancer

Chapter seven presents the findings from the participant interviews and diaries in a chapter which characterises the unique features of 'Being HIV Positive' and 'Having a Cancer Diagnosis' both to highlight the contrast between them and to facilitate a comparative discussion.

Chapter eight presents the findings from the participant interviews under the heading 'Biographical Work and the Mobilisation of Resources' including themes relating to how participants explained and interpreted the experience of a dual diagnosis within the context of their own life and the ways in which they coped and accessed support.

Chapter nine presents the findings from the participant interviews under the heading 'The Experience of Cancer Care by people living with HIV' which includes themes relating to their navigation of healthcare services

Chapter ten provides insight into the healthcare context of a dual diagnosis by presenting the methods used and findings from the observation component of the study which used focused ethnography to characterise the healthcare setting in which patients with HIV experienced treatment for cancer

Chapter eleven synthesises findings from all the data sources, provides linkages and explanations and discusses them in the context of existing evidence. It also presents the limitations of the study and discusses implications for the improvement of services

## **Chapter 2 Systematic Review of the Literature**

### **Exploring the views and experiences of HIV positive patients treated for cancer**

This chapter is based on the findings of my published systematic review on HIV and Cancer Dual Diagnosis (Hainsworth et al 2018, See Appendix 1). The searches were repeated in June 2018 and no new studies were identified.

#### **2.1 Aim**

To find out what is currently known in the literature about patients' experiences of a dual diagnosis of HIV and cancer

#### **2.2 Methods**

The review focused on experiences of HIV positive patients with a dual diagnosis of cancer. It employed broad inclusion criteria and included all study designs. Studies with a purely medical focus, such as antiretroviral/chemotherapy management and epidemiology studies or those with a biology or pathology focus were excluded if they did not provide any perspective on patients' experiences of care.

##### **2.2.1 Search strategy and selection criteria**

The following databases were searched from their inception to June 2016: MEDLINE (Ovid Version); CINAHL Plus; PsycINFO; and EMBASE. These databases were selected to provide an extensive coverage of the biomedical literature as well as include literature from psychology, nursing and allied health fields where one might expect information on patients' experiences to be found. Reference lists of included papers were reviewed and contact was made with authors. A university librarian provided expert guidance on the appropriate use of keyword and thesaurus terms within a comprehensive search strategy. The literature search used the following terms (with synonyms and closely related words): 'cancer' and 'HIV' or 'AIDS' combined with 'interviews as topic' or 'qualitative research' or 'experience' or 'patient satisfaction'

The search was tailored to find research most likely to yield useful information on patient experience, defined by The Beryl Institute as 'the sum of all interactions,

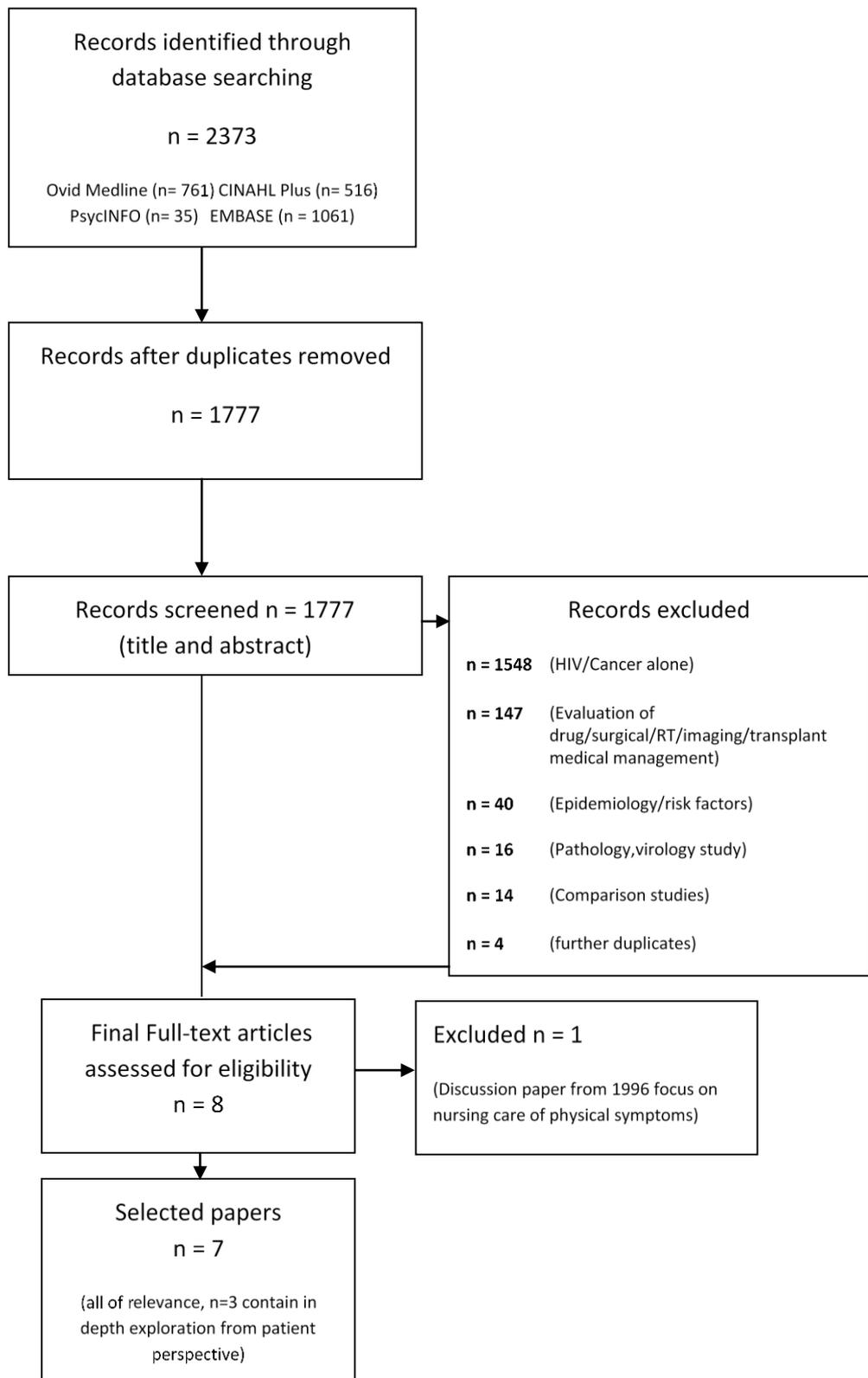
shaped by an organisation's culture, that influence patient perceptions across the continuum of care'. (The Beryl Institute Website). Qualitative research was used as one of a number of terms to capture literature on experience but the overall search was not limited by research method, study design, country of origin or language of publication. An example of the strategy and terms for one of the database searches is provided in Table 2-1. A full breakdown of all the database searches and results is found in Appendix 2.

**Table 2-1 Ovid Medline example of search strategy and terms**

<b>OVID Medline Search 2<sup>nd</sup> August 2016</b>	
<b>Search terms</b>	<b>Results</b>
1 ((cancer* or neoplasm* or tumo?r* or carcinoma*) adj3 (diagnos* or treat* or therap*)).mp.	429125
2 exp Neoplasms/di, dt, pc, th	1092739
3 1 or 2	1312382
4 exp HIV/	88751
5 exp HIV Infections/	249810
6 (HIV or human immunodeficiency virus or acquired immunodeficiency syndrome).mp.	353937
7 AIDS-Related Opportunistic Infections/	20260
8 4 or 5 or 6 or 7	358830
9 Interviews as Topic/	48322
10 interview*.mp.	301485
11 qualitative research/	28387
12 qualitative.mp.	168648
13 experience*.mp.	832382
14 px.fs.	852048
15 exp Patient Satisfaction/	70859
16 Dual diagnosis/	3240
17 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	1872211
18 3 and 8 and 17	<b>761</b>

Records were screened by title and abstract to include all studies featuring a dual diagnosis of HIV and Cancer with a focus on patient experience, including the perspectives of both patients and service providers. Studies with a focus on just cancer or HIV rather than a dual diagnosis were excluded. Of the remaining studies those which focused exclusively on treatment strategies and medical management,

epidemiology and pathology studies and comparison studies were excluded. Figure 2-1 features a flow chart to summarise the process. The full text of the remaining studies was reviewed and information on location, sample size, study design, and narrative summaries of findings were recorded using a data extraction form.



**Figure 2-1 Search Strategy for systematic literature review**

### **2.2.2 Data synthesis**

For each eligible study information about the sample such as the country it was drawn from and the gender and number of participants, along with a description of the research methods were noted. Studies were classified according to whether the aim was to represent service providers or the perspective of patients themselves. This process and the eligible studies are summarised in an evidence table, see Table 2-2.

**Table 2-2 Eligible studies from systematic review**

Reference	Sample no	Sample characteristics	Location	Date	Question	Design/Methods	Results	Comments
<b>Two for the price of one: life with a dual diagnosis of HIV and Cancer</b> Dodds N, HIV Nursing. 8(1): 5-5. 2008	n = 10	Small cohort of gay men with dual diagnosis of HIV and Cancer	London HIV Oncology clinic	2008	To understand the meanings & language that this group of patients ascribe to their illness	Qual methods. 'Exploratory ethnographic study using observation and in depth interviews'	Findings include uncertain lead up to diagnosis, selective disclosure of illness, perception of guilty/innocent illness, lack of control with life-threatening nature of cancer. Explaining cancer, link to HIV, environment, stress	Small, single site, looking at gay men only. Very relevant in exploring patient experience as described by patients themselves.
<b>The experience of African women diagnosed with both HIV/AIDS and cervical cancer.</b> Maboko, E. Mavundla T.R. Africa Journal of Nursing and Midwifery 8(1): 15-30. 2006 (MA in Public Health)	n = 8	Purposive sample of African women aged 31-42 years diagnosed with HIV and cervical cancer	Radiotherapy department Johannesburg hospital, South Africa	2006	How did the sample experience being diagnosed with both HIV/AIDS and cervical cancer?	Qual methods. In-depth phenomenological individual interviews and field notes	Themes emerge as importance of communication ; experience of physical symptoms and emotional experience	A qualitative study looking at dual diagnosis with HIV and cervical cancer. Findings around selective disclosure, useful. Physical symptoms less transferrable. Small sample, 8 participants, one type of cancer. African setting.

Reference	Sample no	Sample characteristics	Location	Date	Question	Design/Methods	Results	Comments
<b>Experiences of Botswana women diagnosed with both HIV/AIDS and cervical cancer.</b> Molefe T; Duma SE. Curationis. 32(4): 29-39. 2009	n = 6	Women diagnosed with HIV and cervical cancer	Oncology & gynaecology department tertiary hospital, Botswana	2007	What are the experiences of Botswana women diagnosed with both HIV/AIDS and cervical cancer?	Qualitative methods. Semi-structured interviews and field notes, phenomenological approach	Emergent themes, deep pain, fear of the future/dying, intimate loneliness, blaming others and themselves, hope and spiritual support,	A qualitative study looking at dual diagnosis with HIV and cervical cancer. Does not explore how the 2 illnesses interplay, or might differ from each other, the themes arise from one entity the dual diagnosis. Small sample, African setting, using convenience sample
<b>Predictors of timely access of oncology services and advanced stage cancer in an HIV-endemic setting.</b> Brown, C. A., et al. Oncologist 21(6): 731-738. 2016	n = 1,146	Oncology patients	Oncology services in 2 hospitals in Southern Botswana	2014	Does engagement in longitudinal HIV care improve access to timely oncology care?	Baseline survey, and review of records for information on symptom/treatment history, HIV testing for those without a test in previous 6 months. Covariate descriptions and measurement of time to enrollment in oncology care	Longitudinal HIV care did not reduce the substantial delay to cancer treatment	Survey collecting demographic information. Interesting suggestion that receiving HIV care does not raise awareness of cancer symptoms and lead to earlier presentation

Reference	Sample no	Sample characteristics	Location	Date	Question	Design/Methods	Results	Comments
<b>An innovative joint approach to HIV and lymphoma care.</b> Dhairyawan, R., S. Longwill, et al. Sexually Transmitted Infections 88(1):71.2012. (Letter)	n = 73	Patients at novel specialist HIV-haemato-oncology clinic at London hospital	London NHS Trust	Nov 2009 - April 2010	Were patients satisfied with experience of specialist clinic?	Patient satisfaction survey. Questions about satisfaction with joint clinic, ability to discuss sensitive topics with sufficient time. Response rate 66%	High level of satisfaction, some patients expressed desire for a support group	Service evaluation, not peer reviewed, one clinic, letter, limited remit, survey rather than qualitative enquiry into experience
<b>Quality of life, characteristics and survival of patients with HIV and Lymphoma.</b> Diamond C et al. Quality of Life Research. 19(2):149-55, 2010	n = 100	50 patients with HIV & NHL, 50 patients with NHL and no HIV using population-based cancer registry for Orange & San Diego Counties	Cancer registry for Orange & San Diego Counties, California, US	Patients diagnosed 2002 - 2006	How do quality of life, characteristics and survival compare between patients with non Hodgkins lymphoma with and without HIV?	Patients completed surveys: medical history, QOL, FAHI and FACT G	HIV infected NHL patients had worse QOL & survival than uninfected patients due to combination of co-morbidity, aggressive histology and lack of social support	Quantitative methods, focus just on HIV & lymphoma but is relevant for dual diagnosis, suggesting it may be more challenging for both medical & social reasons. Low social well-being scores in dual diagnosis

Reference	Sample no	Sample characteristics	Location	Date	Question	Design/Methods	Results	Comments
<b>At the intersection of HIV/AIDS and cancer: a qualitative needs assessment of community-based HIV/AIDS service organizations.</b> Burkhalter JE et al Health Education & Behavior. 40(4):493-503, 2013	n = 10	3 x 7 representatives from community-based organisations serving people with HIV.	New York, US	4 month period 2009 - 2010	To identify capacities, facilitators and barriers to the uptake of cancer-focused programmes by community organizations.	Focus groups made up of reps from community-based organisations, analysis of themes from transcripts	Agencies have limited experience, need resources & collaborative partnerships to effectively incorporate cancer services, staff & clients need education, cancer care providers should be culturally competent	A qualitative study dealing with dual diagnosis but looking from the perspective of community based service providers not from the perspective of the patients themselves. Useful external light shed on perceptions of cancer care providers not being culturally competent

## **2.3 Results**

### **2.3.1 Study selection and characteristics**

The initial search strategy resulted in 1777 records which were screened by title and abstract using the selection criteria described in the methods. 1548 records were excluded as they dealt with HIV alone or Cancer alone. The remaining 229 records were screened and a 10% sample independently checked. The most frequent reason for exclusion was the study having a purely medical management focus; 147 records were excluded as they featured the evaluation of treatment strategies and clinical outcomes in the context of a dual diagnosis. 40 studies reporting epidemiological data on the prevalence and incidence of malignancy amongst the HIV population were also excluded along with 16 that had a biological, pathology focus. 14 studies that included a comparison between the experience of cancer patients and that of HIV patients were omitted as the focus of the search was an exploration of dual diagnosis. Four papers were found to be further duplicates.

Eight full text records were reviewed in depth. One of these was excluded as it was a discussion paper; the remaining seven records all featured an aspect of the patient perspective and experience of a dual diagnosis of HIV and Cancer (see Table 2-2). Due to the small number of results and their disparate nature, the findings were combined thematically and summarised narratively.

### **2.3.2 Patient perspective in studies employing a survey method**

Three studies represented patient experiences using cross-sectional surveys of patients with a dual diagnosis. Brown et al (2016) conducted a survey in Botswana of 1,146 oncology patients collecting information on symptom and treatment history and offering HIV testing to those who had not had a test in the previous six months. They compiled covariate descriptions and measured time to enrolment in oncology care. They found that having been engaged in HIV care did not raise awareness of cancer symptoms and was not associated with an earlier presentation with them. Although this finding has interesting implications for HIV patients' experience of their cancer diagnosis, suggesting as it does that continued follow up in HIV services does not provide the opportunities to diagnose cancer earlier, there are problems with generalising the findings from two Botswanan hospitals beyond this setting and in particular to services in the UK.

In a US study, Diamond, Taylor and Anton-Culver (2010) administered validated Quality of Life instruments; the Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) in 50 patients with both HIV and Non Hodgkins Lymphoma (NHL), and the Functional Assessment of Cancer Therapy – General (FACT G) in 50 patients with NHL alone. The patients with a dual diagnosis had worse quality of life and survival than patients without HIV due to a combination of co-morbidity, aggressive histology and lack of social support. The finding of lower social well-being scores in the dual diagnosis group is relevant to an exploration of patient experience in this group, although the study does not explore this in any depth and is limited to one particular malignancy.

The final survey was featured in a letter describing a service evaluation of a specialist HIV haemato-oncology clinic at a single London site; descriptive in nature and brief it represented patient experience by reporting 73 patients' feedback on their satisfaction with the joint service in terms of it providing the ability to discuss sensitive topics and sufficient time to do so (Dhairyawar et al, 2012). There was an expressed desire among patients for a support group and specific information sheets but the findings reported lacked detail and depth.

### **2.3.3 Service provider perspective**

One of the selected papers looked at dual diagnosis from the perspective of the service provider rather than the patient. A study conducted in the USA comprised three focus groups over a four month period in New York City. The groups were each made up of seven representatives from community based organisations who were selected because of the diversity of the populations they served and their extensive knowledge of the services and structure of their agencies. The focus groups explored the views of community based HIV service providers on what facilitators and barriers existed for them in offering support and information about cancer (Burkhalter et al, 2013). This provided an interesting perspective on relevant issues, for example, some providers' perceptions of cancer services not being culturally competent, although it did not provide any direct information on patients' views and experiences.

### **2.3.4 Patient perspective in studies using qualitative methods**

Three papers featured patients' perspectives of a dual diagnosis of HIV and Cancer using rich data which featured patients' perceptions and understandings and

represented experiences with a depth of insight. Maboko and Mavundla (2006) and Molefe and Duma (2009) described two Southern African studies using in depth interviews and a phenomenological approach to explore the experience of women diagnosed with HIV and cervical cancer. Maboko (2006) performed in depth interviews with eight women with this dual diagnosis, aged between 31 and 42 years who attended the radiotherapy department in a Johannesburg hospital. The findings revealed that some patients chose to selectively disclose their cancer diagnosis and not their HIV diagnosis as a strategy to access social support. This feature of dual diagnosis is potentially of wider relevance, despite the study being focussed on one particular cancer in a South African setting. Molefe (2009) conducted semi-structured interviews with six women with both HIV and cervical cancer who were recruited from the oncology and gynaecology department in a tertiary hospital in Botswana. This study described isolation amongst the women, some of whom found it hard to maintain intimate relationships following their diagnosis, and experienced feelings of guilt around their situation.

Dodds (2008) conducted an ethnographic study looking at a single UK site with a small cohort of ten gay men with a dual diagnosis of HIV and cancer. This study used observation and in-depth interviews to consider the meanings and language that patients ascribed to their illness. He found that different meanings and explanations were assigned to each condition and that having both diseases presented particular challenges including reinforcing experiences of stigma. Themes that emerged included a prolonged and difficult lead up to their cancer diagnosis and selective disclosure, with participants telling work colleagues, family and friends about their cancer diagnosis to elicit support whilst not disclosing their HIV status which they believed would carry the imputation of blame. These findings around selective disclosure support those of Maboko (2006). Perceptions of 'guilt' and 'innocence' in relation to illness were evident alongside patients' personal explanations and beliefs about what had caused their cancer. This study provided a highly relevant insight into patients' experiences of a dual diagnosis; it was, however, limited to a single site and a single cohort of gay men.

## **2.4 Discussion**

This review found the experience of people living with a dual diagnosis of HIV and Cancer to be largely unexplored in the published literature. Patients experience the two diagnoses in different ways, coloured by the powerful cultural meanings and

health beliefs that both conditions arouse. Beliefs and understandings can affect the way in which people navigate both social care and healthcare; potentially impacting on health and quality of life outcomes. Given the increasing number of people internationally who will be living with dual diagnosis this suggests a need to explore this under-researched area.

The findings of the seven studies identified demonstrated that both HIV and cancer are illnesses linked to powerful beliefs and given cultural meaning in a way which impacts on an individual's sense of self, the way they behave and the social responses of others. Molefe (2009) described the increasing social isolation of women as a result of their dual diagnosis. A key theme emerging from both Maboko (2006) and Dodds (2008) was that of patients adopting a system of selective disclosure and talking primarily about their cancer diagnosis as a way of accessing social support. This differential disclosure in favour of their cancer diagnosis seemed to be a way of navigating stigma and negotiating complex social and health pathways. Other studies have identified this phenomenon in the dual diagnosis of HIV and other conditions. Accounts of patients with HIV and tuberculosis and HIV and Hepatitis C respectively, revealed how selective disclosure was adopted to manage stigma with both sets of participants sharing information about the illness that they felt to be less discrediting, with greater caution being applied to information about their HIV diagnosis. (Daftary, 2012; Lekas et al, 2011). Even though the samples were small and specific to very particular groups of patients the selected studies in this review all suggest that a dual diagnosis of HIV and cancer has a powerful impact on individuals' behaviour and that stigma plays a key part.

The evidence suggests that patients diagnosed late with HIV, those who have disengaged with treatment, and those infected by mother-to-child transmission, are at particularly risk of developing the virally driven cancers such as lymphoma, cervical cancer and Kaposi sarcoma (INSIGHT START Study Group 2015). These patients are likely to be a particularly vulnerable group, and possibly members of marginalised populations experiencing stigma from more than one social structural category, for example being gay and / or a migrant. We know that experience of stigma and the fear of disclosure of HIV status can affect adherence to HIV medication (Ware et al, 2006). What is not known is how this HIV related stigma interplays with a patient's presentation with symptoms of cancer and experience of cancer treatments.

Recent policy and practice discourse has framed HIV as a chronic disease like any other, managed by routine medical management (Flowers, 2010). This normalisation narrative in HIV relies upon the success of treatment and a focus on positive and healthy living. Mazanderini and Papparini (2015) showed that tensions, challenges and contradictions to this narrative appeared when stigma continued to have an influence on people's work opportunities, social support systems and family life, and when they experienced health problems these tensions were exacerbated. This study explores how much a cancer diagnosis acts as a challenge to this HIV normalisation narrative.

## **2.5 Limitations**

Publication bias may be a limitation of this review with the published data predominantly featuring empirical studies relating to the medical management of dual diagnosis. It is possible that information about patients' experiences may feature more in the grey literature which is less easy to identify. The number of included studies was too small and they were too different from each other to combine the findings together and produce generalisable results.

## **2.6 Conclusions**

This literature review suggested that further exploration of patients' experiences in the field of dual diagnosis of HIV and cancer would add new knowledge relevant for tailoring improved services. The identified themes around stigma and its effect on patients' access to social support and engagement with services suggested that future research should adopt methods which explore this complexity, capture change over time and generate deeper understandings of patients' behaviour. Patient agency interplayed with stigma, as can be seen with the strategy of selective disclosure; gaining a better understanding of this would provide opportunities to intervene and support service users. This review supports the argument that exploring this area helps to provide a new and greater understanding of a dual diagnosis of cancer and HIV and can potentially indicate how the experiences of this group of patients can be improved.

## **Chapter 3 Theoretical Underpinnings**

### **3.1 Overview of the Literature Review Process**

The motivation for exploring the experience of a dual diagnosis of HIV and cancer came from my own clinical experience and an observation that the styles of delivering care in each area were different. The previous chapter described a systematic review of the database literature which was performed to establish what was already known about this subject. The results suggested that this was an area largely unexplored in the literature. The findings in the identified studies demonstrated that HIV and cancer are illnesses that are experienced differently but both linked to powerful cultural meanings and understandings that influence behaviour in accessing social support and may affect interaction with healthcare services. The systematic review indicated that there was relatively little existing literature on how the two conditions might interplay to affect these behaviours. This study will provide insight into this by taking into consideration the social, personal and health systems contexts in which people create meaning and understanding of their dual diagnosis and use this to navigate their way through their life.

From this starting point wider reading and exploratory searches were performed to incorporate influential sociological texts as well as articles concerned with the cultural construction of illness. The language and metaphors that people use to talk about HIV and cancer originate from the society in which they live and are contained within popular discourse, cultural beliefs and the media. This is related to patients' experience of stigma and the extent to which they are able to draw upon social support. These concepts form part of the social context in which patients frame their illnesses and this social context is the first of three main conceptual groupings identified within this thesis.

Two further conceptual groupings were identified as requiring further investigation and were explored in wider reading and further scoping database reviews informed by the conduct of the first participant interviews. These are the personal context with patients' narrative accounts of their life course and the health systems context in which the patient receives treatment.

The personal context includes those themes that describe how patients might be making sense of and framing their own illness experience in the light of their own biography. They describe how and why people come to see their illness originating

in a certain way and how they account for the way their lives have been disrupted. Biographical disruption, narrative reconstruction, lay aetiology and atrocity tales are all features of patients' narrative accounts of their life course and are useful concepts in exploring how patients with a dual diagnosis of HIV and cancer frame the disruption of taken for granted assumptions and behaviours which may accompany their illnesses.

Literature situated within HIV and cancer treatment itself features patients' experience of negotiating their way through medical language and pathways of care; this is the health systems context. The 'Voice of the Lifeworld': i.e the contextually grounded experience of life events (Mishler, 1984) can come into conflict with medical professionals' dialogue if this is dominated by technical, scientific language that is removed from particular personal and social contexts ('Voice of Medicine'). These themes are relevant to a study of HIV positive individuals encountering an unfamiliar cancer healthcare setting with its own complex language. This study aims to find out if there are different experiences of collaboration and patient empowerment within HIV and cancer services. Patients may find complementary and alternative medicine, spiritual concerns and online support important features of their 'lifeworld', it will be important to establish how far this importance is acknowledged by healthcare professionals. The 'normalisation' of life with HIV through processes of medicalisation, which promise to turn it into an everyday rather than exceptional condition, faces continuing tensions relating to the social context, stigma and the fear of being treated differently, which are described in the literature. It will be important to explore how much a dual diagnosis acts as a challenge to this normalisation narrative.

At the point at which I initially considered this research question I had thought that theories around stigma would be the most pertinent. However, following on from the systematic database review and further wider reading I discovered many more relevant theoretical concepts (some of which are linked to stigma) within the literature. These will be described in more detail in the next section of this chapter under the headings of the three main conceptual groupings: the social, personal and health systems contexts.

## **3.2 The Social Context in which Cultural Systems of Values, Attitudes and Beliefs Shape Behaviour**

### **3.2.1 The cultural construction of HIV and cancer: metaphors and meanings**

Metaphors and meanings are evident in popular discourse, media representation and in cultural and folk beliefs. Metaphors involve a figurative use of language wherein one image stands in the place of another. Meaning represents an individual's understanding of a word, concept or event. HIV and cancer have different associated metaphors and meanings which will be described in this chapter section. Common language and understandings in the cultural mainstream can affect behaviour in both HIV and cancer. In HIV awareness of others' judgmental attitudes, expressed in the language around danger and high risk behaviour, leads to stigma which has been associated with depression and poor self-esteem. This in turn can be linked to health-related factors including seeking healthcare and maintaining adherence to antiretroviral therapy (Ware et al, 2006). In cancer commonly used military metaphors about being brave and fighting their illness can make people feel like failures if they do not respond to treatment, as the language can suggest that overcoming the disease is simply a matter of fighting hard enough (Reisfield & Wilson, 2004). The theme of the cultural construction of illness forms a backdrop to all of the stages in the HIV positive patient's journey through cancer treatment and influences the behaviour of the patient, their families and friends, and that of healthcare professionals providing their care and treatment.

The literature emerging from the late 1980s and early 1990s featured negative and fearful associations with HIV/AIDS. Sontag's work on 'AIDS & Its Metaphors' (1989) was written at this time of moral panic and described the illness being linked to deviant behaviour. Then, being HIV positive was a relatively new and unknown condition, with little in the way of effective treatment and uncertainty as to how it might progress and how widely it might spread. People with AIDS were being viewed as the 'dangerous other' and the risk of contracting the condition was identified with social deviance, promiscuity and vice. Mary Douglas in her work 'Purity and Danger' (2002) described rituals of purity and impurity as creating unity of experience within societies; the impurity associated with this dangerous sexually transmitted illness places those living with HIV as outsiders. The person living with HIV is constructed in terms of a loss of purity and the embodiment of pollution and

danger to others. In the early days of HIV the media reinforced these feelings of fear by exploiting deep-seated anxiety about sex, disease and death with TV commercials featuring dire warnings and apocalyptic images of tombstones (Rhodes & Shaughnessy 1990).

Now we live in different times there are effective treatments and we have a greater understanding of how HIV is managed medically, so it might be assumed that the powerfully negative associations would have lessened. The literature suggests that there have been changes over time in social attitudes but it seems clear that patients and the wider public's negative connotations of HIV strongly persist despite the great advances in treatment and the promotion of a normalisation narrative by medical professionals and policy makers (discussed below). Interviewees' accounts of life with HIV can be 'haunted' by previous representations, with one of the ghosts they struggle the most to exorcise being the image of the virus as a lethal killer (Flowers 2010). Moyer and Hardon (2014) explored tensions within the normalisation narrative in multiple settings in North America, and East and Southern Africa and found that in many parts of the world those living with HIV still struggled with various social and economic stressors within their daily life including having enough to eat, and finding employment and adequate housing. HIV, quite exceptionally, compared to other chronic diseases also continues to be criminalised around the world (Mykhalovisky, 2011). Stigma and discrimination continue to be reported in institutional settings including clinics and those who have been infected through intravenous drug use, sex work, or by men having sex with men, often face double and triple stigma (Deacon, Stephney & Prosalendis, 2005). The thematic analysis of popular discourse about HIV and cancer within newspaper articles featured in this study will help to situate the cultural construction of the two illnesses in today's society and will contextualise the wider societal discourse in which the patients talk about their experience in their interviews.

Cancer is another illness associated with powerful metaphors. Although cancer could be over 200 different types of disease, in lay discourse it is often termed as one illness: 'The Big C'. Weiss (1997) described the metaphors associated with HIV and cancer based on ethnographic dialogue with a group of doctors, nurses and university students. Cancer as a single entity is often presented as cellular and related metaphorically to industrialisation and the harmful effects of toxic chemicals. Although in modern western society with its emphasis on lifestyle choices and individual responsibility, self-indulgence and lack of discipline could be seen as the causes of certain cancers, the imputation of blame seems less pronounced than in

HIV/AIDS: it is not associated with the 'dangerous other' but is something we might all have experience of and therefore have sympathy for. Women's magazines often personalise stories of famous women's experiences of breast cancer where they are held up as an example of personal courage. Hope is the dominant discourse in relation to cancer and the use of military metaphors reinforces this with people lauded if they are brave and show fighting spirit (Lupton 2003). In a similar vein, statements about positive thinking in relation to cancer have been described by Wilkinson and Kitzinger (2000) as an idiom which can be used by people with cancer to conform to societal expectations which endorse this as appropriate and morally desirable.

I contend that cancer is constructed culturally as one illness with powerful associated meanings and metaphors. A dual diagnosis of HIV and cancer is the experience of two conditions loaded with their own distinct meanings. They have been explored separately in the literature but it is important to find out how they interplay. This study with its use of interviews and patient diaries will capture patients' language, metaphors and meanings as expressed in their own words. Focused ethnographic observation within clinical areas where HIV positive patients are receiving their treatment for cancer will provide an insight into the use of language by both patients and healthcare professionals which may not be evident in the more constructed setting of an interview. The language and metaphors used by participants to articulate experiencing HIV and cancer at the same time is not currently described in the literature. It will be important to discover the common features of the language that is used and establish whether there are any ways that people place emphasis on one illness rather than the other to enable them to access wider social support. The findings can be used to help healthcare professionals tailor more effective communication and appropriate pre and post diagnosis treatment.

Metaphors and meanings contribute towards how stigmatising an illness might be and stigma is clearly a feature of the social context in which people frame their experience of a dual diagnosis.

### **3.2.2 Stigma in HIV and cancer**

Both HIV and cancer are illnesses that have stigmatising features which are central to the patient experience of diagnosis and treatment. Important themes relating to stigma were described in Goffman (1963). The term 'moral career' denotes

identifiable sequences in a labelling process in which a person's identity and moral status is progressively changed in the light of 'moral' evaluations which are progressively imposed. Clearly as society changes this concept is being re-interpreted all the time and so should only be adopted with knowledge of its changing nature in mind. For a person with HIV and cancer their 'moral career' would be perceived differently according to when in life each diagnosis occurred. For example, those who are diagnosed with cancer some years after their initial HIV infection will have had the experience of one stigmatising illness and adopted strategies of coping; those who are diagnosed with HIV infection and cancer at the same time will obviously have a very different prior experience of the 'normal' and of stigma and therefore a different moral career. To represent as wide a range of experience as possible this study aims to include interviews with both types of presentation.

Stigma may be experienced differently according to the timing of diagnosis but also other stigmatising factors may be interwoven into peoples' experiences, such as sexuality, ethnicity or immigration status. Context is important when considering stigma; the intersection with social discrimination relating to sexual orientation, gender and ethnicity is particularly relevant for HIV. Literature on stigma has more recently incorporated a new theoretical emphasis which has stressed the need to consider social structural factors in the production of stigma, as well as the interactionist perspective of Goffman. Link & Phelan (2001) describe the importance of structural or institutional discrimination and the exercise of power. Although looking at the wider social order and how it might be in the interests of dominant groups to reinforce stigma is somewhat beyond the scope of the current study, the analysis of popular discourse within newspapers (the social context) provides some insight into this as does the focused ethnography of the healthcare system which is delivering treatment for cancer. The healthcare system represents the physical context in which observation and informal interviews with healthcare professionals took place and participant interviews were conducted within the period of cancer treatment and follow up. The study therefore includes a perspective of some of the structural organisational factors which may shape experiences.

*Felt* stigma involves a sense of shame and fear of encountering discrimination which leads to secrecy and non-disclosure. *Enacted* stigma features actual discrimination on the grounds of social unacceptability (Scambler & Hopkins 1986). There are examples in the literature of both types having an impact upon people with HIV leading to issues around disclosure and increased isolation (Herek 1990,

Block 2009). However, it should not be assumed that all patients will take on the shame of felt stigma as some choose to consciously reject the attributions of shame and blame and resist this according to their identity politics. (Scambler 2004).

The literature largely provides separate accounts of the experience of stigma in each condition. Fife & Wright (2000) conducted a comparison study in the US looking at the effects of HIV compared with those of cancer on self-esteem, body image and personal control. In keeping with the literature about the different metaphors assigned to each illness they found that the HIV sample experienced significantly greater feelings of stigma than cancer patients. Other studies have described the experience of dual diagnosis with HIV and other conditions. As Daftary (2012) and Lekas et al (2011) describe in their accounts of dual diagnoses of HIV and tuberculosis, and HIV and hepatitis C respectively, selective disclosure of information is adopted to manage stigma. Participants in both studies aligned themselves more strongly with, and shared more information about, the illness that they felt to be less discrediting, with greater caution being applied to information about their HIV diagnosis.

Dodds (2008) conducted an ethnographic study looking at a small group of gay men with a dual diagnosis of HIV and cancer. He found that different meanings and explanations were assigned to each condition and that having both diseases presented particular challenges including the experience of previously held feelings of being different, particularly if they had visible signs of their illness. In Dodds' work, and in other findings from the systematic review, stigma influenced the practice of selective disclosure in which patients managed information about their illness and talked primarily about their cancer diagnosis in order to access support.

My study aims to further describe how meanings and explanations interplay within a dual diagnosis of HIV and cancer with a more varied sample group. Data from interviews and diaries provide patient accounts which reveal their perceptions of felt and enacted stigma in their own words and language. Focused ethnography is a method well suited to complement interview and diary data in exploring the theme of stigma. Studies within the literature have provided important insights into using observation as a methodology. Rintamaki et al (2007) performed a study looking at the experience of HIV positive military veterans in which they described a variety of behaviours performed by healthcare professionals (including eye contact, vocal tones, the taking of excessive protective precautions) perceived to be indicative of HIV stigma. It is clear that people express unspoken attitudes and beliefs through

non-verbal gestures and thus it is valuable to include observation to attempt to capture these if they are being displayed. Surlis & Hyde (2001) in their study on HIV positive patients' experience of stigma during hospitalisation found that patients had concerns about confidentiality being breached sometimes unintentionally by the discussing of their case within the earshot of others and the use of red stickers on medical notes to denote a high risk patient. All these types of behaviours and processes are more easily captured with the use of observation than other methods of data collection. The study looks at experience more broadly across a number of sites and also explores the concept of stigma as it occurs outside the HIV specialist centres such as GP services and referring district general hospitals, the specific aim being to identify areas for service improvement. The methodology and theoretical approach of the study will be explored in more detail in Chapter 4.

### **3.2.3 Social isolation**

Social isolation can be the result of the physical limitations of illness and is also strongly associated with the previous theme; felt or enacted stigma. The literature has highlighted the issue of isolation and suggested that a cancer diagnosis could be an opportunity for HIV positive patients to talk about illness with family, friends and work colleagues without fear of discrimination and obtain sympathy for their plight for the first time (Maboko and Mavundla, 2006).

The literature shows that social isolation can have a detrimental effect on physical and emotional wellbeing in both HIV and cancer diagnoses. Charmaz (1983) found that in people suffering from a chronic illness, social isolation was a major consequence of the restrictions of the condition. When ill they were no longer able to take part in shared activities such as leisure or work with visitors required to come to them requiring extra effort and time. In cancer, Kroenke et al (2006) suggested that women who were most socially isolated before their breast cancer diagnosis were twice as likely as women with the strongest social network to die from the disease. Lutgendorf et al (2012) found that women with ovarian cancer who had the most supportive social relationships lived for at least a year longer on average than those without support. There have been numerous studies looking at people living with HIV where social marginalisation has affected well-being including adherence to anti-retroviral medication (Ware et al, 2006) and isolation has been shown to be a consequence of high levels of internalised stigma (Lee et al, 2002). The literature shows us that both HIV and cancer are illnesses where social isolation has a negative impact on outcomes and quality of life. It is important to

establish what happens to a person's ability to access wider social support when they have a dual diagnosis. As described above cancer may provide an opportunity for people who have long kept quiet about their HIV diagnosis to talk about their symptoms and illness and get sympathy which they have previously been denied.

### **3.3 The Personal Context: Patients' Narrative Accounts of their Life Course**

It has already been established that the language, the metaphors and meanings that patients use to describe their experience is important in revealing how they make sense of their illness, access support or alternatively isolate themselves. Important related concepts in the literature attempt to describe how people frame their experience within the context of their own experience and biography. Illness can be seen as a disruption and in some cases a threat to identity. In order to fully understand how participants might be making sense of and framing their own experience it is important to look beyond just the language being used and include the concepts that describe how and why people come to see their illness originating in a certain way and how they personally account for the way their lives have been disrupted.

In a separate literature review to the one presented in Chapter 2, a more exploratory, scoping database search was performed to further identify broad conceptual groups of interest within the theme of metaphors, meanings and the language of patient accounts. The Web of Science database was searched from 2005 – 2015 to capture work relating to experience during a period when antiretroviral therapy for HIV was firmly established. This search used the following terms 'HIV' and then 'cancer, each combined with ('experience' or 'feeling' or 'perception' and 'metaphor' or 'imagery' or 'language' or 'narratives'). The full strategy is provided in Appendix 3. The largest numbers of relevant papers from this search were based on themes of language, metaphors, talking about experience and narratives. Once more, these papers dealt with the experience of HIV and cancer separately suggesting that the exploration of a dual diagnosis would be a new area of research. Reading identified further relevant concepts which were then explored such as loss of self (Charmaz, 1983), narrative reconstruction (Williams, 1984), lay aetiology (Blaxter, 1983) and biographical disruption (Bury 1982, Williams 2000). The relevant literature is critically discussed below.

To fully understand patient experience and those factors that might influence their behaviour or ability to access support it is important to hear the patient's own explanation. This might include medical information but be supplemented by additional meaning and understanding drawn from the individual's biography. Attempts to impose a meaning that makes sense in the face of seemingly arbitrary events and when medical knowledge seems insufficient are crucial to understanding the patient experience. An understanding of this process is important for healthcare professionals if they are to provide appropriately tailored information, support and advice for patients with a dual diagnosis. Literature on the sociology of chronic illness describes concepts relating to this process. As will be discussed in more detail later HIV is increasingly being framed as a chronic illness despite there being some ongoing tensions associated with persistent stigma. Concepts from the literature on chronic illness therefore are relevant to a consideration of an HIV diagnosis, providing the differences in the illnesses which are described (such as rheumatoid arthritis in Bury, 1982) are taken into consideration in their application. Similarly, in cancer biographical disruption is a relevant concept for describing and explaining the experience of cancer. As Hubbard et al (2010) assert, this concept can be relevant irrespective of whether an individual experiences cancer as acute or chronic; in both cases the diagnosis can represent a threat to identity and necessitate biographical work.

### **3.3.1 Biographical disruption**

Bury (1982) in the UK was at the forefront of a focus on the lay voice, recognising the importance of people's preferred identities and identity goals. Bury conceptualised chronic illness as 'biographical disruption' in his field study of rheumatoid arthritis in the North West of England in the 1970s. This disruption involved three stages: the disruption of taken for granted assumptions (of being active and healthy); a re-thinking of biography and self-concept and the creation of their own more comprehensive level of explanation and finally the ability to mobilise resources. Charmaz (1983) in the US wrote about chronic illness as 'a loss of self'; an erosion to former self- image which was a consequence of the loss of a productive function, financial crisis, family strain and a restricted existence.

### **3.3.2 Narrative reconstruction**

The second stage of Bury's concept was expanded on in Williams's (1984) work on narrative reconstruction. In providing their own explanations people are providing

the answer to the question 'Why Me?' Their account of the origin of their illness and what they believe to have caused it can be seen as an attempt to understand their situation in terms of social experience and to affirm that life has a purpose. This lay aetiology forms part of narrative reconstruction, the way in which people frame and recount the story of their illness, and also appears in the work of Blaxter (1983) on working class Scottish women and their accounts of breast cancer

Bury's central concept of biographical disruption describes an individual responding to the disruption of an illness by re-thinking their own life story and creating their own explanation. This concept has been re-visited by Williams (2000) who argues for a series of revisions described below. The development of disability theory places more emphasis on society's prejudices and barriers rather than a 'personal tragedy' emphasis and a narrow look at the limitations caused by an individual's symptoms. Williams (2000) argues that this wider focus on the role of societal barriers should be included in new considerations of the concept. For those groups in society who have experienced a lot of adversity, for example elderly Eastenders who have had a stroke, their illness might be biographically anticipated (Pound et al, 1998). It is possible that HIV positive gay men may view their HIV diagnosis as something which biographically reinforces their identity and 'reaffirms their struggle' (Carricaburu and Pierret, 1995). So in the case of HIV activists a previously stigmatised identity may be transformed into a positive one associated with fighting for a cause. Williams also argues that modern society with more flexible patterns of work and increasing tolerance for diversity and difference may mean that chronic illness is less 'non-normal'.

The formative studies on biographical disruption and narrative reconstruction were looking at rheumatoid arthritis, a long term chronic illness different in many respects from both HIV and cancer. Both themes remain useful ideas in understanding how people with a dual diagnosis might frame their experience with the following provisos. An HIV diagnosis managed successfully on treatment is less likely to feature obvious visible physical limitations which require adjustment: it may be possible to limit disruption in the sense that it is possible to keep it hidden from others and for some groups with HIV such as gay men, the diagnosis may be biographically anticipated. Cancer is often perceived as an acute rather than chronic illness but I contend that biographical disruption remains a useful concept as it is undoubtedly a major disruptive event that challenges taken for granted assumptions and brings to the fore thoughts about mortality which might otherwise seem distant or remote. Hubbard et al (2010) in their discussion of the concept in

relation to patients with colo-rectal cancer supported Williams's assertion about the importance of context. In their study those people who had experienced a 'hard life' did not express the disruption of cancer as a threat to their identity and sense of self, although they did acknowledge its effect on their physical self and the limitations it placed on their daily life.

In summary, biographical disruption, the associated challenges to identity, and narrative reconstruction, are all useful concepts which will be explored in the study. Williams' revisions of theory will be kept in mind to ensure that these concepts are not assumed to be relevant in all cases.

### **3.3.3 Atrocity tales**

Another more specific piece of patient story telling features the route to diagnosis. As well as discussing beliefs about the causes of their illnesses around the time of cancer diagnosis, patients also describe the route to the diagnosis being made. Patient accounts of frequent and frustrating presentations with signs and symptoms before diagnosis have been reported in the literature as an 'atrocity tale'. Webb and Stimson (1976) describe atrocity stories where tellers portray themselves as taking an active role in encounters with a doctor and in which the doctor's actions were criticised; these stories are in marked contrast to what the researchers actually observed which was instead a passive deferral on the part of the patient. Webb and Stimson argue that the story is a vehicle for making the patient appear rational and sensible and for redressing the perceived power imbalance between patient and doctor when the encounter has been uncertain and confusing. Baruch (1981) in his study of parents of children requiring medical treatment found that the atrocity story was a feature of the first medical encounters rather than later ones. Over time the parents learnt more about the condition and the medical language and felt more comfortable and in control. In the stories that Baruch described, the tellers located themselves in the shared everyday world and appealed to these features to show that they had acted reasonably in a time of uncertainty. More recently a study has applied the atrocity tale to staff providing cancer care in the multi-disciplinary team of a hospice and found that these tales similarly facilitated the managing of emotions as well as functioning to manage social interactions (Wittenberg-Lyles et al, 2011). This literature is relevant to exploring the experiences of HIV positive patients who have a difficult route to their cancer diagnosis. The language of atrocity stories used by interview participants to describe their interactions with healthcare professionals will help to reveal the nature of the doctor patient

relationship and indicate how comfortable, or otherwise, they feel in an unfamiliar healthcare system.

### **3.4 The Health Systems Context: in which the Patient Receives Treatment**

My study is situated within HIV positive patients' journeys through a diagnosis of cancer, its treatment and follow up. As this medical setting is the locus of enquiry, any exploration of patient experiences needs to understand how patients negotiate the biomedical environment and apply their own understanding to this medical world.

A further exploratory scoping database search was performed to explore themes within this area under the broad title the Doctor/Patient relationship. The Web of Science database was searched from 2005 – 2015 for relevant studies. The search used the following terms 'HIV' and then 'cancer, each combined with ('patient empowerment' or 'doctor patient relationship'). The full strategy is provided in Appendix 3.

Although the search primarily refers to the doctor/patient relationship this area of enquiry is intended to refer more generally to the healthcare setting: the GP; the hospital trust with all of its employees not just doctors, as distinct from the patients' own day to day lives. Themes which emerged from this search related to the dynamics around shared decision making, medical communication styles, differentials of power in medical encounters and the importance of holistic care for patients. The theme of the 'normalisation' of life with HIV featured as a result of an earlier scoping search looking at metaphors and language. However, this theme sits better within the health systems context as much of the discourse is based upon routine medical management and biomedical monitoring.

#### **3.4.1 Voice of medicine and voice of lifeworld**

This section discusses themes in the literature which relate to treatment within the healthcare system.

As previously described with lay aetiology and atrocity tales, it is clear that there can be a gap between the patient's knowledge and interpretation and that of the clinician. Mishler (1984) asserted that this conflict between the *voice of medicine* (technical, scientific and governed by abstract rules) and the *voice of the life world*

(contextually grounded experience of life events dependent on patient's biographical situation) resulted in ineffective medical care. He based his theory on Habermas' Theory of Communicative Action (1984), both seeing holistic care as an improvement on purely medical approaches.

The differential of power in medical encounters has been discussed in the literature from a socio-cultural context according to different perspectives with the alternative Foucauldian view that holistic care is not always desirable when biomedical control encroaches into the personality as well as the body (Lupton 2003). Barry et al (2001) take a more pragmatic approach, arguing that the 'strictly medicine' communication style is effective for simple unitary problems but reporting that in communication with patients suffering from chronic conditions problems can arise when the life world issues are ignored. I contend that a dual diagnosis of HIV and cancer is such a complex experience with so many life world influences potentially affecting a patient's outlook and behaviour that a 'strictly medicine' communication style would not be effective.

### **3.4.2 Importance of holistic care**

Literature on the importance of complementary or alternative therapy to patients and the negative communication which may result when this is discussed with the doctor in cancer care (Salamonsen, 2013) further suggests the presence of this gap between the two worlds. A systematic review of the literature reported that estimates of the lifetime use of complementary and alternative medicine (CAM) amongst people living with HIV range from 30% to 90% (Lorenc & Robinson 2013). In a synthesis of the literature on CAM, Donald et al (2015) found common features of patients feeling concerned and frustrated by their clinician's apparent disinterest and lack of knowledge about these interventions. To the patients they symbolised taking control and exercising choice and this was found to be important in a time when the medicalisation of HIV care with its focus on routine monitoring of the success of antiretroviral therapy with blood biomarkers threatened to remove aspects of person centred care. Another study of HIV positive African migrants in the UK revealed that they often used herbal medicine and didn't disclose this to their doctor (Thomas et al 2010). Complementary or alternative therapies can be a central feature of patients' life world but the literature suggests that they are sometimes disregarded or disparaged by healthcare professionals. The scoping database review highlighted other areas such as spiritual concerns and the use of

online support which although important in patients' lives did not feature in clinical consultations.

This has implications for understanding the experience of HIV positive patients communicating with clinicians about their HIV and cancer diagnoses. This study originated in the researcher's own clinical observation and a hypothesis that there might be a difference in people's experience of receiving information in the different culture and structure of hierarchy in the HIV and cancer healthcare settings; with HIV having more of a focus on shared decision making. In HIV care this may have changed over time. Flowers (2010) suggests that with the advent of effective antiretroviral treatment and the associated medicalization of HIV there may be a concomitant process of minimising psychosocial issues. Therefore, it is an important time to try and establish whether patients experience a disconnect between the care and communication style provided by the healthcare setting and the support and information that they value the most.

### **3.4.3 The challenge of a cancer diagnosis to the 'normalisation' of life with HIV**

Moyer and Hardon (2014) describe how various medical, policy and institutional discourses have aimed to reframe HIV as a chronic disease like any other. This concept of 'normalisation' is characterised by the provision of routine medical treatment and regular visits to clinic to receive antiretroviral medication and have blood tests. This normalisation narrative when adopted by people living with HIV depends on the availability and success of treatment and has a biomedical underpinning with the routine reference to biomarkers in the blood such as CD4 counts and viral loads (Mazanderani & Papparini 2015). Another feature of this narrative is a focus on positive living, eating healthily and maintaining a positive mental outlook.

However, tensions, challenges and contradictions to this narrative are also evident in Mazanderani & Papparini's study, with stigma and discrimination continuing to affect people's work opportunities, social support systems and family life. When people with HIV experienced health problems that did not match the normalised depiction and failed to stay positive they experienced further discrimination from community groups who had embraced this approach. Wilkinson and Kitzinger (2000) described the concept of 'positive thinking' in cancer as a conversational idiom used as a socially normative moral requirement in conversation to move

away from topics of suffering and distress without unsettling others or attracting censure. These themes of adopting tactics to attract affiliative and supporting responses from others appear in the literature of HIV and of cancer and are therefore pertinent to exploring the experience of a dual diagnosis.

It will be important to explore how much of a challenge the cancer diagnosis is to the normalisation rhetoric.

### **3.5 What it Means to Have a Dual Diagnosis of HIV and Cancer: a Summary of the Theoretical Underpinnings**

To summarise, the motivation for exploring the experience of a dual diagnosis of HIV and cancer came from my own clinical experience and an observation that the styles of the two healthcare systems were different. An initial systematic review of the database literature was performed to establish what was already known about the subject. The results suggested that this was an area largely unexplored in the literature. The findings in the identified studies demonstrated that HIV and Cancer are conditions that are experienced differently but both linked to powerful beliefs that influence negotiation in healthcare and accessing support.

This first investigation of the literature was followed by wider reading and further exploratory searches informed by what had already been discovered and by themes emerging from the first participant interviews. Influential sociological theory was incorporated, as well as articles identified by further citation searching and those signposted by supervisors. Three broad conceptual groupings: the social, personal and health systems contexts, were identified representing different spheres of influence on patients' experiences and relevant themes explored in each.

This chapter has presented the theoretical underpinnings: namely wider conceptual themes in the literature which are relevant to an exploration of patient experiences of a dual diagnosis of HIV and Cancer. The next chapter describes the three different methodological approaches adopted, which comprise a thematic analysis of popular discourse in newspaper articles; a narrative approach with a focus on individuals' stories provided in their own language through in-depth interviews, and focused ethnography used to explore the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis.

## Chapter 4 Methodology

This chapter outlines my own epistemological position in relation to ways of knowing and understanding the experience of a dual diagnosis of HIV and cancer. It then details the three different methodological approaches which were used within my study and explains how these approaches provided a rationale for the particular research methods chosen. More detail on the empirical and analytic methods is provided in later chapters.

### 4.1 The Interpretivist Position

I chose to adopt a broadly interpretivist approach to explore peoples' worlds within the context of their life as a whole, incorporating social and personal influences as well as the biomedical, healthcare arena in which they receive their treatments. This perspective is attuned to my own practice as a nurse who acknowledges the importance of providing holistic nursing care to patients that takes account not only of the effects of illness on the body but also the mind, emotions, spirituality and personal relationships. The earlier systematic review of literature featuring a dual diagnosis of HIV and cancer also indicated the need for a methodological approach able to explore the complexity associated with themes around stigma and its effect on patient access to social support and engagement with services. As described in the previous chapter existing theory and research helped to inform the initial planning and design of the study but the focus of my research was inductive, rooted in the participants' views and experiences as well as the societal context. Individual interpretations, meanings, motivations and values were sought in order to provide a perspective which stayed close to the data; findings were then considered in relation to existing theories.

Further support for this approach can also be found within the medical and scientific community as illustrated in the quote below which acknowledges the limits of focussing solely on disease and medicine in a condition like HIV which is so closely linked to personal and societal beliefs and understandings.

Defeating this awful HIV epidemic requires an understanding of society, as well as individuals, as well as medicine. Without an understanding of all of those, we will never defeat it

This quote by Professor Deenan Pillay featured in a documentary, 'The Truth About HIV' aired on BBC One on 25 May 2017. It described the current situation in which

huge breakthroughs have been made in science and in the medical treatment of HIV and yet people in large numbers still fail to get tested, access or adhere to treatment despite the availability of resources. Thus in order to explore the experience of people living with both HIV and cancer it is important to adopt a position that acknowledges the likely complexity and contextual factors and that facilitates an understanding of how and why people behave the way they do.

Having described my epistemological position the next section of this chapter outlines the three methodological approaches which have been adopted within the study to reveal the social, personal and health systems contexts of a dual diagnosis: (i) a thematic analysis of discourse within newspaper articles; (ii) a narrative approach with a focus on individuals' stories provided in their own language and (iii) focused ethnography used to explore the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis. The three approaches, their characteristics and the rationale for their use will be described.

## **4.2 A Thematic Analysis of Discourse within Articles in London Free Newspapers. The Social Context of a Dual Diagnosis**

### **4.2.1 Research aim**

To understand how HIV and cancer are represented in popular discourse and society and to examine any links between these discourses and patient accounts

In order to fully understand individuals' experience of a dual diagnosis of HIV and cancer it is necessary to take into consideration the powerful sociocultural contexts of both illnesses. Some of this social context will be revealed in the words of the study participants and healthcare professionals provided in interviews and during observation. Their accounts will have been informed by their own personal experience as well as family and cultural influences but will also be delivered within the wider arena of popular discourse which is represented in the news media. Stories in these newspapers are widely read and are part of the social world in which people live. They form part of the wider social context which may affect and have an impact on how people view themselves, talk about their conditions and access treatment and support.

This study comprised a thematic analysis of the representations of HIV and of cancer within newspaper articles from the last five years in the free London newspapers, The Metro and The Evening Standard. It identified the number and types of stories that were written about each condition; moving on to the identification of themes and an analysis of the types of discourse which were reflected in these themes. The analysis moved from an initial look at the content of the articles to the analysis of themes. These themes were identified and informed both by the content of the data but also by existing literature and data from participant interviews. In depth analysis of selected articles based on these themes provided richer detail and information about how language, imagery and rhetorical devices supported popular discourses.

The choice of a thematic analysis method when exploring the social context of a dual diagnosis in newspapers ensured a consistent methodological approach across the data set, as this method was also adopted for the interview and observation data within the study. It was also a pragmatic decision as a discourse analysis method would entail a disproportionate time commitment for what was one component of the overall thesis. Although a pure discourse analysis method was not adopted within this study, discourses around identified themes were described and explored. The next section provides a brief summary of different traditions within which discourse has been examined and will describe how this thematic analysis drew upon some of these methods.

#### **4.2.2 Key concepts and approaches of discourse analysis**

Discourse analysis developed from the 1970s, such as in the work of Michael Foucault (1972), as a move to the study of language as social action rather than the representation of an objective, observable reality. Discourse analysis looks beyond the literal meaning of language and looks at the way it is used to express understandings. There are different approaches within discourse analysis ranging from those at a micro-level which look at detailed studies of language in use in face to face talk, to those that study both language and ideology in order to understand the role of power and knowledge in society (Shaw and Bailey, 2009). Discourse analysis therefore does not just look at the surface content of a newspaper report; it looks critically at the language, structure and rhetorical devices which can reveal a less obvious layer of signification, highlighting relations of power and uncovering the ideological dimension of lay health beliefs. My study drew upon some of the key concepts and approaches of discourse analysis by selecting articles for an in-depth

analysis which looked at both textual dimensions of text (use of grammar, rhetorical devices such as metaphor, overt meaning and content topics and themes) and the contextual dimensions which examined the production and reception processes of the content and the reproduction of ideology in such processes (Lupton 2003). I adopted a reflexive stance throughout to ensure that my own perspective was acknowledged and explicit.

As described in the literature in the previous chapter, metaphors and meanings relating to HIV and cancer are powerful and yet different in both illnesses and can affect behaviour. Discourse in the news media may reveal some of the rhetorical devices relating to each condition and some of the structural influences at play in reinforcing the beliefs and understandings of these two illnesses. Exploring the themes that arise from newspaper articles and the discourse around them adds an important layer of understanding of the social context in which people with HIV and cancer access support and negotiate treatment and provides the opportunity to link this data with the data emerging from patient accounts.

### **4.3 A Narrative Approach: Semi-Structured Interviews and Diaries: The Personal and Social Context of a Dual Diagnosis**

#### **4.3.1 Research aims**

- i) To consider the meanings and understandings that people associate with a diagnosis of HIV
- ii) To consider the meanings and understandings that people associate with a diagnosis of cancer
- iii) To consider the meanings and understandings that people associate with a dual diagnosis of HIV and cancer
- iv) To understand how patients negotiate access to medical treatment and navigate healthcare services
- v) To consider the expression of links between meanings and illness and the mobilisation of wider social support

#### **The Narrative Approach: depth of insight**

The narrative approach is suited to an exploration of experiences as it provides data which is rich and it reflects and respects the way people tell their stories and impose order, meanings and explanations of events in their life. The use of narrative and

biographical methods focuses on individuals' stories as a way of studying wider concepts such as how people cope with illness (Chamberlayne et al., 2000, Roberts, 2002). I therefore used this approach to explore people's accounts of a dual diagnosis in the semi-structured interviews which were conducted with participants based at three London sites. I sought to complement the narrative interviews by asking people to complete a diary. The examining of participant narratives derived from loosely structured interviews provides depth of insight and layers of understandings as to how people interpret the major life events of a HIV and cancer diagnosis and the values, beliefs and explanations that guide those interpretations. It focuses on the words of the participants themselves rather than those of the researcher imposing their own perspective or seeking information through simplified symptom scales and survey questionnaires. Kleinman (1988) described this positivist approach to investigating experience of illness 'a thinned-out image of patients and families' which fails to provide the context and meanings that narrative can elicit in order to create a much deeper understanding. Chapter 3 outlined relevant theories in the literature relating to the lived experience of illness such as narrative reconstruction, lay aetiology and biographical disruption which are all part of a narrative methodological approach. In this study the approach is adopted in the conduct of semi-structured or loosely-structured interviews with participants to explore these concepts.

#### **4.3.2 Semi-structured or loosely-structured interviews**

A topic guide for the interviews was developed which outlined the themes described earlier from the literature review: namely patients' beliefs and opinions about cancer and HIV as illnesses and how they identify with each. It also contained guide questions about engagement with healthcare services and patients' decisions around disclosing their HIV and / or cancer diagnosis in the context of seeking social support from family, friends and wider professional support from services including GPs. This topic guide was piloted with two members of the patient representative group in the process of its development. The initial interviews were conducted with a careful use of this topic guide which can be found in Appendix 4. Having reviewed the transcripts and reflected that the structure of the topic guide at times interfered with the narrative flow and imposed a restrictive order on the interview, I adopted a more unstructured style from the third interview onwards, starting by asking the participants to tell me their story and allowing them to narrate events without interruption. This resulted in a more naturalistic account and I was

able to ask questions about areas that hadn't been covered at the end of the interview without interrupting the participant's telling of their story. So although the interviews are referred to as semi-structured, they quickly became more participant led and in depth, with the topic guide used only at the end to prompt areas that had not been covered. This approach with an emphasis on listening to the narratives rather than asking pre-planned questions has been described in the literature as a discovery interview (Wilcock et al, 2003; Bate and Robert, 2006).

### **4.3.3 Longitudinal interviews and context**

Narratives take place in specific historical contexts and in shifting relations of power and they are constructed at particular moments in time for particular audiences. By conducting repeat interviews at different stages in the participant's journey from initial diagnosis through treatment for HIV and for cancer and during follow up, the information gathered provided contemporary insight into their experience of different stages of treatment. It also provided more than one account from different historical perspectives and allowed identification of any changes in participants' explanations and perceptions over time. This helped to enhance what Sandelowski (1991) describes as 'the understanding of lives in health, illness and transition'. Details of the specific research methods adopted for recruiting participants and conducting the interviews and analysing the data will be presented in Chapter 6. The next section of this chapter will outline the planned use of another method within the narrative approach, the diary method.

#### The planned diary method

One of the primary attractions of using a diary method is its ability to capture events and experiences in their immediate, natural context and in the language of the participant. Ideally, the diary should contain an account close to its occurrence, thus minimising the likelihood of retrospection which may occur if too much time elapses between the event and its reporting (Bolger et al, 2003). In the planning stage of the study I incorporated a diary method for the period between the interviews. The advantage of this lay in capturing thoughts and understandings in the participants' own language as they developed during the course of adjusting to their cancer diagnosis and receiving treatment.

Diaries place a burden on participants in terms of commitment during a time of adjustment and possibly intensive and debilitating treatment. I understood this but felt that whatever information I did collect from this method would be a valuable

addition to the data collected in the interviews. It was therefore important to find a diary method that was as suitable and acceptable for the patient population as possible and that sat practically within the existing study design. Feedback from patient representatives on the acceptability of the proposed diary method in the design phase of the study suggested that this would be agreeable to some and not others and therefore it would be important to offer flexibility in the extent of involvement and the methods used to collect the data. Participants were asked to record daily over one 7 day period occasions when they became aware of their HIV and Cancer diagnosis and were made to think about it. This was intended to capture information about day to day life that might be harder to access in interviews and it was solicited with the following prompts which were handed to participants as an additional information sheet:

- Think about any time during the day when you became aware of your HIV and Cancer diagnosis
- Have you seen, read or heard anything (for example in newspapers, on television etc) that made you think about your illness and made you feel uncomfortable, upset or on the other hand optimistic, reassured?
- Have you had any interaction with family and friends that made you think about your HIV and/or Cancer diagnosis?
- Have you had any medical interaction that made you think about your HIV and/or Cancer diagnosis (for example with doctors at the hospital, your GP, your dentist etc?)

The method of capturing the diary data was left open to include pen and paper, or use of their own smartphone or computer whichever was most convenient, the aim being to be as inclusive as possible. The use of the diary and the method was discussed during the consent discussion prior to the first interview.

#### **4.3.4 Summary of the narrative approach**

In summary the narrative approach is one that is well suited to exploring the experience of a dual diagnosis of HIV and cancer as it provides a rich insight into layers of understanding derived from the participants' own words. Theories within the literature relating to lived experience of illness informed the adoption of this approach which was adopted within this study in the conduct of longitudinal semi-structured or loosely structured interviews with patients with a dual diagnosis of HIV and cancer. A diary method was also planned to provide more data within the

narrative approach. Details of the specific research methods adopted for recruiting participants, conducting the interviews and analysing the data are presented in Chapter 6 prior to presentation of the findings in subsequent chapters.

## **4.4 Focused Ethnography: the Health Systems and Social Context of a Dual Diagnosis**

### **4.4.1 Research aim**

To consider the features of the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis

### **4.4.2 Ethnography**

Ethnography is used to describe whole communities or cultures with in depth observation and ‘cultural immersion’ taking place over long periods of time with many different types of data collection (Fetterman, 2010). An ethnographic approach is appropriate for exploring the healthcare setting in which HIV positive patients receive treatment for cancer. Ethnography is a powerful way to reveal, in context, the elements of interaction; it provides thick description which captures social actions and interprets them within context and allows those involved to speak about their own views and perspectives. Observation offers insight into interactions, processes and subconscious or instinctive behaviours that goes beyond the understanding conveyed in verbal accounts. This can be especially important when there may be social norms or pressures for healthcare professionals to conform to expected behaviours and give ‘the right answers’ to questions about their attitudes towards patients who have stigmatising illnesses. The level of understanding sought with ethnographies typically requires multiple data collection methods including participant observation with ‘cultural immersion’ over an extended period of time (Hammersley and Atkinson 1989). As an approach it can therefore be protracted and resource intensive.

### **4.4.3 Focused ethnography**

Focused ethnography, located within the ethnographic genre, is described by Higginbottom (2013) and Knoblauch (2005) as a methodology characterised by intermittent, purposeful field visits with a focus on particular presentations and participants who have in-depth knowledge and experience of the topic. I chose to

use this approach in my study in order to describe the health systems context in which patients engaged with services relating to their cancer treatment. It incorporated field visits of clinical areas where cancer treatment was delivered to HIV positive patients, with observation and informal interviews of a variety of key informants conducted within that setting.

When looking at a defined context such as the beliefs and understandings held by both patients and healthcare professionals, and a meaningful application of findings to practice, it seemed appropriate to have a more specific focus on those people directly experiencing or involved in this group's care. Focused ethnography represented an approach which was well suited to my aims as patients with HIV appeared in particular cancer day-care units or ward settings sporadically rather than on a day in day out basis. It was more appropriate to focus on the periods when patients were present and receiving treatment and to collect more intensive data at that time rather than to observe the setting for weeks and see no relevant patients.

#### **4.4.4 Ethical issues**

This approach required careful consideration of ethical issues around witnessing bad clinical practice, protecting privacy and establishing proper informed consent. As a registered nurse who was conducting observation in the capacity of a researcher it was important to establish a process by which I could escalate any concerns relating to clinical practice. My position and purpose had to be described in such a way so that people were not prevented from speaking freely but equally were not misled. Reflexivity about my own views and perspectives had to be included to acknowledge and make transparent the researcher position within the data collection process. More detail about the specific measures taken to ensure ethical considerations and reflexivity is given in the research methods section of Chapter 10.

#### **4.5 Summary of Methodological Approaches**

In summary the three methodological approaches of thematic analysis of popular discourse, narrative interviews and focused ethnography adopted within this study all lent themselves to an exploration of patient experiences, each providing rich and in depth data that shed light on societal, personal and healthcare system contexts. They were all in keeping with a broad interpretivist approach which aimed to

understand peoples' worlds within the context of their life as a whole, incorporating social and personal influences as well as the biomedical, healthcare arena in which they received their treatments. These different contextual understandings were put together to build layered insights which were ultimately looked at together within the data analysis to establish common themes across the different perspectives. A summary of the three approaches can be found in Table 4-1

**Table 4-1 Summary of the three methodological approaches**

Research Question	The Fieldwork	Contextual understanding
<ul style="list-style-type: none"> <li>To understand how HIV and cancer are represented in popular discourse and examine any links between these discourses and patient accounts</li> </ul>	<p>Nexis database search and review of articles on HIV and on cancer in London free newspapers , the Metro and Evening Standard in 5 years prior to March 2017</p>	<p>Understanding the social context of a dual diagnosis</p>
<ul style="list-style-type: none"> <li>To consider the meanings and understandings that people associate with a diagnosis of HIV</li> <li>To consider the meanings and understandings that people associate with a diagnosis of cancer</li> <li>To consider the meanings and understandings that people with a dual diagnosis of HIV and cancer</li> <li>To understand how patients negotiate access to medical treatment and navigate healthcare services</li> <li>To consider the expression of links between meanings and illness and the mobilisation of wider social support</li> </ul>	<p>Semi-structured interviews with HIV positive patients receiving treatment for cancer Diary information from interview participants who wished to provide it</p>	<p>Understanding the personal context of a dual diagnosis</p>
<ul style="list-style-type: none"> <li>To consider the features of the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis</li> </ul>	<p>Focused ethnography: participant observation and informal interviews with key informants in the clinical setting where HIV positive patients receive their cancer treatment</p>	<p>Understanding the health systems context of a dual diagnosis</p>

## **4.6 The Study Advisory Group**

A study advisory group was set up in the early stages of the development of the research question. This was made up of a group of key clinicians in both HIV and oncology at each of the three sites, along with two patient representatives and the study's academic supervisors. The purpose of the advisory group was to ensure that the study could be conducted practically and with the approval of key clinicians and managers at each of the three sites and to ensure that the design of the study was suitable to address the research objectives and was of sufficient rigour. The first meeting was held in November 2014 and provided useful feedback from clinicians and patient representatives. As a result of discussion the sample size was increased and it was agreed that it should include a balance of both patients treated in specialist teams (such as for lymphoma) as well as those who have more common cancers, for example, breast and lung cancer and who may be treated more generally within the existing cancer services. It was also agreed that it would be important to try and include those people referred to specialist centres who travel a long way from home for their treatment. These recommendations were incorporated into the protocol that was submitted for ethical and R&D review in January 2015.

## **Chapter 5 The Newspaper Data**

### **A Thematic Analysis of Representations of HIV and of Cancer in Free London Newspapers: The Social Context of a Dual Diagnosis**

#### **5.1 Introduction**

This chapter describes a thematic analysis of representations of HIV and of cancer within newspaper articles from the previous five years in two free London newspapers; The Metro and The Evening Standard. The analysis was conducted to provide an understanding of the social context in which people with HIV and cancer frame their experience, access support and negotiate treatment.

The literature review has already highlighted the importance of language and beliefs about illness that link to stigma and which in turn can be linked to health-related factors including seeking healthcare and maintaining adherence to treatment (Ware et al, 2006). Stories in these free newspapers are widely read and the language contained within them form part of the social world in which people with a dual diagnosis live. Discourses within newspaper stories about cancer and HIV are presented to people on a daily basis and may affect how they view and understand their conditions and talk to others about them. This social context is an important area to explore in order to understand the experience of a dual diagnosis and this work complements the accounts provided in the patient and healthcare professional interviews which form the other components of this study.

The analysis presented in this chapter moves from an initial overview of the content of the newspaper articles to the development and analysis of themes. Themes were initially identified inductively through repeat reading of the articles, but then refined according to existing literature and data from participant interviews. A number of articles were selected for in-depth analysis. These were selected as exemplar cases of the themes and allowed for a comparison to be made between representations of HIV and of cancer. The in-depth analysis captured rich detail and information about the language, imagery and rhetorical devices which form part of popular discourses. I also included a couple of outlying examples where there was not a comparable story between HIV and cancer. The next section of this chapter provides an overview of the methods adopted to perform the thematic analysis of

newspaper articles and the rationale behind their use. It will then move on to a presentation and discussion of results.

## **5.2 The Methods**

### **5.2.1 The Sample: Choice of newspapers and background information.**

The Metro and The London Evening Standard were selected to perform searches for articles on HIV and on cancer in the five years prior to May 2017. London newspapers were selected as the narrative and ethnographic data were collected in London and it was hoped that there would be some cross referencing with narrative accounts potentially featuring some of the same stories that appeared in the news media. They are both free newspapers which have a large circulation and are ubiquitous on London public transport. They are widely read by a broad demographic by virtue of their availability on the transport network where a large volume of people commute to work and will pick them up to pass the time without making a conscious decision to select based on price or political persuasion. The messages they produce are therefore read by many people from a wide range of cultural backgrounds, ethnicity and economic status, and their representations of HIV and cancer form a part of the social world in which people with a dual diagnosis live. Although there are differences in the two publications' content which will be discussed in a later section they both largely feature very short articles with attention grabbing headlines and top-line, heavily summarised, items.

The Metro distributes 1.47m copies of its newspaper published in tabloid format every week day (as of November 2017) in 50 UK cities including London and is the UK's highest circulation newspaper. The Daily Mail group is the major owner, although the paper has never endorsed any political party and claims to take a neutral political stance. The Evening Standard has a Russian-born British chairman, Evgeny Lebedev who also owns the Independent newspapers and is a self-professed strong supporter of press freedom, the arts and philanthropic campaigns. The paper supported David Cameron and the conservative party in the 2015 general election and the former conservative chancellor, George Osborne is its editor. 897, 523 copies are distributed every week day (as of November 2017).

A broad comparison of the nature of reporting in each shows that The Metro has a larger number of very short articles, often around 100 words long in total with just four or five sentences. Human interest stories about HIV or cancer often contain

emotionally loaded or sensationalist language. The Evening Standard has short articles too, but also includes some longer opinion pieces; these may feature stories with a human angle on HIV or Cancer and fall into the paper's tradition of taking a paternalistic and philanthropic approach to social issues.

### 5.2.2 Search strategy

A commercially available on-line database (NEXIS) of newspaper articles was used to retrieve articles on both HIV and cancer from the Evening Standard and the Metro newspapers in the five years prior to the search, see Table 5-1 below

**Table 5-1 Search methods for newspaper analysis**

	Source	Search term	Time period
1.	Evening Standard	'Cancer'	5 years prior to May 2017
2.	Evening Standard	'HIV'	5 years prior to May 2017
3.	Metro	'Cancer'	5 years prior to May 2017
4.	Metro	'HIV'	5 years prior to May 2017

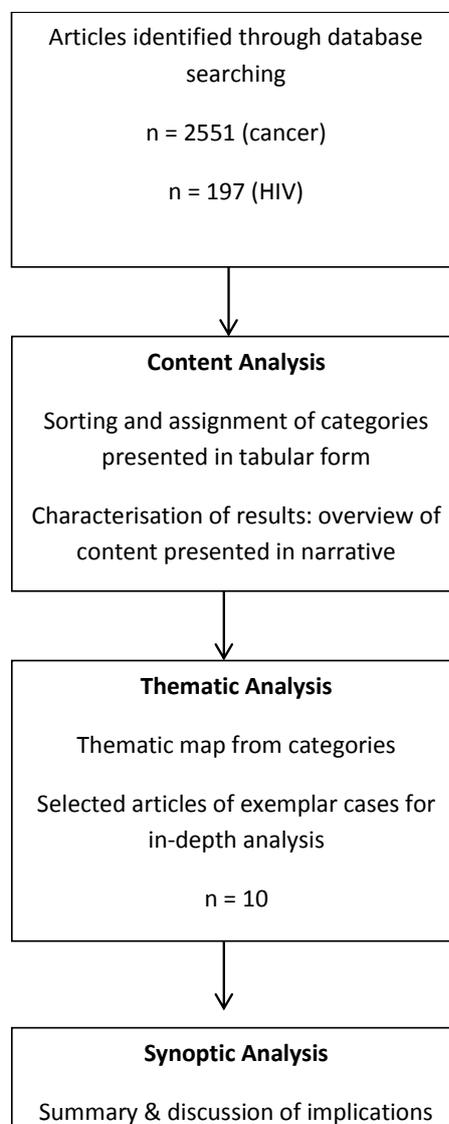
### 5.2.3 The analysis

#### Framing the analysis

The thematic analysis of the newspaper articles was conducted when the majority of in-depth participant interviews had been completed. The process of generating initial data codes and categories from the articles and then the move to arrange these into broader themes was informed by the content itself but also by earlier exploration of the literature and data already collected from the participant interviews. The literature describing the language and metaphors of HIV and cancer outlined in Chapter Three contained relevant concepts which helped to inform the identification of themes from the articles. The literature describes the use of language associated with HIV as being that of danger and high risk, deviant behaviour (Sontag 1989) and that associated with cancer as often featuring bravery and fighting spirit (Lupton 2003). The reading I had already done therefore alerted

me to finding similar language and themes within the newspapers. Other concepts I had explored in the literature such as lay aetiology were also evident with a plethora of news articles on the many purported causes of cancer. The process of identifying themes was also informed by the data from participant interviews. On several occasions participants referenced news stories in their narratives, one example being discussions about the ethics of using antiretroviral Pre- Exposure Prophylaxis (PrEP) and another being talk about celebrities with cancer. Thus the analysis framework was informed by an inductive analysis of the data but also by what was already known from the review of the literature and the narrative data of the participant interviews.

A summary of the different stages in the analysis are represented in Figure 5-1.



**Figure 5-1 Stages of the thematic analysis of newspaper articles**

## **The Content Analysis Method**

The search yielded a total of 2551 articles referring to cancer and 197 articles featuring HIV. With such a large number of results an initial content analysis was performed in order to broadly categorise the types of articles being written about each condition. The results of each search were prepared for review by exporting a numbered list of the full headlines which contained links to the complete article. The entire set of headlines was read and reference was made to the full text to aid the assigning of broad categories. Separate spreadsheets were compiled for HIV and cancer containing the results of both newspapers. An overview of the search results and the category assignment was presented for cancer and HIV in tabular form and then in more detail in a narrative description. A summary and discussion of the content made it clear that there were big differences in the way the two conditions were presented within stories and initial themes were identified from and across the categories which highlighted these points of difference. The next stage of analysis involved further thematic analysis and the selection of a number of articles for in-depth investigation. Those methods are described in the next section.

## **The Thematic Analysis Method**

In order to develop and further define themes within the newspaper article data a thematic map taken from the findings of the content analysis was created. The data was then re-visited to ensure that those themes identified represented the data and had not missed out anything. The themes were reviewed and refined and their selection was informed not only by re-visiting the data but also by the previous literature review and interview data. Articles were chosen for in-depth analysis based on a sampling strategy outlined by Miles & Huberman (1994). This sampling strategy incorporated three techniques: selecting apparently typical or representative examples of a theme; looking for negative or disconfirming examples of these themes and selecting exceptional or discrepant examples. By choosing a combination of typical, disconfirming and exceptional examples the analysis could explore the boundaries and range of views within the dataset. The selected articles for detailed analysis were presented in a table to include the headline and its date, the newspaper it was taken from, the initial coding category that was assigned during the content analysis and the theme it represented. A form was completed for each of the selected articles to tabulate the components of the analysis of the text (Appendix 5). The detailed analysis of the selected articles was then presented in narrative form and included an examination of the context, the surface of the text,

rhetorical devices, content and ideological statements and the overall discourse position and message of each article. The narratives aimed to, where possible, compare representations of HIV and Cancer between articles in order to identify the essential differences in the types of discourse presented.

Finally a synoptic analysis was presented to summarise the themes and to discuss the potential impact that popular discourses around HIV and cancer might have on people who have a dual diagnosis.

## **5.3 The Results**

### **5.3.1 The content analysis: the initial characterisation of the results**

An overview of the search results and the breakdown of numbers into category assignment is presented for cancer articles in Table 5-2. Further detail about the content of each cancer category is detailed in Appendix 6. The same information is then provided for HIV articles in Table 5-3 and Appendix 7. Finally, there is a summary and discussion of the content and an initial identification of themes requiring further exploration with a more in-depth analysis of selected articles presented in the next section.

## Cancer

**Table 5-2 Cancer articles in the newspaper search**

<b>Cancer articles identified by Nexis Database Search May 2012 – May 2017</b>	
Evening Standard	n = 937
Metro	n = 1695
Total cancer articles	n = 2632
Total duplicates*	n = 81
Total without duplicates	n = 2551
<b>Thematic categories</b>	
Cancer Risk	n = 243
Cancer Fundraising	n = 245
Cancer Scams	n = 36
Celebrity Cancer	n = 510
Cancer 'The Human Angle'	n = 331
Cancer New Drugs/Technology/Research	n = 271
Cancer Figures	n = 87
Cancer Funding & the NHS	n = 160
Cancer Diagnosis & Presentation	n = 73
Children with Cancer	n = 147
Cancer Business/Industry	n = 49
Cancer an Incidental Mention	n = 399

\*Duplicates are the same article in different editions of the paper

(Appendix 6 provides a summary regarding the content of each thematic category in cancer)

## HIV

Table 5-3 HIV articles in the newspaper search

<b>HIV articles identified by Nexis Database Search May 2012 – May 2017</b>	
Evening Standard	n = 88
Metro	n = 144
Total HIV articles	n = 232
Total duplicates*	n = 35
Total without duplicates	n = 197
<b>Thematic categories</b>	
HIV Awareness	n = 10
HIV Fundraising	n = 5
HIV 'Commentary'	n = 19
Celebrity HIV	n = 53
HIV First person story 'The Human Angle'	n = 40
HIV advances in treatment/Medical interventions	n = 22
HIV Figures	n = 9
HIV Funding and the NHS	n = 19
HIV & Children	n = 1
HIV Business/Industry	n = 3
HIV an incidental mention	n = 16

\*Duplicates are the same article in different editions of the paper

(Appendix 7 provides a summary regarding the content of each thematic category in HIV)

### **5.3.2 The content analysis: summary and discussion and initial identification of themes**

In the following section I summarise and characterise the broad categories into which the headlines were sorted in each condition, providing an overview of the differences in the way that newspapers represented HIV and Cancer. If there are shared categories I compare the way stories were presented. I also highlight and

discuss the significance of any absences in reporting for one condition or the other. This characterisation facilitated the creation of an initial thematic map which led on to the selection of a sample of articles for in-depth analysis.

I begin by discussing those categories of stories which appeared in the results of both cancer and HIV searches and describing the broad nature of differences that exist between the two.

### **Celebrity stories**

In both sets of results 'celebrity' stories made up the largest proportion of articles in both conditions.

Some of the cancer stories featured actors, singers, TV presenters and sports personalities who were interviewed about their personal experience of having cancer. There was frequent use of metaphors relating to fighting and battling with 29 headlines containing the word 'battle' or 'battling' and a further 31 containing the word 'fight' or 'fighting'. This chimed with existing literature describing the prevalence of military metaphors in cancer (Sontag 1983, Lupton 2003, Seale 2001) and the idea of people being heroic in the face of their illness. Another group of stories featured famous people who had died from cancer and a smaller number of stories featured celebrity support for cancer charities or units. The personal stories of the celebrities' own experience and the positive language used to describe this experience encouraged identification by the reader with the person featured.

Stories including celebrities and HIV featured a smaller pool of celebrities who were primarily linked to HIV charities rather than experiencing HIV themselves. Prince Harry and Elton John were most often mentioned with reference to their promotion of awareness, testing and fundraising opportunities. Charlie Sheen was the only notable example of a commonly featured celebrity who was HIV positive. Rather than the heroic war metaphors used in the cancer stories, language used to describe Charlie Sheen's experience implied that his HIV diagnosis resulted from a lack of moral control. The portrayal of his blackmail suggested without question a societal agreement that HIV was sufficiently stigmatising to be worthy of extortion.

## **'Human Angle' Stories**

The human angle stories in cancer were often personal stories and featured life events that readers could identify with, which were rendered more moving or special because of the association with cancer. Thirty stories featured weddings with a bride or groom with cancer. Thirty-seven stories featured babies, with thirty-two of these being about mothers with cancer compared with five fathers. Emotive language in the headlines such as 'miracle' babies and 'dying groom's last wish' created an almost fairy-tale like discourse where the protagonists: mothers, brides and grooms experienced idealised life events which became tragic with the experience of cancer. Accounts of people overcoming cancer to succeed and creating their 'bucket lists' sustained this emotive angle as did a few stories featuring 'tragic' cancer doctors who were diagnosed with the condition themselves.

Human angle stories in HIV were different in tone and subject matter. If cancer stories had features of fairy tales, the HIV articles were more like cautionary tales often featuring potential danger. There were four first person accounts of living with a diagnosis of HIV which were designed to inform and educate. Aside from these the majority of stories were about court cases in which people with HIV were tried for passing the virus on, doctors and dentists who had been exposed as being positive and people who contracted the virus having received contaminated blood products. The overall effect was to engender fear rather than the empathy evoked in the cancer stories.

## **Children**

There was a striking difference between the reporting of stories relating to children in HIV and cancer, with just one story in the HIV group compared with 147 articles about children with cancer. A large proportion of the cancer stories featured stories about individual children who were 'brave' and did 'battle' with their illness. The language used in some of these accounts served to eulogise these children and lend them almost magical qualities as exemplified by the headline 'Tinkerbell has taken your hair, mum and dad tell brave Alisha'. Phrases such as '..can do more good things from heaven' and 'his spirit lives on' lent religious overtones to these representations. These findings support those found by Dixon Woods (2003) who conducted an analysis of newspaper accounts and parents' accounts of childhood cancer and found that they were very different; the cheerful, brave and uncomplaining newspaper representations did not include the parents' reports of

distress and protest. The public discourse found in newspapers privileges the dominant metaphor of stoicism and an idealised image of childhood and downplays negative emotions and the inevitable complexity of this experience. The aim was to evoke sentiment and identification in human dramas. This is important as the frequency with which these stories appeared suggests that in popular discourse the experience of cancer is one that we are all deemed able to identify with.

There were no equivalent representations of children with HIV. The one result that referenced children referred to a Western ballerina who visited HIV positive Kenyan orphans in a 'slum' to give them dance lessons. This story identified more with the admirable qualities of the ballerina who was the main protagonist, than with the children who were passive recipients. HIV positive children were not viewed in the same totemic way as those with cancer and did not seem to be used by newspapers to promote audience identification.

### **Stories relating to funding and the NHS**

Within the cancer results 41 stories featured accounts with a personal angle where treatments had been approved or alternatively rejected for use within the NHS. The prevailing discourse in these stories was to evoke a sympathetic response by presenting individual stories of dashed hopes. There were also cancer stories around waiting time targets and NHS cancer units and facilities that received large amounts of funding.

PrEP or Pre-exposure prophylaxis is when people at high risk for HIV take HIV medicines daily to lower their chances of getting infected. Debate over the NHS funding for PrEP was a prominent feature of HIV articles in these results. Unlike the cancer stories about funding which seemed unquestioning about whether people were deserving of the treatment, these stories about PrEP raised debates about its justification.

Finally, the other frequently covered story was about the leak of HIV positive patient names from a London NHS HIV clinic again suggesting the shame and secrecy that must inevitably accompany the diagnosis of HIV.

### **Risk factors for cancer and awareness around HIV transmission**

There were a myriad of speculated risk factors for cancer and an apparent appetite for discussing these in newspaper articles. Whether the risks were types of food or drink, pollution or stress, they were often the subject of popular reporting. The

general feeling was that this inclusive discussion was for a wide audience and could be of relevance to the lives of everyone reading. HIV infection was more straightforward in that unprotected sex is the main risk factor. However, there was a clear link made with perceived deviant behaviour such as gay sex and promiscuity and an assumption that infection could be controlled by modification of this behaviour by individuals. The scientific community has a more nuanced approach acknowledging that structural issues and factors may increase the risk of acquisition and transmission and that the overall prevalence may mean that “normal” sexual behaviour is a risk. There were a small number of articles which discussed lack of awareness of routes of transmission with accounts of misinformed beliefs that the virus could be contracted by biting, kissing or sharing utensils. These very small number of articles providing clarification on the routes of HIV transmission were not really comparable to the over 250 articles containing many different proposed causes and risk factors for developing cancer and which were written to be relatable to a wide audience. There was an implied shared understanding that cancer might affect us or someone we know, articles about HIV transmission were much rarer and used language which was more distant and set the issue further apart from the audience’s experience.

### **Categories not featuring in both HIV and Cancer articles**

There were two categories that were a feature of articles about cancer but which did not appear in those about HIV: ‘Cancer Scams’ and ‘Diagnosis and Presentation’. ‘Cancer Scams’ included articles about people faking cancer to raise money, people stealing cancer charity money and the peddling of phony cures for cancer. These reports contained emotive language and a level of outrage that a condition like cancer which evokes sympathetic responses should be cynically used for financial gain. ‘Diagnosis and Presentation’ featured articles about cancer screening programmes such as cervical smear tests and mammograms, stories about individuals’ experience of misdiagnosis and unusual ways in which people found out they had cancer. This reflects the number and variety of presenting signs and symptoms and methods of screening for cancer. Although late diagnosis of HIV remains a concern in public health terms and amongst healthcare professionals in the same way that it is for cancer, there was no evidence of discussion of this in the newspaper articles.

There was one category for HIV articles which did not exist for cancer and this was ‘HIV Commentary’. These featured longer individual opinion pieces or shorter

popular opinions expressed in letters. The Evening Standard contained the longer features which included discussion on various subjects such as the possibilities of the end of an 'AIDS defining era', criticism of 'this new gay hedonism' and a review of Norman Fowler's 2014 book 'AIDS: Don't Die of Prejudice'. The voices behind these opinion pieces included Sam Leith, an Eton and Oxford educated former literary editor of The Telegraph and Ivan Massow a gay rights activist with a background in finance, running a campaign to be the conservative London mayoral candidate. They therefore represented the opinion of a section of the ruling elite and this is reflected in the patrician tone of the features. This type of paternalistic commentary did not seem to be a feature in cancer stories.

### **5.3.3 The content analysis: summary and overview of findings**

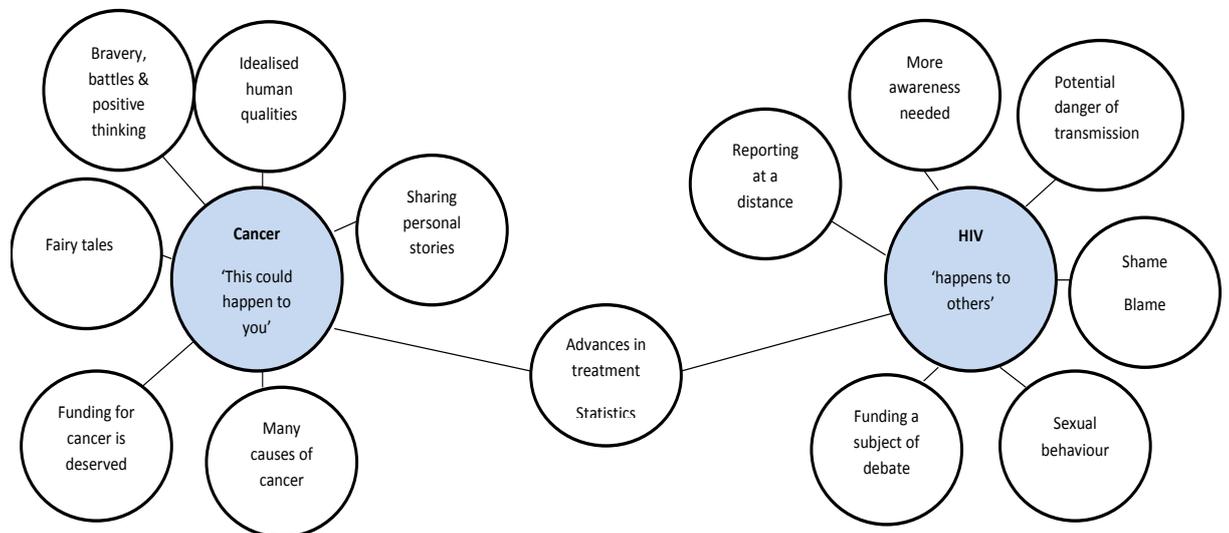
To summarise this initial overview of the search findings the most obvious feature was that cancer as a subject was much more common. There were almost thirteen times as many cancer articles ( $n = 2551$ ) as HIV articles ( $n = 197$ ) illustrating that cancer was much more part of popular discussion. This is unsurprising given the relative burden of disease in each condition (see Section 1.3.1). However, there were striking differences in the way in which the two illnesses were represented.

Cancer articles often used the military metaphors of courage and fighting to simplify human stories and make them positive to promote identification in the reader and evoke sentiment and downplay negativity and complexity. This was most obvious in the results featuring celebrities, the 'human angle' and most notably of all, children. HIV was much less prevalent as a feature of news stories. It was a subject which qualified for authoritative 'commentary' from people who held influential positions in society and those 'human angle' stories about HIV served less to promote identification and more to frame it as an external phenomena coming from elsewhere and other people with the potential to be dangerous. This content analysis helped in the development of an initial thematic map which is presented in the next section along with a discussion of the sample of articles selected for in-depth analysis.

### **5.3.4 The thematic analysis**

In this section I present the results of the thematic analysis which followed from the initial description of content and involved the selection of a sample of articles for more in-depth analysis. The first step in this process was the development of a

thematic map which represented themes drawn from the category content analysis presented in the previous discussion and was also informed by literature and participant interviews. It illustrated two overarching themes in relation to the two conditions. Cancer ‘could happen to you’ and HIV ‘happens to others’. Cancer is not an infectious illness which can be caught from other people, it is largely perceived as blameless and something that the reading audience will find relatable. HIV is dangerous because it is infectious. Not only does it appear as a condition that affects ‘other’ people who are outside of the readers’ experience, there is an additional misguided fear of transmission which overshadows perceptions of it. Other themes are represented in constellations around these larger conceptual groupings with ‘advances in treatment’ and ‘statistics’ being the notable exceptions which could not as easily be assigned to the two thematic representations. These two categories included more straightforward scientific reporting and were more emotionally neutral in tone and sat more independently. This thematic map is shown below in Figure 5-2. The data were re-visited with the thematic map to check that the themes worked well and that nothing had been omitted.



**Figure 5-2 Thematic Map**

### 5.3.5 Selection of articles for in-depth analysis

A sample of 10 articles was selected to enable further exploration of the themes represented in the map. Articles were chosen as typical or representative examples of one or several of the already identified themes discussed above. One cancer and one HIV article was chosen from the same initial category with the articles matched

as closely as possible so that the detailed language, rhetorical devices and context could be compared between the two conditions. Negative or disconfirming examples of these themes were also sought. However, a particularly stark feature of the results was how entrenched the different styles of presentation of each condition were. There were no depictions of brave celebrities with HIV, just as there were no celebrities with cancer being blamed for their predicament. Human angle stories describing idealised behaviour designed to promote identification with the reading audience were not a feature of articles about people living with HIV. The difficulty in finding articles to serve as negative or disconfirming examples of the themes only served to emphasise the contrasting representations. Two articles were selected as exceptional examples where it was not possible to mirror examples between HIV and cancer and the selection of these helped to include the range of stories within the data.

The first two articles featuring a celebrity with cancer and a celebrity who was HIV positive were selected as they shared characteristics which made them suitable for comparison. They were both first person accounts providing an element of 'revealing' their situation and the stories appeared in the same month and year in the same paper, the Metro. They were selected as representing several themes: positive talk about cancer using the metaphorical language of war, and sensational language about HIV linking it to behaviour likely to incur social judgement and blame. A human angle story was selected for both HIV and for cancer. The cancer story featured a wedding which along with stories about having babies was the most popular in this cancer category. It was chosen as a short, attention grabbing article in the Metro of 60 words, typical of the kind of human story featured in this newspaper. The HIV human angle story was also taken from the Metro and was of a similar length (110 words). There were a wider variety of HIV stories to choose from including a couple of first person accounts of experience of stigma, however they were longer and less similar to the bulletin style of the cancer piece, so I made the decision to choose an article which was of a similar punchy style; it also reflected the discourse strands in other results in this category which featured the contaminated blood scandal and doctors and dentists 'exposed' as HIV positive.

There was only one result relating to children with HIV. This was included to provide a comparison with the recognisable discourse around childhood cancer which was very well represented in the article about an 11 year old girl. Finally two articles were selected to provide examples of how the NHS was discussed in both cancer and HIV stories. The cancer story featured a new drug shown to be effective in

clinical trials becoming available on the NHS for lung cancer patients. The selected HIV article had a similar funding theme, this time on the subject of PrEP which appeared in several articles of the time. The two NHS stories were chosen as they were of similar length, contained a similar theme and were both reported around the same time.

The last two selected articles provided examples of the categories 'Cancer Scam' and 'HIV Commentary'. These categories were not shared between the two conditions and were selected as examples of stories that were not mirrored across the two conditions. They were included as they presented discourses which were felt to reveal something interesting about popular representations of each. 'Scams' did not feature in stories about HIV but a cancer scam article was selected as it represented a recognisable discourse strand in which people's desire to show their support for someone with cancer is exploited for financial gain; the resulting outrage sheds light on the popular idealised representations of cancer. The commentary about 'gay hedonism' was chosen as a good example of an Evening Standard longer opinion piece provided by someone with liberal credentials but who nevertheless was speaking from a position of relative power. This not only provided some insight into a distanced type of commentary on issues relating to HIV, it applied an apportioning of social judgement and blame by identifying behaviour which was presented as dangerous and could potentially put other people at risk of transmission. The selected articles are listed alongside the themes they represent in Table 5-4.

**Table 5-4 Articles selected for fine analysis**

<b>Theme represented</b>	<b>Initial category</b>	<b>Source</b>	<b>Headline</b>	<b>Date</b>
Bravery, battles & positive thinking. Sharing personal stories	Cancer celebrity	Metro	<i>BBC Victoria shares brave film diary of chemo battle</i>	12-Nov-15
Shame, blame. Sexual behaviour. Potential danger of transmission	HIV Celebrity	Metro	<i>Sheen reveals his HIV agony to be free of blackmailers</i>	18-Nov-15
Fairy tales. Idealised human behaviour	Cancer the 'Human Angle'	Metro	<i>Mad rush to tie knot for cancer sufferer</i>	08-May-15
Reporting at a distance. Sexual behaviour (criminality)	HIV the 'Human Angle'	Metro	<i>26-year-old accused of infecting lovers with HIV to stand trial</i>	27-Feb-17
Fairy tales. Sharing personal stories. Idealised human qualities. Bravery, battles & positive thinking	Cancer and Children	Evening Standard	<i>My dying daughter inspired my own cancer battle; mother's moving tribute to 11-year-old who was 'wise beyond her years'</i>	07-Mar-17
Reporting at a distance. The overarching 'HIV happens to others'	HIV and Children	Evening Standard	<i>It's really touching to see the joy ballet can bring to African orphans</i>	03-Mar-17
Cancer funding is deserved	Cancer & the NHS	Metro	<i>Last-chance lung cancer drug offered on the NHS</i>	04-Oct-16
HIV funding is a subject of debate	HIV & the NHS	Evening Standard	<i>NHS loses appeal over drug that prevents HIV</i>	10-Nov-16
Idealised human qualities	Cancer Scam	Evening Standard	<i>I feel violated by friend who conned me out of £178,000 says jeweller</i>	10-May-16
Blame, shame. Sexual behaviour	HIV Commentary	Evening Standard	<i>This new gay hedonism is not what I fought for; In a provocative view, a leading gay rights campaigner says obsession with drugs and sex is blighting the cause</i>	28-Jun-13

### **5.3.6 The in-depth analysis of selected articles**

As outlined in the earlier methods section of this chapter, a form was completed for each of the selected articles to tabulate the components of the analysis of the text (Appendix 5). The detailed analysis of the selected articles are next presented in narrative form and include an examination of the following features: the context (who is the author and their usual area of coverage and what is the occasion for the article); the surface of the text (what is the layout of the article, what type of headline is used, any accompanying photographs and how the article is structured into units of meaning); rhetorical devices (what kind of argumentation is used, what symbolism, vocabulary and style and how are the actors portrayed); content and ideological statements (what concept of humankind does the article presuppose and convey) and the overall discourse position and message of each article. The narrative aims to compare representations of HIV and Cancer between articles where possible in order to identify the essential differences in the types of discourse presented.

#### **'BBC Victoria shares brave film diary of chemo battle' (Celebrity story)**

The author of this Metro article was a freelance journalist who writes celebrity and entertainment stories. The article was written in response to a feature on BBC daytime television featuring presenter, Victoria Derbyshire, sharing a video diary of her experience of having chemotherapy for breast cancer. It was consistent with a large number of cancer stories featuring the sharing of personal stories. The headline flagged this as a story that the reader could positively identify with by the use of the term 'brave' and it was accompanied by a photograph of the TV presenter wearing a cold cap during chemotherapy with the caption 'Fear of the Unknown'.

The headline with its use of the words 'brave' and 'battle' set the scene that this was a story featuring human qualities the reader could admire. The content describing the video diary was factual and more straightforward containing quotes of her feeling 'vexed and anxious and apprehensive' and 'increasingly queasy and drained'. Leaving the story at this point would change the tone from the bravery at the start and may leave the reader feeling deflated. The final paragraph returned to the starting theme by detailing the praise she received on Twitter in response to her diary. This contained more eulogising language, describing her as 'brave and honest, raw and inspiring'; 'very inspiring' and 'a wonderfully strong lady'. This

finished the article on a positive note and made the reader feel better. The overall discourse was that sharing information about your cancer experience is praiseworthy particularly if you are a public figure; dealing with cancer is brave. Although the presenter stated that she was not feeling strong in her account the article insisted on imposing this upon her by following up her words with praise of her bravery from others. The device within this article, to follow potentially unsettling details with a positive refrain, echoes elements of the discursive analysis conducted by Wilkinson and Kitzinger (2000). They found that positive talk about cancer served as a conversational idiom, it allowed a 'lightening' of unpleasant experiences or negative emotions and it enabled the conversation to move on. In the same way the article ensured that there was an upbeat end and relieved the readers of the burden of details which may be hard to engage with.

### **'Sheen reveals his HIV agony to be free of blackmailers' (Celebrity story)**

The author of this article was Andrei Harmsworth, the Showbiz editor of the Metro. He usually wrote the celebrity-focused 'Guilty Pleasures' section of the paper but this article was featured as a news item. He has said that his proudest achievement as a journalist had been the championing of LGBT issues. This article reported on the news that the US actor Charlie Sheen had revealed to the public that he was HIV positive in a TV interview.

The headline used attention grabbing emotive language such as HIV 'agony' and chose to feature blackmail as a further salacious detail. It was placed next to a photograph of Sheen with two ex-girlfriends, Bree Olson and Natalie Kenly; all of them are smiling. This was a short article of just 269 words. It started by reporting how Sheen 'told the world' on the Today Show in the US and moved on to give the background to this decision. He was under 'attack' from people who had discovered his HIV status and were blackmailing him. There was mention that he had previously had unprotected sex twice but that both partners were 'under the care of my doctor'. The article also referenced two of his famous ex-partners, it finished with a quote from Sheen's doctor stating that he was 'absolutely healthy' and that the virus was 'undetectable.'

The language around Sheen's situation before he went public described a siege-like scenario, he was in a 'prison' and under 'an onslaught and barrage of attacks and sub-truths'. He was subject to 'extortion by friends and prostitutes' and had already

'paid out millions'. References to extortion, blackmail and prison painted a picture of Sheen being in a situation that all would understand as worthy of extortion and shame. There was no debate as to whether this situation was actually deserved or not or whether blackmail was appropriate, this was assumed. Other details such as an ex-girlfriend described as a 'porn star' provided further evidence of the disreputable and scandalous 'world' in which Sheen lived his life. There was also reference to Sheen being fired from a TV show in 2011 which he said was due to 'roid rage' implying that his use of steroids left him out of control. Although this was unconnected to the story it served as another detail adding to his chaotic portrayal. The story revealed a situation where Charlie Sheen paid millions in an 'onslaught' of blackmail rather than publicly reveal the fact of his HIV diagnosis. It gave the idea that society would not be supportive of anyone revealing their HIV diagnosis, this information was something to be hidden and only revealed under the most extreme pressure. The actual impact on Sheen's health, the fact that he was currently very healthy and the virus undetectable in his blood, was given the most cursory of mentions. What was not mentioned at all was the fact that with an undetectable viral load he would not be able to pass the virus on to anyone else. The focus was on the fact that he was HIV positive and all the associated negative social connotations rather than what it actually meant for him and his health and others.

### **Comparative discussion**

The two celebrity stories contained very different portrayals of the main protagonists and the presentation of their conditions. The cancer article included the moral qualities of bravery and implied that the TV presenter's decision to share her experience was prompted by a desire to help other people. Uncomfortable details were enveloped within a positive start and finish, thus conforming to acceptable conversational idioms and protecting the reader from the need to dwell upon them. The HIV story was by contrast a sensational account, full of details and language which intended to grab the attention and shock rather than promote reader identification and sympathy. Charlie Sheen was physically well and strong and one could argue had demonstrated bravery by publicly sharing information about his diagnosis; however this was not the narrative that the article wished to pursue. There was little in the way of education about how having HIV may impact on health aside from a citing of the Terrence Higgins Trust website. The suggestion was that this story was a spectacle rather than something which might affect the reader in some way; HIV was a concern of 'others'.

### **‘Mad rush to tie knot for cancer sufferer’ (Human angle story)**

This article was very short comprising of three sentences and just 60 words, a brevity which was typical of many Metro features. No author was acknowledged; it had a telegraphic style and featured a human story about a wedding. There was a use of old fashioned language symbolising romantic marriage such as ‘sweetheart’, ‘wished to wed’ and ‘tied the knot’. The bride’s quote ‘we are now complete’ at the end of the piece brought it to a conclusion in the manner of a fairy story. The piece was too short to include much detail about the actors but they were named as the ‘terminal cancer patient’, the ‘sweetheart’ and their two children, thus describing a conventional nuclear family. Although this scenario of an unmarried couple living together with children could be potentially stigmatising this was not the narrative within the article. The groom with cancer lent poignancy to a wedding story which reinforced traditional family values, the reading audience were led by the language and rhetoric to identify with the story and emotionally connect with the protagonists.

### **‘26-yr-old accused of infecting lovers with HIV to stand trial’ (Human angle story)**

As with the previously selected article, this feature was short, comprising of five sentences and 110 words. It was another story dealing with sexual relationships but in a very different way. In a terse and factual reporting style the reader was told about a 26 year old HIV positive male hairdresser who was pleading not guilty to four counts of grievous bodily harm by sleeping with alleged ‘victims’, a trial was scheduled for later in the year. This appeared to be straightforward reporting from the court and the language was mostly factual apart from one sentence which contained some more exaggerated phrasing ‘accused of deliberately infecting a string of male lovers with HIV’. This phrase encouraged the reader to imagine a longer list of people than the four cited earlier. The language did not contain any personal details; the audience were not led to identify with the protagonist and were not given any material to do so. The article presented a story of the transmission of HIV as a criminal act. Even though it is a controversial issue and charities have expressed concern that such prosecutions undermine efforts to stop the spread of HIV in the UK and serve to increase stigma, this newspaper article presented the court case with no acknowledgement of this and no comment.

## **Comparative Discussion**

The human angle cancer story was about relationships, it described a nuclear family and a romantic wedding with a fairy tale ending of making the family 'complete'. It did not dwell on the fact that they already had two children. Romance and the heterosexual normality of a nuclear family were emphasised, with sex outside of marriage 'resolved' by this wedding creating a secure union. Its aim was to get the reader to identify with the story in a sweetly superficial way which did not dwell on any unpleasant detail. There was no notion of blame relating to the diagnosis of cancer. The HIV story also dealt with sexual relationships but was reported on from a distance; the audience was not encouraged to identify with the protagonist and there was no comment provided about the debate around making HIV transmission a crime. Here homosexual sex was foregrounded alongside promiscuity (as opposed to monogamy) and a lack of commitment to a partner and their health. Once again, the HIV story was remote from the reader.

### **'My dying daughter inspired my own cancer battle; mother's moving tribute to 11-year-old who was 'wise beyond her years'' (Story about children)**

The article's author was Sophia Sleigh an Evening Standard reporter who covered London based stories with a human interest and often a shock value such as stabbings and cyclist deaths on the roads. It was written as the featured family were recognised for their bravery by the charity Cancer Research UK and it also provided details of a fundraising campaign to which readers could donate.

A long headline signposted this as an inspirational, emotive story which privileged the positive qualities of the 11 year old girl. The accompanying photograph featured the mother and daughter facing the camera and was captioned 'brave'. The story first presented the girl's mother who was diagnosed with cancer just weeks before her daughter who had subsequently died; it was written with quotes from the mother who paid tribute to her. This was a striking story as it described a very unusual scenario of a mother and daughter who were diagnosed with cancer within weeks of each other. The mother's representation of her daughter was wholly positive, she was stoical, 'never complained, never wallowed in self-pity'. It also described her kindness and desire to help other people and gave an example of her writing Christmas cards and wrapping up presents for friends, family and nurses at a time when she was very unwell. This was written to evoke sentiment and identification

with its reference to Christmas traditions. It portrayed behaviour which was not typically childlike, describing the girl as 'smart and wise beyond her years' and referencing her goodness by suggesting that she was in heaven 'I know Sophie will be looking down smiling'. The article conveyed an image of an idealised girl, wholly positive and inspiring in her response to her cancer diagnosis; it left no room for any difficult or distressing details. As it contained details of how to donate money at the end of the piece it could be that the story was deliberately framed in such a way to maximise donations. However, it did share features with many of the stories about children and cancer in the search results which often focused on the brave stoicism of the child and made no reference to any more complex emotions or details perceived as negative.

**'It's really touching to see the joy ballet can bring to African orphans; ENB star ballerina tells how dance is helping children in one of Kenya's worst slums' (Story about children)**

This article was written by a general news reporter at the Evening Standard and was reporting the visit of an English National Ballet star's visit to Nairobi and a school that is funded by UK charities.

It was clear from the headline that the main protagonist of the story was the ballerina and it was accompanied by a photograph of the young white dancer holding a graceful posture whilst the Kenyan children emulated her. There was just one mention of the children being HIV positive. HIV was framed in the story as another element along with the poor surroundings which elevated the dancer's actions. The environment in which the children were taught was described as a miserable 'slum' with 'dirt floors' and 'desperate and desolate conditions'. This was presented in contrast to the effects of the dance lesson which brought 'true joy', 'happiness' and 'big smiles on their faces'.

The article uncritically reported that the African children were delighted and uplifted by their Western ballet lesson although it did not appear to ask them their views. They appeared more as passive recipients of the dancer's benevolence and their HIV status seemed to be just another feature of the depiction of a group of children who were poor and deprived and very different and separate from the experience of the reader. This article also situated HIV within the otherness of Africa and a colonial past with a Christian charitable approach. Ibelema (2014) refers to this

element of otherness in the general framing of western news about Africa where there is a continued portrayal of it as largely outside the sphere of modernity.

### **Comparative discussion**

The article featuring a child with cancer was framed as an inspirational and moving story which idealised the child, lending her wholly positive qualities. The child was iconic and angelic and the piece evoked a kind of romantic sentiment which was designed to strike an emotional chord with the reader. The HIV story featured not one, but a group of children who were described as African orphans. This story idealised the Western dancer, the children were presented in a one-dimensional, passive way. They appeared more as a device within the article to promote the virtue of the ballerina who was the protagonist that the reader was encouraged to identify with and admire. HIV was portrayed as another marker along with race, poverty and being orphans that defined them as separate from the world of the reader. Children were a very common feature of cancer stories in newspapers, there was no similar type of representation for children living with HIV, suggesting that they would not be considered to appeal to the reading public sympathies.

### **‘Last-chance lung cancer drug offered on the NHS’ (Story about the NHS)**

The author of this article was a Metro reporter who wrote health and lifestyle features. The story reported that a drug treatment for lung cancer had been made available through the NHS Cancer Drugs Fund due to its promising results. The headline was short and direct with the term ‘last-chance’ suggesting an urgency that might draw a reader to the story. There was no photograph to accompany the text.

This was a short article of six sentences. It used the language of the medical journal including terms such as ‘mutation’ and ‘clinically effective’ and reported figures ‘two-thirds of the 411 patients....had a good reduction in the size of their tumours’. This treatment was unusual and worthy of comment as it had been made available through the cancer drugs fund whilst still undergoing trials. The feature included the quote of a medical expert, a Professor, who was a director with the health regulator NICE. It ended by providing the cost of 30 tablets of the treatment if bought privately but provided no comment on this cost to the NHS. This article provided direct reporting on a funding decision for a new treatment in lung cancer, there was no discussion about the deservedness of this funding or the ethical complexity surrounding funding in the NHS

## **‘NHS loses appeal over drug that prevents HIV’ (Story about the NHS)**

The article was written by a general news reporter for the Evening Standard, John Dunne, who covered a variety of big London stories. The occasion for the article was a Court of Appeal ruling that Pre-exposure Prophylaxis (PreP) should be funded by the NHS.

This was a short article of just six sentences with no accompanying photographs or graphics. It started by giving the background that NHS England had initially claimed it could not legally commission PreP as it only had responsibility for treating people already infected and this had led to an appeal. The appeal had since been lost. The piece provided the overall cost of providing PrEP (£10 million to £20 million a year) and stated that it had been shown to reduce the risk of HIV infection by more than 90% among high-risk people. Lastly there was a sentence describing the wider impact of this funding on NHS services and providing examples of childhood conditions where services may be affected as a result. Examples include ‘hearing implants for children’ and ‘a drug for treating certain mutations among children aged 2 to 5 who have cystic fibrosis’. These examples were provided without further comment but the idea had been planted in the reader’s mind that a potential impact of PreP was to reduce support for children aged between two and five years old, as such it was likely to stir up differences of opinion as to whether the recipients of PreP were as deserving. By juxtaposing prevention of HIV with children’s health an ideological perspective entered this seemingly factual report about a Court of Appeal ruling.

### **Comparative discussion**

The two funding stories both included more neutral and straightforward factual reporting than in some of the other categories. The main area for comparison between the two was the indirect signposting of the issue of deservedness in the HIV story. Although there was often an acknowledgement within cancer stories that treatments were expensive, examples were not usually given of what the money could be spent on instead. This may be an indication of a popular acceptance and support for the funding of cancer treatments which is not complicated by discussion about relative merit.

The following two articles were representative of categories which were unique to either cancer or HIV. They have been included as they presented discourses which

were felt to reveal something interesting about popular representations of each condition.

### **‘I feel violated by friend who conned me out of £178,000 says jeweller’**

This article was written by an Evening Standard journalist who covered London based stories with a shock value such as stabbings and cyclist deaths in road accidents. The occasion for the article was the sentencing in a court case in which the accused was jailed for fraud, he persuaded the main protagonist of the story, a female Mayfair jeweller whose smiling photo accompanies the piece, to give him money and lied to her that his daughter had a rare form of cancer. The story was presented in moral terms with the fraudster fooling his victims and ‘making up a lie’ about his daughter’s cancer. The jeweller was described as a single mother with three children who has gone through ‘hell’. She was shocked and has felt ‘violated’ by his actions and described his lie as ‘the lowest of the lowest’. She appealed ‘How can you do that? It’s a horrible thing to do’. Language such as ‘violated’ and the description that he ‘groomed’ his victims equated his behaviour to that of a sexual predator. The story portrayed the harm inflicted by the fraud made much worse by the deceit about having a daughter with cancer. The language suggested that by exploiting the naturally sympathetic response to cancer diagnosis the act of fraud had been exacerbated

### **‘This new gay hedonism is not what I fought for; In a provocative view, a leading gay rights campaigner says obsession with drugs and sex is blighting the cause’**

The author, Ivan Massow, was a London entrepreneur, businessman and ex-chairman of the ICA who also ran as the Conservative candidate for London Mayor in 2016. He was an establishment figure, unusual for being openly gay. Often his articles contained strong, provocative opinions. This article appeared just before London’s Gay Pride in 2013. ‘Gay hedonism’ is a phrase which was upfront and eye-catching in the headline and it is clear from the headline alone that this was not a good thing in the author’s view. The headline was accompanied by a photograph of participants in a previous gay pride, they were semi-clad and wearing masks, chains and gold shorts in an extravagant display. The text was arranged to reveal a stark contrast between the author’s account of the early, idealistic days of pride and the antithetical situation which in his view characterised the current situation. The rhetoric of the piece idealised the past, and described the early marchers as having

a 'dream', being 'proud' and displaying 'camaraderie' echoing the language of a noble struggle for civil rights. To depict the time in which the article was written the 'gay community' has been labelled as one entity and the author used language which was bluntly judgemental and critical with no room for nuance or complexity. He described the group as 'obsessed with sex', 'unable to take responsibility' and inhabiting the 'soulless and empty world of hedonism'. The ideological theme in the article was that the gay community had lost its way, had become selfish and was 'partly to blame for the spread of HIV'. This blaming and judgement implicitly presented a discourse that sections of the gay community deserved to get HIV because of the behaviour they adopted. The preceding cancer article presented the social unacceptability of lying about a cancer diagnosis in order to get sympathy, implying that cancer was something that always inspired a sympathetic response. This article in contrast focused on socially unacceptable behaviour which was to blame for people contracting HIV. There was a notable lack of sympathy demonstrated in this case.

#### **5.4 The Synoptic Analysis.**

##### **How might the findings from the content and thematic analysis impact upon an individual's experience of a dual diagnosis?**

The initial content analysis enabled the identification of themes represented in the thematic map. It was then possible to select articles representative of those themes for a further detailed analysis. The following discussion of these findings helps to further describe the type of newspaper stories produced daily which in turn form part of the social context in which people experience their dual diagnosis of HIV and cancer.

From the sheer number of results in the cancer search compared to those in HIV it seems evident that popular discussion about cancer is more prevalent and accepted in our society. This reflects the fact that there are many more people diagnosed with cancer than living with HIV, but the cancer stories also differ in that they are inclusive in their language and widely encourage the identification of the reader. There appears to be an idealised aspect to a lot of cancer stories, particularly in those dealing with a human angle and most especially with children. The reader is encouraged to identify with the protagonists in these stories which largely demonstrate cultural pressure to observe appropriate and morally desirable devices such as positive thinking and don't include too much difficult detail or

negative emotion. The over-riding message that is conveyed is that cancer is ordinary and could happen to any of us. There is also a moral component in that people with cancer are portrayed as largely innocent and deserving of our sympathies. This popular discourse may translate into experience by allowing people with a cancer diagnosis to talk about their cancer openly and receive sympathy and support. It may also mean that they feel the need to earn this support by conforming to devices expressed in the popular discourse and framing their experience in terms of a brave struggle characterised by a positive attitude. Wilkinson and Kitzinger (2000) demonstrated that devices relating to positive thinking reflect a pervasive societal norm with a moral pressure to comply which exists in everyday conversation as well as in media representation. Statements about positive thinking are taken as evidence of a 'fighting spirit' which is considered a good mental adjustment to cancer and they can be used as a conversational device to follow on from talk about suffering and distress so that they do not disturb others or attract censure. This societal norm has been further illustrated and reinforced by the cancer stories discussed in this analysis.

HIV appears much less frequently than cancer in newspaper stories and the nature of the reporting has some differences. A lot of the existing literature on media representation of HIV and AIDS comes from the late 1980's and early 1990's when HIV was a new disease, perceived as a growing problem without effective treatment. At this time Clatts and Mutchler (1989) described representations of HIV/AIDS as being linked to promiscuity and social deviance and a certain type of person which the virtuous 'normal' average American was insulated from. Clarke (1992) compared representations of cancer, heart disease and AIDS in the media and found that HIV/AIDS was described in moral terms in a way that the other two conditions were not. Clarke also described the media as separating the idea of risk from the reader; the risk was a problem for those involved in immoral conduct who were portrayed as separate and other. In the current discourse analysis, 25 years on, elements of this representation remain despite huge progress in the medical management of the condition and attempts by healthcare professionals to present it as a 'normal' chronic illness. The sensational language around the behaviour and lifestyle of Charlie Sheen, the depersonalised portrayal of an HIV positive individual and link with criminality which was a feature of the selected human angle story and the issue of deservedness when related to the funding of treatment are all factors that continue to present HIV as a condition of 'others'. For the most part the reader is not invited to identify with the protagonists on a personal level in the same way as

in cancer stories. Prince Harry, Elton John and Charlie Sheen have played a role in raising awareness and knowledge about HIV and there are a few examples of first person accounts describing life with HIV which serve to educate but these are in the minority. The results demonstrate that popular discourse in the news media still retain many of the negative and stigmatising connotations which are likely to make people with a HIV diagnosis feel inhibited sharing their experience and accessing support. This could lead to entrench and confirm the otherness and fear of blame that they may feel. Those with a dual diagnosis may therefore choose to prioritise the sharing of information about their cancer diagnosis as an acceptable condition deserving of support in order to gain support from others. HIV is presented as a condition of others in the media and associated with behaviour which is not seen as mainstream. This may accentuate existing inhibitions and worsen internalised stigma which has been described in the literature. This may have an impact for some people in disclosing their HIV diagnosis as they may feel this could attract some of the blame and shame prevalent within news stories.

## **Chapter 6 Interview Data: The Methods**

### **A thematic analysis of participant narratives provided in longitudinal, semi-structured interviews: the personal context of a dual diagnosis**

#### **6.1 Introduction**

Having explored discourses around HIV and cancer that provide the wider social context in which people with dual diagnosis live, I will now consider people's personal accounts of their experiences with these conditions. This chapter presents the methods of a thematic analysis of participant narratives in order to provide insights into the personal context of a dual diagnosis and address the following research aims:

- vi) To consider the meanings and understandings that people associate with a diagnosis of HIV
- vii) To consider the meanings and understandings that people associate with a diagnosis of cancer
- viii) To consider the meanings and understandings that people associate with a dual diagnosis of HIV and cancer
- ix) To understand how patients negotiate access medical treatment and navigate healthcare services
- x) To consider the expression of links between meanings and illness and the mobilisation of wider social support

The narratives were provided in longitudinal, semi-structured interviews with 17 patients with a dual diagnosis of HIV and cancer who were recruited from three London sites. Chapter 3 outlined relevant theories in the literature relating to the lived experience of illness such as narrative reconstruction, lay aetiology and biographical disruption. The data from the interviews and prior reading around these concepts informed the analysis and identification of themes. The next section of this chapter provides an overview of the methods adopted to perform the thematic analysis of the participant interviews and the rationale behind them.

## **6.2 The Methods**

### **6.2.1 The sample: choice of three London sites**

The three London sites were selected as large centres with a big and diverse population of HIV positive patients. London has over three times more new HIV diagnoses than anywhere else in England (Yin et al 2014) and it contains a broad range of affected populations including men who have sex with men (MSM) and black Africans. As such it is an appropriate location from which to recruit a sample with a wide range of characteristics within the study timelines. All three hospitals treat HIV positive patients with cancer who travel in from areas outside London with one site a national referral centre treating large numbers of patients from all over the UK. The study sample aimed to include those patients who had prior experience of smaller general hospitals as well as the London specialist centres in order to capture the full range of experience.

### **6.2.2 The sample: interview participants**

As the study was designed to capture rich and detailed data and generate hypotheses a pragmatic approach was adopted to recruit as wide a range of participant characteristics as possible. Obviously cancer is not one disease and it affects people living with HIV in particular ways. Rates of some cancers remain higher in people with HIV than the general population and even when people take HIV treatment there are subtle changes to the immune system which seem to affect the control of cancers. Three cancers are termed as 'AIDS-defining cancers' and are more likely to occur in people who are immuno-compromised and have a low CD4 count; these may be more commonly seen in people who are diagnosed late with HIV. They are Kaposi's Sarcoma (KS), Non-Hodgkins lymphoma and invasive cervical cancer. Other cancers which are seen as HIV-related have an underlying viral cause and they include anal cancer (linked to the Human Papilloma Virus HPV), Hodgkins lymphoma (linked to the Epstein Barr virus) and liver cancer (linked to the Hepatitis B or C virus). Finally, HIV treatment has increased the life-span of people living with HIV and so, like the general population, they risk developing common cancers such as prostate and breast cancer as they age. In terms of having a representative sample of people with a dual diagnosis the aim was to include people with HIV-related cancers where one might imagine services were better integrated having had more experience in their management, and the more common cancers where people living with HIV were treated as part of general

cancer services. I decided to exclude people with Kaposi's Sarcoma as medical management differs from that of other cancers and I believe it is framed differently in people's minds as more of a chronic condition. I aimed to represent the experience of both men and women, and a range of countries of origin to try and ensure that the sample represented as far as possible the racial and cultural diversity of people with HIV in the population who have a cancer diagnosis. In the analysis quotations from participants were labelled with the participant number, gender, age and timing of HIV diagnosis. This and other demographic information is presented in Table 6-1 below and provides contextual detail about the people interviewed.

**Table 6-1 Demographic Information for the interview participants**

Participant number	Site	Gender	Age	Place of origin	Timing of HIV Diagnosis	Type of Cancer	No of interviews
1	1	F	50's	West Africa	Prior HIV	Non Hodgkins Lymphoma	1
2	2	M	30's	South America	Prior HIV	Rare Lymphoma	3
3	1	M	50's	UK	Prior HIV	Head & Neck	2
4	2	M	60's	UK	Prior HIV	Colo rectal	2
5	1	M	60's	UK	Prior HIV	Myeloma	1
6	3	M	20's	Eastern Europe	Synchronous	Hodgkins Lymphoma	1
7	3	F	30's	West Africa	Prior HIV	Squamous cell	1
8	2	M	50's	UK	Prior HIV	Non Hodgkins Lymphoma	2
9	1	M	30's	Southern Africa	Synchronous	Non Hodgkins Lymphoma	1
10	3	F	40's	UK	Prior HIV	Hodgkins Lymphoma	1
11	1	M	30's	South America	Prior HIV	Non Hodgkins Lymphoma	2
12	2	M	50's	UK	Prior HIV	Colo rectal	2
13	2	M	50's	East Africa	Prior HIV	Rare Lymphoma	1
14	1	M	30's	Eastern Europe	Synchronous	Non Hodgkins Lymphoma	1
15	1	M	60's	UK	Prior HIV	Prostate	1
16	1	M	50's	Middle East	Prior HIV	Lung	0
17	1	F	30's	UK	Prior HIV	Melanoma	1

### 6.2.3 Identifying and recruiting participants for interview

Information about the study was presented to clinicians and key members of the multi-disciplinary team at all sites and a system of identifying potential participants was agreed. The first approach to the participants to find out whether they would be interested in finding out more about the study was made by a member of the clinical team. If they were interested in finding out more I would then arrange a mutually convenient time to meet them to discuss their participation further and hand out the information sheet. They would be given sufficient time to consider taking part and have the opportunity to ask questions before signing the study consent form at a subsequent meeting.

### 6.2.4 The interviews

All interview participants gave written informed consent. See Appendix 8 and Appendix 9 for the patient information sheet and consent form. The timing of the first interview was important in capturing participants' initial beliefs and understandings about their dual diagnosis thus enabling any changes in these to be tracked as they evolved. Subsequent interviews were negotiated according to participants' preferences. Six participants had two or more interviews. For the remaining participants the reasons for no further interviews being performed are listed in Table 6-2

**Table 6-2 Number of participant interviews**

No of interviews	No of Participants	Comments
3	1	
2	5	
1	10	3 lost to follow up, 5 died, 1 discharged from follow up, 1 recruited at end of data collection period
0	1	Consent taken, 3 attempts to interview as inpatient, too ill on each occasion then died

The number of interviews performed for each participant varied. In many cases loss to follow up was due to the study participants becoming increasingly unwell and dying. It was therefore not possible to perform longitudinal interviews for a substantial number of participants. This serves to highlight the particular nature of this sample group with many people being interviewed when they were very sick and in three cases lying in bed as an inpatient attached to intravenous lines delivering treatment. This group may normally be a hard to reach group for researchers and being a cancer nurse was certainly helpful in assessing the appropriateness of the interview proceeding. In one case, although the participant expressed their willingness to be interviewed and we arranged three separate meetings, on each occasion I felt that they were too tired or in too much pain for it to be ethical to continue.

Owing to the exploratory nature of the interviews and depth of information acquired over time, the amount of data was constantly reviewed with ongoing analysis. Data collection ceased when it was felt there was sufficient coverage and variation in responses and no new ideas were forthcoming.

Interviews were audiotaped. The length of interviews ranged from 33 minutes to 101 minutes with the average length of 57 minutes.

### **6.2.5 The diaries**

Guidelines on the use of a diary for a seven day period between interviews was given out to each participant at interview (Appendix 10) and the method was discussed as an option. Most participants were reluctant to commit to completing a diary even for seven days from the outset. The reasons they gave for their reluctance predominantly centred on a wish not to be made to think about their situation at a time when they were struggling to get through their treatment and when distraction from their circumstances seemed more tolerable than a focus on them. Three of the 17 participants agreed to complete a diary. One recorded information on an Ipad and then emailed it to me. Another showed me a hardback diary bought for this purpose and which contained many pages of entries. Unfortunately this participant died before they were able to return the diary. The third participant who initially agreed then told me at their second interview that after some thought they did not want to do it.

On reflection the diary method was too onerous for participants and was not perceived by most as something they would find beneficial. In some cases

participants felt that it would actually be detrimental to their progress through treatment to be dwelling on the nature of their situation. This information in itself sheds light on the coping strategies of people with a dual diagnosis, suggesting as it does that distraction and avoidance play a role that is as important as some of the more expected coping strategies such as seeking support and talking.

#### **6.2.6 Ethical issues**

There are obviously ethical concerns associated with approaching patients at the time of diagnosis when they are unwell and dealing with a large amount of new information along with intensive and potentially debilitating treatment. However, in order to gain a full understanding of the experience of dual diagnosis I felt it should be explored in real time as far as possible. Consultation with patient representatives supported this approach, their view was that provided that approaches to patients were handled sensitively and guided by input from clinicians there should be no reason why study participation should not be discussed. This was always done with respect and participants were informed that they could stop or re-schedule the interview at any time. Another issue which needed careful consideration was that of confidentiality which was especially important to participants who had not disclosed their HIV status to family and friends. Data was collected in accordance with the NHS Research Ethics Committee approved patient information sheet and consent form with all personally identifiable information removed from transcripts and replaced with study numbers. Permission was sought within the consent form for quotes to be used within reports and publications without names being used. Particular sensitivity was adopted in the approach to participants ensuring at all times that study information was discussed discretely and with others in the vicinity in mind.

#### **6.2.7 Field notes and researcher reflexivity**

Reflective field notes were written after every interview to record my own reactions and feelings in response to the participants' narratives and to acknowledge my own position and influence over what was being said.

## **6.2.8 The thematic analysis**

### **Framing the analysis**

The analysis of the interview data took an interpretivist approach and aimed to explore peoples' worlds within the context of their life as a whole, incorporating social and personal influences as well as the biomedical, healthcare arena in which they received their treatments. Existing theory and empirical findings from the literature review helped to inform the planning and design of the topic guide, however the analysis was initially inductive and rooted in the participants' narratives. Individual interpretations, meanings, motivations and values were explored and initially grouped under descriptive categories with each grouping containing original data extracts of the participants' own words. The descriptive groupings were then re-examined by going back to the entire interview data set to refine the categories and build initial themes. As the analysis progressed existing theory in the literature were also considered and compared with the findings from the inductive analysis.

### **Analytic Methods: Audio recordings and Interview Transcription**

I transcribed all 23 audio recordings and made efforts to transcribe as soon as possible after each interview. This helped to ensure an in depth familiarisation with the data, and enabled small details and non-verbal communication to be captured from memory. Verbatim transcription augmented by the researcher with notation of nonverbal behaviour has been cited as critical to the reliability and trustworthiness of interview data (Easton et al 2000). The addition of notation to include 'uh-mms', speech pauses and false starts as well as emotional content notations were included to help reveal more of the meaning and aid understanding of the participant narrative (Seale & Silverman 1997). Field notes recorded immediately after the interviews, containing reflections on my own reactions and feelings about the interaction, were constantly reviewed during transcription in order to explore and acknowledge the interpretive nature of the final transcript. These field notes provided further context and detail to support the transcript itself. As an example, I became quite anxious and uncomfortable in one interview caused by the non-verbal communication and silence of a participant who had been asked about contracting HIV. I felt this tense situation could be caused by the participant's difficulty in accepting how he became infected. The reflective notes provided extra non-verbal

details, helped me to acknowledge my own role and how I felt about the interview and also prompted me to reflect critically on my own interpretation.

### **Analytic Methods: Organisation, Management and Analysis of Interview and Field Note Data**

I imported all my audio recordings, field notes and interview transcripts into NVIVO V.10. This software worked well as a tool to initially store, manage and organise large volumes of data. During the analysis I worked from the paper transcripts and field notes and I developed themes by organising data within tables which I had created myself outside of the NVIVO software. This system allowed my analysis to stay very close to the interviews in a form that I found most useful in recalling and contextualising them.

A thematic analysis approach was used to analyse the interview and field note data following a similar process to that outlined in Braun & Clarke (2006). This process started with a thorough familiarisation with the data, re-listening to the audio recordings and re-reading the transcripts. Initial codes were generated to cover as much of the data as possible and indexed by placing them next to the relevant section of the transcript text in the margin using the software package NVIVO. These initial labels were low inference and descriptive and stayed close to the data. A list of 38 initial labels was generated and these are listed in Appendix 11. Material with similar content or properties was then sorted into thematic categories. The descriptive thematic categories were then organised into broader themes and sub-themes using an inductive process linking them directly to the data. The data lent itself to an initial division between three broad groupings with the headings; Being HIV Positive, Having a Cancer Diagnosis and Dual Diagnosis.

The analysis first of all involved the identification of themes which characterised the experience of being HIV positive and having a cancer diagnosis separately. This separation was a contrived one as all participants had a dual diagnosis at the time of being interviewed. However, this decision was made consciously to provide a descriptive context which would offer a frame of reference for the following analytic chapters; it also complemented the prior thematic analysis conducted of newspaper articles which looked at each condition separately.

Themes developed from the data relating to the experience of a dual diagnosis were initially grouped into three headings: Themes around Beliefs and Perceptions, Seeking and Managing Information and Sources of Support and Coping. These

were subsequently re-worked and refined into two broad conceptual groupings. The first, Biographical Work and the Mobilisation of Resources encompassed themes relating to how participants made sense of, explained and framed their own illness experiences in the light of their personal biography. Concepts included the processing of challenges to their future expectations and plans, the framing of their sense of self and identity in the light of these challenges, how they are able to cope and access support and to what extent they wanted or were able to preserve continuity with their life pre-illness. The second, The Experience of Cancer Care by People Living with HIV, had a greater focus on how people navigated their way through the healthcare system. This includes areas such as the patient journey through chemotherapy and other types of treatment, their understanding of the medical terminology and language used to explain care and the extent to which participants felt that the services on offer matched their particular needs. Data from longitudinal interviews was analysed to explore differences over time in both the biographical and cancer care themes. Three distinct groupings of participants were identified according to the timing of their HIV diagnosis and certain themes were compared across these different groups.

The analysis was developed by constant comparison and the moving backwards and forwards between original data and emerging interpretations (Spencer et al 2003). This process was applied to the first interviews working closely with the input of my PhD supervisors to ensure that it was rigorous and of good quality. Initial descriptive categories were re-examined by going back to the entire interview data set and systematically populating tables with examples of the source data which supported these categories. This rigorous process of re-examining each transcript helped to refine the categories and build initial themes and ensured that the analysis stayed close to the original data. The entire interview data set was constantly re-visited to explore developing concepts from new interviews as well as ideas drawn from existing theory. Drafting and re-drafting written presentations of the themes also helped to refine and focus the analysis with the input of my supervisors. The repetitive re-examination of the source data helped to test the relevance of these new ideas in relation to the data as a whole. Examples of outlying or negative cases that ran counter to emerging themes were sought out in order to refine the interpretation.

### 6.2.9 Researcher reflections

I was introduced to potential interview participants by their clinical teams. Although I stated that I wished to be introduced as a researcher, often the explanations of my role came out differently and I was described variously as a research nurse (which is my day job) or as someone who was 'checking up to see that we are doing things properly'. When I sat down with the patients I explained that I was interviewing them as a researcher and that even though I was a nurse I did not have knowledge of their particular situation and treatment beyond what they told me. I reiterated that if there were specific clinical issues that they wished to raise I would refer them back to the clinical team at the end of the interview. Despite this I feel that participants did talk to me with the idea in their minds that I was a nurse and that this influenced the information they gave. This was evidenced by comments such as 'you would know better than me' or asking me to provide the names of drugs that they could not remember. I do not however think that they felt I was connected to the teams providing their care as they did not seem inhibited in being critical of their experience. The positive aspect of this conception was that participants did not appear to feel any pressure to put a positive gloss on their experience or spare any difficult details. The expectation that I was used to dealing with people in their situation meant that they felt they could be honest. There may also have been a feeling among some participants that they wished to have their experiences recorded in order to put things right, as one woman who had repeated presentations to her doctor before her cancer was diagnosed explained;

So this is why I'm talking to you, I'm doing this interview this research, my doctor even did a breast examination a couple of years ago where I had hardened tissue here which was my lymph nodes and he said that hardened tissue was normal for a woman of my age.' (P10, Female, 40s, Prior HIV diagnosis)

I was very aware of my own situation and how my work might be perceived during the interviews. Although I have looked after patients with HIV and Cancer as a nurse, as a middle class white British woman I was an outsider to the experience of many people I interviewed. My field notes which contained reflections as to how I felt during interviews helped to provide a space in which I could critically review my own responses and attempt to remain as objective as possible. Regular meetings with my supervisors and with patient representatives to provide them with updates on the progress of the study also helped to reassure me that my approach was appropriate, sensitive and acceptable to the people I was interviewing.

Six patients died before they could have follow up interviews and in some cases their deterioration was rapid and their death quite sudden. I was very aware that I had privileged access to people who were facing enormous challenges at the time of being interviewed. This made it more important for me to do justice to the valuable data that I had access to and represent their experience as faithfully as I could.

### **6.2.10 Ethics and research governance**

The study was submitted for ethics approval and was approved by NRES Committee London Camberwell St Giles on 18 March 2015 (15/LO/0230). I obtained NHS to NHS Permission approval and a Letter of Access at each of the three sites. I performed the necessary training in Research Governance and Information Governance which was a requirement of local approvals. The study was also peer reviewed by the UCLH Applied Health Research in Cancer Governance Group.

### **6.2.11 Data management and information governance**

The audio recordings were downloaded and transferred to a secure encrypted server as soon as possible after the interview was performed and then deleted from the voice recorder. The interviews were transcribed and the transcripts were then anonymised, given study numbers and stored on a UCL server with user unique login details. Field notes were transcribed and stored electronically with a study number in the same way. Paper copies of the field notes and transcripts were anonymised and stored in a locked filing cabinet in the UCL Cancer Institute controlled by the researcher. Relevant sections of the anonymised data were shared with my academic supervisors as described within the patient information and consent form.

### **6.2.12 Informed consent**

Informed consent was obtained from all participants who were interviewed. They were given plain English information sheets detailing the purpose of the study and explaining what taking part would involve for them (Appendix 8). I went through the information carefully with them and answered any questions they had. It was made clear that participation was voluntary and that they would be free to withdraw at any time and they were given at least 24 hours to make a decision, before returning to sign consent and have the first interview if they were happy. The information sheet

contained my contact details and the contact details of the local Patient Advice and Liaison Service should they need to report any concerns or problems.

### **6.3 Summary**

This chapter described the methods adopted to perform the thematic analysis of the participant interviews and the rationale behind them. It characterised the sample in terms of the research sites and the interview participants and also provided information about the number and nature of the interviews performed. The process for collecting interview and field note data was documented along with its management, organisation and analysis. A section on researcher reflections was included to acknowledge and describe methods used for critically appraising my own position and influence within the interviews and analysis. Finally, the ethical and research governance processes underpinning the study were reported. The next chapter moves on to a presentation and discussion of the results of the analysis.

## **Chapter 7 Interview Data: The Findings**

### **Being HIV Positive and Having a Cancer Diagnosis**

This chapter primarily reports on the analysis of data collected from interviews although diary data is also included here. Although only a small amount of diary data was captured it is analysed together with the interview data to provide an additional layer of context.

#### **7.1 Introduction**

The following chapter presents the interview and diary data which relates to the participants' experience of a dual diagnosis of HIV and Cancer and which addresses the following research aims:

- i) To consider the meanings and understandings that people associate with a diagnosis of HIV
- ii) To consider the meanings and understandings that people associate with a diagnosis of cancer

The previous chapter described the methods adopted to perform the thematic analysis of participant interviews and diary information. This descriptive chapter presents the results of this analysis as it relates to the headings 'Being HIV Positive' and 'Having a Cancer Diagnosis'. Although this separation is a contrived one as all participants had both conditions at the time of being interviewed, it was made as a conscious decision to present those examples which seemed unique to one or the other illness within the accounts and helped to highlight the contrast between them and facilitate a comparative discussion. The initial descriptive analysis was based around the headings that were mirrored in both conditions, listed in Table 7-1, and this provided the context for further interpretative analysis summarised at the end of each section and informed the later analysis of the experience of dual diagnosis, which is presented in the next chapter.

**Table 7-1 Headings for initial descriptive analysis**

<b>Being HIV Positive</b>	<b>Having a Cancer Diagnosis</b>
Journey to HIV diagnosis	Journey to Cancer diagnosis
Personal Reaction to HIV diagnosis	Personal Reaction to Cancer diagnosis
Others Reaction to HIV diagnosis	Others Reaction to Cancer diagnosis
Disclosure of HIV diagnosis	Disclosure of Cancer diagnosis
HIV treatment	Cancer treatment
Beliefs about contracting HIV	Beliefs about causes of cancer

## **7.2 The Diversity and Complexity of the Sample Group**

Before moving on to the interpretation of the data it is important to say something about the heterogeneity of the sample group and to stress that there was far from one single narrative within the participant accounts. Perhaps the most obvious difference which had implications for the way in which people framed their experiences was the timing of their HIV diagnosis. Some of the participants were diagnosed with HIV in the late 1980s, early 1990s, in the midst of the AIDS crisis with no effective treatment available and with partners and friends dying around them. Obviously the impact of this HIV diagnosis in terms of their expectations for the future at that time and their subsequent adjustment to this were very different from those who were diagnosed at a time when HIV could be managed effectively on one pill a day with the expectation of normal health and life expectancy. This experience is different again from those who were told about their HIV and Cancer at the same time in a synchronous diagnosis in a situation where they were acutely unwell and hospitalised. The group was also culturally diverse, with different ways of expressing their understanding about both HIV and cancer influenced by the language used in their country of origin. Some self-identified as gay and others described heterosexual relationships, and they received a range of different cancer treatments for a range of different cancer diagnoses. This complexity illustrates the diversity of the dual diagnosis group and highlights the underlying 'difference' that the participants described feeling when they went through their cancer journey.

## **7.3 Being HIV Positive**

This section describes participants' accounts of their experience of being HIV positive. It covers their reactions and responses to the initial diagnosis, their

narratives about who they told and the reactions of others, both those anticipated and actually experienced. It also presents the data relating to the experience of taking treatment for HIV. More detailed discussion with illustrative data extracts and the identification of some key findings follow below.

### **7.3.1 Journey to HIV diagnosis**

The participants reported varied journeys to their HIV diagnosis, some described it as expected, some indicated their shock, and a few people were unwilling to talk about it at all. Those who were expecting their HIV diagnosis were gay men, some of whom were having unprotected sex in the 1980s and described their first awareness of the effects of the virus. One participant described being part of a gay community in the late 1970s, early 80s in America where in the spirit of exploration he had had many sexual partners in bathhouses:

and of course unfortunately part of that was sexual exploration going on there and we would go to the bathhouses for multiple sex, that time, of course that was when the first virus was being passed around.....so I , I became infected some time during that 2 year period (*P4, Male, 60's, Prior HIV diagnosis*)

These participants were aware of HIV, had either friends or partners who were HIV positive and understood that this was something that might happen to them. They also understood that this was potentially fatal at a time when no effective treatment was available.

For others who were not expecting their diagnosis it was either discovered incidentally whilst other conditions were routinely being investigated or followed up or they presented with an illness which they thought would turn out to be something else, such as malaria. Three of these were heterosexual women, one who was diagnosed unexpectedly with HIV as part of an asylum test when she went to live in another country:

and I applied for asylum, that is there when you apply for asylum, everyone gets tested, so that's when I knew. And it hit me hard (*P1, Female, 50's, Prior HIV diagnosis*)

In these accounts individuals were not anticipating the result, although they had had their blood taken and tested, the positive diagnosis came out of the blue. The remaining participants avoided talking about their HIV diagnosis completely and appeared to deflect questioning, keeping the focus on their cancer experience. The

journey to a HIV diagnosis was reported in terms of expectations and reactions rather than the logistical process of visiting clinics and having a blood test. Participants tended not to dwell on descriptions of having the test and there was not the sense of a protracted process with repeat presentations leading up to it. This reflects the simplicity of the single blood test which is used to diagnose HIV, unlike cancer which can involve a host of scans, biopsies and referrals. Whether the result was expected or not the majority of people who were interviewed found the experience of receiving their HIV diagnosis traumatic.

### **7.3.2 Personal reaction to HIV diagnosis**

The majority of people interviewed described a strong emotional reaction to their HIV diagnosis. If they had been diagnosed in the 1980s and 1990s it signified death, but even for those diagnosed more recently the memory of HIV as a killer seemed to persist. This theme was presented in the literature by Flowers (2010) who described how accounts of life with HIV can be 'haunted' by previous representations, with one of the ghosts they struggle the most to exorcise being the idea of HIV as a deadly condition. This theme seems to be borne out by the interview data, examples of which are provided later. Only a couple of people stated that they were untroubled by their diagnosis.

### **7.3.3 A diagnosis with a powerful personal impact regardless of timing**

Many participants gave accounts of powerful personal reactions to their HIV diagnosis, including shock, fear, and depression and in once case attempted suicide:

so I just felt I wanted to kill myself, in fact I tried it. Twice. *(P1, Female, 50's, Prior HIV Diagnosis)*

These devastating reactions were described amongst those diagnosed both historically and more recently. The strength of the reaction seemed to be as powerful for those diagnosed at a time when effective treatment was available as when not and so did not seem exclusively related to worries about prognosis.

### **An HIV diagnosis during the AIDS era**

For those participants who received their diagnosis during the period of the AIDS epidemic, an HIV diagnosis meant death and hopelessness as at the time they were witnessing at first hand people who were suffering from AIDS and dying from it

and feeling as though there was nothing that could be done to treat the condition. One man described this fear and the prevailing mood of fatalism:

obviously very scared cos in those days it was the AIDS epidemic, you're going to die and there's nothing we can do for you" (P4, Male, 60's, Prior HIV diagnosis)

The early days of HIV meant a particular experience for these people who did not expect to see a future and were living their lives in the short term accordingly:

people dying around us...and I was getting involved in the conversations that were going on like some not planning for the future, some not planning beyond a month, 2 months, maybe 6 months (P8, Male, 50's, Prior HIV diagnosis)

These individuals were diagnosed during an extraordinary period in history characterised by moral panic and fear, when having HIV was viewed as a death sentence and when the gay community was being scapegoated. Some lost partners and friends and they were expecting to die themselves in a situation one man described as a 'warzone'. Faced with such a traumatic situation they found themselves utterly changed.

### **An HIV diagnosis in the era of effective treatment**

Treatment for HIV with antiretroviral drugs was introduced in the mid-1990s and has been so successful that people who adhere to it have an excellent prognosis and comparable life expectancy to the overall population. Despite the huge developments in the treatment of HIV, connections to death and hopelessness persisted amongst some people who had only known the time of effective therapy. One woman described her response to receiving her HIV diagnosis and how she believed it to be a life limiting condition without any treatment available:

How long have I got to live? And she said No, no, it's not like that! It's how long have you got until you need to go on medicine. I said what medicine? I didn't even know there was medicine. No. I didn't know at all. How ignorant. I said what medicine, it's come on a hell of a way cos I was still stuck in the 80s like most people were (P17, Female, 30's, Prior HIV diagnosis)

A man who was diagnosed in the 2000s seemed to recall the apocalyptic television adverts of the 1980s as a more recent memory. He described his diagnosis as taking place just after the adverts of the 1980s when in actual fact almost 20 years had elapsed since they had been broadcast. This demonstrates the enduring impact of the air of fear and stigma surrounding HIV:

To my mind there's a stigma attached to it, It's all, when people are HIV, it's a bit, a bit dirty. I dunno, it's just...back then it was all.....cos it was just after the big adverts... (P15, Male, 60's, Prior HIV diagnosis)

Another man explained he didn't share his diagnosis as other people still had an enduring belief about transmission being possible via non-sexual contact:

people still have this thing from the 1980s that it's spreadable, it can be passed on (P12, Male, 50's, Prior HIV diagnosis)

The review of newspaper articles featuring HIV presented in Chapter 5 revealed a small number of articles which discussed a lack of awareness of routes of transmission with accounts of misinformed beliefs that the virus can be contracted by biting, kissing or sharing utensils. Misconceptions about the transmission of HIV persist in society and interview participants acknowledged and reflected this. The recent slogan 'Undetectable=Untransmittable' (U=U) launched by the Prevention Access Campaign promoting the finding that people infected with HIV who are virally suppressed cannot sexually transmit the virus to others is now accepted as a result of accumulating evidence since the early 2000s. However, this was not mentioned by any of those interviewed.

The persistence of the fear of HIV as a killer which is easily spread contrasts with advances in its management. The development of effective antiretroviral treatment first introduced in 1996 represents rapid progress the speed of which has not been matched in other areas of medicine such as the introduction of antibiotics or programmes of vaccination all of which took considerably longer. For the woman who asked how long she had to live and the man who recalled the advertising campaign of the 1980's, HIV was still a condition connected to the doom-laden imagery of tombstones and linked to fear and death. These seem to be the images and associations that stay with people, while the reality of a condition which is hard to pass on and with an excellent prognosis managed on a daily pill has taken longer to permeate public consciousness.

### **A synchronous diagnosis of HIV and cancer**

Three of the participants were diagnosed with both HIV and Cancer at the same time and in all three cases the HIV diagnosis seemed much less of a concern. All had experienced dramatic admissions to hospital with life-threatening cancers and were interviewed at the time of initial treatment when this was all consuming and seemed to be the major threat to survival. All were diagnosed at a time when effective HIV treatment had long been established which may also explain its lack of

prominence in their accounts. One of these men had seen his relatives live healthy lives with HIV:

I've known family members who've had it...who are still around after 25, 30 years now, you know and they're doing very well. So, that didn't give me a headache as much (*P9, Male, 30's, Synchronous diagnosis*)

#### **7.3.4 Others reactions to HIV diagnosis**

Others participants' reactions to a diagnosis of HIV were characterised by stories of actual rejection from those who knew about it or accounts of what they *anticipated* would be the response of people finding out. These hypothesised examples of how they expected people to respond, incorporated the use of the language of the 'dangerous other' linking HIV to behaviour likely to incur social judgement and blame. This was often used as a justification for not disclosing their HIV status. Examples from the data are provided and discussed below.

#### **Actual cases of rejection or discrimination**

There were accounts of actual cases of rejection or discrimination in response to other people learning about their HIV status, some examples came from friends and work colleagues. One man described friends from his army days turning their backs on him when they found out about his HIV diagnosis and how difficult that was for him:

yeah I had a lot of friends from when I was in the army who I still knew. About my diagnosis, they turned their backs on me, because they didn't know how to handle it and um it was hard (*P3, Male, 50's, Prior HIV diagnosis*)

Another man gave an account of his work colleagues in the hotel trade finding out about his HIV status and actually leaving the job because they were worried about the infection risk:

the people at work, one found out because I had a really bad night one night and I let the beans out as it were.... And a couple of people just left, because they didn't want to catch it off me (*P5, Male, 60's, Prior HIV diagnosis*)

Some accounts featured overt discrimination from health care professionals. One example was provided by a man who related a night he spent in hospital following surgery when the night staff refused to wash him because of his HIV status:

I had a diarrhoea in the night, and the night staff I heard them say, Oh he's got AIDS, I'm not touching him. No-one came to clean me up after surgery (P4, Male, 60's, Prior HIV diagnosis)

Other examples of reported discrimination came from everyday life such as an appointment to have some laser hair removal at a beauty salon. One woman recounted a situation where a member of the salon staff told her that she could not treat her because she was not allowed to use a razor in her case:

then she came back and said I'm sorry but we're not allowed to use razors on people who, you know, we're not really wanting to treat you. I said what do you mean, you're going to be using a separate razor and I said I'm on therapy so I haven't got any viral....so... so she said I'm really sorry we just don't want to risk anything (P17, Female, 30's, Prior HIV diagnosis)

### **Anticipated rejection or discrimination**

There were more projected and imagined reactions of other people described by participants as actual reactions. It seemed that people confidently anticipated a negative response which they could discuss hypothetically, this included examples within the data such as a prediction that they would lose their job if their employer knew their status or that people would think they would catch the virus from sharing cutlery with them. One man recalled hearing his brother talk about not letting anyone who was HIV positive near his children and his feeling of horror in response:

like I remember my brother.....I remember him saying he wouldn't let..... anyone with HIV he wouldn't let them near his kids..... And I thought Oh God...(P15, Male, 60's, Prior HIV diagnosis)

None of the actual or anticipated reactions of other people to a HIV diagnosis were given any positive features in participant accounts. There seemed to be an unquestioning expectation that the news would be received badly and incur negative consequences.

### **The language of the 'dangerous other'**

As described in the discussion of the literature in Chapter three, the language and metaphors used to describe an illness can have an impact upon behaviour. In HIV, awareness of others judgmental attitudes expressed in the language around danger and high risk behaviour leads to feelings of stigma which have been associated with depression and poor self-esteem. This in turn can be linked to health-related factors including seeking healthcare or maintaining adherence to antiretroviral therapy

(Ware et al 2006). Examples of this language of the 'dangerous other' which links behaviour perceived as socially undesirable to HIV were used by the participants themselves, sometimes to describe the anticipated responses of others. One man used this language to explain what people would think if they knew about his HIV status; linking it to promiscuity, being gay and deserving to die as a result:

They're thinking I've been dirty, I've been promiscuous, um and it's a gay disease. So...and you should die for it (*P11, Male, 30's Prior HIV diagnosis*)

A West African woman described prevailing beliefs about HIV amongst people from her country which linked HIV to the supernatural as well as visiting sex workers:

You know, that person is bewitched so we knew that maybe if you have it, it is either bewitchment or you know going around for prostitutes, you know who are going around with different kinds of you know (*P1, Female, 50's, Prior HIV diagnosis*)

A young white middle class woman encountered a GP who struggled to believe that she could be HIV positive and who revealed the mental associations they made about people with the virus by checking whether she had contracted it by using drugs:

and then he said 'do you mind me asking how did you get it? And I said 'I do mind'. I said, 'you know the usual route'. He said 'Oh, but not drugs then (*P17, Female, 30's, Prior HIV diagnosis*)

Participants readily used the language of the 'dangerous other' linking HIV to sex and promiscuity, recklessness, drugs, and bewitchment. Often this was not directly quoting other people but putting words into their mouths by postulating how people would react if they found out about their diagnosis. This language echoes stories featuring HIV which appeared in the newspaper analysis reported in chapter five. For example, articles about the HIV positive Charlie Sheen focused on drug use and prostitution and linked the condition to behaviour worthy of judgement and blame. Likewise, stories on criminal transmission of HIV in the media sensationalised and gave the exaggerated impression of threat, thus demonstrating the wider social context and popular discourse around HIV. The anticipation of judgement and potential rejection from others was a major feature of people's accounts, suggesting that they had internalised some of this societal stigma and this was often used as a reason not to disclose. The idea of deserving blame for having HIV as opposed to cancer is illustrated in the following quote from a man

who did not disclose his HIV status but happily talked about cancer which appeared to him free from blame:

I don't want the guilt as well. Because they'll say well this is something that you could have avoided and I'd have to admit to them that I was reckless at the time and I don't want to face that really. I think that's one of the reasons. Cancer I, I, as far as I'm aware, I haven't done anything that's caused this, I've tried to live as healthy a life as possible and so it's not as though anyone can say oh yeah you've got it because you did a, b and c..... (P12, Male, 50's Prior HIV diagnosis)

Clearly fear of HIV-related stigma guides disclosure behaviour and the interview data suggests that anticipated discrimination appears to play a major role in this. These findings lend support to Olley et al (2016) who emphasized the role of anticipated discrimination in HIV-related stigma and its impact on self-disclosure of HIV status.

### **'Othering'**

An interesting feature of four accounts was the identification of the behaviour of other people which they found to be more blameworthy and deserving of judgement than themselves. In doing so they demonstrated their own code of morality and gave examples of people who contravened this. This was evident in one participant who had reservations about the use of PrEP (Pre-exposure prophylaxis; a course of HIV drugs taken before sex to reduce the risk of getting HIV)

sometimes I have that opinion to myself, why should they be spending whatever it is, £400 a month on somebody just so they can go and fuck around in clubs and have multiple partners..I just can't help but be moralistic (P15, Male, 60's, Prior HIV diagnosis)

Another man in his 60's who had been diagnosed in the 1980's also commented upon what he believed to be the irresponsible behaviour of young gay men who are contracting HIV in the present day, even though in an earlier account he described his own situation of contracting HIV in bathhouses:

I think so many of them are drug addled and you know, irresponsible..... (P4, Male, 60's, Prior HIV diagnosis)

These examples serve to further reinforce the inextricable link between thoughts about HIV and blame. Participants may have internalised shame and stigma associated with being HIV positive but they identified scales of behaviour which meant that they could identify people who were more deserving of judgement, thus framing their own situation in more acceptable terms.

### 7.3.5 HIV disclosure

#### Personal rules about disclosure

HIV disclosure was a problem for most of the participants and was guided by a complicated set of personal rules. Mostly people shared their diagnosis with very few people and worked hard to conceal it. Some of the language used to describe the act of disclosure was powerful and violent as though it had potential to cause actual physical harm.

Only two participants, both of whom had been diagnosed in the 1980s, stated that they were completely open about their HIV diagnosis:

I never denied it. I really won't have any truck with guilt or denial, they're destroyers, they're not in my vocabulary (*P4, Male, 60's, Prior HIV diagnosis*)

These people were involved in early AIDS activism and saw their status as a badge of pride. It seemed that disclosure was linked to extremes. For the two activists it was important to tell everyone, while for everyone else it was important to keep their diagnosis as quiet as possible. For the majority, disclosure of HIV status was something which appeared to have quite a complicated set of considerations and rules attached to whether to share and with whom. What was striking was the very few people who participants disclosed to and the lengths they would go to keep this information private. Several participants stated that certain people such as family members or particular friends 'don't really need to know'

This judgement seemed to come from the perspective that they did not feel an obligation to share the information for the other person's benefit rather than the idea that sharing might elicit support or sympathy for themselves. Family members were variously described as too old and conservative or not knowledgeable enough about HIV to be told about the diagnosis. In one example a participant whose mother was always present in his hospital room explained a complicated situation where his mother knew he received medication that is given to people with HIV but that he had told her he was receiving it for another indication:

She knows I'm on medication sent for HIV people (*points to some on the table in front of him*), she knows that, but I kind of go into a ....I try to cover myself by saying that I am using them for other reasons. But if she bite the lie...I hope she does (*P11, Male, 30's, Prior HIV diagnosis*)

Another woman described when it wouldn't be appropriate to disclose (whilst working in a profession) and when it would be ok (whilst volunteering for a HIV group)

If I'm working in a profession like you know, medical profession, teaching profession, I doubt if I would share but what I'm doing right now, volunteering with a people in the same setting, it is easier for me to talk about *(P1, Female, 50's, Prior HIV diagnosis)*

Although the rules around decisions to disclose or not appeared to be personal to individuals there did seem to be a scenario in which it was agreed by several people that disclosure was necessary: before having sex. One man described how he felt obliged to tell potential sexual partners about his HIV status so that they could decide whether they wanted to continue:

sometimes you have like a 'pre-chat' before and I really put it in the discussion because I can't make choices for other people *(P6, Male, 20's, Synchronous diagnosis)*

### **The language linked to disclosure**

Some of the language used to describe disclosure was very powerful. Accounts of occasions when participants described actual or imagined disclosure of their HIV diagnosis contained striking and powerful language; the language of violent assault. One woman provided a very shocking example of this when describing how her mother was told about her diagnosis over the phone and likening this to her receiving a gunshot to her head:

I just passed the phone to the counsellor and she said 'Are you sure you want me to?' And I said yes I can't and then she shot my mum in the head with the news *(P17, Female, 30's, Prior HIV diagnosis)*

For a man whose sister and brother in law accompanied him to a cancer appointment the idea of HIV being disclosed was similarly catastrophic and he described it as though it were a bomb which could blow up:

they don't know I'm HIV positive , how am I going to get over this? I don't want them to find out...It'll explode, there will be terrible chaos! *(P12, Male, 50's, Prior HIV diagnosis)*

The extreme nature of the language used demonstrates the perceived destructive power of sharing their HIV diagnosis and their fear of its potential to cause actual harm to others.

### 7.3.6 HIV treatment

Everyone diagnosed with HIV is recommended to take antiretroviral treatment and it has been shown to be better for health to start this sooner rather than later. People with HIV who are not taking anti-HIV treatment or who have a low CD4 count are at greater risk of developing lymphoma, a type of blood cancer, than other people with HIV. Anti-HIV drugs work by lowering the amount of HIV (the viral load) in the blood with the aim for this level to be undetectable. HIV is normally treated with a combination of three different drugs some of which can be combined into one or two daily pills. Without continued adherence to a life-long regime of this antiretroviral treatment HIV is a life-limiting condition and people living with the condition need to understand their medication and be able to self-manage it as well as attending 4 – 6 monthly monitoring appointments with a specialist clinician. Despite this significant and long-term commitment, when HIV treatment was discussed in the interviews it was not described as a major disruptive element which interfered with people's lives. Several participants described a trouble-free experience of taking treatment for HIV:

they take the bloods, they give you the results from the previous 6 months ago, because it's always been stable and tap on wood, it's always been good (*P12, Male, 50's, Prior HIV diagnosis*)

Reluctance to start or to continue to take HIV therapy was a feature of a few accounts:

yeah, if it was all fine I'd go alright I'll stop taking the pills then. That's why in the beginning I had so many visits...because I just stopped taking them, as soon as the results were fine I just stopped taking the pills (*P5, Male, 60's, Prior HIV diagnosis*)

The reasons for being reluctant to start or continue taking treatment were varied. One woman described being put off by scare stories shared in an HIV support group in which she was advised by other members to keep off the medication for as long as possible in order to avoid side effects. Another man seemed to be under the impression that as long as he was not physically unwell he did not need to be on any HIV treatment. There did not seem to be an awareness amongst these individuals that not being on treatment could increase their risk of developing cancers such as lymphoma. Several people reported having to change HIV regimens to avoid troubling side effects such as insomnia and gastrointestinal symptoms. However, on the whole HIV treatment was not a prominent feature of

interview accounts suggesting that it was integrated into most people's lives without too much disruption.

### **7.3.7 Beliefs about contracting HIV**

In terms of the beliefs that people held about contracting HIV, the majority identified unprotected sex as the cause. Some accounts described non-consensual sex as leading to their infection; others provided detail and explanations which served to mark out unprotected sex as unusual for them perhaps in an attempt to distance themselves from the perceived judgement of others.

Three participants did not talk at all about how they contracted HIV and two stated that they did not know how they had become infected. For one of them it was a complete mystery and he thought he may have been infected when working on a building site where intravenous drug users had left their needles. This individual was not happy to talk about HIV at all during his interview and kept the subject on his cancer diagnosis. The other reported only ever having protected sex :

and I always had safe sex so I didn't have any worries about ever getting HIV. And I still don't know to this day...*(P15, Male, 60's, Prior HIV diagnosis)*

For those who did talk about how they had contracted HIV, some included extra context to stress that unprotected sex was unusual for them as in the case of the man who was at pains to stress that this had only happened once or twice. He was shocked that he had contracted HIV when other people he knew who had had many more unprotected encounters did not:

I knew that I got HIV because I had unprotected sex although I was a bit shocked because people that I know, like other friends, that I knew, they told me actually that they were a lot more adventurous sexually you know and I wasn't like that. So I thought oh my god like some one or two times that I didn't use protection that wow, and it happened to me and not to him? *(P2, Male, 30's, Prior HIV diagnosis)*

This seemed to highlight an incongruence between what he believed to be his own likely individual risk perhaps based on public health messaging around behaviour and what actually had happened. Davison (1991) wrote about a 'prevention paradox' in relation to coronary heart disease in which he described how messages on preventable behaviour lower risk in the general population but do not provide guarantees for each individual. People talk about and notice those cases that seem to fall outside of the popular conception of a 'candidate' for heart disease, for

example the fit runner who drops dead during a marathon. In a similar way it might be that these participants were describing their own experience as outside of the popular understanding of what is a 'candidate' for contracting HIV. By doing this they may be using the interview as an opportunity for retrospective rationalisation in defence of actions perceivable as socially unacceptable, and protecting themselves as moral subjects. This desire to provide context and justify their own situation as a way to avoid judgement appears elsewhere in accounts such as with the man who recognised his own desire to distance himself from behaviour that he felt would incur blame:

I don't want people to think that I was fucking around. I want them to think that I'm a nice innocent sweet gay person who wears frilly shirts and doesn't do sex things (P15, Male, 60's, Prior HIV diagnosis)

### **7.3.8 Being HIV positive: summary of themes**

In summary, the interview data which related to the experience of being HIV positive revealed a diagnosis that had a very powerful impact regardless of its timing in relation to the availability of effective HIV treatment. This was evident in the accounts of real trauma related by some individuals. Whether it was actual or anticipated rejection on the part of others in response to hearing about the diagnosis, both were related in sometimes extreme language and linked to the behaviour of 'dangerous other' by the participants themselves. Connotations of death and hopelessness which originated in the experience of HIV and AIDS in the 1980s and 90s persisted in some of the language of people diagnosed in an era of effective treatment. All these factors appeared to influence behaviour and ensure that for the most part people kept information about their HIV status a secret. Despite the lifelong commitment required to adhere to HIV treatment, this was not expressed as a major disruption to people's lives in their accounts. Unprotected sex was believed by the majority of participants to be the cause of their HIV infection with many providing additional detail and justification about how they contracted the virus to distance themselves from behaviour which might incur judgement or blame. The next section characterises the interview data relating to the experience of having a cancer diagnosis.

## **7.4 Having a Cancer Diagnosis**

This section describes participants' accounts of their experience of having a cancer diagnosis. It presents the interview data under the same thematic headings as

those used to describe being HIV positive. These include the journey to a cancer diagnosis; their own and others reactions; who they told; their experience of cancer treatment and their own beliefs about its causes. More detailed discussion with illustrative data extracts and the identification of some key findings follow below.

#### **7.4.1 Journey to cancer diagnosis**

The period leading up to participants' cancer diagnosis was often described in great detail. As the first interview was timed to take place close to initial diagnosis, this information was fresh in people's minds. For several people their journey was characterised by some frustration with repeat presentations to healthcare professionals with longstanding symptoms. Others were diagnosed following a drastic emergency presentation and one person's cancer was detected via a routine screening test.

A woman who had noticed feeling tired and having night sweats which got progressively worse over a period of years was relieved when these symptoms were finally taken seriously:

And I was quite relieved because this had been going on for years, I was tired, run down, losing weight was another one and none of those symptoms had been picked up on (*P10, Female, 40's, Prior HIV diagnosis*)

One man who was diagnosed with lymphoma had presented many times prior to this with raised temperatures which were put down to infections. He described how he had to persevere in seeking help and finally how he had to challenge the doctor to explain his long standing symptoms:

there was so many misdiagnoses. I had an ear infection, eye infection, chest infection all infections you can get with fever related...yeah?...but then he, he couldn't um describe why. So, I kind of insist, persist for a long time. And I went into kind of like, persist, persist, persist...and to the point where I confront the doctor and I say what is wrong with me? (*P11, Male, 30's, Prior HIV diagnosis*)

Five of the participants were diagnosed with cancer following a drastic presentation to hospital as an emergency, as in the case of one man who was admitted in an unstable condition and had to remain on a ward for three days before having the appropriate investigations:

after staying at my best friend's house for like 3 days, I felt really sick and I went to the emergency room um, I had low blood pressure and it

took 9 hours to stabilise me, um and then I was moved to a ward, where I stayed for like 3 days (*P6, Male, 20's, Synchronous diagnosis*)

One person discovered their cancer diagnosis as the result of a routine prostate screening test:

And they did a PSA test and uh the PSA test came up higher than it should have (*P15, Male, 60's, Prior HIV diagnosis*)

The route to a cancer diagnosis was at times a complicated and frustrating one which probably reflects the variety of symptoms with which people presented, some of which could be non-specific and put down to other things. Some of these accounts shared features of 'atrocious tales' which have been described in the literature (Webb & Stimson 1976). In these the tellers play an active role in encounters with their doctor and in this portrayal redress a perceived power imbalance brought about by the confusion and uncertainty of the situation. The interview data seems to depict a similar picture to the general population's presentation with cancer in the UK which often follows repeat visits to healthcare professionals and in 23% of newly diagnosed cases, as emergency presentations at hospital (NCIN Data Briefing 2013).

#### **7.4.2 Personal reaction to cancer diagnosis**

Shock and fear were recurrent terms that participants used to describe their own reaction to their cancer diagnosis; this seemed to be related to the uncertainty around the outcome, the possibility that this might be life-threatening and the prospect of cancer treatment. One man described his shocked reaction, he found the diagnosis hard to believe because he did not think cancer was something that happened in his family, he was concerned about the treatment and by the realisation that it might be life threatening:

I was in a state of shock. I was ...but this can't be true, it can't be true..it's not in my family. How has this happened?..... I'm going to have serious treatment. I mean I get out of it, I'll get through it, but this liver thing, I might die! (*P12, Male, 50's, Prior HIV diagnosis*)

Sometimes the shock was accompanied by anger about the delay in getting a diagnosis and a fear that this may have compromised the success of treatment. One woman described her fury that she had such obvious physical signs which had been allowed to advance without treatment before her cancer was acknowledged and diagnosed:

I was relieved that it had been found. But I was really angry. I was furious by then. I just thought, I **know**, the person walking down the street knows that something's wrong, it's absolutely glaringly obvious, my lymph nodes coming out through my neck to my rib cage from under my arm back around, it was huge. You know there was no doubt that something was wrong, for it to get to that extreme was really unnecessary and um so I just felt disappointed (*P10, Female, 40's, Prior HIV diagnosis*)

Personal reactions suggested that a cancer diagnosis had a powerful impact on individuals, it evoked shock and fear and many linked this to the uncertainty relating to the impending treatment and worries about whether they would survive. These emotions did not appear to be coloured by any shame or feeling that others might blame them for having cancer.

### **7.4.3 Others reaction to cancer diagnosis**

Although some participants reported that others appeared to avoid them or worried about saying the right thing in response to news of their cancer diagnosis, the most common initial reaction of others was to offer sympathy and support. Most people reported instances of others offering help, in some cases this support came from those who had been previously unfriendly. An example of this was provided by a woman who commented how easy it was to share information about cancer and reported that her neighbours, who had never spoken to her before, started opening up and speaking to her once they learned that she was receiving treatment for cancer:

Cancer you will share it with anyone cos there is no really stigma around it, it is accepted within the society so people can even pity you, I don't know if that's the word, pity you and feeling sorry even the people who don't normally speak to you, cos (laughs) I have my neighbours and they are a bit funny, so usually they don't talk but this time when they saw me coming from.....hospital....and they are, since we are neighbours they just asked where are you from, I said from hospital, what is it, I've been diagnosed and now on treatment, so now it opened a rapport with them, so I said OK this is good, I've also been trying to reach out to them and they are closed (*P1, Female, 50's, Prior HIV diagnosis*)

Several people reported that this was the first time they had been able to get support from others; this was something that was lacking when they had got their HIV diagnosis. One man from a Catholic background received religious tokens from family members in response to news about his cancer, and there was a sense in which he was accepted into the mainstream by virtue of this. He had not felt able to share his HIV diagnosis with these people. A woman diagnosed with HIV some

years before had not told friends about her HIV diagnosis, which she referred to as 'the other one' as though it was an illness that could not be named, but felt she could talk about cancer:

So, there I was, able to...because a lot of these friends don't know about the other one, so I sort of you know, 10 years on I was getting some support that I never had got.....You know I've been pulling on that, not in a poor me type of way, but just in allowing people to rally round (*P17, Female, 30's, Prior HIV diagnosis*)

One man was moved by the reaction of a managing director at his work who responded warmly to him when he reported that his cancer treatment was working:

And the managing director, he's quite a burly sort of a guy....he said that his sister had cancer and he was very supportive....I told him that the treatment was working...and he gave me a hug! And I nearly cried, I nearly burst into tears (*P12, Male, 50's, Prior HIV diagnosis*)

This warm response from a senior colleague seemed to him to be remarkable and marked an acceptance that he found surprising and emotional. This individual had been living with a HIV diagnosis for many years but had never shared this with his work colleagues.

### **Cancer: "you hear about it, you see it"**

A contributing factor to this social acceptance of people's cancer diagnosis is the sense, often expressed by the participants, that cancer is everywhere in UK society (some described a very different situation in other countries where cancer was a taboo subject). Cancer frequently appears in news stories and television programmes and is openly and freely talked about. People talked about their awareness of cancer in widely publicised fundraising activities in the media and in stories of celebrities who had shared their personal experiences. One woman described how cancer is widely accepted within society:

it is accepted within the society...you hear about it, you see it, you know....donate, do this..... (*P1, Female, 50's, Prior HIV diagnosis*)

This made it easier for people to share their diagnosis with others. Having cancer did not mark them out as different or blameworthy as cancer was perceived as affecting anyone and was deserving of sympathy. The literature on language used to talk about cancer describes the use of military metaphors with people lauded if they are brave and show fighting spirit (Lupton 2003). In a similar vein, statements about positive thinking in relation to cancer have been described by Wilkinson and Kitzinger (2000) as a device which can be used by people with cancer in their

conversation to move on from any uncomfortable or distressing detail and ensure that they do not disturb others or attract censure. In the interviews there were only a couple of examples of the use of heroic military metaphors such as with the woman who wanted to overcome cancer in order to honour her brother:

I've got to fight for my life now...my brother would appreciate this, I'll beat this cancer, I'll do it for you (*P10, Female, 40's, Prior HIV diagnosis*)

But there was a notable lack of use of military metaphors in the majority of the accounts with some people providing an alternative view point. One man questioned the school of thought that thinking positively could help to cure cancer; he was firmly of the opinion that the only thing that could do this was medicine:

thinking positive isn't going to cure you of cancer, hard drugs do it....there's nothing fluffy or My Little Pony-ish about cancer (*P4, Male, 60's, Prior HIV diagnosis*)

This quote was provided in response to a discussion about a cancer documentary which he had seen on television. In his account the protagonists in the programme made much of idealised life events such as weddings and he described one man who was featured stating that his goal was to be able to walk his daughter down the aisle. He did not recognise these events as being part of his life and seemed to suggest they were some people's way of avoiding the realities of a cancer diagnosis. This ties in with the analysis of newspaper articles and the theme that people with cancer are often presented in idealised stories featuring heteronormative nuclear families. The participant was referring to this representation and rejecting its accuracy in terms of its positive spin and its relevance to his own situation as a gay man who lived alone. Cancer is an illness which is seen as everywhere and deserving of sympathy and allows acceptance into the world of the 'normal'. However, at the same time its heteronormative presentation within the media could highlight the difference of those with a dual diagnosis and a tension for them within society's acceptance.

#### **7.4.4 Disclosure of cancer diagnosis**

The majority of people shared their cancer diagnosis widely with family, friends, neighbours and work colleagues although one man did not tell people at work as he thought it might damage his reputation for being reliable and affect his ability to attract work opportunities:

cos obviously my job involves reputation and it involves reliability. So I didn't want anyone to, to think that I wouldn't be able to do the job or be ill or something like that (P15, Male, 60's, Prior HIV diagnosis)

Most individuals reported the disclosure of their cancer diagnosis as a largely positive experience and there was a palpable sense of relief in being able to share and make the most of others' support. One man described using his cancer diagnosis as an opportunity to get as much sympathy as possible:

I was sharing all my pitiness, I wanted to get all the sorry I want to get. I was having to hang on to people, to kind of lay into my stress (P11, Male, 30's, Prior HIV diagnosis)

Participants sensed that they would get a supportive and positive reaction to news of their diagnosis and had much less trepidation about the likely response of other people and this encouraged them to share it. The possibility of a sympathetic response was welcome and a novelty for people who had been used to keeping information private. It appeared to be one good thing resulting from the difficult experience of having cancer:

well the good thing was though at least when I got cancer, I got a bit of sympathy (P10, Female, 40's, Prior HIV diagnosis)

#### **7.4.5 Cancer treatment**

The first interviews performed with participants were usually conducted shortly after their cancer diagnosis and were right in the middle of cancer treatment. The information about treatment was therefore current and fresh in people's minds and it was also coloured by the uncertainty of the outcome. Cancer treatment varied from person to person and there were a wide range of treatment modalities including surgery, radiotherapy, chemotherapy and bone marrow transplant. There were some striking examples of cancer treatment being invasive, unpleasant and having nasty side effects. One woman described what it was like to have intrathecal chemotherapy (chemotherapy injected into the cerebrospinal fluid):

it comes up and your head is just (*makes buzzing noise*), the pressure is just unbelievable and all your gums start to bleed, you can't eat, you can't put any pressure on your teeth. Your nose gets all sores and everything, your eyes get sore and weep, you know, your ears get weird, your mouth, everything goes, it's the worst one (P10, Female, 40's, Prior HIV diagnosis)

Other accounts contained traumatic details of the toxic side effects of cancer treatment including hearing loss as a result of chemotherapy, naso-gastric feeding

due to head and neck radiotherapy, colostomy formation following surgery for colorectal cancer and incontinence following prostate radiotherapy. One man had a particularly alarming episode with a sudden hyperpigmentation reaction following some intensive chemotherapy which made his skin change colour and caused his mother not to recognise him. Everyone had at least one account of an unpleasant physical experience relating to cancer. Cancer treatment was for the most part difficult to tolerate although there was one individual who had been feeling so very sick from the cancer that he noticed feeling better once the treatment had started. The side effects could be overwhelming and interfere with activities of daily life and also make people look different. The one participant who was happy to write a diary focused his entries on the effects of his hair loss which he found personally very traumatic both in anticipating it and when it actually happened. His diary entries describe his fear of his own reaction and that of others and a profound sense of shock at his altered appearance:

I am afraid, even though I just said I was going to be brave, I am afraid of what my reaction might be....And I don't know, I don't want people who know me to see me bald.....

Losing my hair was a bit more traumatic than I thought it would be. I went to a barber shop to have it shaved. After it was done and I looked myself in the mirror I didn't recognise myself....I told myself that it would be nothing to worry because it's just hair and it grows back but somehow I couldn't shake this feeling of shock off of me (*P2, Male, 30's, Prior HIV diagnosis*)

The physical manifestations resulting from cancer treatment were a real and visible reminder to people and those around them that they were sick, that something very serious was wrong which could not be ignored. The visible changes in appearance which some reported were frightening and upsetting and meant it was not possible to hide or avoid what was happening.

#### **7.4.6 Beliefs about the causes of cancer**

Although cancer could be over 200 different types of disease with varied and complex risk factors, in lay discourse it is often termed as one illness. As described earlier some cancers have been shown in the medical literature to have a relationship with HIV, with other types the relationship is not established and their incidence may simply relate to ageing, genetics or lifestyle in the same way as with people who are not HIV positive. It has been shown in literature featuring accounts of breast cancer patients (Blaxter 1983) that alongside the complexity of scientific

explanations people like to provide their own interpretations which relate to their particular biography and experience. Similar personal explanations were seen in the accounts of the participants who reported a wide variety of explanations as to the causes of their cancer. Some believed that environmental factors such as the drinking water or processed food had played a part. Others attributed their cancer to emotional problems that they had experienced such as an intense period of stress, suppressed anger or in the case of one man's explanation, being unable to forgive someone:

but it's no external material factor that brings it on. I think it's everything because of our minds. And a trauma, something that you couldn't forgive (*P6, Male, 20's, Synchronous diagnosis*)

These explanations were given in the context of the participants' biography and many were emotional and personal rather than scientific. Cancer was framed and explained by other events in their own personal life story including in one case the fact that they had been taking HIV medication for years:

I sometimes wondered as well whether it's the drugs and you're poisoning yourself all the time....I've been taking these drugs for 15, 16 years, there could be toxins building up.... (*P15, Male, 60's, Prior HIV diagnosis*)

Only two people linked their cancer to specific genetic mutations and provided a more straightforward scientific explanation.

The variety and personalised nature of people's beliefs about what caused their cancer shares features of the themes lay aetiology or narrative reconstruction described by Williams (1984). In providing their own personal explanations about the causes of their illness participants were attempting to understand their situation in terms of social experience and affirm that their life had a coherence and purpose.

#### **7.4.7 Having a cancer diagnosis: discussion of themes**

In summary, the interview data which related to the experience of having cancer revealed a diagnosis that had a powerful and traumatic impact which was related to worries about survival and the prospective of invasive cancer treatment. Personal reactions were characterised by some frustration at the time taken to get diagnosed and a lot of fear and uncertainty about what might be the outcome and whether they would survive. Other people's reactions were largely positive and supportive with a sense that cancer is socially acceptable, widely discussed and deserving of sympathy. Some participants described the support and acceptance offered by

others as surprising and emotional. The fact that cancer is so extensively accepted and largely free from judgement made it easy for people to share their cancer diagnosis widely. The data provided striking examples of the invasive and toxic effects of cancer treatment which in most cases interfered with the activities of daily life. For those people where cancer treatment meant that they looked different, such as with hair loss from chemotherapy, scarring from surgery or skin changes, this was very distressing as it served to remind them of the severity of their condition and it was also obvious to others. Participants expressed a range and variety of beliefs about what had caused their cancer. Environmental factors, emotional and personal explanations were frequently offered which situated cancer within their own life story.

Having explored how participants viewed being HIV positive and having a cancer diagnosis as separate entities, the next section of this chapter will present a comparative discussion of the two. The following chapter will move on to describe the results from the interview data dealing with themes which relate to having a dual diagnosis and exploring further how the two conditions interplay.

## **7.5 Comparative discussion being HIV positive and having a cancer diagnosis**

In both conditions the news of the diagnosis had a powerful and traumatic impact on participants. For cancer this fear was related to uncertainty about the effects of the treatment that lay ahead and whether they would survive. It was thus firmly moored in the physical experience of the illness and its response or lack of response to medical intervention. For many the cancer diagnosis was indeed life threatening, the treatment was toxic and debilitating and the prognosis very uncertain. An HIV diagnosis was described by participants as equally shocking and traumatic but, for those diagnosed during the era of effective treatment, this time the fear was associated more with the social consequences of being HIV positive rather than considerations about the physical experience of the condition itself. HIV treatment was largely described as easy to take, the prognosis was known to be excellent and yet most participants went to enormous lengths to keep their diagnosis secret in an effort to avert rejection and discrimination both actual and anticipated. There is a clear and striking contrast between the severity and uncertain prognosis of many participants' cancer diagnoses and their very well medically-managed HIV which on its own gives them the same life expectancy as

someone who is not HIV positive. The HIV is the condition they cannot talk about. Fear of HIV-related stigma dominated decisions around disclosure. This stigma appeared to be fuelled by persistent memories from the 1980s and 1990s when HIV and AIDS were portrayed as deadly killers. It was also evident in the language of participants who themselves linked HIV to the 'dangerous other' and to behaviour deemed blameworthy by society. Participants expressed the strength of this stigma in the words they used to link the disclosure of HIV diagnosis as causing actual harm to people around them. By comparison, cancer, a more serious physical condition, was an acceptable diagnosis to share and experienced as largely blame free. In some cases this led to acceptance into the mainstream and an opportunity to access support and sympathy for the first time. The two diseases appear conversely as a serious, potentially life threatening condition which is easy to talk about and garner support for and a potentially well-managed stable condition which has to be hidden and kept secret for fear of rejection and discrimination.

The next two chapters present the results from the interview data dealing with themes which relate to the experience of a dual diagnosis and exploring further how the two conditions interplay.

## **Chapter 8 Interview Data: The Findings**

### **Biographical Work and the Mobilisation of Resources**

#### **8.1 Introduction**

The following chapter presents the interview and diary data which relates to participants' experiences of a dual diagnosis of HIV and Cancer and addresses the following research aims:

- To consider meanings and understandings that people associate with a dual diagnosis of HIV and Cancer
- To consider expression of links between meanings and illness and the mobilisation of wider social support

The previous chapter presented interview and diary data and the themes separating out what it meant to be HIV positive and what it meant to have a cancer diagnosis, in order to facilitate a comparative discussion and highlight contrasting features. This chapter will present themes developed from participants' narratives relating to how they make sense of, explain and interpret the experience of having both conditions within the context of their own life. The interview data revealed a wealth of information illustrating personal beliefs and explanations about both conditions and how they related to each other; how participants have framed what has happened to them over the course of their lives; the challenges they have faced from both HIV and cancer and how they have coped and accessed support. This chapter will present an interpretation of the data to include these wider themes under the heading 'biographical work' and the mobilisation of resources.

##### **8.1.1 'Biographical work' and the mobilisation of resources**

The themes presented in this chapter relate to how participants made sense of, explained and framed their own illness experiences in the light of their own personal biography. Bury (1982) described the concept of 'biographical disruption' in the context of one chronic illness, (rheumatoid arthritis) and defined three stages. First is the challenge of taken-for-granted assumptions brought about by illness, when expectations and plans for the future have to be re-examined. Second, is a re-thinking of a person's biography and self-concept, an idea which was also explored by Charmaz (1983) who described a 'loss of self' for those experiencing a chronic

illness which occurred when former positive self-images were no longer available. Third, is the response to the disruption involving the mobilisation of resources.

These concepts were originally developed in relation to the experience of one chronic illness rather than a dual diagnosis but they remain useful tools in the exploration of participants' narratives. They help provide a framework for examining how people explained the impact of their dual diagnosis within their life stories. This examination is important as it provides a deeper understanding of personal meanings and explanations which people use to describe their experiences and provides a context for health-related behaviour. A disruption which challenges individuals' valued sense of self can cause uncertainty, anxiety and stress and can have negative consequences for engaging with healthcare services, adhering to treatment and accessing support (Tyler-Viola et al 2014). In its potential to affect health and well-being it is therefore as important to understand as the biomedical and physical management of illness.

I have chosen to adopt and explore aspects of these biographical concepts under three broad headings: (i) the possibility of outward continuity; (ii) the inward sense of self and identity; and (iii) the mobilisation of resources and accessing support.

The first explores the challenge to future expectations and plans presented by either condition or the ability to preserve continuity with pre-illness life. This looks at participants' accounts of presenting outward continuity or the lack of continuity as a result of their experiences of both cancer and HIV; whether they could continue in the same employment, carry on with the same daily activities and maintain the same social network.

The second heading is the dual diagnosis and the framing of sense of self and identity. This section deals with how participants inwardly framed their own sense of self in the light of their dual diagnosis and how they dealt with conflicting identities in relationships with others.

Finally, the mobilisation of resources and coping strategies section describes the nature of the social support that participants talked about and presents some of the coping strategies they utilised.

As described in Section 7.2 those interviewed were purposively sampled to reflect the heterogeneity of people living with a dual diagnosis. Participants differed from each other in the timing of their HIV diagnosis, their gender, sexuality and cultural

and ethnic backgrounds as well as cancer type. The result was many different stories and a complexity that was evident in the interview accounts.

## **8.2 The Challenge to Future Expectations and Plans and Ability to Preserve Continuity with Pre-Illness Life**

Interview participants' experience of a dual diagnosis differed in some immediately obvious ways according to the timing of their HIV and cancer diagnosis. The degree to which an HIV diagnosis obviously challenged future expectations and plans depended on the period of time in which it was received. For those who were diagnosed HIV positive in the 1980s and early 1990s when effective treatment was not available and when they themselves expected to die, this challenge to future plans was dramatic in nature and likely for many to lead to a marked discontinuity with their pre-HIV life; for example some people were no longer able to work and had to claim benefits, some lost partners and close friends leading to a clear and obvious visible disruption. For those diagnosed with HIV in the era of effective treatment the challenge to future plans could be less outwardly obvious to others. It may be possible to preserve a surface continuity with their pre-illness life but this is not to say that they did not experience challenge and disruption which, although less obvious to others, may be equally troubling and affect their behaviour and the way they felt about themselves. For those participants who were diagnosed with HIV and Cancer at the same time, the cancer diagnosis was often the more immediate challenge and focus. The time frame of the interviews did not allow for a later exploration on the impact of being HIV positive for these individuals. The next section explores the challenge to future expectations and ability to preserve continuity within these three groupings of participant, this being an obvious way to look at the accounts. However, this division is not a clear and neat one as the discussion will illustrate.

### **8.2.1 An HIV diagnosis in the era of AIDS**

For several individuals diagnosed with HIV in the late 1980s and early 1990s the assumption of a normal life expectancy, being healthy, able to work or indeed have even a short term future were seriously challenged. In some cases their partners had died from AIDS and they faced the prospect of facing a similar terminal decline, alone and with no hope of treatment. Amongst the interview participants two men described a marked outward discontinuity with their pre-HIV life and provided

striking examples of the HIV diagnosis changing their life story. Both described an abrupt end to their previous career and developed a new life with the battle against HIV at the centre. There was a sense in which they actively rejected a discredited identity associated with HIV stigma. As will be discussed in more detail in the later section on identity there was a recognised language and cause to identify with at this point in time; the language of activism as exemplified by groups like ACT UP who united diverse people to take direct action to engage politicians, the public, clinicians and scientists to raise awareness and develop treatments for HIV. The distinct break between life before being diagnosed with HIV and that afterwards was summed up by one of the men who was admitted to hospital with an AIDS related illness and from that point onwards left behind his previous life as a well-paid copywriter in advertising:

then I was taken into the ward there and overnight you know from having lived in wonderful luxury out in Bangkok I found myself on an AIDS ward, people dying all around me.... it was when one life stopped and another one began (*P4, Male, 60's, Prior HIV diagnosis*)

For this man his life had thereafter been one about survival. Cancer was another illness amongst others that he had faced and learned to cope with and was therefore framed as part of the struggle of this changed post-HIV life. He talked about his 'new' life being about working at survival and characterised life post diagnosis as moving from paid work to the work of survival:

My work has been surviving for these last 20 years, I haven't worked for 20 years but I have worked, I've worked on surviving

The new way of living could take the form of HIV activism. One participant who had worked in the hotel and restaurant business became involved in a buyers' club in the US following his HIV diagnosis, which marked the start of a 25 year long career working in HIV charity, local authority and activist groups. AIDS buyers' clubs were a feature of the early days of the HIV/AIDS epidemic and became important as a means of obtaining medications not yet licensed for use that members thought would be useful for treating HIV and opportunistic infections. They also distributed information about the disease and became an important source of AIDS treatment and advocacy. This man's work and his identity as an HIV activist continued throughout his cancer diagnosis and beyond. In an interview when he had successfully completed his cancer treatment he stated:

It's cured. Just life. I have no particular feelings about the cancer diagnosis, it's part of life, it's something I would've expected being a person living with HIV (*P8, Male, 60's, Prior HIV diagnosis*)

Even though the cancer diagnosis for this individual had left him with major long term side effects such as neuropathy which interfered with many day to day activities, he did not frame it as a very disruptive event within the story of his life. The major biographical change occurred for both of these individuals with their HIV diagnosis, and cancer was presented within their life story as one in a series of challenges they had subsequently had to face.

Another example of a dramatic break from pre-HIV life was provided by a West African woman who discovered her HIV status in the early 1990's as part of the process of seeking asylum. Following the initial trauma of this diagnosis she converted from Islam to Christianity and changed her name, literally assuming a new identity. Her Christian faith remained central throughout her life and at the time of interview it was helping sustain her through her cancer diagnosis. Although cancer caused disruption to work and physical limitations to daily living for these people it did not appear to constitute a break with the past in the same way as their HIV diagnosis.

Not all of those interviewed who experienced the early days of HIV talked of such a drastic break in their lives. One man was symptom free and continued in the same employment throughout both HIV and cancer, but it was clear from the language he reported as being employed by those around him that this was a momentous period in history in which shock and devastation at being HIV positive was widely recognised as valid and irrefutable. This was illustrated by his friends' response when he shared his HIV diagnosis with them at the time:

They were terribly shocked....they were...Oh my God you're going to die (*P12, Male, 50's, Prior HIV diagnosis*)

### **8.2.2 A synchronous HIV and cancer diagnosis**

The three individuals who were diagnosed with HIV and cancer at the same time were all interviewed once during the initial and acute period of cancer treatment. Two were hospital inpatients and connected to intravenous therapy, one was receiving cycles of chemotherapy every three weeks as an outpatient. All were primarily concerned with the immediate cancer diagnosis which they recognised as life threatening and more pressingly dangerous than the HIV. As one man put it:

I think cancer is just deadly....yeah....that's how I find it. It puts a stop to everything. Because if I didn't have cancer, HIV I'd take my tablets for a little while and I'd bounce back (*P9, Male, 30's, Synchronous diagnosis*)

In terms of providing his perspective on his situation he acknowledged that the outcome of his cancer treatment was uncertain. When envisaging life beyond this initial period of treatment he talked about plans such as getting married and adopting a new vision within his business ventures whilst at the same time acknowledging that these things might not be possible. When talking about his fiancé he described how he had been honest about the uncertainty of his situation and about the potential impact of the treatment on his fertility:

Only she can decide for herself what she wants to do. So at any minute now she's got until that time, she's still got that time to run if she needs to (*P9, Male, 30's, Synchronous diagnosis*)

For another participant in his 20's, it seemed as though he had not yet established a clear occupational pathway for himself. He referred to a variety of jobs in the past with an opportunistic approach to work. His valued identity related to his energy, optimism and independence and he greatly valued his striking physical appearance. He described HIV as a background condition:

HIV is really background. HIV at this moment is kind of mechanical, even the pills when I take them. I'm just taking them, I really don't think about it (*P6, Male, 20's, Synchronous diagnosis*)

Cancer treatment and its impact on his energy and self-image had made him retreat from his social world as he did not want his friends to see him differently:

I've always been very independent and always my friends said to me that I'm a very strong person. But that changed....that changed. That's why I tend not to let people around me after chemo, I prefer not to. Because I don't want to change that tag that I was tagged with. (*P6, Male, 20's, Synchronous diagnosis*)

It was not possible to find out to what extent he resumed his previous lifestyle after his cancer treatment as he was lost to follow up. The other two participants with a synchronous diagnosis died shortly after their interviews. These two men were very reluctant to discuss their HIV diagnosis at all, preferring to discuss the situation with their cancer. I sensed that the subject was difficult for them but it was not possible to infer why this was. One spoke of his preferred personal explanation for having lymphoma which he put down to his diet of processed food whilst alluding to the fact that he may have been HIV positive for a long period prior to his diagnosis. This suggests that his reluctance to talk about HIV in his interview may also reflect a

reluctance to acknowledge the possibility that he had lived with HIV that was previously undiagnosed and that this may be partly responsible for him having cancer now:

As your immune system falls very low you are more prone to lymphoma...So maybe I might blame it on the processed food for the comfort of my own mental status but it could well be maybe I'd been HIV for a long time way before (*P9, Male, 30's, Synchronous diagnosis*)

It is likely that these individuals had a late diagnosis of HIV meaning that they were diagnosed once their HIV infection had become advanced. This is associated with increased mortality and shorter life expectancy. The reluctance to talk about the HIV diagnosis and this individual's acknowledgement within the quote above that he may have been HIV positive for some time suggests a deeper denial which may have prevented earlier testing and access to treatment.

Although there is no longitudinal data for this group, their accounts suggested a period of extreme crisis relating to the serious and life threatening nature of their cancer diagnosis which stalled their pre-illness life. Owing to the all-encompassing nature of this crisis, the HIV diagnosis remained in the background during the acute period of cancer treatment, and as the day to day routine was put on hold so was the issue of dealing with this diagnosis. Although pushed to the background the HIV diagnosis remained troubling. This was exposed by participants' unwillingness to talk about it.

### **8.2.3 Prior HIV diagnosis in an era of effective HIV treatment**

For those participants who received their HIV diagnosis before they were diagnosed with cancer in a time when effective treatment was available, the challenge of HIV to future expectations and plans was less outwardly obvious and it was more common for them to describe being able to maintain a surface level of continuity in their life. One participant described having his HIV test in his lunch break and returning to work that afternoon. He described his feelings of difference from other people and how this affected his mental health:

just like walking on the street and feeling different from everyone else...and I got really depressed (*P2, Male, 30's Prior HIV diagnosis*)

Although the HIV diagnosis may have been described as personally devastating this is a revealing example of how it was possible to hide the internal biographical disruption and distress and continue with outward appearances. As I shall discuss

in a later section of this chapter a diagnosis of HIV had a big impact on participants' sense of self and personal identity. In order to maintain the continuity of their work and social life they described internalising stigma and working hard to manage information that they felt may discredit them if revealed. There was still a disruption to their biography but instead of it being obvious and external it was often managed so as to minimise the possibility of it becoming evident to others. The extent to which the disruption of the HIV diagnosis was internalised is exemplified by one West African woman who described her complete isolation and difficulty dealing with it emotionally while contrasting this with the ease of being on treatment:

At first I didn't accept it very well, but then um I came to um....accept it and I swallow it, kind of dealing with it by myself and I didn't tell any family member, I didn't tell nobody.....so yeah, I started on the treatment...about 2 months after that, I started on the treatment and it's been fine. I haven't had any reactions to the medications (*P7, Female, 30's, Prior HIV diagnosis*)

On the surface an HIV diagnosis could be fitted into daily life and remain largely invisible. Treatment managed in a discrete way by the HIV clinic with infrequent visits to attend appointments helped to enable this hiding from view. This is illustrated in the following account by a man describing the minimal impact of HIV on his life as just a tablet before bed and a check-up twice a year:

it's hardly part of my life...it's just a tablet before I go to bed and I just come in every 6 months for a check up (*P12, Male, 50's, Prior HIV diagnosis*)

In the context of HIV being relatively easy to manage without outward disruption to occupation and social life, for this group it was the cancer diagnosis which caused interruptions in activities which were more obvious to others. The disruption came from the uncertainty around the physical impact of cancer and the extent to which it would affect their life expectancy. There were several examples of participants being able to continue with work in some capacity even during chemotherapy treatment. In these cases they worked in jobs in which their employers offered them adaptations such as reducing their hours, giving them lighter duties and allowing them to work from home. This ability to tell employers about the cancer diagnosis and gain sympathy and support facilitated this continuity even when they were undergoing extremely debilitating treatment. One man described his experience at work whilst receiving chemotherapy:

I'm still working. I'm going to work, I like doing that. I've only got 2 projects...I should be running 4 really, if I was really running at full

steam but I'm not because I do feel a bit tired in the afternoon...I'd had pains in my stomach, it flares up occasionally in the night and because it wakes me up, it makes me very tired and that has a knock on effect and I just don't think I was being very productive in the office but at least I was making the effort to go in...I'm dedicated to my job (*P12, Male, 50's, Prior HIV diagnosis*)

This individual died not long after this interview from cancer. This interview shows the importance of work to his identity and need to live a meaningful life. The cancer diagnosis meant he could share this and get support to continue working despite feeling very unwell at times. Not everyone had an occupation that allowed them to continue working, as in the case of participants who worked in more physical roles such as the provision of care or teaching assistants. As the interviews took place over a relatively short period it was not always possible to find out whether the disruption caused by their cancer diagnosis resolved and whether they were able to return to work, but most expressed at the time of the interview a wish to continue with their pre-illness occupation in some capacity.

In summary, for the group diagnosed first with HIV during the era of effective HIV treatment, most could maintain an outward surface continuity in their life after this diagnosis despite experiencing personal disruption and an internalised discredited sense of self (this will be discussed in more detail later). The cancer diagnosis caused more obvious disruption to their daily activities but it was socially acceptable, meaning it was possible to be open about this diagnosis and receive support. In some cases this helped them to preserve some valued aspects of their pre-illness life.

### **8.3 The Dual Diagnosis and the Framing of Sense of Self and Identity**

As described in the previous section, the ability to deal with a potentially stigmatising diagnosis and preserve outward continuity with a pre-illness life or shape a new one incorporating altered circumstances was closely linked to individuals' sense of self and their felt identity in relation to others. The next section discusses the data relating to this theme exploring how it relates to the experience of a dual diagnosis of HIV and cancer. In Kelly's (1992) work on self, identity and radical surgery, self is defined as an imaginative view of ego by ego which is constantly being rehearsed, built and re-constructed by an individual. Self is an inner, private phenomenon, unknowable to others and is linked to social context and social relationships by identity. Identities, or the way people present themselves

in interactions with others, are given a greater or lesser prominence depending on social context (Stryker 1968).

### **8.3.1 Framing a sense of self**

Charmaz (1983) described the 'loss of self' in people with chronic illness. People's former self-images are eroded by illness without the development of equally valued new ones, and suffering occurs from leading a restricted life, social isolation, being discredited and burdening others. The literature is largely based on people experiencing one chronic illness. HIV, with its life-long requirement for anti-viral treatment to control it, can be seen as a chronic condition. Cancer is different in that it can be cured by treatment but does share features of a chronic illness when people experience long-term side effects from the condition itself or from treatment such as fatigue, pain or loss of certain physical functions. It is also associated with an uncertain future. This study comprised interviews conducted during the cancer treatment period and therefore had somewhat limited scope to find out to what extent participants had long term chronic problems associated with their cancer diagnosis. However, the theme of self-image and its adjustment in the face of illness is still a relevant one to explore. The interview data revealed a complex picture relating to how participants with two conditions described their sense of self and identity and the extent to which they were able to hold on to valued identities according to the timing of their diagnoses and the particular circumstances and limitations incurred by their conditions.

HIV, as we have seen from the previous chapter, is a condition which, if well managed on treatment often has minimal impact on the daily activities of living and so, on its own, need not lead to a restricted life or being a burden on others. At the same time it is an infectious and life-long condition which carries negative connotations which continue to be reinforced in the media and society. Participants provided examples of felt stigma which influenced their view of themselves and led some to secrecy and concealment. Scambler and Hopkins (1986) described felt stigma, in the context of people living with epilepsy, as the anticipation of actual discrimination which also encompassed a feeling of shame. This concept applies to those participant accounts where non-disclosure of HIV status was justified on the grounds that others would judge them negatively. It was clear that this negative judgement could also be internalised as exemplified by the account of the man who presented guilt about his own behaviour as a reason for not telling his family about his HIV status:

I don't want the guilt as well. Because they'll say well this is something that you could have avoided and I'd have to admit to them that I was reckless at the time and I don't want to face that really. I think that's one of the reasons. *(P12, Male, 50's Prior HIV diagnosis)*

His reluctance to disclose his HIV diagnosis revealed internalised stigma and personal shame which made him discreditable, a concept described by Goffman (1963). In order to 'pass' as 'normal' and avoid being discredited he kept his HIV status a secret. Felt stigma associated with being HIV positive clearly affected participants' sense of self and influenced their behaviour in disclosing their status. The cancer diagnosis did not carry the same threat of being discredited as it was publicly discussed and understood and more socially acceptable, but it brought an uncertain future, debilitating and toxic treatment with physical limitations and visible signs obvious to others which could influence how people felt about themselves. There was evidence within the accounts of the physical impact of cancer and its treatment having a long lasting effect on how people viewed themselves as evidenced by one man's account of having an altered sense of self following on from his successful treatment for cancer. He described a changed self which was not visible to others:

They can see the difference in me physically and they can see that physical side come back and I'm looking better. But even though people can see the physical, it's what they can't see.....having to deal with ongoing pain, being uncomfortable .....it's psychological too...coming to terms with everything that's happened in such a short period *(P3, Male, 50's, Prior HIV diagnosis)*

Cancer may respond to treatment and be cured and therefore not have the longevity of a chronic illness, but the treatment could also cause long term physical side effects that might impact upon people's lives thereafter and the emotional impact of the fear of recurrence may also persist over time. Both HIV and cancer are conditions that have the potential to affect an individual's sense of self, and the extent of this varied from person to person, but the data suggested that HIV's impact related primarily to its capacity to discredit whilst cancer's impact related more to physical symptoms and the uncertainty of outcome. There is clearly considerable complexity in examining how participants' sense of self affected their interactions with others. The following section will explore this under the heading of 'identity work' and will consider how identity was both understood and enacted by participants.

### **8.3.2 Identity Work: incorporating HIV and cancer into identity and interactions with others**

Having considered the impact of having a dual diagnosis on participants' sense of self, this section goes on to explore how they presented themselves to others and incorporated the two conditions into their identity.

The two individuals described earlier in this chapter who were diagnosed with HIV in the AIDS era and who gave accounts of a marked discontinuity in their life course incorporated HIV into their identity and their interaction with others. It was socially acceptable to be devastated by their diagnosis because the condition was untreatable and they were diagnosed at a time of HIV/AIDS activism when it was possible to use a language of empowerment. The activists were happy to make HIV a prominent feature throughout their subsequent life, including their journey through cancer. By working in the field of activism or volunteering in HIV support groups they maintained an identity and language strongly linked to being HIV positive and enacted this widely to different groups of people in the world of work, family and friends.

For the majority of other people who were interviewed it appeared much more challenging to incorporate HIV into their identity in a way which was empowering. They may have been devastated by their diagnosis but with treatment available and routine medical management on offer there seemed less opportunity to express their distress about it in a way that would be socially understood. It is possible that some people diagnosed with HIV now during an era of effective treatment still feel this sense of activism but none of those interviewed demonstrated any evidence of this. Most did not interact with many other people who knew about their HIV status. A couple of female participants had attended HIV support groups. One West African woman found it a helpful experience, the other who was white and heterosexual reported feeling out of place at the group's social event:

it was just like a meat market of gay men and then this little corner of black women all sat together all round the buffet (laughs) and there was just nobody for me (*P17, Female, 30's Prior HIV diagnosis*)

In this case her attempts to incorporate HIV into her identity by attending a group did not encourage her to continue with this venture and made her feel a misfit and more isolated in her situation.

The majority of other participants who were diagnosed during the era of effective treatment talked about being HIV positive with a very small number of individuals, sometimes just one other person and it was generally not a feature of their social interactions. They therefore made other identities more prominent in order to achieve a more stable sense of self, this included aligning themselves more closely with their cancer diagnosis and keeping other valued identities primary, for example that of church-goer or professional. The next section will discuss in more detail how people emphasised what they felt to be more positive aspects of their identity in their interactions with others and how secrecy about their HIV diagnosis remained a constant threat with the potential to undo the valued and pure identity that they had constructed.

### **Conflicting identities: efforts to focus on the positive**

#### **Foregrounding the cancer diagnosis**

One man felt it was important to talk about his cancer diagnosis at work, describing himself as an 'ambassador' for this issue. He gave several examples of how he had been able to help individuals at work and his brother in law who had experience of cancer by being open and happy to talk about it:

I'm open about it, they're not afraid to come and ask me and say how are you doing, how are you feeling. I can say, oh I'm ok today, or I'm alright today, I feel a bit tired...where I feel if I didn't say anything people would be worried oh should we say anything? I won't say anything because maybe he doesn't want me to talk about it but I said people need to, I almost feel like I'm an ambassador for this sort of problem, people need to be open about it and be able to talk about it (*P12, Male, 50's, Prior HIV diagnosis*)

He felt that being able to enact the identity of a cancer patient to family members, neighbours and work colleagues was valuable and that he was doing good work to reduce fear and misunderstanding about cancer. This has concordance with the messages conveyed in wider society in the discourse of newspaper articles discussed earlier. This is the idea that cancer is ordinary and could happen to any of us, and that it has a moral component with people who have cancer portrayed as largely innocent and deserving of our sympathies. By talking about cancer openly you can receive sympathy and earn support by conforming to devices expressed in the popular discourse; namely framing experience in terms of a brave struggle characterised by a positive attitude. With regard to his HIV diagnosis he had never told his family or anyone at work:

telling them I was HIV positive would be , would be, that would scare people too much

The confidence he felt in sharing his cancer experience and the desire to be open and dispel myths was in stark contrast to his absolute conviction that he could not share information about his HIV diagnosis - openness contrasted with closed secrecy. In the same way that participants described the positive nature of disclosing their cancer diagnosis and getting support for the first time, it seemed that the cancer diagnosis also opened up the possibility of a role with greater agency: sharing, raising awareness, and helping others in a similar situation which allowed people to feel valued. Another participant described how he wished to share his experience of a bone marrow transplant with others:

hopefully, because that's my hope, a figure of cancer knowledge, I can tell my story to people and how I went through and they can see...it's a responsibility on it. It's um yeah. But it's rewarding because what I want to do in the future is to help others in the situation I was in (*P11, Male, 30's, Prior HIV diagnosis*)

It seemed that participants separated their dual illness identity, enacting the cancer identity across a wider and more varied group of people than they did with their identity as someone who was HIV positive, as it provided an opportunity for them to feel empowered and valued.

### **Other valued identities**

Valued identities such as those linked to work and being part of a religious community were also given prominence in participant accounts. Often there was a concurrent management of information to keep their HIV status a secret from the groups of people who they were interacting with, thus there was a constant internal tension and the ever-present potential of this positive identity being damaged. There were a variety of identities which were given prominence. Those individuals with creative occupations where their work expressed aspects of themselves such as singer or artist were able to enact their professional identity across a very wide group of people and this identity remained strong throughout the experience of both conditions. One man who was a singer who had continued in his work throughout both his HIV and cancer diagnosis explained how HIV had the potential to damage his career whereas he was prepared to share his cancer diagnosis more widely without the same perceived consequences:

I don't identify myself as an HIV positive person...I don't think so...I wouldn't wear a badge. I mean I know a lot of people do come out and I admire these people greatly, the ones who just come out straight away

and then they're writing, but for me that would affect my job. I don't want people to know because it would affect my job.....I probably identify myself more with cancer (*P15, Male, 50's, Prior HIV diagnosis*)

Others gave accounts of participating in a religious community as being very important to their identity and providing them with support during illness. One woman described the response of her church to her cancer diagnosis:

everyone went on their knees..and started praying. I don't know if you believe in God, I don't know if you have faith but we believe in the Creator and he is able to do all things. So everybody went on their knees, friends, well-wishers...so everybody praying, fasting, calling on God. So, and um, that kept me going as well (*P7, Female, 30's, Prior HIV diagnosis*)

When asked whether her church and friends knew of her HIV diagnosis the response was:

No! Like the same reason yeah? So. People are not educated. Forget about what sort of a degree people have, still the knowledge is not there

Although she spoke frequently during her interview of the importance of being part of a religious community and was gaining support during her cancer diagnosis from this, there was an aspect of her life that these people did not know about and it was clear she thought they might reject her if they did. Therefore there was a sense she was at the same time isolated and set apart from the group she identified with and got support from. These examples illustrate how some people put an emphasis on valued identities in their interactions with others; they also reveal an underlying tension in this strategy with their HIV status acting as a potential threat which could undermine this work.

### **'Bracketing off' of illness**

Not everyone worked on a dual illness identity by foregrounding their cancer diagnosis. There was another approach adopted by one participant of treating both HIV and cancer in the same way and attempting to deny and 'bracket off' all signs of illness for both conditions. Although this had been possible after his HIV diagnosis, at the time of our interview a very serious and life threatening cancer diagnosis was making this struggle to deny illness very difficult to sustain. He described how he was running errands for friends and family and solely taking care of the household tasks during a period in which he was receiving chemotherapy and feeling unwell. I later learned that his cancer was not responding to treatment, he deteriorated quite quickly and died a couple of months after this interview. It was not obvious during the interview how aware he was of the gravity of his situation.

Clearly it was very important to him to continue to enact this capable identity which he had maintained his whole life and he kept returning to his assertion that he did not want to be defined by illness and being a patient:

but you know, it's back to this, I don't want to become a patient with cancer.....although I am. But I don't want to become a patient with HIV, although I have.....HIV still has as a stigma attached to it and also I've always been um, again, the fact that I'm gay, I've never let that you know.. I'm not gay first and then me, you know? I've always been me whatever you know has come in the way, you know, and then if you've wanted to know then I will sort of say yeah by the way....So I've treated HIV the same way, um being gay the same way, cancer the same way  
*(P13, Male, 50's Prior HIV diagnosis)*

Yet, the struggle to maintain an identity which was being challenged by a serious illness was causing him some frustration and resentment towards his partner:

So I wish my partner would understand, you know, what I do. You know, cos he comes home and he has no worries. You know, the laundry's done, the shopping's done, there's food in the fridge....you know anything to do with the car, I sort it out....All he does is spend time on his mobile phone

This frustration came up many times during his interview and highlighted the conflict and effort required to deny any form of illness identity and illustrated the toll this took on other areas of his life. His comments about not being defined by his sexuality and his HIV diagnosis seemed to suggest that he had been working on foregrounding what he perceived to be more valued identities for a long time. Now he seemed to be in an impossible situation when he was very unwell with cancer; he did not want to acknowledge his own physical limitations and deal with other people's emotional reactions to his situation; he presented a capable identity to the world which then caused him to be exhausted and to suffer resentment towards others. This leads on to the next section of this chapter which looks specifically at the impact of the cancer diagnosis. We have seen that cancer was viewed as socially acceptable and could be talked about with others to gain support but have yet to discuss the social rules around talking about it or how its life threatening nature, physical limitations and uncertainty of outcome affected how participants felt about themselves and interacted with others. During the period of being diagnosed and receiving treatment for cancer all the identity work that participants sustained in the past could become too much and some revealed a period of acute crisis in which they reached the limit of their resources particularly when it was no longer possible to conceal visible signs of illness.

## **Reaching the limits of resources: visible signs of cancer and the impact on existing felt stigma**

An HIV diagnosis is not visible to others. Participant accounts revealed how it was possible to continue to go to work, take medication unobserved and control information so that most people they came into contact with were unaware of their HIV status. At the level of their private self we have seen that many had internalised stigma and blame associated with the condition but were mainly able to keep this from others and maintain their chosen public presentation. The physical changes caused by having cancer or treatment for cancer added something visible and impossible to hide and this in turn intensified the stigma of a HIV diagnosis which under normal circumstances could be ignored or concealed.

One woman described this link in her account. She related how she had joined dating sites and had attempted to meet people since her HIV diagnosis and stated that she thought no-one would ever want to be with her because of her HIV status. Later, when talking about a scar that was the result of surgery from cancer treatment she became very emotional and linked this physical and visible sign to her previous statements about meeting someone:

I see it every day....my scar. I get really upset about that. Just because it's physically, it's like, cos it also impacts me thinking about relationships.....and it's oh so depressing (P17, Female, 30's, Prior HIV diagnosis)

The same feeling was described by participants who were very affected by losing their hair and felt a palpable sense of shock and upset at their changed appearance. One man who had described in his diary entries the horror he felt at losing his hair mentioned a couple of incidents going through chemotherapy in which people did not recognise him. He seemed to find this particularly distressing:

xxxx on the reception, like he will always recognise me from the beginning, he would say my name, and then like it was 3 weeks..... It was strange, and he said ok 'May I help you?.....and then even my flatmate...it was only the first time to be honest, like we arranged to meet in a coffee shop and then he was looking for me and he says 'where are you? I cannot find you, I'm here for 5 minutes' I said 'I'm here,' and then he saw me and turned back and said 'Oh I'm sorry I didn't recognise you (P2, Male, 30's, Prior HIV diagnosis)

This man retreated during his cancer treatment, worked from home and severely restricted his social activities. He described a period of intense isolation going through his cancer treatment which was exacerbated by the strange experience of people he knew not recognising him. Although the shock of a changed appearance

might be expected in any young man with a cancer diagnosis even without being HIV positive, the isolation and distress appeared enhanced in this individual. His family were far away in another country and were not aware of either condition. He had stated in his interview that HIV prevented him dating and made the prospect of meeting a partner difficult. The lack of close relationships and support seemed most striking at a time when he also looked different; he responded by withdrawing completely.

Another young gay man coped with his cancer treatment by completely retreating from his usual social circle which he associated with having fun:

Ok when you are 75, 60 years old it's different, you get cancer, you did something with your life. But when you are 26 you are just thinking that....shit....With these friends I used to do other stuff, fun, it's just I don't like to involve them (*P6, Male, 20's, Synchronous diagnosis*)

This man later referred to the gay scene as being superficial and at times nasty and he was clearly concerned by his hair loss due to chemotherapy and the weight he had lost. The physical changes which were a consequence of having cancer now made it more difficult to enact an identity he felt good about and his answer was to isolate himself completely. He was a young man in his 20's whose family lived thousands of miles away and who were unaware of either his HIV status or his cancer. All his social contacts appeared to have been formed around his hedonistic lifestyle where appearances were very important. With his changed physical appearance caused by cancer treatment he seemed to have no-one to support him. This idea of an illness which is visible becoming a source of tension between a person's private self and public social identity as described by Kelly (1992) in his work on ileostomy is relevant here. An ileostomy is when the small bowel is diverted through an opening in the abdomen and a special bag placed over the opening to collect waste products. Someone with an ileostomy can become highly skilled in the art of impression management and work on a normal self-presentation but anxiety and difficulty relates to those situations where the ileostomy is visible or potentially visible. Cancer had the potential to shine a light on the difference of the person living with HIV both by imposing physical differences but also in situating the individual in unfamiliar healthcare systems where HIV could be brought up in the context of their treatment and where other people being treated for the same cancer would not be HIV positive. For the person living with HIV maintaining a surface continuity in life and managing information in order to foreground valued identities and minimise potential discrediting was lonely and hard work. The effort involved in

engaging in this work was cumulative over time and with the advent of a debilitating cancer diagnosis which was visible and reminded them of their difference and isolation it could become impossible to sustain. In some cases the response was simply to cope alone. The next section moves on to discuss in more detail some of the coping strategies and support that participants described.

## **8.4 The Mobilisation of Resources and Coping Strategies**

The previous sections have indicated how people felt about themselves and behaved in interactions with others in order to feel better and elicit support and also how they could reach the limits of this approach when they had a cancer diagnosis which resulted in treatment that was visible on their bodies and also emphasised their feelings of difference. The next section describes the nature of the social support that participants talked about and presents some of the coping strategies they utilised.

### **8.4.1 Talking about cancer has a set of social rules that add to the burden of information management for those with a dual diagnosis**

We have seen examples of participants feeling able to talk about their cancer diagnosis in order to gain support and also to feel a sense of status in being able to share information and raise awareness amongst others. This was positive but there were also examples in the data of participants feeling that the support associated with a cancer diagnosis could come with conditions. Some spoke of other people reacting awkwardly; this included avoidance of the subject in conversation or making them feel that they were causing upset or bringing the mood down. This caused them to manage information about cancer and play down aspects of their diagnosis and treatment to make it more palatable for others. This conscious decision to limit how much information they told others was described by one man:

It is easier to talk about cancer to a certain point you know. Because it makes people uncomfortable...I think it can be a bit too much for most people....I think now I'm going to start saying less (*P2, Male, 30's, Prior HIV diagnosis*)

The upset that talking about cancer could cause in others was also highlighted by another man:

The interesting thing about cancer, or having cancer, is that I've found that telling people, I ended up having to counsel people, you know. The minute you tell them they start breaking down going 'Oh no...' and I go 'it's not, it's alright'.... (P13, Male, 50's, Prior HIV diagnosis)

Although it could be argued that people with cancer who are not HIV positive negotiate these social interactions and manage the information they tell other people in order to conform, what marks those with a dual diagnosis as different is the amount of extra work they constantly engaged in to protect themselves from others' negative appraisal. One man described how some friends lost touch with him when they learned of his cancer diagnosis. He went on to envisage how much worse their response might have been if they had found out about his HIV status, thus highlighting the continual mental processing and assessment of risk which was a feature of his life with a dual diagnosis:

I just imagine...just from the kind of C word they walk away. I just imagine if HIV were to come to light they would just run even more miles (P11, Male, 30's, Prior HIV diagnosis)

As mentioned earlier, in popular discourse cancer could be talked about but within a context of being brave and positive and steering clear of distressing or discomfiting detail. Participants appeared at times to feel social pressure to protect other people from the pain associated with it, adding yet another layer of work and management on top of all those layers which already existed to keep their HIV status secret. The burden of this complex management strategy was very evident in one woman's account of meeting someone else with a dual diagnosis of HIV and cancer and in a striking contrast suddenly finding this burden lifting:

He said I think you need to know that I'm also HIV positive and I'm just coming up to my fifth year of being cancer free...It was just amazing, this whole weight just fell away, somebody else! It was so fascinating, I didn't ask him what specific type of cancer he had, it didn't really matter, and he did have to go through chemo and he did have to you know...so just to have somebody that had been there, done that and just and he was still ok, uh and he and so he became my real lifeline actually (P17, Female, 30's, Prior HIV diagnosis)

Although she had been to HIV support groups and met other people with cancer it was the fact that she had met someone with both conditions that made this encounter so important and this quote gives an idea of the weight she was carrying in managing both diagnoses.

The sources of social support that people identified outside of healthcare services included partners, family, friends and work colleagues. As has been demonstrated

sometimes the accessing of this support involved the management of information and could leave people feeling essentially quite isolated and lonely. Pets such as cats and dogs were for some an important and trusted source of support and these participants spoke about them with a lightness and affection which seemed uncomplicated in comparison to the relationships they described with family and friends. One man described the comfort of his dog's company which helped mitigate some of the suffering he had endured in his life:

And she was gorgeous and she filled.... there was always someone at home waiting for me, scratching on the door, a little lick. And it also gave me, you know I had to get up to walk her, I had to make sure that I fed her. Those things when the grief and my mourning and the stress of my life and you know having been told to wait to die and all things like that. So she was part of one of the bits that I'd picked up from the Titanic. *(P4, Male, 60's, Prior HIV diagnosis)*

#### **8.4.2 Coping strategies: self reliance and retreat**

Given the burden and complexity of some people's reported social interactions it is perhaps not surprising that self-reliance emerged as a recurrent theme in their accounts with many people describing a simple survival strategy in which they kept their head down during cancer treatment and distracted themselves from thinking too much. One man described a strategy where he largely cut himself off from the world and played video games during his cancer treatment in order to provide distraction:

Well, I try not to think about it, you know? Like I just don't read, don't think, don't talk about it at all, you know? So, I just work and because I don't go out a lot, like I'm afraid of going out, of catching an infection or something like that, so I stay home most of the time and I work from home. So I just *(laughs)* I just play video games all the time *(P2, Male, 30's, Prior HIV diagnosis)*

In a later interview once his treatment was complete he described a change in this behaviour as he was then going out and socialising more. Once he was outside of the period of treatment there was a sense that this head down strategy could be relaxed and it was possible to engage more with other people. He then went back to managing information and keeping much of his cancer diagnosis and everything about his HIV diagnosis a secret. He needed to be outside the period of treatment to be strong enough to maintain this approach. This links to the earlier theme of a crisis of identity taking place in the middle of debilitating cancer treatment and running out of resources to present an acceptable front. In this scenario retreat from others and self-reliance seemed like the most appropriate coping strategy and for

this man whose cancer responded to treatment it was temporary. For another man who had been diagnosed with HIV in the AIDS era and who had described a marked discontinuity in his biography, his reclusive coping strategy appeared to extend beyond his cancer treatment period and had become a way of life:

I won't go out just for the sake of it because I have to pace myself very carefully so I've developed a whole lot of kind of slightly reclusive, I love 90% being on my own, I've learnt to enjoy being on my own. I don't need to worry about my partner saying this and that, going here and there, I've worked a hermit type of life (*P4, Male, 60's, Prior HIV diagnosis*)

### **8.4.3 Coping strategies: complementary and alternative therapies**

We have seen how HIV treatment could be successfully integrated into people's lives without too much disruption and despite the discrediting features of being HIV positive participants seemed to have accepted that they could expect to remain physically well if they adhered to treatment. They also seemed familiar with the requirements of their HIV regimen and could describe it with confidence. Cancer treatment was perceived as having a much more uncertain outcome in terms of prognosis. As we shall see in the later section on participants' experiences of cancer healthcare services, a period of cancer treatment could be characterised by confusion about the complexity of the medical language and a feeling that decisions about treatment and understanding likely outcomes were out of their control. One way to assert some command over this precarious situation was to exercise some choice and take action and adopt complementary therapy or lifestyle changes. Several participants described their use of this strategy. One woman was a fierce advocate for a whole range of alternative and complementary therapies and this subject dominated her account. She provided a long list of what she believed to be causes of cancer and the therapies and treatments she believed would help keep her healthy. Pollution in the air and drinking water, pesticides and chemicals in conventional medicines were all given as examples of carcinogens and her response was to adopt remedies that she viewed as being natural such as fruit and vegetable juices, filtered water and oxygen therapy:

I've got to reduce my chemical intake in any way shape or form, I've come to xxxxx I've reduced my pollution levels, I've got a juicer, you know I drink filtered water. These are all the things I need to turn this one over. I need to cut that out, it's got sugar in it, I can't eat it (*P10, Female, 40's, Prior HIV diagnosis*)

The link made between invisible pollutants, radiation and food additives with cancer reveal the uncertainty related to the condition and more widely the human inability to control the effects of technological progress. This woman championed natural alternative therapies and described her very active role in adopting them, presenting herself as knowledgeable and in control of her chosen programme of recovery. This was in stark contrast to her portrayal of her progress through chemotherapy in which she appeared a passive recipient of very invasive treatment which had severe side effects. The language ascribing purity and cleansing properties to these therapies also demonstrated an outlook which was the opposite of popular constructions of impurity in language about HIV and the dangerous other and the toxic chemical associations with chemotherapy.

Not everyone held such strong beliefs but even people who expressed some doubts about the efficacy of things such as dietary supplements to treat cancer still read about them and were willing to try them. One man described how he had been taking some vitamin B supplements because of what he had read; at the same time he mocked himself by acknowledging that experts such as Cancer Research UK might advise against it:

because you know 1 in 8 women now have got breast cancer in this country and...whereas in some nations it's not, you know like Japan. There's less prevalence of it. Something to do with eating so...um, it seems to be a lot of places that eat well. Eat this particular B17. *Me: So have you started taking that?* I've started for a bit. You know, you obviously read all these things, I read all these things and you read the Cancer Research thing and they say don't be so ridiculous, don't take all that shit, you know..... (*P15, Male, Prior HIV diagnosis*)

Even though on one level he understood there might not be scientific evidence supporting his use of the supplements, the draw of being able to read about something and make his own decisions seemed to be a strong one. The use of complementary therapies such as massage, yoga, reflexology and dietary supplements featured in participants' accounts and was characterised by more in depth attention being paid to their personal experience and role as an active partner rather than passive recipient in their care. This seemed important during cancer treatment where more conventional treatment seemed to involve confusion and uncertainty about their prognosis.

## 8.5 Longitudinal Interviews and Biographical Work

Repeat interviews were performed with six people who in most cases had completed their cancer treatment and their experience of an acute period of crisis had receded somewhat at their final interview. The data from earlier and later interviews was compared to establish whether experience relating to biographical work (including the ability to maintain continuity with a pre-illness life, framing a valued identity and mobilising resources) changed over time following their cancer treatment. For those whose cancer treatment had been effective and who did not appear to have lasting side effects there was evidence of a return to some of the activities of their pre-cancer diagnosis life which had been put on hold during their treatment. Returning to work, starting to socialise once more and discussion about future plans including planned holidays, paying bills and thinking about new jobs were a feature of some interviews. In terms of mobilising resources, it did not appear that they had new sources of support but rather that they now had the physical energy and mental space to continue to manage information and resume the identity work they had conducted previously. For those whose acute period of retreat into illness had passed it could become a foundation for re-evaluation as exemplified by one man who was thinking about exploring a new career:

I'm starting to think more about the future ...I don't know if it's because of the cancer or if it's because of my age.....so I'm feeling like I need to act now, I don't know if I want to continue what I'm doing now.....I don't love doing that...you know I think it's quite boring, you know.....I'm just doing a lot of research and things that I can study, you know to change profession...that's what I'm looking to do (*P2, Male, 30's, Prior HIV diagnosis*)

The situation was less positive for those who had lasting limitations from their cancer or cancer treatment. One man whose radiotherapy had left him with longstanding, painful oral ulcers which affected his ability to eat had difficulty responding positively to people around him who expected him to be happy that his cancer had been cured:

when you've been given um clear of cancer, you've been cleared, everybody thinks there's nothing wrong with you, you can celebrate. But they don't realise that's not the case, cos you've got to recover through the treatment that you've just had. They automatically think you are back to the old xxx. That's not the case. (*P3, Male, 50's, Prior HIV diagnosis*)

There was a sense in which he felt he was almost not allowed to talk about the continued problems he faced as a result of his cancer treatment and an expectation

from others that he should conform to the popular social convention of talking about cancer in a brave and positive way and steering clear of distressing or uncomfortable detail. At the time of his last interview he seemed stuck in a continued period of illness and restriction of his daily life despite his cancer being medically 'cured'.

We have seen that for those diagnosed with HIV in the AIDS era they maintained a strong valued identity associated with being HIV positive which remained intact throughout their cancer treatment. After cancer treatment was finished they expressed more concern about what getting older might mean for them rather than how they had dealt with their cancer. They were aware of their relative isolation and lack of support networks and worried about the future as expressed very eloquently by one man:

I think you know, my biggest fear is, not about cancer or HIV but just about old age. Ending up, because I'm so poor in some God damn awful NHS care home, being slapped about, left in poo overnight, you know that isn't how I want to...no dogs, no garden, just sat there. That is the issue for me more at the moment, I think that ageing has taken over rather more than HIV or cancer. (*P4, Male, 60's, Prior HIV diagnosis*)

The social isolation that many people had experienced throughout their lives had implications for ageing. Without obvious social support the thought of dependency and becoming more vulnerable was very frightening.

## **8.6 Summary: Biographical Work and the Mobilisation of Resources**

This section presented themes from the interview data relating to participants' framing and explanations about their illness experiences in the light of their own personal biography. There were some obvious differences in the accounts relating to the timing of the HIV diagnosis and whether there was effective HIV treatment available at the time. Of those interviewed some participants who were diagnosed with HIV in the 1980's and early 1990's incorporated a lasting and strong HIV identity and lived a new and different life following this diagnosis. Although a later cancer diagnosis could bring with it physical limitations it was more likely to be framed as just another challenge facing them in their post HIV life course. These individuals presented themselves as lone survivors or warriors with a strong sense of, and connection to, the horrors of the AIDS era.

Those who had a synchronous diagnosis of HIV and cancer were being interviewed in a period of acute crisis where the cancer outcome was far from certain. For these people HIV was largely a background concern when their primary concern was survival. They were living from day to day within a predominantly medical environment, unwell, shocked and finding it hard to conceive of their life beyond this acute period. Although HIV was in the background in terms of a threat to their survival it was not viewed as inconsequential as evident in their continued attempts to manage information about it, for example by telling healthcare staff that they must not mention it in front of visitors.

The largest group were those diagnosed with HIV some time before their cancer diagnosis when effective HIV treatment was available. This group largely managed to maintain a surface continuity with their life pre HIV diagnosis. They continued with work or studies and interacted with others but they kept their HIV status a secret, internalising the stigma associated with it and foregrounding other more valued identities to avoid anticipated blame, judgement and rejection. There was a constant tension that all of this work could be undone by the discovery of their HIV diagnosis. A cancer diagnosis could provide the opportunity to share information about themselves and get support but its uncertainty, the perceived societal prohibition around talking about it and its physical limitations often pushed people to the limits of their resources and shone a light on their difference. Managing information about HIV throughout their life involved work and when faced with a physically debilitating cancer diagnosis with an uncertain prognosis on top of this, some found it impossible to maintain this work and responded by retreating and coping alone. Isolation and self-reliance were strong themes which ran through many of the participant accounts. Positive coping strategies included the uncomplicated company of pets and the adoption of complementary therapies which allowed them a greater degree of control when conventional cancer treatment left them feeling like passive recipients. Longitudinal interviews conducted with people who had completed their cancer treatment suggested that in some cases this acute crisis and self-imposed isolation might be temporary. However, for those who had longer term side effects as a result of their cancer or its treatment their ability to resume activities and interact more widely was likely to be affected for longer. The time period for collecting interview data in this study did not allow for additional follow up to establish the longer term impact of the cancer diagnosis.

## **Chapter 9 Interview Data: The Findings**

### **The Experience of Cancer Care by People Living with HIV**

#### **9.1 Introduction**

This chapter presents the interview data which relates to participants' experiences of a dual diagnosis of HIV and Cancer and addresses the following research aim:

- To understand how patients negotiate and access medical treatment and navigate healthcare services

The previous chapter explored themes relating to the ways in which participants framed their dual diagnosis and what had happened to them over the course of their lives, including how they coped and accessed support. The uncertainty of a cancer diagnosis in terms of prognosis, the bewildering nature of treatment, and the feeling of being a passive recipient featured prominently in their accounts. This chapter will focus in more detail on the particular experience of cancer care as described by participants and will characterise the features of this experience.

The participants were all interviewed either during their cancer treatment or very shortly afterwards and so the experience of navigating cancer services was fresh in their mind. As discussed previously, participants were being treated for a variety of different cancers and their treatment modalities included chemotherapy, radiotherapy, surgery, and in one case, a bone marrow transplant. Chemotherapy can have an effect on the immune system and can potentially interact with HIV medication to make it less effective, therefore it is important that the immune system is carefully monitored during this period and that medication is reviewed and changed as necessary to avoid interactions. Participants worried about what would happen with their HIV during cancer treatment and there were examples in the data of them feeling responsible for monitoring this and making sure that healthcare professionals were aware of the issues. Cancer treatment often involves invasive and toxic therapies which cause a range of unpleasant side effects and there is a vast technical, medical language which healthcare professionals use to describe it which can be very daunting and sometimes unintelligible to people who have never heard it before. Faced with a life-threatening illness and information which is difficult to understand participants often described feeling powerless and having a lack of control during their cancer treatment. This uncertainty and lack of control was made

worse by their feeling that they were misfits within the cancer services. They were often the only patient with HIV in the cancer clinic or ward and they could feel that their treatment was therefore not tried and tested for their particular circumstances in the same way as for people who did not have HIV where there was published evidence to support their management. Not being able to take part in cancer clinical trials and tension about the role of the GP were other areas which emphasised their perceived lack of fit and difference. These areas are described and discussed in more detail in the next section.

## **9.2 Loss of Control**

### **9.2.1 HIV management during cancer treatment**

Participants spoke confidently in the medical language of HIV management. They demonstrated their understanding of the process of surveillance of the strength of the immune system by measuring CD4 counts in blood. They were also aware of potential problems with interactions between HIV and cancer therapies. However, they were not at all confident that the cancer team was similarly informed and they gave examples of having to take responsibility for this, something which caused considerable anxiety. One woman, who was receiving her chemotherapy at a hospital near her family home, had to repeatedly remind the medical team that they should be checking her CD4 count. This was continually missed so she felt it necessary to return to London to have it measured; she then found it had dropped to a low level. She felt the onus of having to remind the team of her HIV status and it added to her anxiety about her management:

Basically because they weren't aware of my CD4 I just kept on trying to bring it up and it wasn't in my notes and I had to tell, I had to mention to the nurses that I was HIV positive and they were like 'Oh are you?' kind of thing. You know they only knew I was HIV positive because I had like verbal diarrhoea and let them know (*P10, Female, 40's, Prior HIV diagnosis*)

During one of the interviews whilst one man was in the day-care unit waiting for this chemotherapy I witnessed a long exchange in which he had to ring the pharmacist based at his HIV clinic to check whether an anti-sickness medication he was being handed at the time was contraindicated alongside his HIV medication. He handed the phone over to the nursing team who established that the drug would interact. Without him acting as an intermediary between the two teams it seemed likely he would have been given the contraindicated drug. This was not a situation he was

happy with and he explained how he did not want to be put in the position of checking the medication he had been prescribed :

I'm going round making sure that, having to make sure, you know what I mean.....you know I'm not knocking any of the staff, they're really good, they do a wonderful job here. I just, I'm not in the medical field to specialise in what I should be taking or whatever but you know I've got to check up and make sure I'm taking the right medication (*P3, Male, 50's, Prior HIV diagnosis*)

This situation occurred more often when cancer care was being provided in a non-specialist setting, either in a hospital outside of London or in a London centre where the treatment was within a service which was not familiar with looking after patients with HIV.

This worry that the effects of cancer treatment would trigger problems with the care of their HIV was expressed by several participants. One man described the HIV virus as being asleep and feared that being anxious about the cancer would wake it up:

I felt that if I panicked and stressed I felt that the HIV would feed off that and my main concern was to try and keep the HIV asleep (*P4, Male, 50's Prior HIV diagnosis*)

Many participants were aware that cancer treatment would have an effect on their immune system and that this might compromise control of their HIV. They had become used to the medical management of this condition which was perceived as routine and non-threatening and so they could confidently use what Mishler (1984) described as 'the voice of medicine' when discussing their HIV. In some cases they felt that they had more knowledge in this area than the cancer teams taking care of them. Although they demonstrated confidence in using medical language to talk about their HIV diagnosis, this was not the case where cancer was concerned. In cancer care it is recognised that due to the overwhelming complexity of the treatment and language many cancer patients prefer less active participation in medical decisions (Ernst et al 2011). However, in the examples provided participants felt obliged to get involved to ensure their HIV was taken into account at a time when they might have preferred to leave their care in the hands of others.

### **9.2.2 Loss of control in the experience of cancer treatment**

The interview accounts conveyed a sense of feeling powerless during the period of cancer treatment when participants did not have the knowledge or language to do

anything other than acquiesce with the regime prescribed by their medical team. They used metaphors such as being shipwrecked and making a life raft, and surviving day by day. Unlike the largely predictable and routine course of HIV medical management, cancer treatment was often extremely complex and it was not always possible to anticipate its outcome or effects. Healthcare professionals spoke in highly technical terms which participants did not understand and because of the complexity of the information it seemed impossible to them to be able to play a useful part in decision making. Part of their strategy was to go along with whatever their clinical team had decided and indeed some participants were annoyed when they were asked to make decisions about something they didn't fully understand:

You just go with whatever they suggest. Although you know um, there's been a few occasions where, I mean this particular lymphoma is um quite rare, quite difficult to treat, there's been occasions where one or two doctors have said to me 'Well what do you think?' and I think well, (laughs), what do I think about should we carry on with this treatment or do that treatment (laughs) and I think I really don't know. That's what you should be telling me about. Even this morning they said 'I think we should crack on don't you?' I thought 'Well.....yeah' you know? If you've got a flat tyre you don't look at it and say 'Oh you've got a flat tyre, shall we repair it?..... Or leave it?' (P13, Male, 50's, *Prior HIV diagnosis*)

The unthinking use of medical language by healthcare professionals with the assumption that everyone could follow and understand it caused genuine distress and real anger. One man was actually given his cancer diagnosis over the phone by a doctor who used terms that he had to google following the conversation. An extract of his account of this conversation is below:

He told me over the phone.....So you've got lymphoma. So I said what is it? What is lymphoma? And he said it is a B cell thing. And I said ok, what does that mean for me?....so I now have to go back to Google and worry about it (P9, Male, 30's, *Synchronous diagnosis*)

Another man described being told that he had a secondary in his liver. He assumed, given that in normal conversational parlance secondary meant less serious, that this was not a problem and so he was not too concerned. At a later appointment he realised that having a secondary was actually a serious problem which indicated that his cancer had spread. He felt confused and anxious that he had not appreciated the significance of what he had been told.

Working in cancer myself I am aware that this language is so commonly used amongst healthcare professionals on a daily basis it is easy to assume everyone

understands it. Yet, the consequences of not explaining properly and checking understanding are clear in these examples and show that this assumed knowledge leads to additional anxiety and distress. Feeling powerless in the face of the complexity of cancer and the language used to deliver care is not unique to individuals who are HIV positive (Ernst et al, 2011). However, the experience of the culture of cancer care could feel different from that of the HIV services they were used to and make people with HIV feel even less sure about their circumstances. The more hierarchical structure and formality in consultations was remarked upon by some participants:

I think there's probably more camaraderie up at xxxx(HIV clinic), you know, there's more...they're all. They've got to know each other and there's a bit of fun up there....You can go in and have a chat. Um, whereas here it's probably much more, you're coming to see the cancer specialist you know. It's not, not camaraderie between the patients. I mean I would call her Dr xxxxxx, I wouldn't call her xxxxxx. Whereas I would call, it's all first names up at the HIV um.... (P15, Male, 50's, Prior HIV diagnosis)

The more informal, collaborative culture where patients' views were taken into account and decisions made jointly was described as a feature of HIV services and seemed to hark back to the early days of the AIDS era when little was known about the condition. For those who had engaged with HIV care for years the more formal culture within cancer services could feel impersonal and add to the perception of being out of place and lacking control. This 'lack of fit' in the experience of cancer care was illustrated in a number of areas which will be explored in the next section.

### **9.3 'Lack of Fit'**

#### **9.3.1 Being 'the only one': feeling like a guinea pig**

Often participants might be the only person on a cancer ward or in a cancer clinic who was also HIV positive. The idea that they were an unusual or interesting case was sometimes conveyed to them and mixed opinions were expressed as to whether this was a good or bad thing. One man who had been HIV positive since the 1980s and who had had three different cancer diagnoses over the years felt that the rarity of his medical history played to his advantage in that eminent doctors were keen to study his case:

So I use that.....the AIDS/HIV card to your benefit. And one way of doing it is to get access to the top medical people, because they're all

interested in people like myself. So I mean again that's another way of turning a negative into a positive *(P4, Male, 60's, Prior HIV diagnosis)*

Others found it more of a problem that there was a lack of experience and precedent in caring for people like them. Looking at information online about the outcomes of their particular cancer was frustrating because it was not possible to draw the same conclusions from studies based on people who didn't have HIV. There was an element of receiving special attention but also a great deal of uncertainty about the outcome with no previous research to guide predictions and a sense of powerlessness that they were unable to make choices based on existing evidence. The realisation that medical knowledge was incomplete and that treatment might contain trial and error affected how they contended with the acute period of receiving cancer care.

This links to a theme described earlier relating to coping strategies in which participants felt they just had to put their head down and ride out their treatment without thinking about it too much. It might also explain the importance of complementary therapy, also described previously, which enabled them to feel in control and make decisions about some aspects of their care and support. Two people in the study were undergoing treatment which they had been told was the first or second of its kind to be given to someone with HIV. These two participants both independently used the term 'guinea pig' to describe their management, a not entirely positive phrase which suggests they viewed their treatment as a kind of experimentation and possibly reinforcing their difference from others. One used this term to describe the type of bone marrow transplant he was undergoing:

I know I'm the guinea pig, there's no denying to that, I'm going to be the first, the second in the world.....*(P11, Male, 30's, Prior HIV diagnosis)*

### **9.3.2 HIV can disqualify you from equitable cancer treatment**

Some participants felt that their HIV status denied them access to treatment options which they believed would have been available if they were not HIV positive. One woman described old feelings of upset about her HIV diagnosis re-emerging when she was told this made her ineligible for a clinical trial offering treatment otherwise not available. She related how this exclusion shone a light on and compounded old feelings of stigma:

Because I'm HIV positive I'm not eligible for the clinical trials which are currently the thing that they offer somebody in my position...I was really upset, because yet again it's just another thing to make me feel um....it

sort of compounds...even though you've put the HIV thing to the back of your mind it all comes to the surface again (*P17, Female, 30's, Prior HIV diagnosis*)

HIV is a common exclusion criteria in cancer clinical trials. In a study looking at lymphoma patients who were HIV positive (Venturelli et al 2015) it was found that there was no scientific or safety justification for excluding people living with HIV from most lymphoma clinical trials and no clear justification provided for the exclusion. It would seem from this account that the impact of this on patients who were aware that they were denied access was a reinforcement of stigma. The other participant who provided an example of what he described as 'discrimination' occurred when he was told he could not have a particular type of bone marrow transplant. He went on to seek a second opinion from another hospital and went ahead to have this procedure.

Because I was HIV I was denied a transplant. No more than that. I felt really discriminated (*against*) (*P11, Male, 30's, Prior HIV diagnosis*)

Not being able to access the same cancer treatment as those who were not HIV positive without a clear justification was perceived by participants as unfair and provoked feelings of discrimination. It links to findings in the earlier chapter on popular discourse around the deservedness of provision for cancer treatment or prevention which in newspaper stories was never questioned, whereas stories relating to HIV issues such as the funding of PreP to prevent the transmission of HIV, caused debate over whether this money could be spent more deservedly elsewhere. These feelings, as evidenced in previous discussions about anticipated rejection in response to HIV, seemed never very far from the surface. It also reinforced participants' perceptions of being a misfit in cancer services.

### **9.3.3 Tensions relating to the role of the GP**

Another major theme which recurred in the data relating to healthcare services was participants' feelings about the role of the GP, usually a key component in the provision of supportive care and follow up for cancer patients. The distrust that they had for GPs and their reluctance to engage with them was an area in which they felt different from other people with cancer. This routine aspect of cancer services provided additional sources of anxiety and stirred up fears of being discredited for their HIV status.

Participants' relationships with their GP was a feature of many of the accounts and the main issues of concern which were articulated were about lack of trust and

worries about confidentiality, lack of knowledge and seeing a different GP each visit. Cancer services rely greatly on the supportive aspect of GP care during chemotherapy treatment. Patients are advised to see their GP to deal with minor symptoms between cycles of treatment and arrangements may be made for the GP to prescribe and administer supportive medication, an example being GCSF (granulocyte colony stimulating factor) a growth factor which helps the bone marrow produce white blood cells to reduce the risk of infection after some types of cancer treatment. Involving the GP is very much a feature of cancer care but participants expressed a reluctance to see their GP and an unhappiness with the service provided. When participants talked about fears regarding confidentiality and lack of knowledge it was the HIV diagnosis which was the problem. One man described this reluctance as originating from a period when he was first diagnosed HIV positive and he was worried about the GP maintaining his confidentiality:

it sounds strange that you were going to your doctor and not telling him about this major thing but I just didn't have the confidence that it wouldn't get out (*P12, Male, 50's, Prior HIV diagnosis*)

GP surgeries were located in their local community and attended by their neighbours. The sensitivities to maintaining confidentiality which were a feature of their HIV service they did not feel could be guaranteed here, and there was a fear that information about their status would be revealed and potentially discredit them in their neighbourhood. For some, their GP was informed of their HIV status by default and without their permission as part of the routine practice within cancer services that a discharge letter was sent containing past medical history. They were unhappy about this due to fears about confidentiality generally and that the GP would be obliged to disclose their status to 'third party requests' such as those from mortgage companies, employers and solicitors. These types of concerns led to some not having a GP at all. This may reflect a historical situation where HIV clinics have picked up all aspects of health care and patients may have become used to relying on them for HIV related and sometimes non-HIV related problems. A cancer diagnosis highlighted the need for GP support and this caused the participants unease. For those who had registered with a GP, alongside worries about confidentiality was a complaint that they were always seeing different doctors and consequently had to update different people about their current treatment. It also raised the prospect of discussing their HIV status with someone they did not know which was a perpetual source of stress. This stress was evident in the following account from a woman:

So you go in there the GP practice, and there are 5 in there. This day you meet this one, the next day you meet the other one, they want the history..... I don't know one day I went in and I shouted , I shouted 'don't ask me, just check that computer, I'm tired, when I come here it is you, it is who, it's different faces I'm looking at (P1, Female, 50's, Prior HIV diagnosis)

In addition some GPs they saw were not well informed about HIV and their cancer diagnosis and in their view this led to delays in referring them for cancer investigations. This was another situation in which they felt different and experienced a lack of fit; the generalist knowledge of the GP meant that participants felt worried about information being missed and a lack of confidence that they would spot issues of concern.

It should have been a real red flag. But the fact they didn't assume it was liver cancer, it just wasn't on the radar.....GPs don't have the information. They have the information on diabetes, they're very well informed. They don't have the information on HIV' (P8, Male, 50's, Prior HIV diagnosis)

#### **9.3.4 Professional support is not always well matched to the needs of a dual diagnosis**

Participants described a variety of different professional support services that they had accessed at various stages, some they utilised following their HIV diagnosis and some during their cancer treatment when they had the dual diagnosis. These included psychological support as well as specific physical therapy. Financial or benefits advice was also mentioned by a few people but in general there were no additional comments to suggest that it caused them concern aside from a couple of people who had an issue with the cancer support services. One man felt that they made a judgement based on his relative youth that he did not require the same support as more elderly service users:

when I asked for financial help, I felt like they were helping me but because I was a young person I felt kind of discriminated, like for the older person you could see all the attention there, I was young so they said 'you do it, you do it, you do it (P11, Male, 30's Prior HIV diagnosis)

This idea of cancer support services dealing best with a specific demographic was also evident in an African woman's account of the wigs that were provided:

They are very good, very expensive but the style is mostly of white people....Straight, you know, so sometimes on you it is a bit....you need a bit curl curl you know (P1, Female, 50's, Prior HIV diagnosis)

As mentioned at the start of the previous chapter the sample group was very diverse. This diversity and difference combined with their own hyper vigilance and sensitivity about the discrediting nature of their HIV status meant that they often felt like misfits in the experience of their cancer care. Existing support services either HIV or Cancer specific were not well matched to the needs of everybody and this could serve to make people feel further marginalised. Of note there was no mention of any support that catered specifically for people with a dual diagnosis.

#### **9.4 Longitudinal Interviews and the Experience of Cancer Care**

For those people who took part in follow up interviews after they had finished their cancer treatment the majority referred to some long lasting effects of treatment. Although they were not in the midst of the acute crisis as they were in their first interviews, they were still going to appointments to deal with persistent side effects following on from chemotherapy, radiotherapy or having a bone marrow transplant. These participants were now more familiar with some of the medical language used in cancer care and were using it themselves at times within the interviews which suggests that they had assimilated knowledge and had more confidence and perhaps a feeling of greater control over their situation. There did seem to be some continued concern about HIV and cancer teams not working together which echoed earlier complaints about lack of communication between the two. Some described the difficulty in getting long-term side effects properly addressed as a 'passing the buck' between the teams:

I didn't want to feel like they were passing the buck because something wasn't working for me when they were treating me, this is not cancer-related, this is HIV, you'd best go and see your HIV team (*P3, Male, 50's, Prior HIV diagnosis*)

They perceived that rather than being viewed holistically by their medical team in the period of follow up, there was still a feeling of two distinct services who did not share information and work together well. It was clear that many people had limiting side effects such as neuropathies, pain from radiotherapy sites and surgery which were not expected to resolve quickly. One man described the effects of a painful neuropathy in his hands and legs which had been exacerbated by his chemotherapy. The language he used about working with the medical professional suggested a confidence about the subject matter and a sense of greater control which was not evident in his first interview:

It probably started 3 or 4 years before chemo due to the HIV. Um, but that was just a very mild starting and this is just after discussion with Professor xxxx, but he said obviously the Vincristine has really had a major impact on it, so we're going to spend the next couple of months doing some more investigations, but it is very clear that it will never heal, there will never be a cure but he doesn't think it's going to progress, but it might progress a bit (*P8, Male, 60's, Prior HIV diagnosis*)

As with many cancer patients these participants were experiencing late effects from their cancer treatments evidence of which emerged in later interviews. The management of these could be complicated by their care being provided by two separate services.

## **9.5 Summary: the Experience of Cancer Care by People Living with HIV**

The period of receiving cancer treatment was characterised by many participants as one in which they felt their situation was precarious. In contrast to the management of their HIV which they appeared to understand and feel confident in talking about, they did not understand the medical language used to describe their cancer and its treatment. Cancer could be a life threatening condition and its treatment very invasive, complex and unpleasant. Its outcome was uncertain, and for people living with HIV they were aware that there was not a huge body of research evidence to indicate what treatments would provide the best outcomes for their particular situation. They were also aware at times that the cancer teams were not that knowledgeable about their HIV management and that they might need to intervene to make sure this was taken into account. In contrast to their confidence about HIV management they felt a loss of control and were ill equipped to share in decisions about their cancer care. This loss of control was exacerbated by their sense that they were misfits within the cancer services. This was expressed in relation to being excluded from cancer clinical trials, not being suited to cancer support services and in the problems they had with using the GP service for supportive care. The journey through cancer treatment was thus characterised as a frightening and confusing time which served to further emphasise the participants' sense of difference and isolation. Longitudinal interviews revealed that it was possible to emerge from this acute phase of cancer treatment with a greater degree of knowledge and ability to talk about it, however there could be long lasting effects from the cancer itself or its treatment which placed long term limitations on people's lives.

## **9.6 Overall Summary of the Interview Data Relating to a Dual Diagnosis of HIV and Cancer**

The previous two chapters have presented themes relating to the experience of dual diagnosis of HIV and Cancer drawn from the interview and diary data: these are summarised below.

Interview participants' experience of their dual diagnosis had some differences in their accounts according to the timing of their HIV diagnosis. Those diagnosed with HIV in the early days of the 1980's and early 1990's were more likely to describe a marked discontinuity with their pre-HIV life and go on to incorporate HIV into their identity which they enacted publicly in the role of activists, volunteers or simply survivors. Those diagnosed with HIV and Cancer simultaneously were being interviewed during a period of acute crisis in which the primary concern was survival of the cancer diagnosis with HIV a more background feature at that time. Finally, those who were diagnosed with HIV prior to their cancer diagnosis and who were managed successfully on HIV treatment were more likely to describe a surface continuity in their life prior to getting cancer. This continuity was characterised by maintaining outward appearances whilst dealing privately with cumulative internal disruptions caused by managing information about HIV and keeping it largely secret.

Aside from the activists and survivors, most participants kept their HIV status concealed from others because of their belief that it had the potential to discredit them; this remained a constant threat which cast a shadow and caused uncertainty, anxiety and stress. Accounts revealed evidence of participants foregrounding what they perceived to be more valued identities such as their occupation, church going and even being a cancer patient. Their ability to access support could be dependent on carrying out continuous work such as managing information about their HIV status and conforming to social expectations that cancer should be talked about in upbeat and positive terms. There were constant tensions and contradictions apparent in this work to maintain valued identities. It was clear from many accounts that their feelings about being HIV positive affected their ability to make close relationships, and loneliness and isolation was a feature of many.

During the acute period of being treated for cancer, participants described a loss of control and a lack of fit with existing cancer services. They were familiar with the medical management of HIV but found the language of a cancer diagnosis and its

treatment hard to understand and they did not feel able to share in any decision-making relating to this. They felt out of place in the cancer services: they had to remind people about their HIV care, they might be the first person with HIV to receive a certain type of treatment, they were excluded from clinical trials and there were tensions in involving the GP service. Add to this debilitating physical symptoms, visible signs of illness and an uncertain prognosis and the work they had been doing to maintain valued identities could become too much. Some reached the limits of their resources and retreated to become utterly isolated; they described 'putting their heads down' and simply rode out the treatment on their own. The interviews afforded privileged access to and insights into the experience of a group of patients, some of whom were extremely sick and vulnerable, as evidenced by the fact that six participants died shortly after providing their accounts. For those who were interviewed again after completion of their cancer treatment, it was possible to explore to what extent this period of acute crisis passed. Those who did not have significant persistent side effects from their disease or late effects from the treatment did seem to get through this crisis period and were able to resume activities of their pre-illness life. For those who were left with long term significant problems this seemed much harder to achieve. As interviews took place over an 18 month period it was not possible to assess to what extent these issues were short term or permanent.

## **Chapter 10      Observation Data: Methods and Findings**

### **Focused Ethnography: The Health Systems Context of a Dual Diagnosis**

#### **10.1 Introduction**

The following chapter describes the methods and presents the results of the observation component of the study which was conducted at all three sites to characterise the health systems context in which participants with a dual diagnosis experienced their cancer care. This addressed the following research aim:

- To consider the features of the healthcare setting in which HIV positive patients engage with services relating to their cancer diagnosis

Muecke (1994) uses the term 'focused ethnographies' to mean time-limited exploratory studies in a discrete community or organisation, limiting the number of key informants to people with relevant knowledge or experience. In contrast with more conventional ethnography this approach is usually carried out by researchers who have an extensive background knowledge of the field and is characterised by short-term, intermittent and purposeful field visits (Higginbottom et al, 2013). Focused ethnographies have been used in hospital and healthcare practice to determine ways to improve care and they are pragmatic and efficient in capturing data on a specific topic of importance (Smallwood 2009).

I deemed this method most suitable for collecting data in busy clinical areas such as chemotherapy day units and wards where HIV positive patients were only being treated sporadically. As a cancer research nurse I had an existing familiarity and background understanding of the setting and so could focus my visits on the presence of key individuals and those interactions and procedures which would be most likely to yield the most relevant information. Seven participant observation sessions (taking the role of observer as participant) were conducted initially and observations were recorded in the form of detailed written notes. Seven semi-structured interviews with healthcare professionals were performed at a later time point with the use of a topic guide and were audiotaped. Reflective field notes were written after every interview to provide details of the context and to record my own reactions and feelings in response to the accounts. The topic guide for the interviews (Appendix 12) contained nine questions informed by themes developed

from patient interviews. These formed the basis of the interviews but conversation was allowed to flow and if other topics were raised by interviewees these were explored. The observation data was intended to help describe the health systems context and provide a supplementary layer of understanding of the patient experience. Data collection ceased when it was felt there was sufficient coverage and variation in responses and no new ideas were forthcoming.

### **10.1.1 Participant observation of the clinical setting**

Participant observation involved following HIV positive patients within the clinical setting and included observing cancer treatment being administered; attending a ward round and a handover, and sitting in on clinic visits. The role of participant as observer was adopted in that I observed as unobtrusively as possible whilst remaining open about my purpose. Although I was not participating in the setting as a nurse I did instinctively perform tasks such as helping patients to reach drinks and adjusting pillows which were informed by my nursing background. Further reflections upon my role can be found in section 10.2.5. This observation was conducted at the start of the study before any participant interviews were conducted and served a number of purposes. It was intended to facilitate and build positive relationships among key individuals whose help, approval, knowledge and insight were needed for the study to work. Data collected during initial observation was used to inform later methods such as patient interviews by ensuring a more thorough contextual understanding of how cancer treatment was given. This data included information about the physical environment, the human setting (how staff are allocated work and how patients are grouped and treated); the interactional setting and the programme setting (ie how the system works, what guidelines and processes are followed).

This early observation provided valuable familiarisation with the setting and helped in the formation of key contacts as well as providing important information about interactions and non-verbal behaviour amongst patients and healthcare professionals. Patient participant interviews began to be conducted following this initial period of observation and a decision was made to perform the informal, semi-structured interviews with healthcare professional key informants towards the end of the study when the questions could provide another perspective on themes which had been developed from the accounts of patients.

### **10.1.2 Interviews with key informants**

Focused ethnography was chosen as an appropriate approach which suited busy clinical areas with its focus on the availability of relevant participants for the informal interviews which took place at a later time-point in the study. I planned my visits to coincide with the presence of key informants. The topic guide for these interviews was informed by themes which had been developed from patient interviews relating to interactions with the healthcare system and aimed to seek the healthcare professional perspective on issues such as communication between HIV and cancer teams, disclosure, and the role of the GP, as well as including broader, more open questions. The topic guide can be found in Appendix 12.

## **10.2 The Methods**

### **10.2.1 The sample**

#### **Participant Observation**

Seven participant observation sessions were conducted along with reflective field notes. I decided to perform the observation at two of the three London sites where the patient participants were recruited. The third site was where I was based as a cancer research nurse and was an environment I was already familiar with. I foresaw potential problems with performing this observation in a setting where I normally worked in a different capacity; this is discussed in more detail in the reflections in section 10.2.5. I felt it was a priority to familiarise myself with the other two sites and get to know the context in which patients with HIV were treated for cancer. A variety of settings were selected to include different types of cancer service and different treatment scenarios. These included observations of both staff and patient interactions and staff opinions sought in informal conversations and on one occasion in an education session. A total of 27 hours of observation was performed. Details describing the observations conducted are provided in Table 10-

1

**Table 10-1 Details of observations conducted**

Date	Site	Setting	Description	Hours
12-May-15	2	HIV specialist daycare	Patient receiving intravenous chemotherapy	6
20-May-15	2	General oncology daycare	Patient receiving intrathecal chemotherapy	3
24-Jun-15	3	Specialist HIV and Cancer service (including some general oncology)	Daycare, observation and informal chats with patients and staff	7
06-Jul-15	3	Specialist HIV and Cancer service (including some general oncology)	Observation in clinic, post weekend handover and ward round	5
05-Oct-15	2	General oncology daycare	Observation of patient having pre-chemotherapy checks	2
14-Oct-15	3	Specialist HIV and Cancer service (including some general oncology)	Teaching session with nurses working in daycare plus discussion	2
11-Nov-15	2	General radiotherapy unit	Observation of radiotherapy waiting area	2

### **Semi-structured Interviews with Key Informants**

Semi-structured interviews were conducted with seven healthcare professionals. These were chosen to provide a range of perspectives from staff involved in the care of people with a dual diagnosis of HIV and cancer who came from both general cancer services and specialist HIV services. They included doctors, nurses and a research practitioner. These interviews were all performed with the exception of one, at one site. There were two reasons for this. During the course of the research study some oncology services had been merged and centralised at this site and so it provided the largest pool of healthcare professionals. Practically, it proved the most workable option as attempts had been made to arrange interviews at other sites which were not successful. It was difficult to arrange interviews even with the staff at the site where most of the interviews were conducted due to their busy workloads. In order to address this I consulted with a key informant on the best

approach to recruiting them. On their advice I sent an email to an oncology distribution list covering wards, nurse specialists and day-care units and made up of 265 healthcare professionals. All those who responded to this email were interviewed. The two doctors were approached separately because of their expertise and knowledge in caring for people with a dual diagnosis. Interviews ranged in duration from 14 minutes to 38 minutes with the average length of 27 minutes. Details of the interviews are provided in Table 10-2

**Table 10-2 Interviews with key informants**

Participant no	Date	Site	Department	Role
1	06-Jan-17	1	Haematology oncology service	Nurse
2	24-Jan-17	1	HIV Services	Doctor
3	24-Jan-17	1	Haematology oncology service	Doctor
4	14-Mar-17	1	Haematology oncology service	Nurse
5	29-Mar-17	1	Oncology service	Allied Health Professional
6	30-Mar-17	1	Haematology inpatient ward	Nurse
7	14-Sep-17	3	Haematology oncology service	Nurse

### **10.2.2 Ethical issues**

In observing the administration of cancer treatment to HIV patients it was acknowledged that there may be some concern amongst patients that the researcher's presence would somehow reveal their HIV diagnosis. In order to address this concern the aims of the study were shared with the staff in the clinical area but written and verbal information provided to patients on the day of observation only referred to a study looking at the experience of patients receiving treatment for cancer with no reference to HIV (Appendix 13). All patients were reassured that no identifiable information would be recorded during observation.

Agreement was initially obtained from the consultant and department manager. Information about the study was disseminated widely to as many people as possible in advance by presentation at staff meetings and handovers. On the day of observation all relevant personnel were alerted to the researcher's presence and purpose and verbal consent was obtained. Assurance was provided that the identities of the people observed and the healthcare professionals interviewed would be protected, with no identifying data recorded, it was also emphasised that people were not required to be observed or interviewed and that if they wished not to be observed or interviewed their wishes would be respected. As observations were being recorded via a notebook there was no risk of incidental behaviour being recorded without permission as might be the case with a video recording.

Thought was given to potential circumstances, where as a nurse in a clinical environment, duty of care may dictate my escalation of certain situations. This was discussed with the ward/unit manager and a clear contact for the escalation of any clinical concerns was identified in advance.

### **10.2.3 Field notes and researcher reflexivity**

Reflective field notes were written during and immediately after each period of observation and informal interview to describe the environment and provide more context and detail to the interactions. The field notes also recorded my own reactions and feelings in response to what I observed and to acknowledge my own position and influence over what was happening and being said.

### **10.2.4 Thematic analysis of the data**

#### **Framing the analysis**

The analysis of the observation data employed an inductive and deductive approach. In the initial observation sessions performed in 2015 the data concerned physical descriptions of the setting, the interactions witnessed, and the words spoken by those observed. An inductive approach paved the way for providing an understanding and characterisation of the healthcare environment in the different sites. The initial data informed the design of later patient interviews by providing a cultural understanding of interactions in the healthcare environment. The healthcare professional informal interviews were carried out at a later point in the study and were informed by the newspaper analysis (see Chapter 5) and the patient interviews (Chapters 7, 8 and 9). They were happening at a stage when themes

had already been developed within the social and personal context of a dual diagnosis experience. Therefore a more deductive approach was applied in that the topic guide for the interviews was developed with these themes in mind. As the interviews were semi structured and questions were open ended it was possible for those interviewed to talk about other things that they felt to be important to allow for new perspectives and ideas not just those that had been included within the topic guide. Notes from the informal conversations performed in the observations were also looked at during the analysis of the later more structured interviews. Relevant sections of the field notes recorded during participant observation which related to the content of the later analysis of the interviews were included.

### **Analytic Methods: Observation field notes and audio transcription of healthcare professional interviews**

Observation field notes were typed up within two hours of each visit to allow further details and impressions to be captured from memory in order to provide accurate and rich descriptive accounts of the clinical setting. I transcribed the seven audio recordings of the healthcare professional interviews and made efforts to do this as soon as possible after each interview. This helped to ensure an in depth familiarisation with the data, and enabled small details and non-verbal communication to be captured from memory. Field notes recorded immediately after the interviews, containing reflections on my own reactions and feelings about the interaction, were constantly reviewed during transcription in order to explore and acknowledge the interpretive nature of the final transcript. These field notes provided further context and detail to support the transcript itself.

### **Analytic Methods: Organisation, Management and Analysis of Observation field notes and healthcare professional interview data**

I imported all my audio recordings, field notes and interview transcripts into NVIVO V.10. This software worked well as a tool to initially store, manage and organise the volume of data. During the analysis I worked from the paper transcripts and field notes, developing themes by a process which initially involved applying descriptive labels. These initial descriptive labels can be found in Appendix 14. These labels were grouped and synthesised into larger concepts which were explored, tested and refined with the help of tables populated with corresponding extracts from the data which I had created myself outside of the NVIVO software. This system

allowed my analysis to stay very close to the observations and interviews in a form that I found most useful in recalling and contextualising them.

### **10.2.5 Researcher reflections**

I introduced myself to patients and staff as a nurse who was in the clinical setting in the capacity of a researcher looking at patient experience of cancer care. I decided not to perform observation at the site where I normally worked as a research nurse. As I was familiar with the environment and known in a different capacity there was a danger that I would bring my own preconceptions to the setting based on previous experience. My presence was also more likely to generate confusion amongst clinical trial nursing staff who might approach me about work issues unrelated to my research. Even in the two sites where I was not known my presence initially generated a level of suspicion amongst healthcare professionals which became evident when I was asked whether I was performing an audit or was there to look at chemotherapy administration technique. This led me to reflect on what might be better ways to gain access and acceptance. In one unit I arranged to update the nursing team about my study as part of their monthly teaching session which was held early in the morning before their shift began. This was a way to offer something to the team at a time when they were not as pressured so that they had time to take on board the purpose of my presence. It resulted in better relations with the team in subsequent visits and an informal and very useful discussion at the end of the session, which provided valuable material about their thoughts and views in caring for patients with a dual diagnosis.

Reflection also helped me refine the methodological approach to observation when it became clear that the initial plan of turning up to clinical areas to observe non-verbal communication with HIV positive patients was not going to be feasible as these patients were not being treated in the units on a daily basis. The choice of focused ethnography with its intermittent and purposeful field visits which could be planned to coincide with the presence of the relevant individuals and treatment scenarios was adopted after reflection following the first observation visits.

I was aware that as a nurse there were occasions when I felt frustrated by not knowing the medical background and rationale for the management of the patient I was observing. I realised that I am accustomed to knowing information about patients with cancer such as the name of their diagnosis, the number of cycles of treatment they have had, and when they are scheduled to have a scan to assess

their response. In one conversation with a patient the phrase 'poor historian' came to my mind as a term that might be used by myself or colleagues in day to day practice to describe a patient who cannot provide this detail. Reflection helped me recognise and resist this urge to categorise (and judge) according to the medical agenda and instead observe and listen to the interactions in front of me which would provide me with a greater insight into what the patient was experiencing.

### **10.2.6 Data management and information governance**

Observation field notes were typed up and transferred to a secure encrypted server as soon as possible after each visit with study identifiers to denote the site and department. The audio recordings of the interviews with key informants were downloaded and transferred to a secure encrypted server as soon as possible after the interview was performed and then deleted from the voice recorder. The interviews were transcribed and the transcripts were then anonymised, given study numbers and stored on a UCL server with user unique login details. Paper copies of the field notes and transcripts were anonymised and stored in a locked filing cabinet in the UCL Cancer Institute controlled by the researcher. Relevant sections of the anonymised data were shared with my academic supervisors

### **10.2.7 Summary of methods**

This chapter described the methods adopted to perform the thematic analysis of the observation component of the study which was conducted at all three sites to examine and characterise the health service context in which participants with a dual diagnosis experienced their cancer care. It characterised the sample in terms of the research sites visited and scenarios observed as well as the number and nature of the key informant interviews performed. The process for collecting observation and field note data was documented along with its management, organisation and analysis. A section on researcher reflections was included to acknowledge and describe methods used for critically appraising my own position and influence within the observation and analysis. Finally, the ethical and research governance processes underpinning the study were reported. The next section moves on to a presentation and discussion of the results of the analysis.

## **10.3 The Findings**

This section will present the findings from the seven participant observations, reflective field notes and seven semi-structured interviews with healthcare professionals. It will begin by providing a summary characterisation of the two broadly different settings which were observed. The division which appeared the most relevant in terms of patient experience was that between specialist services where the staff administering cancer treatment were also HIV trained ( which will be termed as specialist HIV services) and those cancer services where staff were solely trained in oncology (termed as oncology services). With various medical, policy and institutional discourses aiming to reframe HIV as a chronic disease like any other, one could argue that part of this process should involve people who are HIV positive being treated for cancer within the same services as everyone else, i.e. within the general oncology service. Themes which were developed from the data in both settings lent themselves to an exploration of the arguments for and against framing HIV as a normal chronic disease 'like any other' within the context of cancer treatment; this therefore is the conceptual framework within which the analysis of the observation data is presented.

The next section will describe the different characteristics observed in specialist HIV services and general oncology services that provide cancer treatment for people who are HIV positive. It is important to acknowledge that participant observation and interviews were conducted at just three London sites and it is therefore not possible to say how far these differences might be reproduced in other settings. The experience in smaller district general hospitals outside the capital is likely to be different again and was not represented in this observation data.

### **10.3.1 Cancer treatment within specialist HIV services**

The two HIV specialist settings that provided cancer treatment gave relatively few chemotherapy treatments; one gave nine per day, the other one or two per week at most. The atmosphere in both services was informal and relaxed; in one unit the nurses did not wear uniform. Patients received one to one attention from staff who the patients were likely to know, or at least have seen before. Cancer treatment took a long time because all aspects of the checks and reviews were conducted in one place and relied on medical staff, and in one case nursing staff, coming to the unit from elsewhere. One patient who was being reviewed in this specialist service had undergone surgery as part of their cancer treatment elsewhere within a general

cancer service and commented on the contrasting formality which he experienced there. He described it as having a 'different feeling' which was 'old fashioned and hierarchical' in comparison with the informality he experienced in the specialist HIV setting. His clinic visit which I observed was relaxed, with jokes shared between the patient and doctor suggesting they knew each other well. Conversations with the staff revealed that they felt responsible for many aspects of their patients' care beyond the delivery of cancer treatment. They provided examples such as sorting out HIV medication over the phone whilst patients were on holiday and making arrangements for patients to be seen who 'refused' to go to their local emergency department or who did not want to be admitted to a non-specialist ward. Both doctors and nurses described instances of 'sorting everything out' for their patients.

### **10.3.2 Cancer treatment within oncology services**

The two oncology services giving cancer treatment to HIV positive patients which were observed gave many more chemotherapy treatments, one delivering between 80 and 100 per day. In this service there were more staff on duty, they wore uniform and often completed tasks at speed in what felt like a very busy environment. There appeared to be less time for conversation with patients, consultations were relatively short and focused on the safe delivery of treatment. Patients were given the responsibility of getting their pre-treatment bloods taken; they went to a different floor to the phlebotomy service then returned to the treatment floor once this was completed. Due to the high numbers of staff, patients reported being treated by different people at each visit. Clinics were held according to cancer type. They were busy and time pressured and patients were called into the consultation room by an electronic message board in the waiting area.

The second oncology service I observed was smaller in scale but similar in feel with the focus on maintaining a production line and throughput of treatment cases in a day. Staff in the treating area were largely task orientated and did not always appear to know a lot of personal information about their patients. Although every patient was assigned a clinical nurse specialist who acted as a key contact and support throughout their cancer treatment, these nurses had huge workloads and a specific focus on newly diagnosed cases. Conversations about their work largely featured practical issues related to the journey through treatment delivery. These services also had Macmillan support and information services attached to them where patients could access psychological support, information on finance and benefits and a range of complementary therapies.

### **10.3.3 Being treated for cancer: a challenge to the ‘normalisation’ of life with HIV**

This section presents themes developed from the observation data which relate to the health systems context of HIV positive patients being treated for cancer. As discussed in Chapter 3 the literature describes the concept of the ‘normalisation’ of life with HIV. Moyer and Hardon (2014) describe how various medical, policy and institutional discourses have aimed to reframe HIV as a chronic disease like any other. This concept of ‘normalisation’ is characterised by the provision of routine medical treatment and regular visits to clinic to receive anti-viral medication and have blood tests. It is therefore clearly situated within the health systems domain. Mazanderani and Papparini (2015) outlined some of the challenges to this ‘normalcy’ which came from wider societal influences including socio-economic hardship, ill health, stigma and discrimination. The observation data in this study was collected within a different health systems context: that of being treated for cancer and the following analysis aims to characterise any challenges drawn from the observation and discussion with healthcare professionals that undermine HIV positive patients’ ability to experience the service like others. One view expressed by a couple of the healthcare professionals I interviewed was that by treating people with HIV separately as ‘special cases’ you would be doing them a disservice and they might miss out on the best care at oncology centres of excellence. Within their argument the benefit of being treated as part of the oncology service was framed in the language of medical management and equitable treatment outcomes, it did not acknowledge any of the wider social issues which may influence the delivery and experience of cancer care. The following section presents themes from the observation data exploring the extent to which people with HIV are treated for cancer in the same way as those without HIV and identifying the particular challenges and tensions that exist for them within the healthcare setting.

#### **Stigma**

We have seen from the earlier newspaper analysis in Chapter 5 that HIV retains negative and stigmatising connotations which are presented in popular newsprint and are part of the wider social context. The participant interviews (Chapters 7, 8 and 9) also featured HIV-related stigma as a theme which dominated personal decisions around disclosure with many people managing information about their HIV status for fear of rejection and discrimination. The healthcare setting also provided evidence of the influence of HIV-related stigma. Healthcare professionals

demonstrated awareness of societal attitudes that perpetuated this stigma and in a more subtle way used language which incorporated notions of difference and on occasions implied a degree of judgement. Examples of this are provided in the following section.

### **Awareness of societal HIV related stigma**

Many of the healthcare professionals recognised the existence of HIV related stigma in society despite the advances in treatment:

the treatment has come on leaps and bounds but it's the perception of it and there's still some people still see it as dirty' (P7 Nurse, Haematology/Oncology service, Site 3)

One nurse described an emotionally-charged situation with a patient who disclosed his HIV status to a close relative when he was very sick with his cancer diagnosis shortly before he died. His family member discovered that this was an HIV related cancer and held the ex-partner responsible for his death. This illustrated to her the extent to which HIV can be framed differently from other co-morbidities that cancer patients may have. In this example the grieving family member openly blamed an individual who they believed had caused their relative's death. This powerful accusation seemed to suggest some sort of intent and deliberate action on the part of the ex-partner, a clear wrong that did not allow for likely complexities, and all the information they could not know about someone else's intimate relationships. Healthcare professionals seemed very aware of the stigmatising nature of HIV and its association with danger, blame and judgement.

Healthcare professionals also acknowledged an area within cancer services that involved treating people living with HIV differently and potentially discriminating against them; namely, their exclusion from cancer clinical trials. Staff from both the oncology services and HIV specialist services commented on this. With cancer treatment entering a new era of personalised medicine, clinical trials were sometimes the only way that patients could have access to promising targeted and biological therapies for potentially incurable cancers. Within HIV services staff felt this exclusion was unfair, with one nurse highlighting the contradiction in the idea that HIV is a 'normal' chronic illness whilst denying patients the option to participate in a trial which may be their only option for further treatment:

I think people have accepted that HIV is a chronic illness, then yes I think it's wrong. I think it's wrong because we've had occasions where we've had patients where we couldn't offer them any more treatment,

where the only treatment available is a trial..... (P7 Nurse ,  
*Haematology/Oncology service, Site 3*)

An HIV clinician stated that there was no evidence to show that people whose HIV viral load was undetectable on antiviral therapy had any worse outcomes than people who were not HIV positive, therefore there would be no additional risk to including them within the trial. An alternative view was offered by an oncologist who believed there to be sound sampling reasons behind this, in that there were very small numbers of people with HIV who could be included. An oncology nurse specialist supported this view and did not believe that HIV was being singled out as an exclusion. She described other chronic illnesses which were also treated in the same way:

I understand why trials exclude HIV, they want a comparable outcome. Having people with HIV makes the comparison unreliable. There are so many other exclusions in trials, a long list: rheumatoid arthritis etc so it's not just HIV (P1, Nurse , *Haematology Oncology Service, Site 1*)

Even with the proffered scientific justifications for not including HIV patients in clinical trials, it was clear that some healthcare staff felt this was unfair and we have seen in the participant interviews that they themselves framed and felt this as discrimination (see Chapter 9, 9.3.2). It was therefore an area of tension which emphasised the perception of difference for individuals who were HIV positive within the cancer treatment setting.

### **HIV related stigma amongst healthcare professionals**

Unsurprisingly there were no overt statements that revealed discrimination on the part of the healthcare staff who were interviewed. There was however, evidence in accounts of extra care being taken and special infection control precautions being adopted. Staff are trained to treat all body fluids with the same 'universal precautions' in the wearing of gloves, aprons etc to ensure that they are protected from infections that may not be known. One practitioner described a situation he had witnessed where extra precautions were being taken with a patient who was HIV positive:

one of the patients bleeds quite heavily when they have procedures, they have a PICC line fitted and that was bleeding.....so another nurse cleaned it up and she was hurried over to a corner by another nurse to tell her this patient has HIV and be careful.....but really you should be careful with any patient (P5, *Allied Health Professional, Oncology service, site 1*)

The language used to talk about patients with HIV was also revealing in the way that it was used to link HIV with generalised groups of people and behaviour that could be judged in moral terms. One nurse described a patient who went out to clubs after being discharged from hospital and linked this to promiscuous behaviour, although it was not clear that this was something she had been specifically told:

he used to when he was discharged, go out clubbing and you know do all the things that gay men do, promiscuous and his chest was really bad....and he smoked like a trooper (*P6, Nurse, Haematology inpatient ward, Site 1*)

Another staff member revealed their own judgements of innocence and guilt in relation to HIV in a statement where they were ostensibly berating others for linking HIV to 'bad behaviour':

I think there is still an assumption in society that HIV is a consequence of bad behaviour or all of that sort of madness. So, you know, people don't actually think this poor woman might have contracted HIV because her husband had sex with someone else (*P4, Nurse, Haematology/Oncology Service, Site 1*)

This healthcare worker implied that there are gradations of blame. Rather than having sympathy for all people who are HIV positive regardless of how they became infected this example indicated a belief that there are particular cases where people who are not seen to have played a part in their infection are more deserving of compassion. At another point in her interview she also talked about blame associated with lung cancer and described reported anger from patients' relatives and their difficulty with their own feeling that the patient was responsible for their situation by smoking. This appears to be the only example in the interviews of a cancer that had some blame and stigma associated with it, a position that has been supported in the literature with Rohan et al (2016) describing lung cancer patients' perceptions that they had less public support and were blamed for their condition.

In summary, HIV related stigma was recognised by healthcare professionals in the cancer setting as a feature of society which impacted on patients and their families. Exclusion from clinical trials was also identified by staff as an area where patients were treated differently, although justifications were also given for this. More subtly, some healthcare staff revealed in their language and in some practices that they viewed HIV positive patients as potentially more dangerous than others in terms of infection risk and at times associated them with behaviour that was deserving of blame. These tacit views suggest some under-the-surface tensions in the ability of

staff to treat cancer patients with HIV in the same way as everyone else. Another scenario in which differences appeared more stark and tangible was evident in the problems that staff encountered around disclosure of HIV status in the treatment setting. Here, these occasionally resulted in challenges to providing safe care and this will be explored in the following section.

### **Healthcare professional issues around patient disclosure of HIV**

In settings such as wards or day care units where cancer treatment was administered healthcare workers described 'confusion and secrets' as a feature of some of their interactions with patients who did not want the visitors present at their side to know their HIV status. They did not always express empathy in relation to the patients' wishes to protect information but talked more in terms of the impact on their established working practices. The pressure to protect patient confidentiality could make staff feel worried and inhibited from talking freely to their patient whilst delivering cancer care and this could potentially affect the quality of this care. This situation was experienced in both specialist HIV services and oncology services but oncology staff felt less prepared to deal with it. One nurse described a situation where complicated instructions in handover about people who did or did not know a patient's HIV status had the effect of closing down their communication with that patient completely:

It is made a point of in handover, they don't want anyone other than you know one or whoever, to know. And then often you wouldn't know who the person they would want to know is.....so I found myself not discussing anything really (*P6, Nurse, Haematology inpatient ward, Site 1*)

This chimes with my own experience when interviewing patients on the ward. I felt a constant need to be vigilant about who was in the vicinity and how much could be said without being overheard. Even the patient information sheet which I gave to patients who I was planning to interview had to be handled carefully and folded to obscure the HIV lettering on the front. On one occasion, a patient who had been given this information sheet panicked and quickly ripped it up when someone knocked on the door to visit him. This created an environment which was not conducive to open communication. One staff member recounted a situation where a patient had a friend who did not know his HIV status who never left his side whilst he was an inpatient. This made any discussion about HIV medication or the level of his immune function very difficult and in a busy environment these discussions could just be omitted. The safe administration of HIV medication was an area that

was highlighted as potentially difficult in this environment of secrecy. A nurse described how she had to behave in a way that was outside usual medicine management procedure in order to protect confidentiality:

It's very difficult because you have to go in and give the drugs and if you're being 100% um...what's the word...sticking to policy procedure, you're supposed to go...what's your name? date of birth? I am giving you this and this for this....but they don't want their family to know what is wrong with them (P6, Nurse, Haematology inpatient ward, Site 1)

Medicine policies that have step-by-step procedures to ensure the right medication is administered to the right patient were being adapted to circumvent concerns about breaching confidentiality. Although there were no reported errors resulting from this, the nurse did acknowledge that she was missing an important checking stage in a process designed to eliminate administration mistakes. The oncology services observed were busy and time pressured, relying on standardised processes, checklists and protocols to ensure safety and efficiency. This worked well for the provision of cancer treatment where medications and treatment plans could be openly discussed, but this system did not easily adapt to account for individual sensitivities and complexity around information and protecting confidentiality. Several members of staff and patients described occasions when GPs had been informed of someone's HIV status as part of the routine past medical history section of the discharge letter. This was another example of the usual procedure and protocol not taking into account special circumstances. Within the HIV specialist services, staff provided similar examples of issues around disclosure; they still experienced problems but appeared to have a bit more time and were better prepared and practised at having conversations with patients about anticipating and pre-empting difficult situations with visitors who may not know about the HIV diagnosis.

### **Varying levels of awareness regarding the impact of felt stigma**

Healthcare professionals involved in giving cancer treatment to people with HIV appeared to understand the reasons why patients did not always want to share their status with family and friends and they provided examples of societal stigma that explained this. Scambler and Hopkins (1986) described felt stigma in the context of people living with epilepsy as the anticipation of actual discrimination which also encompassed a feeling of shame. Healthcare staff showed less understanding of the impact of felt stigma and this was vividly demonstrated by an experienced HIV clinician. He reported having held many conversations over the years with patients

who were unhappy with the interactions they had with healthcare professionals outside HIV services. Often their distress was caused by ill-judged attempts to talk about HIV in a bid to be friendly and normalise the situation. He argued that healthcare professionals outside of HIV services did not appreciate the level of sensitivity and hyper vigilance which patients carried around with them and instead of putting people at ease, found that their approach caused upset. The HIV clinician described this sensitivity in powerful terms, likening having an HIV diagnosis to something deeply personal such as an experience of rape or domestic abuse. In the same way that talking about such trauma could cause anxiety and distress, talking about HIV could be upsetting; it could not be made 'normal'

It's not normal...people who've got HIV don't like talking about it. They haven't got it normalised within them....they've got it all nice and buried. There's this belief that you have these nice chats with people, you're chatting about it as if you're chatting about a soap opera you watched last night. If you don't do it with rape, you shouldn't do it with HIV (P2, Doctor, HIV services, Site 1)

The clinician thought that many such conversations were well meaning but unnecessary. The staff may have believed that they were breaking down barriers and showing their acceptance and ease with the situation but the HIV clinician informed by years of listening to his patients, found that this approach was often misguided.

I have a lot of patients who say this is the only....when they come to see me in the clinic, maybe once or twice a year, it's the only time they ever talk about the HIV. I mean they're getting on fine. But then all of a sudden they're bombarded by talk about it if they get another health problem, more so than they would want

In his opinion, conversation about HIV in the cancer setting could be limited to one simple discussion about HIV drugs and their potential interactions. This sensitivity about unnecessary conversations initiated by healthcare professionals was also evident in some of the participant interviews, as in the case of one woman who described an unwanted exchange with a doctor who thought he was complimenting her by expressing his surprise about her HIV status. Oncology staff did not appear to appreciate this sensitivity, conversely believing they were being accepting by discussing the subject conversationally. This situation was not reported in the specialist HIV service; staff were described by patients as being more knowledgeable about both conditions and appeared to be more trusted. The HIV clinician interviewed felt that this situation was further exacerbated in the oncology setting when staff revealed to patients that they did not know very much about HIV

generally and antiviral treatments in particular and this will be discussed in the following section.

### **Oncology healthcare professionals don't always seem to know much about HIV**

The observation data showed that there was a widespread lack of basic knowledge on this topic particularly in oncology services and this could contribute to patients feeling unsafe. If patients did not appreciate staff talking about HIV unnecessarily, they felt worse when the people looking after them talked openly about not knowing anything about it. An HIV specialist reported how patients could experience a loss of trust in their medical management because of this apparent ignorance:

And they're saying that they can't pronounce the (HIV) drugs and you'll have to get them all sorted out and the patient feels that the person doesn't seem to know what they're doing, it makes them lose confidence about the whole treatment programme (*P2, Doctor, HIV services, Site 1*)

This is consistent with the findings from participant interviews presented in Chapter 9 (9.2.1) in which patients were taking on the responsibility for checking whether their HIV drugs would interact with cancer therapies themselves because they did not have confidence that the cancer teams had the knowledge to manage both conditions. Many of the staff interviewed who worked in oncology services admitted to not knowing much about the HIV medicines and acknowledged that this could affect their ability to provide holistic care during cancer treatment. For staff accustomed to being experts in providing advice this lack of knowledge could feel unfamiliar and be experienced as potentially undermining to their sense of professional status. One nurse stated how she felt a loss of control in caring for patients when there was an aspect of care that she did not understand:

I definitely don't know if the drugs are doing what they're meant to be doing...with the antiviral drugs I honestly haven't got a clue. And I feel a loss of control over that in some ways (*P6, Nurse, Haematology inpatient ward, Site 1*)

In the interview accounts it appeared that where cancer treatment was administered outside of HIV specialist services, therapy for both conditions was often given according to a silo mentality with little evidence of communication between the two specialities. When cancer treatment was being given by people who openly professed their ignorance about HIV this could make patients feel insecure and personally responsible for their own care. It was also frustrating for the healthcare

workers who expressed unease at their lack of knowledge. There were several examples of poor communication between the services, with oncology staff not aware of who to contact with any concerns about a patient's HIV management. The onus seemed to be on the patient to relay information between the two. In cases where patients had mental health issues or difficulty communicating then liaison between services might not happen at all. The HIV specialist clinician described a situation when one of his patients was not able to drive this liaison between services and this meant that she had been very anxious about her HIV throughout her cancer treatment but had suffered this alone:

she had cognitive impairment from her HIV and self-esteem, depression in the past so really wasn't in a position to do that (*drive the liaison between the two services*)....but spent a lot of time being worried about her HIV...but I wasn't aware(*P2, Doctor, HIV services, Site 1*)

A contrasting situation where communication was maintained and led by staff was in evidence when cancer treatment was given within HIV specialist services. There were many examples of healthcare professionals taking on this responsibility for managing the exchange of information between their unit and other external services, for example surgery and radiotherapy. One specialist nurse explained how even when their patients were receiving treatment elsewhere, for example the work up for a transplant, she kept in constant touch with them and continued to manage aspects of their care such as blood tests and maintenance of any central lines. Even when they were receiving treatment at the other site they kept in touch with her in what appeared to be a very close relationship:

whilst they do the work up, generally patients still come back here because they've been here for so long so they still have their weekly line care and bloods done here and a catch up, then get admitted there and I get emails all through and pictures of everything and then once they're done they come back to us (*P7, Nurse, Haematology/Oncology service, Site 3*)

This care came from her understanding that patients needed support from a trusted source and a sense of responsibility to ensure that all was running smoothly. This nurse explained that cancer care for patients with HIV could not be easily standardised; checklist questions about side effects during chemotherapy did not take into account the mental toll and vulnerability of their situation and for this reason she remained closely involved in their care even when it was conducted by other services. This could be seen as an example of patients being treated as 'special cases' based on a view that patients with HIV should not be treated for cancer like everyone else. It did, however, seem like a very resource intensive

approach that still could not prevent some of the problematic issues discussed earlier from occurring when patients inevitably had to receive parts of their care from outside services.

#### **10.3.4 Summary of the observation data findings: the healthcare context of a dual diagnosis**

Observation and informal interviews took place in various cancer treatment settings which fell into two broadly distinct categories; those HIV specialist services where cancer treatment was given by staff with training and experience in HIV care, and oncology services where the staff were exclusively from an oncology background. The HIV specialist services did not treat the same volume of people for cancer on a daily basis, on the whole they were more informal and relaxed and staff got involved with lots of aspects of patient care including coordinating treatment and keeping in touch with them when they were being seen elsewhere, providing a more holistic approach. Healthcare professionals within this service seemed to have a better understanding of the influence of both societal and felt stigma and were more confident in handling the complexities of disclosure issues in the clinical setting. They did however recognise that patients were very dependent on their service and that they took care of issues that were not always strictly within their remit, this type of service was only feasible due to the small numbers of patients it involved. The staff in the specialist services did not seem to subscribe to the idea that HIV could be managed in the same way as any other chronic disease and provided care which went over and above that which was offered in more general cancer care.

In contrast, the oncology service had a much larger throughput of patients and people with an HIV diagnosis were a small proportion of this. The staff here were more time-pressured and had a shorter time to devote to each patient, the system was organised to be efficient and gave the patient more responsibility in ensuring that they attended different departments for blood tests and checks. This type of service did not always provide the most holistic type of care but it signposted other services such as the Macmillan Support and Information Centre for additional support and it had the advantage of oncologists with lots of specialist cancer experience and cutting edge facilities that focused on good treatment outcomes. When it came to HIV treatment the oncology healthcare professionals were not always knowledgeable, and some described that they felt this as a barrier to providing comprehensive care. It could be argued that if HIV were a chronic illness like any other then patients should be treated in the same way as other people with

co-morbidities within the oncology services. Themes developed from the observation data highlighted some tensions and contradictions within this argument. Not only did staff feel that their knowledge about HIV treatment and care was sometimes lacking, they did not always know where to get this information from, and subsequently the responsibility for liaising between the two teams was left with the patient. One could argue that similar situations might occur in conditions such as diabetes or rheumatological conditions in terms of staff not having knowledge about the treatments and management. What was strikingly different however, was the environment of 'confusion and secrets' that characterised people's personal situations regarding disclosure of their HIV status and the sensitivity that they felt about HIV being discussed generally. The deeply personal nature of this information was not always appreciated by oncology healthcare professionals and not accommodated within services that were geared towards efficiency; this most of all undermined the argument that people with HIV could experience cancer care in the same way as others.

## **Chapter 11      Thesis Discussion and Conclusions**

### **11.1 Introduction**

This thesis provides a compelling depiction of the experiences of a dual diagnosis of HIV and cancer. The data, when brought together from the different perspectives, showed that these experiences were characterised by layers of challenge and difficulty. Some of the challenges were easily visible, such as the toxic side effects of cancer treatment. Many others were buried below the surface, as in the case of powerful felt stigma relating to HIV which influenced how people accessed support, and perceived and experienced care within cancer services. The presentation of these challenges in this discussion makes a persuasive case that patients with a dual diagnosis do not receive the same experience of care as those who have cancer alone. This work therefore highlights an important area which has implications for the improvement of services. This chapter will begin by providing a table of the summary of key findings from across the data presented in Table 11-1. It will then move on to a discussion which will begin with an overview of the relevant underpinning theoretical themes before moving on to discuss their translational importance in the context of the study data and key findings. It will explore the ways in which theory is relevant to, and impacts on, practice in the access and experience of cancer care. The study's limitations are then presented followed by a discussion of the implications for improving the cancer care for this growing cohort of people living with HIV.

**Table 11-1 Summary of key findings from across the data**

Research Question
<p><b>To understand how HIV and cancer are represented in popular discourse and examine any links between these discourses and patient accounts</b></p> <ul style="list-style-type: none"> <li>• The conditions of HIV and cancer are presented very differently in popular representations within newspaper articles.</li> <li>• Cancer stories are more common, they include metaphors of courage, evoke sentiment and idealised human qualities deserving of sympathy and downplay negativity and complexity. Cancer could happen to any of us is the underlying sub-text</li> <li>• HIV stories are less common and frame it as an external phenomena affecting 'others' with the potential to be dangerous. They include sensational language around behaviour and lifestyle, link HIV with criminality and debate the issue of deservedness around funding. HIV happens to other people and retains negative and stigmatizing connotations.</li> <li>• Some of the language and stigmatising features of popular discourse about HIV were reproduced in both patient and healthcare professional accounts. Anticipated rejection based on similar views was used as a reason not to disclose their HIV status</li> <li>• News of a cancer diagnosis was shared and more frequently talked about with others by patients who recognised that they would get sympathy and support in response</li> </ul>
<p><b>To consider the meanings and understandings that people associate with a diagnosis of HIV</b></p> <ul style="list-style-type: none"> <li>• An HIV diagnosis had a powerful impact regardless of its timing in relation to the introduction of antiretroviral treatment.</li> <li>• Patients used stigmatising language to talk about it and connotations of death and hopelessness from the 1980's and early 1990's persist to the present day.</li> <li>• HIV treatment was not very disruptive</li> <li>• It is now a medically well managed, stable condition but one which has to often be kept secret for fear of rejection and discrimination</li> </ul> <p><b>To consider the meanings and understandings that people associate with a diagnosis of cancer</b></p> <ul style="list-style-type: none"> <li>• A cancer diagnosis had a powerful impact which was linked to the prospect of invasive treatment and uncertain prognosis</li> <li>• Cancer is socially acceptable, widely discussed and deserving of sympathy</li> <li>• Cancer treatment can disrupt daily life and alter appearance</li> <li>• Patients held a variety of beliefs about what caused cancer, sometimes offering personal and emotional explanations situated within their own life story</li> <li>• A serious potentially life threatening condition which is relatively easy to talk about and gain support for</li> </ul>

**To consider the meanings and understandings that people associate with a dual diagnosis of HIV and cancer**

- There are some differences of experience relating to timing of HIV diagnosis
- Those diagnosed with HIV in 1980s and 1990s before effective HIV treatment were survivors, often incorporating a strong and lasting HIV identity, cancer seen as just another challenge within this narrative
- For those with a synchronous dual diagnosis, cancer was seen as the immediate life threatening problem with HIV in the background, although not insignificant
- The largest group were diagnosed with HIV in era of effective HIV treatment some time before their cancer diagnosis. They maintained a surface continuity following their HIV diagnosis, managing information and foregrounding valued identities, including those related to their acceptable cancer diagnosis, to avoid blame and rejection. Cancer could provide an opportunity to share and get support although there were societal conditions about talking about it in a positive way. If cancer was very physically debilitating all the work could get too much and patients could become totally isolated

**To interpret patients' accounts of negotiating the complexities of their medical treatment and engaging with healthcare services**

- Patients worried about the management of their HIV during cancer treatment and often took responsibility for aspects of it, such as checking contraindicated medication
- Cancer treatment was felt to be complex and the language hard to understand and it was delivered in a more formal environment than they were used to
- Patients described a lack of fit with the cancer services, they talked about being excluded from cancer clinical trials and described tensions relating to the role of the GP

**To consider the expression of links between meanings and illness and the mobilisation of wider social support**

- Patients acknowledged societal stigma relating to a HIV diagnosis and used some of the same language as popular representations in newspapers linking it to blame and shame in their own accounts. Many kept their diagnosis a secret from their families and friends to avoid anticipated rejection and carried the burden of this alone
- Patients understood that cancer was socially acceptable and deserving of sympathy in popular discourse. They shared their cancer diagnosis much more widely with family, friends and work colleagues and received a supportive response. There were however societal conditions which meant that they were expected to avoid negative or distressing details relating to their cancer diagnosis. They therefore also managed information about cancer accordingly

**To consider the features of the healthcare setting in which HIV positive patients engage with services relating to their Cancer diagnosis**

- The study collected data from two different settings: the specialist services where staff administering cancer treatment were also HIV trained and the cancer services where staff were solely trained in cancer
- The specialist setting was more informal, provided more examples of holistic care and saw small numbers of patients
- The cancer setting was more formal and hierarchical, large numbers of patients were seen in a busy and time-pressured environment
- Healthcare professionals were aware of societal stigma. They did not express any overt stigmatising views of their own but there was evidence of extra infection control precautions being taken. Some used language suggesting they believed in a scale of deservedness for people's HIV status based on how it was contracted
- Healthcare professionals felt inhibited by patient wishes to keep their HIV status secret from family and friends who accompanied them and did not always empathise with their concerns. This could restrict open communication and interfere with some processes designed to ensure safe administration of medication
- Some oncology healthcare professionals admitted that they did not know a lot about HIV and its treatment and this could make them feel insecure. Cancer treatment was given in its own silo and although additional support was signposted, the onus was on the patient to access it
- When cancer care is given in a HIV specialist setting healthcare professionals revealed that they felt responsible for many aspects of their patients' care beyond the delivery of cancer treatment

## **11.2 Discussion of the Relevant Underpinning Theoretical Themes in the Understanding of a Dual Diagnosis of HIV and Cancer**

### **11.2.1 HIV today: the normalisation discourse and its problems**

HIV is now a condition which can be managed easily with a treatment taken once a day. This treatment is minimally disruptive and routinely managed with six monthly visits to the clinic for blood tests to monitor the immune system. Providing the treatment is adhered to, people with HIV can expect to have the same life expectancy as those without. Furthermore, the 'Undetectable = Untransmittable' (U=U) consensus statement based on recent evidence (Rodger et al 2016, Cohen et al 2016) has provided a clear message that a person with sustained undetectable levels of HIV virus in their blood cannot transmit HIV to their partners. This statement has been endorsed by many HIV professional associations who have encouraged its dissemination in the belief that it will help reduce stigma caused by fear of infection. Moyer and Hardon (2014) have described a 'normalisation' discourse in which various medical, policy and institutional discourses have aimed to reframe HIV as a chronic disease like any other because of all of these features that make it easy to manage in the present day.

The findings of this study make it clear that despite these advances in medical management and the ease with which it can be treated, HIV continues to carry a huge impact. The newspaper articles which focused on danger and risk in relation to people with HIV rather than featuring stories on developments of HIV science or education illustrated how popular knowledge is out of date and out of sync with progress. Thirty years on from the days of the AIDS crisis when the media exploited deep-seated anxiety about sex, disease and death with TV commercials featuring dire warnings and apocalyptic images of tombstones (Rhodes & Shaughnessy, 1990) these are the associations that many people still retain despite the fact that most now live a healthy life with HIV and cannot transmit the virus to others. Whilst people were able take their HIV treatment without too much disruption to their daily life, this study found evidence in the language used and the views expressed by both patients and healthcare professionals of the persistence of social attitudes framing HIV as dangerous and blameworthy. Thus, although HIV could be kept hidden and unobtrusive, awareness and internalisation of these societal attitudes wielded a real impact on the experiences of cancer care for people living with HIV.

This study therefore adds weight to the findings within the literature describing tensions within the normalisation discourse and the 'haunting' of the present day by previous representations of HIV as a lethal killer (Flowers 2010, Mazanderani and Papparini 2015), and it goes further in describing the impact of this within the cancer healthcare setting. The persistence of HIV related stigma lies at the root of this failure to 'normalise' the condition and the next section of this chapter discusses the theoretical themes around stigma which are relevant within the context of a dual diagnosis.

### **11.2.2 HIV-related stigma**

HIV has several characteristics which make it stigmatising. Being HIV positive can be thought to be the result of personal irresponsibility or moral fault and is often associated with behaviours evoking social disapproval (such as same sex relationships, promiscuity or injecting drug use). It is an incurable condition which is still believed by some to be fatal, and as an infectious disease is therefore dangerous to others, although the risk of this danger is often overestimated (Herek, 1990).

All of these characteristics were in evidence in the language and views expressed across the study data. The study revealed that although there were a few examples of overt discrimination, which were more commonly experienced in the smaller oncology services, on the whole HIV related stigma was more likely to manifest itself as a more subtle unspoken pressure experienced by the patients as a powerful felt stigma. This sense of shame and anticipation of encountering discrimination was a common theme which influenced the study participants' behaviour by making them constantly aware of their HIV status and reinforcing their belief that its disclosure had the potential to cause damage and discredit them. It resulted in many people working hard to keep their HIV status a secret and worrying about it being revealed in an unfamiliar oncology setting. These findings are in keeping with Scambler and Hopkin's work on epilepsy (1986) of 30 years ago which described how felt stigma led people to deny themselves full engagement in society and affected their relationships, lifestyle and work. Felt stigma's very prevalent presence in the study data attests to the 'invisible' and below the surface nature of the tensions associated with HIV despite advances in its management. These unseen tensions stand in marked contrast to the universality of talk about, and social acceptance of, cancer which appeared by contrast a very socially visible condition

### **11.2.3 Selective disclosure**

Other studies have described the experience of dual diagnosis of HIV and other conditions. As Daftary (2012) and Lekas et al (2011) describe in their accounts of dual diagnosis of HIV and tuberculosis, and HIV and hepatitis C respectively, selective disclosure of information is adopted to manage stigma. Participants in both studies aligned themselves more strongly with, and shared more information about, the illness they felt to be less discrediting and more socially acceptable, with far greater caution being applied to information about their HIV diagnosis.

The findings of this study also illustrate that the technique of selective disclosure, favouring the sharing of information about a cancer diagnosis in order to access support, is a strategy which is adopted within a dual diagnosis of HIV and cancer. For the woman gaining valued support during her cancer treatment from her church there was an unresolved tension in accepting that support, as she anticipated that it may be compromised if her fellow churchgoers knew the full story. The man who described acting as an ambassador for people with cancer by being open about it with work colleagues justified not telling anyone about his HIV status by saying that they would be scared by it. He also did not tell his family because he felt they would blame him for being reckless and he concluded that they would be right. This study demonstrates that many people with a dual diagnosis were constantly working extremely hard to manage information and were often withholding aspects of their life to avoid anticipated rejection; this work took a huge emotional toll. They seemed certain that disclosure of the less socially acceptable condition would lead to rejection and a withdrawal of support.

### **11.2.4 Cancer's visibility: opportunities for accessing support but with conditions**

As alluded to earlier, cancer as a condition is widely visible and socially acceptable. The popular representations of cancer in newspapers revealed that talk about cancer is everywhere, it is considered largely blame-free and deserving of sympathy and this social context was recognised by participants who shared information about it, often widely. Sometimes this was the first time they had felt able to share information about themselves and expect a supportive response, and

on more than one occasion their cancer diagnosis was described as being a 'relief' as it opened up avenues of communication and a chance to receive sympathy.

The nature of stigma as it applies to cancer is different in nature to that associated with HIV. Knapp et al (2014) described how cancer-related stigma has declined over time and is now more subtly related to characteristics such as perceived controllability (for example lung cancer being caused by smoking) and by how visible the effects of the disease and treatment are on the person. Although its visibility meant an opportunity for sharing information and getting support from others, this visibility is not always positive particularly when it applies to altered personal physical appearance and this suggests a more complex and nuanced picture in relation to this theme. One of the most overt and visible challenges of a dual diagnosis was the physical limitation of the cancer itself: the debilitating symptoms, the toxic side effects from treatment such as nausea, pain and fatigue, all of which interfered with activities of daily living. Participants described physical changes, such as scarring from surgery, having to have a colostomy, and the experience of losing their hair, in terms which left no doubt about their traumatising impact. These changes and the physical toll of cancer reached a peak during the treatment period when participants often reached the limits of their mental and physical resources. At this time when they were exhausted they may also be feeling responsible for making sure their HIV treatment was taken into account and continuing to keep information about their HIV status secret. This combination of visible and invisible pressures created an acutely difficult situation which was emotionally draining and could result in complete social isolation as a response. This will be discussed in more detail in the context of the study data later.

Whilst it was possible to share a cancer diagnosis and expect to receive support, talking about cancer was not without its own set of rules. The literature has described the social prohibitions that required cancer to be discussed in positive courageous terms steering clear of distressing details. Newspaper articles used military metaphors such as being brave and battling the condition which could have the effect of making people who did not respond to treatment feel as though they had failed.(Reisfield and Wilson 2004). Wilkinson and Kitzinger (2000) found that positive talk about cancer served as a conversational idiom, it allowed a 'lightening' of unpleasant experiences or negative emotions and allowed the conversation to move on.

This study found that people with a dual diagnosis of HIV and cancer were at times editing the amount of information they shared about their cancer, presenting a censored version of their experience and putting a positive gloss on it in order to prevent others becoming distressed. An extreme example of the extent to which information could be managed to provide an acceptable representation to others was provided by one man whose family lived in a distant country and who were unaware of either his HIV status or his cancer diagnosis. When chemotherapy caused his hair to fall out he posted historical photographs of himself on social media from a few months previously when he had hair, thus presenting a public image to his family that completely belied the reality of his situation.

This example highlighted the extent to which he felt compelled to present an acceptable self-image and how much he was bearing the burden of his situation in utter isolation. The careful management of information relating to self-presentation and also in talking to other people about cancer added yet another pressure. When combined with the physical challenges of cancer and its treatment and the ever present worry about HIV, its management and its potential to discredit, there was the creation of a perfect storm of tensions which made this group of patients uniquely vulnerable. The next section of this chapter will explain why all of this matters from a healthcare perspective and will explore how these tensions were translated into practice. For people living with a dual diagnosis of HIV and cancer these difficulties had a tangible impact on their experience of cancer care. This study contributes to an understanding of this impact which will enable the identification of potential areas which can be improved to better address this group's particular needs.

### **11.3 How Do These Themes Translate Within the Experience of Care?**

This section presents the argument that these themes dealing with both the visible and invisible pressures facing people with a dual diagnosis have a real translational importance and implications for their experience of cancer care.

As outlined in Chapter 10 which presented data drawn from the healthcare context there were two broadly different settings which were observed within this study: specialist services where the staff administering cancer treatment were also HIV trained (termed as specialist HIV services) and those cancer services where staff were solely trained in oncology (termed as oncology services). Not surprisingly staff

knowledge about HIV and awareness and understanding of issues around stigma was greater within the specialist HIV services as compared with the more general oncology services. However, even within this service societal stigma impacted upon patients' experiences, and patients being treated there still had to access aspects of their treatment (such as surgery or radiotherapy) from other more general oncology settings. The findings are therefore relevant within the context of both types of service provision.

Before moving onto the discussion about the translational importance and relevance of the theory it is important to consider the particular nature of the sample group of participants who were interviewed within the study. These were the accounts of people who were in some cases very sick, six of whom died not long after being interviewed. This was not something I had anticipated at the outset but as it turned out this study provided a privileged insight into a group of people whose voices are not normally heard. I was struck by how many lacked any family or peer support and were undergoing their cancer treatment on their own; they seemed a marginalised group some of whom faced the additional social disadvantages of being migrant or gay. Social isolation and a lack of social networks to help them was one tangible consequence of powerful felt stigma which impacted on the experience of care and this will be discussed further below.

### **11.3.1 Social isolation**

Lee et al (2002) demonstrated that social isolation was one consequence of high levels of internalised stigma amongst people who were HIV positive. The data from this study contained many examples of people who were socially isolated. Many of the interview participants described a system of social support which was complex and relied on the management of information including selective disclosure. Some had lost their partners in the 1980s and 1990s and remained single; others had moved to the UK leaving behind families in far away countries who were completely unaware of their HIV status and in some cases their cancer diagnosis too.

Social isolation seemed particularly acute and marked during the period of cancer treatment when the physical toll of cancer meant that people simply did not have the energy to carry the burden of managing information; it seemed easier to retreat completely and get through each day at a time. One man borrowed a friend's dog for company and spent the period when he was undergoing treatment away from his usual social group of friends whom he associated having 'fun' with. Another man

played endless video games at home to the extent that he ended up dreaming about them in an effort to get through the side effects of chemotherapy and to protect himself from others comments about his changed appearance and hair loss. Many of those interviewed spoke about lack of contact with their families and the difficult prospects for meeting potential partners, and during treatment their loneliness was particularly marked.

The literature shows us that both HIV and cancer are illnesses where social isolation has a negative impact on outcomes and quality of life (Kroenke et al, 2006, Lutgendorf et al, 2012, Ware et al, 2006). A survey conducted by Macmillan Support in 2013 found that cancer patients who were socially isolated were more likely to skip meals, miss appointments and not collect prescriptions, all behaviours with the potential to adversely affect the success of their treatment (Burki, 2013). Although this study did not seek to find particular examples of this type of information, many individuals were very distressed and anxious during their cancer treatment and were dealing with this alone. It is possible that in some of the cases where participants were lost to follow up, this could have been driven by this anxiety and distress. Longitudinal interviews within this study revealed that it was possible to emerge from this acute phase of cancer treatment and resume the work entailed to manage information; however, there could be long lasting effects from the cancer itself or its treatment which placed long-term limitations on people's lives. Societal stigma and personal experience combined to characterise a particular vulnerability amongst those with a dual diagnosis with social isolation being one significant consequence. Within the healthcare context there were other tangible consequences of the group's difference and vulnerability and these will be discussed in the following section.

### **11.3.2 Experiencing a sense of difference in the cancer healthcare context**

The study data provided examples of people with a dual diagnosis feeling out of place in cancer services because of their HIV status and indicated occasions when their care was adversely affected. This was due in part to the way services were structured but also to a combination of lack of knowledge and information about HIV on the part of cancer healthcare professionals. All of this was set against the backdrop of the influence of societal attitudes and stigma.

When patients were excluded from participation in clinical trials and therefore denied their only option to receive a new cancer treatment, and when there was an unquestioning expectation that they would be happy to use GPs to access cancer supportive care, it was clear that cancer services were not structured to meet the particular needs of people living with HIV. Communication between cancer and HIV healthcare teams was often disjointed, with the onus of the patient to drive the liaison at a time when they were likely to be feeling the most unwell and vulnerable.

Cancer healthcare professionals freely admitted that they did not know much about HIV medication and often relied on the patients' own knowledge or ability to go and find out from their HIV team. Having witnessed a patient taking it upon himself to ring a pharmacist to check his cancer medicines and heard participants talking about their sense of responsibility to be vigilant about this, it was clear that the onus was often being placed on the patient to avoid potential drug interactions between HIV and cancer treatment.

It has been recognised within the literature that due to the overwhelming complexity of the treatment and the language, many cancer patients prefer less active participation in medical decisions (Ernst et al 2011). May et al (2014) described a situation within some areas of health services in which in response to growing populations with long term conditions, 'work' such as that aimed at managing symptoms has been delegated to patients, founded on ideas of self-care and self-empowerment. Some of this work can place demands on patients that they experience as burdens and which have the potential to overwhelm them, particularly if they do not have social networks to share the work. This study showed that people with a dual diagnosis were feeling the responsibility of ensuring that their HIV was appropriately managed at a time when they were feeling overwhelmed, when often they did not have a social network for support and when they would have preferred to leave their care in the hands of others. Lack of healthcare professional knowledge about HIV and its management therefore created a situation where patients were being given work as 'expert patients' which they did not welcome and which added to the mounting pressures they experienced during the period of cancer treatment.

Evidence suggests that some of the challenges facing people with a dual diagnosis of HIV and cancer might be the same as those for others with a concurrent long-term condition. Bone et al (2014) looked at the results of the UK National Cancer Patient Experience Survey and found that patients with various long-standing

conditions reported significantly less positive patient experiences than those without, and patients with long-term illnesses such as diabetes and chronic heart disease were less likely to rate care as 'excellent' or 'very good'. Whilst it may be true that cancer services do not always do well in catering for the needs of patients with other co-existing conditions, the data suggests that the combination of structural factors, lack of knowledge, and in particular the stigmatising nature of HIV, made the experiences of this group of patients more challenging.

What made these experiences unique were those underlying pressures which shaped and informed particular perceptions and behaviour. Cancer patients with diabetes and cardiovascular disease may also be excluded from clinical trials and encounter a lack of knowledge about their particular condition in the oncology service. They might also feel obliged to drive the liaison and sharing of information between the different services. The difference is that these conditions are better understood and are morally neutral. They could be openly discussed without fear of judgment or blame. Within this study it was clear that the extra work required to shoulder some of the communication between services was made more onerous by the pressure to maintain secrecy about HIV due to its stigmatising nature. Secrecy was evident across the data: in newspaper stories of blackmail, in personal accounts and in situations related by healthcare professionals. The under the surface pressure to maintain this secrecy made the dual diagnosis of HIV and cancer uniquely different from experiences of cancer and other co-morbidities. These will be discussed in more detail in the following section.

### **11.3.3 The influence and impact of stigma in the healthcare setting**

Healthcare professionals administering cancer treatment openly acknowledged the existence of societal stigma related to being HIV positive and demonstrated how they may have incorporated some of this stigma into their own behaviour. This could be by adopting excessive precautions with body fluids, or by making statements about certain people who were HIV positive being innocent and deserving of sympathy (and thereby implying that others were guilty and undeserving). For the patients, issues around secrecy and disclosure of HIV made their experience of cancer treatment more stressful. The cancer service setting was often an unknown arena, and with repeated cycles of chemotherapy often delivered by different people there were many occasions for unfamiliar healthcare professionals to risk inadvertent disclosure of HIV status. The staff were not always empathetic about these concerns. They reported that 'confusion and secrets'

relating to which visitor knew what could inhibit open communication about care and lead to situations where medication was administered with obvious differences from normal procedures in the omission of required verbal checks.

In more subtle ways these internalised stigmatising influences could lead to behaviours that demonstrated a misunderstanding of the patient with a dual diagnosis's needs. These 'misunderstandings and misjudgements' are discussed below.

### **Healthcare professionals' misunderstandings and misjudgements**

Some of the language that healthcare professionals giving cancer treatment used to talk about patients with HIV was revealing in the way that it was used to link HIV with generalised groups of people and behaviour that could be judged in moral terms such as gay men being promiscuous, clubbing and taking drugs. There were examples within the data of staff using labels to describe patients which referred to symbolic associations with groups or behaviour evoking social disapproval. This was the case for one man who described his meticulous planning before he was due to have chemotherapy. He cleaned his flat and did a week's shopping to prepare for feeling ill and exhausted in the following week. He also described how difficult he found chemotherapy and how he had experienced panic attacks during his treatment; when he became very distressed he struggled to attend all of his appointments. The staff talked about him to me as someone who was 'chaotic'; a description I did not recognise from our interview and it did not appear as though they understood the full picture in relation to his behaviour. It is possible that knowledge about this man's sexuality and prior drug use had the effect of obscuring some of his psychological distress in the eyes of the staff providing his treatment. The use of the term 'chaotic' seemed to me to refer to a generalised disapproval of past behaviour that did not take into account the current reasons for him missing appointments and the result was that appropriate support was not offered. This example illustrates the complexity of the impact of societal attitudes within the healthcare setting but does suggest it had real consequences for the experience of patients.

Healthcare professionals' misunderstanding of the impact of felt stigma was another area where communication could be misjudged in the healthcare setting. This was evident in patients' accounts of ill-judged attempts to talk about HIV conversationally in a bid to be friendly and show their acceptance. Although these

attempts were well meaning they revealed a failure to understand how any discussion about HIV was perceived as deeply personal and that introducing it as a casual topic of conversation was not welcome and caused anxiety and offence. In summary, societal stigma interplayed with personal sensitivities within the healthcare context and resulted in patients with a dual diagnosis experiencing care which was often poorly matched to their needs. Rather than being overt examples of enacted stigma many of the tensions were complex and below the surface for both patients and staff.

#### **11.4 Summary: A Unique Convergence of Pressures within the ‘Visible’ Cancer and the ‘Invisible’ HIV**

Cancer and HIV are two conditions with a powerful impact which are experienced differently. Having two serious illnesses, one which is lifelong and stigmatising, and one which is potentially life-threatening but socially acceptable, undoubtedly adds to the burden of having just one individually. The relationship between the two is complex however. Each condition has its own challenges as well as opportunities for accessing support and maintaining a valued identity. In the combination of a dual diagnosis those opportunities can be compromised and there is a powerful convergence of challenges both visible and hidden. Cancer is a visible condition which can be talked about widely and is viewed sympathetically as a condition which deserves support. The discernible consequences manifested in the symptoms and side effects of treatment are less positive aspects of its visibility. In addition there are societal expectations that place pressure on people to think positively about their cancer which add to these challenges. HIV is a largely invisible condition which due to effective treatment can be hidden from view. It retains powerful stigmatising connotations which exert social and psychological pressures on patients to manage information about it, and the impact of these under the surface tensions can be seen within their experience of care. When the two conditions are combined, these tensions can have the effect of undermining previously adopted coping strategies and making this group uniquely vulnerable during the acute period of cancer treatment. Because some of these pressures are not immediately obvious they are not always recognised or fully understood by healthcare workers particularly in oncology services where limited time often means the main focus is a standardised safe journey through treatment delivery.

## 11.5 Limitations of the Study

The entire study dataset comprising of the newspaper analysis, the participant interviews and observation of the healthcare setting was drawn from London and it could be argued that some of the findings might not therefore easily translate to other geographical areas. London was chosen as a large centre with a big diverse population of people living with HIV. It therefore allowed the collection of views and perspectives of people with a wide range of characteristics within the required study timelines. In order to address this limitation, participants who had prior experience of areas outside of the capital including other countries and other areas within the UK such as small district general hospitals were included for interview and this aspect of their experience sought out.

The intention at the outset of the interview study was to capture longitudinal interviews with all study participants in order to capture changes in the experiences of a dual diagnosis over time. In the event, this was possible with only six out of the 17 participants who were recruited, partly as a consequence of people becoming lost to follow up, but also because six participants died before it was possible to perform a repeat interview. This was not something I had anticipated happening. This serves to highlight the particular nature of this sample group with a lot of them being interviewed when they were very sick. A major strength of the study was that it included so many experiences from a group of people who were seriously ill and in the middle of treatment. This group is normally hard to reach and the research allowed these voices to be heard.

My role as a nurse at one of the sites where patient interviews and observation was conducted was likely to have had an influence on the data collected. Although I ensured that I made it clear that I was there in the capacity of a researcher there were occasions when being known as a nurse changed the nature of conversations at times; for example patients asking me the names of drugs that they could not recall, and healthcare professionals being initially wary that I might be auditing aspects of their work. I endeavoured to distance myself from my usual role by constantly reflecting on potential influences and adjusting my approach accordingly and by not wearing uniform and booking rooms for interview at the university rather than the hospital.

## **11.6 Implications for Improving Care of Patients with a Dual Diagnosis**

This study observed two types of healthcare setting; 'HIV specialist services' where those staff administering cancer treatment were also HIV trained and 'oncology services' where staff were solely trained in cancer. The HIV specialist services provided cancer care which demonstrated a much greater understanding of the challenges of a dual diagnosis but it was acknowledged by those who worked there that this was very labour intensive, and even within this service patients needed to have some treatment such as surgery or radiotherapy in an outside oncology service. Existing evidence refers to a trend to implement the centralisation of specialist cancer services citing the potential to increase the numbers of patients seen, reduce the variations in access and improve patients' outcomes by providing access to experienced specialist and support provision (Melnychuk et al, 2018). It seems likely that the growing numbers of people with a dual diagnosis will increasingly receive at least some of their cancer treatment within oncology services and this is an area in which the findings of this study would be most useful in improving knowledge and understanding.

This study has found that patients with a dual diagnosis are less likely to have the capacity to successfully navigate oncology services providing standardised pathways through treatment which do not take into account the complexity of their experiences and preferences. It has been argued that by treating people with HIV separately as 'special cases' and providing their cancer care as part of their HIV service you may do them a disservice and they might miss out on the best care at oncology centres of excellence. But within this argument the benefit of being treated as part of the oncology service is framed solely in the language of medical management and equitable treatment outcomes without reference to wider social influences. The study findings demonstrate that there are particular differences in the way in which people with HIV experience cancer treatment. These differences, which are particularly acute and often poorly understood in oncology services, are influenced by powerful societal and personal pressures which affect both the delivery and experience of cancer care and raise the risk of poorer treatment outcomes. Long term HIV is a relatively new phenomenon and many healthcare professionals have low levels of knowledge and familiarity with HIV, which has historically been treated entirely within specialist clinics. All this suggests that oncology services could improve the care they provide to people with a dual

diagnosis by having more knowledge about HIV and a greater understanding of dual diagnosis experiences in order to deliver care which is more patient centred. Any future interventions aimed at improving these experiences would need to acknowledge the shared social narrative around HIV and the powerful impact of stigma so that this burden is not carried by the patient alone. It has already been argued that treating people with HIV for other long term conditions should not simply involve importing the same approaches which are used for those without HIV (Baylis et al, 2017) and the findings of this study support the view that services providing cancer care should adapt existing provision to take account of the unique needs of this growing group of patients.

Finally, the findings relating to the impact of stigma and social isolation could be used within oncology services to understand the experiences of other marginalised groups and provide care which is better tailored to their needs.

In conclusion, a growing number of people living with HIV will experience a cancer diagnosis. This study has shown that patients with this dual diagnosis are uniquely vulnerable. An understanding of their experiences as outlined in the findings of this thesis will be important to inform the improvement of cancer services and the provision of good, patient-centred care.

# Appendix 1 Published Systematic Review



**AIDS Care**  
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## Exploring the views and experiences of HIV positive patients treated for cancer: a systematic review of the literature

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## Appendix 2 Results of database searches

**Appendix 2 Table 1 CINAHL Plus Database Search**

	CINAHL Plus Search 2nd August 2016	Results
	Search terms	Results
1	cancer* or neoplasms or oncology or tumour* or malignancy	413,240
2	hiv or aids or hiv/aids or human immunodeficiency virus	101,590
3	interview*	206,067
4	qualitative research	9,664
5	qualitative	96,753
6	Experience*	229,303
7	Dual diagnosis	2,534
8	3 or 4 or 5 or 6 or 7	414,725
8	1 and 2 and 8	516

**Appendix 2 Table 2 OVID Medline Database Search**

	OVID Medline Search 2nd August 2016	Results
	Search terms	Results
1	((cancer* or neoplasm* or tumo?r* or carcinoma*) adj3 (diagnos* or treat* or therap*)).mp.	429125
2	exp Neoplasms/di, dt, pc, th	1092739
3	1 or 2	1312382
4	exp HIV/	88751
5	exp HIV Infections/	249810
6	(HIV or human immunodeficiency virus or acquired immunodeficiency syndrome).mp.	353937
7	AIDS-Related Opportunistic Infections/	20260
8	4 or 5 or 6 or 7	358830
9	Interviews as Topic/	48322
10	interview*.mp.	301485
11	qualitative research/	28387
12	qualitative.mp.	168648
13	experience*.mp.	832382
14	px.fs.	852048
15	exp Patient Satisfaction/	70859
16	Dual diagnosis/	3240
17	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	1872211
18	3 and 8 and 17	761

## Appendix 2 Table 3 PsycINFO Database Search

PsycINFO Search 2 <sup>nd</sup> August 2016		
	Search terms	Results
1	((cancer* or neoplasm* or tumo?r* or carcinoma*) adj3 (diagnos* or treat* or therap*)).mp.	14213
2	exp Neoplasms/di, dt, pc, th	0
3	1 or 2	14213
4	exp HIV/	36417
5	exp HIV Infections/	0
6	(HIV or human immunodeficiency virus or acquired immunodeficiency syndrome).mp.	44216
7	AIDS-Related Opportunistic Infections/	0
8	4 or 5 or 6 or 7	47495
9	Interviews as Topic/	0
10	interview*.mp.	310851
11	qualitative research/	6981
12	qualitative.mp.	116869
13	experience*.mp.	536400
14	px.fs.	0
15	exp Patient Satisfaction/	4676
16	Dual diagnosis/	1866
17	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	808088
18	3 and 8 and 17	<b>35</b>

## Appendix 2 Table 4 EMBASE Database search

EMBASE Search 2 <sup>nd</sup> August 2016		
	Search terms	Results
1	((cancer* or neoplasm* or tumo?r* or carcinoma*) adj3 (diagnos* or treat* or therap*)).mp.	759523
2	exp Neoplasms/di, dt, pc, th	1221235
3	1 or 2	1647954
4	exp HIV/	159431
5	exp HIV Infections/	326897
6	(HIV or human immunodeficiency virus or acquired immunodeficiency syndrome).mp.	413500
7	AIDS-Related Opportunistic Infections/	3154
8	4 or 5 or 6 or 7	457019
9	Interviews as Topic/	97983
10	interview*.mp.	352603
11	qualitative research/	37249
12	qualitative.mp.	205606
13	experience*.mp.	1085382
14	px.fs.	0
15	exp Patient Satisfaction/	102869
16	Dual diagnosis/	39
17	9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	1572935
18	3 and 8 and 17	<b>1061</b>

**Appendix 2 Table 5 Breakdown of process for including eligible studies**

Cinahl	516
Ovid Medline	761
PsycINFO	35
EMBASE	1061
Total	2373
Duplicates screened in Endnote programme	-55
Duplicates handsifted by title	-541
Remaining total for screening	1777
Stage 1 1777 titles and abstracts screened to keep any study dealing with dual diagnosis of HIV and Cancer. Excluding studies on cancer alone, HIV alone, KS, Cancer screening programmes in HIV, prevention	228 papers dealing with dual diagnosis of HIV and Cancer (1549 excluded)
Stage 2 228 titles and abstracts screened to include patient experience of dual diagnosis from the patient perspective. Excluding epidemiology, evaluation of treatments, medical management, pathology, biology studies, description of clinical outcomes	8 papers included (1 discussion paper on nursing symptoms then excluded) 7 papers finally included

## Appendix 3 Exploratory scoping literature reviews

**Appendix 3 Table 1 Summary of scoping review on Experience, Metaphors, Meanings & Narratives**

Web of Science	EXPERIENCE, METAPHORS, MEANINGS & NARRATIVES	
Search Terms	HIV and (Experience or Feeling or Perception) and (Metaphor or Imagery or Language or Narratives) Combine with: Cancer and (Experience or Feeling or Perception) and (Metaphor or Imagery or Language or Narratives)	
Timespan	2005-2015	
Search Language	English	
Results	HIV search 464 papers screened 11 initially selected Cancer search 1626 papers screened 15 initially selected	
Exclusion	Medical management, studies in developing countries, IV drug use focus, HIV prevention	
Themes	Theme name	No of papers
	Language, metaphors, Normalisation,	10
	Talking about experience, narratives (work on the self)	10
	Spirituality	2
	Stigma	1
	Complementary therapy (positive work on self)	1
	Isolation	2

**Appendix 3 Table 6 Summary of scoping review on Patient/Doctor Relationship**

<b>Web of Science</b>	<b>DOCTOR PATIENT RELATIONSHIP</b>	
Search Terms	(HIV OR Cancer) AND ('patient empowerment' OR 'doctor patient relationship')	
Timespan	2005-2015	
Search Language	English	
Results	1,162 papers screened, 31 selected	
Exclusion	Studies focusing on healthcare system outside of UK, technology studies, specific focus on one type of cancer, screening programmes	
Themes	Theme name	No of papers
	Shared decision making, medical communication styles	14
	Holistic care: consideration of the whole person	5
	Spirituality as discussed with doctor	2
	Online support	4
	Complementary therapy as discussed with the doctor	3
	GP contact	2
	Liminality	1

## Appendix 4 Initial Topic Guide for Patient Interviews

### Topic Guide Interviews

#### Introductory checks

- Introduce myself:

'I currently work as a research nurse in UCLH Cancer Clinical Trials Unit. I have also worked as an HIV nurse in the past. Today I am talking to you as a researcher who is conducting a study as part of a PhD. If you have any questions relating to your care would it be OK to leave these to the end and I can refer you to the most appropriate person for support.'

- Outline the objectives of the study:

'I would like to find out about the experience of HIV positive patients who are diagnosed and receive treatment for cancer. It is hoped that the study will provide important new knowledge on how people feel about having both conditions and what their particular needs are during their cancer diagnosis and treatment. The information we find out will be used to develop improvements in services.'

- Is it okay if I record our conversation to make sure that the information is accurate and complete.?
- It will take up to one hour and a half, is that okay?
- Possible to stop the interview at any stage if you wish to do so, either to take a break or end it
- Everything you say will remain anonymised, transcript of the interview will have identifiers removed. It is possible that quotes may be used for the purpose of the research as explained in consent
- I will start by asking questions about Cancer then we will move on to HIV

### **Exploring beliefs and opinions about Cancer**

- Tell me a bit about when you got your cancer diagnosis
- How did it make you feel/ what was your initial reaction?
- Who have you told about your cancer diagnosis?
  - why?
- People hold all sorts of beliefs and theories about why they get cancer, do you have any particular views about why this has happened? Have other people expressed views on this?
- Do you think people can tell you have cancer?
  - Anything visible in your appearance? (eg hair loss, weight change)
  - Do you go out of your way to hide any of these visible signs if there are any?
- Where are you in your cancer treatment?

### **Exploring beliefs and opinions about HIV**

- Tell me a bit about when you got your HIV diagnosis
- How did it make you feel/ what was your initial reaction?
- Who have you told about your HIV diagnosis?
  - why?
- People hold all sorts of beliefs and theories about people with HIV, do you ever get affected by this in any way?
- Do you think people can tell you have HIV?
  - anything visible in your appearance? (eg lipodystrophy)
  - Do you go out of your way to hide any of these visible signs if there are any?
- What sort of treatment are you taking for your HIV?

### **Having a Dual Diagnosis: metaphors and meanings**

- How do you feel / how does it affect your life about having both Cancer and HIV?
- Do you identify with one more than the other? How? (Eg would you describe yourself as a Cancer patient with HIV or an HIV positive patient with Cancer).

### **Disclosure**

- Is it easier to talk about one condition rather than the other?

- Do you talk about both diagnoses equally to family, friends or work colleagues, GP, do you speak more readily about one?
- Do you ever keep quiet about your diagnosis in any situations?

**Experience of healthcare**

- Tell me a bit about your cancer treatment
- Was there ever a time when you felt healthcare professionals reacted to you differently because of HIV or Cancer
- Do you feel that the healthcare professionals focus on one diagnosis more than the other?
- In your opinion what is the communication like between HIV and Cancer doctors about your care?
- Is there any more information you would like to have had at any point?

## Appendix 5 Components of the text analysis

Title of article. Date and source
<b>Context</b>
Who is author?
What are their areas of coverage?
What was the occasion for the article?
<b>Surface of the text</b>
What is the layout like?
Any pictures or graphs?
How is the article structured into units of meaning?
What topics (discourse strands) are touched upon?
<b>Rhetorical means</b>
What kind and form of argumentation?
What logic underlies?
What implications allusions does the article contain?
What collective symbolism is used?
What are the vocabulary and style?
What actors are mentioned and how portrayed?
What references are made?
<b>Content &amp; Ideological Statements</b>
What concept of humankind does the article presuppose and convey?
What concept of society does the article presuppose and convey?
What perspective regarding the future does the article give?
<b>Discourse position and overall message of the article</b>

## Appendix 6 Cancer Thematic Categories

Thematic category	No of results	Brief summary of Category
Cancer Risk	243	Stories featuring risks for developing cancer including food and alcohol, inactivity, depression, anxiety and stress, the HPV virus, the sun and UV rays, smoking, pollution, poverty and mobile phones
Cancer Fundraising events	245	Stories featuring Sports events such as CRUK's Race for Life and the London Marathon, Parties and Galas, Concerts and Comedy gigs, celebrity endorsements for fundraising and widely popular campaigns such as the 'No Make-up Selfie' and 'Movember'
Cancer Scams	36	Stories include those about people faking cancer to raise money, people stealing cancer charity money and the peddling of phony cures for cancer
Celebrity Cancer	510	Stories feature actors, singers, sportsmen and women who have or have had cancer (eg Anastacia, singer, Kylie Minogue, singer, Victoria Derbyshire, TV presenter, Billy Connolly, comedian, Lance Armstrong, cyclist); Stars who have died from cancer such as David Bowie, Alan Rickman and Victoria Wood; Stars who provide accounts of their increased risk of getting cancer (eg Angelina Jolie and Kelly Osborne); and stories featuring celebrity support for cancer charities and units.
Cancer the 'Human Angle'	331	These stories feature personal stories about members of the public with cancer. They often focus in a sympathetic tone on significant life events which have been rendered more emotionally resonant by the experience of cancer such as weddings and having babies. Other stories in this category feature people overcoming cancer to succeed, 'bucket list' stories and freak or shock stories of unusual misfortune
Cancer New Drugs/Technology Research	271	These stories feature developments in using genes and DNA to predict outcomes and more accurately target cancer treatments; stories about unusual cures or diagnostic techniques using unlikely sounding items (such as emu eggs, shark antibodies or rainbow coral to name a few). Other stories deal with simple tests to detect cancer and 'pills' with the promise of simple but impressive effects
Cancer Figures	87	These stories feature figures of cancer death rates (which are in the main part falling), overall and

<b>Thematic category</b>	<b>No of results</b>	<b>Brief summary of Category</b>
		specific cancer type incidence, and survival rates (which in the main part are improving)
Cancer Funding and the NHS	160	A large number of stories feature new treatments and give accounts of those that have been approved or alternatively rejected for use on the NHS. There are also stories about waiting times for diagnostic tests and cancer treatments and projects or units that have received large amounts of funding.
Cancer Diagnosis and Presentation	73	These stories promote and discuss potential benefits of screening programmes for different cancers, they also feature tales of misdiagnosis and cases where cancer was missed by healthcare professionals. There are also stories of unusual ways in which people discovered they had cancer.
Children with cancer	147	These stories of children with cancer often use emotive language relating to courage and fighting metaphors. There is also the language of miracles, heaven and angels which lends some headlines a semi-religious quality. Prominent stories in the media featuring children with cancer at this time are those about Ashya (whose parents removed him from the country and against medical advice to receive proton beam therapy) and Neon whose mother 'kidnapped him' to avoid him receiving radiotherapy
Cancer Business & Industry	49	These stories only featured in the Evening Standard and were mainly concerned with the fortunes of big pharmaceutical companies who manufacture cancer drugs
Cancer an incidental mention	399	The articles assigned this category were those where cancer was an incidental mention in a story with a different focus, they also included star signs, music reviews and TV guides

## Appendix 7 HIV Thematic Categories

Thematic category	No of results	Brief summary of Category
HIV Awareness	10	These stories featured charity and public health initiatives to promote awareness about HIV in particular to improve knowledge about how it is transmitted
HIV Fundraising events	5	Small number of disparate events raising money for HIV charities
HIV 'Commentary'	19	Opinion pieces containing discussion as to how to improve knowledge about HIV, comment about huge progress in treatment but continued barriers which affect testing and access to treatment and two longer pieces in the Evening Standard about 'gay hedonism'
HIV Celebrity	53	Stories feature a few prominent celebrities who support HIV causes, promoting awareness, testing and fundraising, Prince Harry and Elton John featuring the most amongst this small group. Featured HIV positive celebrities are Charlie Sheen and a 'porn star'
HIV first person story –the human angle	40	Four stories feature first person accounts about the personal experience of living with HIV. A large proportion of these stories feature criminal transmission of HIV, HIV positive doctors and dentists and individuals affected by the contaminated blood scandal
HIV advances in treatment/medical interventions	22	These stories cover early intervention programmes, the treatment of at risk babies, HIV vaccines and bone marrow transplants
HIV Figures	9	These stories deal with number of HIV infections, at various times within the 5 year period they are up or down, a large number of new cases are reported to be in London
HIV funding and the NHS	19	A prominent story featured seven times is the debate over NHS funding of PrEP. Other articles deal with cuts in HIV support services, NHS offering routine testing in A&E departments and the leak of patient names in a HIV clinic
HIV & Children	1	Just one result about African orphans given ballet lessons by Western ballerina in 'slum'

Thematic category	No of results	Brief summary of Category
HIV Business & Industry	3	Three results featuring pharmaceutical company that makes HIV drugs and firm that makes equipment to perform HIV blood testing
HIV an incidental mention	16	Stories where HIV is incidental mention rather than main theme

## Appendix 8 Participant Interviews Information Sheet

### Patient Information Sheet

#### Exploring the Experience of HIV Positive Patients Treated for Cancer

#### Patient Interviews

*You are being invited to take part in a research study. Before you decide it is important to understand why the research is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have. This should take about 30 minutes.*

*Talk to others about the study if you wish.*

#### **What is the Purpose of the Study?**

This study wants to find out about the experience of HIV positive patients who are diagnosed and receive treatment for cancer. It is being conducted as part of a PhD by the research nurse, Emma Hainsworth. There is not a lot of published evidence about this group and it is hoped that the study will provide important new knowledge on how people feel about having a dual diagnosis and what their particular needs are during their cancer diagnosis and treatment. The information that is found out will be used to develop improvements in services.

#### **Why have I been invited?**

You have been invited because you are HIV positive and have a cancer diagnosis for which you are receiving treatment.

The study aims to include up to 20 participants from a number of sites.

#### **Do I have to take part?**

It is up to you to decide whether to join the study. The researcher will describe the study and go through this information sheet. If you agree to take part, you will be asked to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

#### **What will happen to me if I take part?**

If you decide to take part you will be asked to attend up to 3 interviews (2-3 months apart) with the first interview taking place as near to the beginning of your treatment for cancer as possible. Each interview will last for about an hour and a half and will include questions on subjects such as beliefs and opinions about both illnesses, any issues around telling others, seeking support from friends and family and what it is like to receive cancer care. With your permission the interviews will be audio recorded but no identifiable information will be stored with the recording or transcription. With your permission quotes may be used in reports, publications and presentations of study findings without using your name.

A suitable date, time and place for the interview will be discussed and arranged according to what is convenient for you and your circumstances.

In between the interviews you will be asked to keep a diary to record your thoughts on those occasions when you are made aware of your HIV and/or Cancer diagnosis and are made to think about it, for example, reading something in the paper, seeing something on TV or having a conversation with a friend or family member. This information can be provided in a pen and paper diary or by video diary using a laptop or smartphone, whichever method is preferred. As it will vary according to the individual how much information you wish to provide or indeed what information you feel to be important, this process will be left relatively unstructured and will be negotiated with you at the first interview.

After your interviews you will be asked if you would like to stay in contact and be invited to attend group discussions at the end of the study to share findings and suggest possible ideas for service improvement. If you agree you will be asked for permission to keep some contact details on a password protected NHS server with sole access by the researcher.

### **Expenses and Payments**

There will be no payment for taking part in the study

### **What will I have to do?**

You will be invited to attend up to 3 interviews (each around 90 minutes long held about 2-3 months apart) in a venue and at a time of your choosing. You will also be asked to keep diary information between interviews in a format that best suits you and which will be discussed and agreed upon with the researcher in the first interview.

**What are the possible disadvantages and risks of taking part?**

You may find it upsetting to talk about your HIV and Cancer diagnosis at a time when you are dealing with a lot of new information, having new treatments and perhaps not feeling well. On the other hand some people may find it helpful to talk through how they feel during this time. You must decide what is best for you. Should you become upset the researcher will stop the interview as appropriate and if necessary put you in touch with relevant support services.

**What are the possible benefits of taking part?**

The information from this study may help improve services for HIV positive people with Cancer in the future. Some people may find it helpful to talk about their experience with a researcher.

**What if there is a problem?**

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask the researcher if you would like more information on this.

**Will my taking part in this study be kept confidential?**

All information collected about you as part of the study will be kept strictly confidential.

With your permission interviews will be audio recorded and then transcribed into a document. All personally identifiable information will be removed from the transcripts and will be stored securely with a study number.

Diary records made with pen and paper will be stored in the same way in document form with a study number and personally identifiable information removed. For those participants using electronic methods to record their diary, the transfer and storage of the data will be agreed in order to comply with UCL policies.

The anonymised data collected will be used solely for the purposes of this study and will be destroyed once the study is complete.

**What will happen to the results of the study?**

The findings of the interviews will be shared widely with relevant patient representatives and healthcare professionals as part of the study itself with the aim of developing ideas for the improvement of services. Results will also be circulated to relevant HIV and Cancer patient support networks and charities such as Terrence Higgins Trust, Macmillan Cancer Support and Cancer Research UK. Results may also be presented at academic conferences and published in relevant academic journals. No patient will be identified in any report or publication.

### **Who is organising and funding the research?**

The study is being undertaken as part of a PhD at University College London. It is not in receipt of any funding.

### **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by xxxxxxxxxx Research Ethics Committee

**You will be given a copy of this information and a signed consent form to keep**

### **Further Information and Contact Details**

For further information about the study please contact the researcher, Emma Hainsworth

## Appendix 9 Participant Interview Consent Form

### Exploring the Experience of HIV Positive Patients Treated for Cancer

Researcher: Emma Hainsworth

Please initial box

<p>1. I confirm that I have read and understand the information sheet dated .....(version .....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	
<p>2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.</p>	
<p>3. I understand that relevant sections of the data collected during the study, which will be anonymised, may be looked at by individuals such as the researcher's academic supervisors. I give permission for these individuals to have access to this anonymised data</p>	
<p>4. I give permission for quotes to be used in reports, publications and presentations of study findings. My name will not be used.</p>	
<p>5. I give permission for my diary entries to be stored securely by the researcher. Written and transcribed audio diary entries will be anonymised and stored in the UCL Data Safe Haven and/or on an encrypted memory stick I wish to record diary information using <b>pen &amp; paper</b> or <b>electronic method</b> (please circle)</p>	
<p>6. I agree to take part in the above study</p>	

**Name of Patient**

**Date**

**Signature**

.....

.....

.....

**Name of Person**

**Date**

**Signature**

**taking consent**

.....

.....

.....

## Appendix 10 Diary Guidelines for Participants

**Why keep a diary?** In your first interview you will have discussed with the researcher the option of keeping a diary to record your feelings and your thoughts at the time of the diagnosis. A diary includes your reflections about the day to day that you find to be important. It provides important information which may not come up in interviews which will greatly add to our understanding of what it means to have an HIV and Cancer diagnosis.

**Do I have to keep a diary?** It is up to you to decide whether you would like to keep a diary. The method of collecting diary information, how much detail and how often will have been discussed with the researcher in your first interview and is kept flexible to include as many people's preferences as possible. You are free to stop at any time; this will not affect the standard of care you receive.

**What sort of information should I record?**

*You are encouraged to record whatever information you feel to be of importance.* The suggestions on page 2 have been made as rough guide. However, they are only suggestions as there is no right and wrong way of keeping a diary. What you include should be **what you think to be of relevance** in understanding the experience of having a diagnosis of HIV & Cancer.

**Will my diary information be kept confidential?** For those using a pen and paper method of recording their thoughts the data will be transcribed into a word document with all personally identifiable information removed. The anonymised data collected will be used only for the purposes of this study and will be destroyed once the study ends. For those people using electronic methods to record their diary, the transfer and storage of the data will be agreed with you and in order to comply with UCL policies and maintain security and confidentiality.

- Think about any time during the day when you became aware of your HIV and Cancer diagnosis
- Have you seen, read or heard anything (for example in newspapers, on television etc) that made you think about your illness and made you feel uncomfortable, upset or on the other hand optimistic, reassured?
- Have you had any interaction with family and friends that made you think about your HIV and/or Cancer diagnosis?
- Have you had any medical interaction that made you think about your HIV and/or Cancer diagnosis (for example with doctors at the hospital, your GP, your dentist etc?)

## Appendix 11 Interview Data Initial Descriptive Labels

Journey to cancer diagnosis  
Chemotherapy treatment  
Seeking cancer information  
Uncertain outcome of cancer treatment  
Beliefs about causes of cancer  
Personal reaction to cancer diagnosis  
Others reaction to cancer diagnosis  
Disclosure of cancer diagnosis  
Different cultural attitudes to cancer  
Journey to HIV diagnosis  
HIV treatment  
The framing of living with HIV  
The early days of HIV  
Personal reaction to HIV diagnosis  
Others reaction to HIV diagnosis (became enacted stigma theme)  
Disclosure of HIV status  
Beliefs about contracting HIV  
Beliefs about the relationship between HIV and cancer  
Communication between HIV and cancer teams  
Doctor patient relationship  
Being a guinea pig  
Physical signs of illness  
Constraints and limitations  
Professional support  
GP  
Support groups/social support  
Finance  
Work  
Coping strategies  
Online research  
Self-reliance  
Personal resilience  
Alternative/complementary therapies/diet/exercise  
Close relationships/partners

Support spiritual  
Isolation/loneliness  
'Others'  
Turning point

## Appendix 12 Topic Guide for Interviews with Key Informants

Do you see many people with a dual diagnosis of HIV and Cancer?
Is your perception that this number is fairly constant in the last couple of years, decreasing or increasing?
Tell me about your experience of caring for people with a dual diagnosis
What are the challenges of caring for this group of patients from your perspective as .....?
How is the communication between the cancer and HIV services?
What are your views on HIV being an exclusion for participation in cancer clinical trials?
Have you been involved in any instances where disclosure of HIV status and confidentiality has been a problem?
What is the GP role with this group of patients in your experience?
In your view is HIV just like any other chronic disease?

## **Appendix 13 Patient Information on Observation**

### **What is the Purpose of the Study?**

This study wants to find out about the experience of patients who are diagnosed and receive treatment for cancer. It is being done as part of a PhD. The information we find out will be used to develop improvements in services.

### **Why is observation taking place and what will the researcher be doing?**

Observation of cancer treatment being given in hospital day units and wards is just one method of collecting information within this study which will also include patient interviews and group discussions at a later stage. Observing the physical surroundings and the interactions between patients and healthcare staff will provide a more complete understanding of the way in which patients experience their diagnosis and treatment. The researcher will be observing and taking written on the spot notes on the physical setting and interactions between healthcare professionals and patients. Observations will include the researcher shadowing healthcare staff such as nurses during the course of a day (for a total of 2 weeks) Information will be recorded on how treatment is given and will include detail on the nature of greetings, exchange of information, non-verbal expressions such as smiling, touch, eye contact and tone of voice. The researcher would also like to hold a few informal conversations with staff and patients in order to find out about systems and processes relating to this group of patients receiving care. This will only be done if informed consent has been taken in advance. The discussions will be audio-recorded with your permission.

Should any concerns or malpractice be observed the researcher will notify the senior members of staff on duty and ensure that appropriate support is given to those involved and that the incident is reported according to trust policy.

### **Can I be identified in the information collected during this research?**

It will not be possible to identify people being observed in the data. The identities of all people being observed will be protected with no personally identifiable or hospital site information being recorded. On the spot notes taken by the researcher will be carefully anonymised and stored using study numbers.

**Do I have to be observed?**

If you do not wish to be observed your wishes will be respected and the researcher will not record any information relating to you. If you decide to opt out of being observed after initially agreeing, you can do so; all information relating to you will then be excluded from the study.

**Who is organising and funding the research?**

The study is being undertaken as part of a PhD at University College London. It is not in receipt of any funding.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by Camberwell St Giles Research Ethics Committee

**Further Information and Contact Details**

For further information about the study please contact the researcher (details provided)

## Appendix 14 Observation Data Initial Descriptive labels

Patients from 'AIDS era'  
Complementary therapy  
GP  
Holistic care  
Lack of fit  
Perceived characteristics of dual diagnosis patients  
Cancer treatment  
Cancer treatment environment  
Clinical trials  
Communication between HIV and oncology services  
HIV disclosure issues  
Fair treatment  
Healthcare stigma  
Over dependence of HIV patients  
Own knowledge about HIV or cancer  
Language about people living with HIV  
Making patient responsible for HIV care  
Normalisation of HIV  
Patient knowledge  
Patient felt stigma  
Societal stigma

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