INDIGENOUS KNOWLEDGE AND SOCIAL EXPERIENCES ON CANCER IN ZIMBABWE: A CASE STUDY OF HARARE

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I declare that while registered as a candidate for the Doctor of Philosophy Degree I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution.

I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work.

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ABSTRACT

Official statistical and anecdotal evidence in Zimbabwe indicates that the incidence of new cancer cases in the country is on the rise. Apparently, this rise in cancer cases has met a lethargic response from the government and non-state actors. As such, this phenomenological thesis study aims to describe and analyse indigenous [local] cancer causing narratives, lived illness experiences and health-related help seeking behaviours of people diagnosed with cancer in Harare, Zimbabwe. This study was prompted by the paucity of qualitative analyses and sociological nuances with regard to an illness that is increasingly being diagnosed among resident black African Zimbabweans. Current empirical studies and scholarship on cancer in the country show a preponderance of quantitative analyses grounded in bio-physicist perspectives. The trend also seems to be that of exploring incidence and survival and mortality rates including survey research on the knowledge [biomedical] levels on cancer. Relevant though such studies may be, they remain superficial, as they are divorced from the intimate, lived realities of people living the experience.

Grounded in Heideggerian interpretive hermeneutic phenomenology and utilising qualitative methods, namely life histories, semi-structured interviews, focus group discussions, key informant interviews and semi detached observations, the study sought to fill the existing knowledge gaps. The central thesis of this research is that an understanding of indigenous [local] cancer narratives provides comprehensive information of the illness and a combination of novel data capturing methods engendered in hermeneutic phenomenological thinking enables the extraction of novel fringe data. The thesis established cosmopolitan narratives on causes of cancer, which espoused participants’ lifeworlds as shaped in part by their socio-cultural milieu, lived experience and [biomedical] knowledge from health care professionals. The varied, novel lived-illness-experiences shared were enriched by dynamics of gender, age, level of social support, environmental factors and personality characteristics in a multiple and indeterminate fashion. Data on the health-related help-seeking behaviour of participants diagnosed with cancer illuminated the interplay of a complexity of factors, most of which were shaped by popular beliefs and/or ‘myths’ on cancer, experiential knowledge and interpretation of initial symptoms. Of note, one of the major contributions of this study is in the extraction of marginalised evidence from indigenous [local] knowledge on cancer treatment and care reflected, partly in the activities of traditional health practitioners. Taken as a whole, this evidence can assist in the framing of educational resources and inform oncology nursing and other societal support systems in the management of clients with cancer in personally meaningful ways. Cultural competence in oncological nursing management can enhance health behaviours, satisfaction, adherence, and quality of life of people diagnosed and living with cancer.
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<td>Traditional Health Practitioners</td>
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<td>CAZ</td>
<td>Cancer Association of Zimbabwe</td>
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<td>Medical Research Council of Zimbabwe</td>
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<td>Non-Communicable Diseases</td>
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<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>PSA</td>
<td>Prostatic Specific Antigen</td>
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<tr>
<td>NCPCS</td>
<td>National Cancer Prevention and Control Strategy</td>
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<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
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<tr>
<td>IARC</td>
<td>International Agency for Research on Cancer</td>
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DEDICATIONS

To all people of the World living with cancer, to my mom Kreya, to Emily my wife, to my late father Enock Muvirimi Mandizadza, to Arch Bishop L.M Manhango.
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1. CHAPTER ONE: INTRODUCTION AND BACKGROUND TO THE STUDY

1.0 Chapter Introduction

This introductory chapter gives a conceptual background to the study. It situates the study in the intellectual arena and highlights the existing knowledge gaps which it seeks to fill. The chapter then briefly presents the trends on cancer morbidity at global and regional levels. The chapter also provides a detailed national picture of cancer morbidity. The national picture is divisible into the components of morbidity and mortality, cost of hospital cancer treatment and available treatment, care and support services on cancer. These sections discuss the inadequacies of infrastructure and the associated challenges faced by people diagnosed with cancer in the context of rising morbidity and a lethargic government response. The chapter then moves to the problem statement, the significance of the thesis and the objectives of the study. Finally, the chapter outlines the basic knowledge on cancer from a biomedical orientation angle and does so by focusing on disease aetiology, types of cancer, risk factors, basic symptoms, disease staging and main treatment regimens. Such knowledge presented in a simpler fashion is handy to both the researcher and to readers from the social sciences who find medical jargon mystifying.

1.1 INTRODUCTION

Several studies conducted on cancer in Sub Saharan Africa (including Zimbabwe), have predominantly focused on capturing the incidence, survival and mortality trends in cancer cases as informed by bio-physicist (or biomedical) paradigms. In Zimbabwe, these studies include the connection between cancer and the AIDS epidemic (Chokunonga, Levy, Bassett et al, 1999); trends on cancer incidence in the African population of Harare (Chokunonga, Levy, Basset et al, 2000); cancer incidence in five continents (Chokunonga, Borok, Mauchaza et al, 2007); cancer survival in Africa, Asia, the Caribbean and Central America (Chokunonga, Borok, Chirenje et al, 2011); cancer in the African Population of 1
Harare, Zimbabwe, 1990-1992 (Bassett, Chokunonga, Levy et al, 1995); cancer survival in a Southern African Urban Population (Gondos, Chokunonga, Brenner et al, 2004); age-adjusted cancer survival estimates when age-specific data are sparse (Gondos, Parkin, Chokunonga et al, 2006). The thin qualitative insights on cancer illustrated in some surveys on (medical) knowledge levels tended to perpetuate and buttress biomedical thinking. Such studies include assessing rural women’s knowledge, constraints and perceptions on cervical cancer screening in Mutoko and Shurugwi rural districts in Zimbabwe (Mangoma, Chirenje, Chimbari et al, 2006); assessing the incidence, mortality, knowledge, prevention and treatment of cervical cancer in Sub Saharan Africa (Anorlu, 2008); estimating the proportion of rural females who have received cervical screening and to assess knowledge, beliefs, attitudes and demographics that influence cervical screening in Zimbabwe (Mupepi, Sampselle, and Johnson, 2011) and a situational analysis of cervical cancer diagnosis and treatment in East, Central and Southern Africa (Chirenje, Rusakaniko, Kirumbi et al, 2001). Such studies, relevant though, remain superficial, as they are divorced from intimate, lived realities of people living the experience and local narratives on the cancer illness.

Thus, the ensuing sociological and phenomenological thesis on indigenous [local] narratives on cancer, drawn mainly from Zimbabweans confirmed to be afflicted with cancer, grew out of my long interest in the social dimensions of health and medicine and in advancing social science and qualitative analysis in a field dominated by the biomedical perspective. The study aimed to capture local narratives on the causal-attribute of the cancer illness, lived illness experiences and health-related help-seeking behaviour of selected people diagnosed and living with cancer. An in-depth understanding of such narratives from the actual people living the experience, enables us to extract hitherto marginalised, novel and nuanced data, sometimes unknown in the public sphere yet
instructive to nursing, clinical practice, health policy and to groups which provide support to people living with cancer. In addition to contributing to the existing corpus of knowledge on cancer, this study also adds to the currently thin qualitative and phenomenological scholarship on cancer in the country. As with all other human illnesses, cancer is diagnosed in people, experienced by people, and studied by people, thus yielding phenomenological research whose thrust is that of understanding the essences of Being. Accordingly, a phenomenological study proffers thick descriptions, interpretations and explications of experiential meanings as we live them. It is a systematic study of human phenomena and a search for what it means to be human. The study humanizes discourses on cancer as well as adding new insights to the subject.

**Use of the notion of ‘Indigenous Knowledge’ Explained**

One issue that every social science researcher has to contend with is lack of specialised discipline terminology or language in social science, unlike in biomedicine and other *hard* sciences. Thus, it is prudent to operationalise or contextualise the use of some contested terms, notions or concepts in a particular study, to evade perennial debates and assist readers to understand a study. The notion of ‘indigenous knowledge’ (beyond various debates on the notion in literature) in this study implies a focus on localised [lay] conceptualisations, perceptions and beliefs on cancer as espoused mainly by people diagnosed and living with the cancer illness as well as available ethno-medical knowledge on cancer as found in cultural repertoires. The general assumption is to view such knowledge as pristine, traditional and restricted. A prudent position taken in this study is to view such knowledge as cosmopolitan, involving a conglomeration of discourses from health professionals; popular myths about the illness, knowledge propagated from various media and from experiential knowledge as individuals interact with others, locally or globally. Similarly Agrawal (1995) rejects the reification of the notion and instead...
underscores the overlaps between ‘indigenous’ and ‘Western’ or ‘modern’ knowledge. I argue that it is the situatedness of participants in a particular context, which engenders localised experiences that can be made intelligible at global and local levels. In addition, ‘indigenous knowledge’ (as it applies in this study) points to a field of study, (sociology of health and illness) capable of advancing a social science perspective on cancer. This perspective invites the researcher to regard local conceptualisations of cancer embodied by participants in their everyday expressions as the point of departure. Most quantitative studies, grounded in biomedicine, devote attention to a particular location (type) of cancer, for instance cervical cancer. Hardly are there any studies seeking to examine the whole notion of cancer in its totality, especially as expressed in the local language. ‘Gomarara’ is the ubiquitous word used by people who live the experience in Zimbabwe. The point is that, our people in everyday expression, do not define cancer using the over 200 or so cancer typologies presented in medical journals!

1.2 BACKGROUND

1.2.1 Trends on Cancer Morbidity and Mortality: A Global, Regional and National Picture

The case of Non-Communicable Diseases (NCDs) received its highest recognition by the convening of a United Nations summit on NCDs on the 19th and 20th of September 2011, after years of an unenthusiastic response at global level. According to the latest World Cancer Report, an estimated 14.1 million new cases of the global cancer burden were recorded in 2012. This figure is expected to rise to 22 million per annum in the next decade (International Agency for Research on Cancer, 2014). It is projected that the global cancer burden will exceed 20 million new cancer cases per year by 2025 (IARC, 2014). Of note, about 70% of global cancer deaths come from Africa, Asia and Central and South
America. More than 60% of the world’s cancer cases occur in Africa, Asia and Central and South America (IARC, 2014). It is noteworthy that the incidence and mortality rates of cervical cancer in Sub-Saharan Africa are 34.8 and 22.5 per 100 000 respectively, the highest of any world region (IARC, 2014). Given that the Sub-Saharan region has the highest HIV prevalence rate in the world, incidences of cancers associated with the HIV, like Kaposi Sarcoma are very high.

1.1.2 The Cancer Situation in Zimbabwe

Official statistics and anecdotal evidence from Zimbabwe show that the incidence of new cancer cases in the country is on the rise. Statistical data on cancer in Zimbabwe come from a population-based Cancer Registry that captures hospitalised cancer cases in private as well as public hospitals. The major case study and focal point of the Cancer Registry is Harare, the capital city. The cancer data of cases from satellite health care centres in the whole country are fed into the database in Harare. The World Health Organisation (2014) report on country profiles noted that NCDs accounted for 31% of all deaths in Zimbabwe, with cancers taking 10% of this share. According to the latest annual report from the Zimbabwe National Cancer Registry (ZNCR), the total number of new cancer cases recorded among Zimbabweans in 2013 was 6 548, comprising 2 777 (42.4%) males and 3 771 (57.6%) females (Chokunonga, Borok, Chirenje et al 2015). The leading cause of cancer among black Zimbabwean men in 2013 was prostate cancer (17.8%) while the leading cause of cancer among Zimbabwean black women was cervical cancer (32.1%) (Chokunonga et al, 2015). In Harare the capital, 2 459 new cases of cancer were recorded in 2013 comprising 1 167 (47.5%) males and 1 292 (52.5%) females. Cancer of the cervix uteri (18%) was the most frequently occurring cancer among Zimbabweans of all races, followed by Kaposi sarcoma (10%) and breast as well as prostate both at 7% in 2013 (Chokunonga et al, 2015). According to a triennial report for Harare (2010-2012), 6 345
new cancer cases, comprising 44.9% males and 55.1% females were recorded among residents of Harare City of all races during the three year period (Chokunonga, Borok, Chirenje et al, 2014).

**Figure 1: Registration of Cancer Data: 2005-2013**

![Graph showing cancer data registration from 2005 to 2013](image)

**Source:** Zimbabwe National Cancer Registry 2013 Annual Report

The histogram above (Figure 1) shows the generally upward trend of recorded cancer cases from 2005 to 2013. The years 2007 to 2009 show a distorted picture of a downward trend. This was the period which brought in the advent of the economic meltdown experienced in the country, when the sick were not being attended to in the hospitals due to lack of user fees, the erratic availability of drugs and medical staff (African Development Bank, Organisation for Economic Cooperation and Development, and United Nations Development Programme, 2014). The health sector and the ZNCR were not spared either. Suffice to say that there was a blackout in every sense and some people could have died at homes without the cause of death being ascertained and certified.
1.2.3 The Limits of Official Cancer Statistics

The foregoing national cancer statistics do not necessarily capture all the cancer cases occurring in the country because they derive from recorded hospitalised cases. This factor is acceded to in the National Cancer Prevention and Control Strategy for Zimbabwe 2014-2018 (Ministry of Health and Child Welfare, 2014). Those cancer cases that do not find their way to the hospital and all uncertified cancer deaths are left out. The same applies to people confirmed as having cancer but who somewhere along the way discontinue treatment due to the prohibitive costs or fear of treatment. There is every reason to believe that the cost of diagnosis in terms of scans and laboratory tests turns away a considerable number of people who cannot afford these exercises. It is likely that some die without having had a diagnosis. Another point is that the sociology of official statistics has taught us that the figures presented tend to play a symbolic or political role, where seemingly low figures may not be enough to persuade policy action. A human illness may not need to become an epidemic first in order to compel government into action!

1.2.4 Current Cost of Hospital Cancer Treatment in Zimbabwe

The current cost of cancer treatment is far beyond the reach of many ordinary citizens. There are three main modalities of payment for hospital-related cancer treatment in Zimbabwe as follows: medical insurance, cash and the Social Dimension Fund (SDF). Hospital treatment is available in both public and private entities. The SDF targets the poor and the vulnerable and involves a recommendation by the attending doctor or oncologist. Generally, private entities do not accept a letter from the SDF as a modality of payment for services rendered. The SDF letter either can be accepted, or rejected, by the accounts departments of the public hospitals in Harare, and even Bulawayo, the county’s second major city and referral centre.
Besides the major costs of mainstream treatment, clients also incur other associated costs of cancer treatment regimens. The following costs were obtained (at the time of the interviews in 2014) from the Parirenyatwa Group of Hospitals in Harare, the major referral centre for all cancer cases in the country. These costs include the payment for blood tests before a chemotherapy session at a cost of 50 United States Dollars (USD). In the case of surgery and low hemoglobin levels, blood transfusion costs about USD 140 per unit. X-ray and liver function tests range from USD 20 and vary with each service provider. External beam radiotherapy, which on average takes 23 days, costs 417 United States Dollars at Parirenyatwa. Chemotherapy drugs range from USD 15 for cisplatin per 500 miligrams, USD 45 for carboplatin to USD 200 for the cost of paclitaxel (260/300 miligrams) for those with cancer of the breast. Some clients with cancer of the prostate may require zoledronic acid to deal with bone pain at a cost of USD 130. The cost of antiemetic palonesetron, prescribed to prevent excessive vomiting caused by chemotherapy drugs, ranges from USD12 to USD 25. It is a common feature that clients undergoing chemotherapy require an injection for neupogen to boost a low white blood cell count. This injection costs USD 59 (during chemotherapy both good and bad white blood cells are destroyed). After radiotherapy sessions, a client with cancer of the cervix is required to undergo a procedure known as Bracky therapy (to clean the cervix) which costs 500 United States Dollars. On average, the monthly salary of a civil servant (civil service is currently the major employer) is USD 300 per month and USD 80 for a pensioner.

Though non-state organisations like the Cancer Association of Zimbabwe (CAZ) assist with meeting the cost of drugs for some clients who are under the SDF, the coverage is insignificant given the overwhelming numbers and in a context where the organisation has not been immune to the harsh economic climate. The CAZ gets most of its funding from
membership subscriptions, corporate partners and willing donors. Most rural clients may not even be aware of the existence of cancer service organisations like the CAZ.

1.2.5 Cancer Policy, Treatment, Support, Care and Education Infrastructure in Zimbabwe

Most of the evidence presented in this section was extracted from the five-year National Cancer Prevention and Control Strategy (NCPCS) 2014-2018 for Zimbabwe, crafted by the division of The Epidemiology and Disease Control through the Non-Communicable Disease Unit under the auspices of the parent Ministry of Health and Child Welfare (MoHCW).

Cancer Policy

Recently the government of Zimbabwe through the Ministry of Health and Child Welfare inaugurated a five-year National Cancer Prevention and Control Strategy (NCPCS) 2014-2018, signed by the responsible minister in 2014. In 1994, a National Cancer Control Action Plan for Zimbabwe (NCCP) was launched with the overall aim of formulating, planning and implementing a coordinated program. However, there were problems with regard to the implementation. Successful implementation of earmarked plans became difficult because of, among other things, the lack of access to the document by most health professionals, poor monitoring, omission of cancer incidences among children and oversight over the association between cancer and HIV and AIDS (MoHCW, 2014). Although the preceding National Health Strategy (2009-2013) enumerated cancer prevention and control, most strategies enunciated became obsolete without ever having been implemented. A further deficit arises from the fact that the policy on Non-Communicable Diseases (NCDs) is still in draft form and is yet to be endorsed by stakeholders (MoHCW, 2014).
Funding

Cancer programmes are grossly under-funded when compared to HIV and AIDS as well as malaria. There is an AIDS levy, which funds HIV and AIDS programmes in addition to funds received from the Global Fund and other donor agencies. There is no such levy to fund cancer in the country. Funding is inadequate even though there are a few international and regional partners rendering support (MoHCW, 2014). These international partners have confined themselves to cancer of the cervix.

Training

In terms of the training of personnel, the University of Zimbabwe runs an undergraduate programme on Radiation Oncology, where postgraduate students in paediatrics do rotations in the paediatric oncology unit as fulfilment of partial requirements for the degree. However, there are currently no facilities in the country to train Nuclear Medicine personnel. The few so far trained, received their training abroad with the help of the International Atomic Energy Agency. The training of oncology nurses is in its infancy with the first group of trained nurses only expected in November 2015. This is a problem given that nursing is critical in illness management. The MoHCW (2014:5) notes that, “the current guidelines for cancer management titled Oncology in Zimbabwe, is long outdated having been formulated in 1992, hence management of cancer is not standardised, with differing management protocols and guidelines at different levels of the service delivery system”.

Information, Communication and Education on Cancer

In terms of access to information, communication and education there is currently no coordinated, consistent communication except for the Cancer Association of Zimbabwe. CAZ is a non-state organization that provides free health education materials in two
languages (Shona and English) including carrying out small-scale outreach programmes in and out of the city of Harare. To date, Zimbabwe is yet to inaugurate a fully formulated cancer prevention strategy. As of now, only a few educational and awareness programmes are being run mainly by the CAZ and its partners in a few cities and rural areas. These programmes include commemorations like World Cancer Day sponsored by the MoHCW.

**Cancer Diagnosis, Treatment and Care Infrastructure**

With regard to diagnosis and treatment, there is very limited infrastructure in Zimbabwe. The few available facilities are located mainly in the two major cities of Harare and Bulawayo, and in the private sector. There are only two Radiotherapy Treatment Centres in a country of 13 million people with many people, especially those in rural areas and the poor failing to meet their travelling costs. Histopathology services are centralised in urban areas in the whole country. There are only five pathologists instead of the optimal 48, a serious human resource gap (MoHCW, 2014). While the early detection of cancer can enhance effective treatment of the disease, approximately 80% of clients in Zimbabwe present late (third and fourth stage). The result of that is a high rise in morbidity and mortality rates (MoHCW, 2014).

In Zimbabwe, the national rolling out of screening programmes is still in the embryonic stage. Most screening services in the country are offered in the private sector and are centralised in urban areas. The cost of screening is prohibitive, as most health insurance does not cover for screening services. In addition, screening for paediatric (childhood) cancers is yet to be put in place.

Nuclear medicine plays a part in the management of cancer illness especially in the staging and monitoring of cardiac function for some clients on chemotherapy. Currently there are only two government owned nuclear medicine facilities in the country, in Harare and
Bulawayo with challenges of machine breakdowns. This has deprived people with cancer of getting optimal care for a long time. In terms of radiotherapy, for about a decade, only one sub-optimally functioning radiotherapy machine has been serving the whole country with the facility at Mpilo Hospital radiotherapy facility in Bulawayo having been down since 2003 (MoHCW, 2014). There is a general shortage of critical staff for radiotherapy and chemotherapy in the country.

Generally, palliative care in relation to clients with cancer in Zimbabwe is quite scarce with Tariro home in Harare, which used to offer accommodation having been closed for several years now. Private players like Island Hospice and Bereavement Centre, formed in 1979 and the Cancer Association of Zimbabwe, currently offer palliative care. In terms of cancer surveillance and research, the country has an active, well-established population based cancer registry established in 1985. The registry is in Harare the country’s capital. Another registry branch is located in Bulawayo was recently resuscitated after downing operations at the peak of the economic meltdown in 2006.

It is against such a background that this study seeks to identify and examine causal attribution narratives on cancer by participants, extract available ethnomedical knowledge on cancer in the country, describe the lived social experiences of people living with cancer and explore their pathways to treatment and management of the illness.

1.3 Problem Statement

The morbidity and mortality rates of cancer, at a global level, in Sub-Saharan Africa and Zimbabwe in particular, have been on a steady rise (as presented in the preceding background to the study section). Yet the value of a qualitative research may not necessarily find justification from robust statistics but is intrinsic in a study of human beings who act, feel, think, interpret and in the inestimable value of human life. In my
introduction, I alluded to the dearth of qualitative studies on cancer in Zimbabwe and on a preponderance of cancer studies grounded in quantitative methodologies informed from the bio-medical paradigm. The few qualitative studies on cancer available are exploratory surveys on cancer knowledge, which by their very pre-set questions, resemble and buttress bio-medical knowledge. This is not to say that there is no value in bio-medical knowledge on cancer, which, so far has contributed to our understanding and improvement in treatment, survival rates and quality of life of people diagnosed and living with cancer in the world. The point is that, clinical studies, illustrated in quantitative research fall short in illuminating how an illness is experienced by living human beings, in specific contexts as well as in enhancing our understanding of the ingenuity and tenacity that may be demonstrated by people faced with a life threatening ailment like cancer, in their quest to become well.

Interpretive phenomenological research makes it more compelling, by privileging insights from the actual people living and experiencing the illness. The paucity of such a research thrust is in stark contrast to profusion of qualitative and phenomenological studies on cancer, available online, carried out in regions and countries like America, Western Australia, Western Europe, Asia and some few African countries. This study is one of the first such in the country, which seeks to describe and examine local cancer-causing discourses, rooted in peoples’ lived experiences and available ethno medical knowledge embodied in cultural repertoires. The central argument of this study is that an understanding of indigenous or local cancer discourses is fundamental to our acquiring of comprehensive knowledge of the illness, its manifestations and dynamics, which in turn may inspire any programmatic interventions to ameliorate the negative impacts of ill health related to cancer. In a similar vein, a combination of novel data capturing methods engendered in interpretive hermeneutic phenomenology provides in-depth, holistic,
nuanced, fringe data, grounded in context-specific case experiences, which enhances our understanding of the impacts of the cancer illness on society, on families and to the concerned individuals. Such an approach underscores the weight of the social cosmos and individual exertions in the health matrix and not just emphasizing the physical-medico elements.

1.4 Study Aim and Objectives

The primary aim of the thesis is to describe and analyse local cancer-causing narratives, lived illness experiences and health-related help seeking behaviours of people diagnosed with cancer in Harare, Zimbabwe.

The specific objectives are to:

1. Describe and analyse indigenous knowledge and causal-attribution narratives on cancer in Harare, Zimbabwe.

The aim here is to document personal perceptions or beliefs of causes of one’s cancer illness expressed in the question, ‘personally, what do you attribute your cancer illness to?’ OR ‘after being diagnosed with cancer, what came into your mind to explain your cancer diagnosis?’ The focus is on individuals’ perception, belief and lived experience, which become vital texts to interpret the cause of their illness. Additionally, data on this objective came from explanatory narratives of key informants/experts especially traditional health practitioners and older participants with cancer. Currently, there is paucity of such research data, which may be at variance with scientific evidence. To Stewart, Cheung, Duff et al (2001: 179) “This may assist in framing the management of patients in personally meaningful ways, which may increase health behaviours, adherence, satisfaction and quality of life”.

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2. **Describe and interpret lived illness experiences of selected people diagnosed and living with cancer in Harare, Zimbabwe.**

This objective, notwithstanding its intrinsic value as contributing to new insights, illuminates on the hallmark of the tradition of phenomenology—*the study of lived experience* as an emphasis on the uniqueness of each human being. As noted by Auden (1967) cited in van Manem (1990:6), “As persons, we are incomparable, unclassifiable, uncountable, irreplaceable”. Though there is a thin line separating general lived experiences from illness experiences, the thrust was to explore lived experiences in the context of illness.

3. **Describe and analyse health related help-seeking behaviours and pathways to treatment adopted by people living with cancer in Harare, Zimbabwe.**

This objective is crucial and stands to provide some answers to frequently asked questions like; *why do many clients present late with advanced disease? Where are people diagnosed with cancer receiving treatment from, in a context of prohibitive treatment costs and centralisation of treatment infrastructure in Zimbabwe?* Ideally, the pathways to treatment may be conceived as linear yet can be discontinuous or circular given that from common experience, when human beings are faced with a life-threatening ailment they practise health/medical pluralism.

4. **Identify the existential challenges faced by people diagnosed with cancer in Harare, Zimbabwe.**

Transcending the usual journalistic mantra, this objective sought to discuss any emergent challenges experienced by people living with the cancer illness in their daily
lives in Zimbabwe. Concisely, this objective illuminated on *what it is like to live with cancer for an ordinary citizen in Zimbabwe today.*

5. **Deduce and document, suggestions for intervention measures to deal with the existential challenges faced by people with cancer in Harare, Zimbabwe.**

Departing from the conventional (the idea that at the end of every research writing should appear a section on recommendations mainly proposed by the researcher), this objective mainly drew from suggestions given by people diagnosed with cancer.

The foregoing study objectives are guided by the following **research questions:**

1. How do people living with cancer account for their cancer and the general rise in the cancer illness in Zimbabwe?

2. What are the local perceptions, beliefs, cultural interpretations on the causes of the cancer illness in Zimbabwe?

3. What is the lived experience of people with cancer in Zimbabwe?

4. What are the trajectories followed by people living with cancer in their quest to become well, to manage the pain and the debilitating impacts of the illness in Zimbabwe?

5. How can we characterise the help-seeking behaviour of people living with cancer in Zimbabwe?

6. What existential challenges do people diagnosed with cancer in Zimbabwe experience?

7. How can we address challenges facing people living with cancer in the country, to improve their quality of life?
1.5 Significance of the Thesis

1.5.1 Ontological Justification

Ontologically (what is the form and nature of reality and what can be known about it) Heideggerian interpretive phenomenology adapted to this study as a theoretical framework perceives not one but many realities which may be altered by the investigator (Moran, 2000). Reality is constituted in the essence of lived experience, experience that is historically situated and generated (Moran, 2000, 2005). Heidegger’s phenomenology gives central focus on the situatedness of research participants and the idea that meaning as found in our experience is generated in historical processes of collective experience over time. Noteworthy, the tradition of hermeneutic phenomenology enables the study to investigate and decipher insights into local narratives on the cancer illness, rooted in history, cultural repertoires and beliefs on disease conception, causation, progression and concomitant therapies. Older and experienced Traditional Health Practitioners (THPs), community elders and some older people diagnosed with cancer especially those who reside in rural areas may espouse such evidence. In an environment where clinical knowledge on cancer pervades government policy, the national health delivery system and informs available institutionalised cancer care and treatment infrastructure, there is research lacuna on such knowledge and data in a canonised form. My study can serve as step in such a direction.

1.5.2 Epistemological Justification

In terms of epistemology (what is the nature of the relationship between the knower and what can be known about it/or the science of knowledge) interpretive phenomenology acknowledges that there ensues a relationship between the researcher and the participants (Heidegger, 1962). Husserl (touted as father of modern phenomenology) vaunted for
Bracketing, a process involving the researcher identifying all personal biases, values and characteristics which may influence the research process and interpretation of results and holding them in abeyance (Moran, 2000, 2005; Ajjawi and Higgs, 2007). In contradistinction, Heidegger (1962) argued for incorporation of such personal subjectivities as embedded knowledge, which enhances our understanding, and interpretation of phenomena (Norlyk and Harder, 2010; Larkin, Watts and Clifton, 2006; Ajjawi and Higgs, 2007). In essence, in hermeneutic phenomenology, there is no dividing line between the individual and experience, interpreting them as co-constituting each other (Larkin et al, 2006). From such a standpoint, bracketing is impossible, as one cannot stand outside the pre understandings and historicality of one’s own experience (Heidegger, 1962). The researcher is called, on an ongoing basis, to give considerable thought to his own experience and to explicitly claim the ways in which his/her position or experience relates to issues being discussed (Wilson, 2007; Friberg, Andersson and Bengtsson, 2007). Researchers keep a reflective journal, which assists them in the process of reflection and interpretation. I found Heidegger’s phenomenological episteme, prudent given the nature of my study, which invites one to be empathetic and reflexive throughout the research process. Acknowledging the influence of personal values is both an act of integrity to self and to the professional community. I am persuaded to go with Goethe (1963:83) “One learns to know only what one loves, and the deeper and fuller the knowledge is to be, the more powerful and vivid must be the love, indeed the passion”. My epistemological position is fresh to the horizons on cancer research in Zimbabwe and stands to add new insights on the subject matter.

1.5.3 Methodological Justification

In terms of methodology, (how can the inquirer go about finding out whatever they believe can be known) the goal of hermeneutic investigation is in understanding, of which
linguistic and historical frameworks are part of the process (Laverty, 2003: 3). The emphasis is on use of everyday language, which enables one to present and analyse data with a strong emotional appeal and communicative power, unlike superficial reality engendered from preconceived scientific concepts (van Manem, 1997; Heidegger, 1962). As observed by Stark and Trinidad (2007), qualitative research methods enable researchers to delve into questions of meaning, examine social and institutional processes and practices, identify any emergent barriers and facilitators to change and reveal the underlying reasons for the success and failure of interventions. The study is a contribution to thin qualitative and phenomenological research and scholarship on cancer in Africa and Zimbabwe and adds ethno-socio medical insights to the study of cancer, which is often outflanked, or sidelined by clinical knowledge.

1.5.4 More Justification

Additionally, there are three positions which I took in this study, which proponents of scientific medicine may deem as odd, which I need to clarify and justify. Firstly, medical science conceives of cancer as not one disease but a group of diseases. In fact, over 200 cancers are presented in medical journals! In my study, I have selected participants who have cancer located on different body sites, and in the field of medical science, this can prove difficult if not impossible to interpret data meaningfully compared with a study dedicated to one type of cancer. My argument is that, my study is from sociology or social science, which seeks to understand and examine the cancer illness from people’s narrative accounts and their own frame of reference, thereby transcending the bio physicist view.

In essence, our people (in Zimbabwe) in everyday expressions talk of cancer as gomarara, or nhuta all in Shona language or Imvukuzani in Ndebele (differences only come from different dialects associated with cultural geography). Thus, in people’s local
understanding, there is one cancer illness or *gomarara* which is only distinguished by where it chooses to manifest itself (that is its location on the human body). They would then refer to *gomarara rake riri pazamu kana chibereco* (one’s cancer is located on the breast or uterus). Our people do not think, talk or conceive of cancer as the several hundreds of diseases but as one. It suffices that, being a social science student who would like to advance people’s embodied knowledge and their lived experience and who is not an expert in discussing scientific medical aetiology of cancer, I found my approach not only well placed epistemologically, but as an ontological reality, at least, from the viewpoint of my participants. Premising my study in firm conventional medical research of pre-set medical categories was not only going to contribute less to existing knowledge gaps on cancer but it will be poor mimicking of biomedical understanding on cancer!

The second point is on the use of the designation *cancer patient* (s) which I am reluctant to adopt in my study, or at least I found it incompatible with the general epistemology adopted in the study. The designation ‘cancer patient’ is eschewed in this study primarily for three reasons. Firstly, the phrase raises connotations of an all-season, sick person yet people with cancer may be active, productive people (each case nonetheless varies with the severity or stage of the illness). Secondly, the label conforms to Howard Becker’s (1963: 32) *master status*-as if the cancer illness becomes a central feature of person identification-invoking some kind of stigmatization. The work of Little, Jordens, Paul et al (1998: 1486) strike a similar cord with my position of what they call ‘cancer patientness’, some “...persistent identification as a cancer patient regardless of time since treatment and presence or absence of recurrent or persistent disease”- a scenario which creates some alienation or *boundedness* or ‘*liminality*’. Thirdly, the designation ‘cancer patient’ invokes asymmetrical power relations the idea of ‘them’ and ‘us’. Instead, the designation ‘clients’ is used interchangeably with persons/people [diagnosed] with cancer. It is critical to be
reflexive, and acknowledge my epistemological grounding rather than remaining mum about it.

Lastly, I clarify my fondness with the term *illness*. Notwithstanding the contested nature of defining concepts associated with health, the distinction made by Professor Marshall Marinker, a general practitioner, over 20 years ago, helps in distinguishing ‘disease’, ‘illness’ and ‘sickness’ (Boyd, 2000). Disease is a pathological process, which signals some deviation from the biological norm—some objective view, which is the linchpin of the bio-medical view of [ill] health. Illness is the person’s experience of ill health, which is entirely personal, interior to the person, sometimes when no disease can be found. Sickness is the external and public mode of ill health, a social role, a status, a negotiated position in society (Boyd, 2000). This study seeks to understand persons’ experiences of cancer, hence its use of the term ‘illness’ throughout the thesis, though diagnosis makes *disease* the departure point and sickness espouses the interaction of the ill person with ‘significant’ and ‘generalized others’.

1.6 Understanding Cancer from the Bio physicist View: A Brief Picture

In this section, I present basic scientific knowledge from the bio-physicist paradigm on cancer aetiology (study of disease) and associated clinical treatment. As I am no expert in the area, there is no attempt made at interpreting on the knowledge. It was critical for the researcher and readers to have some appreciation of the knowledge. The information below is adapted from Dollinger, Rosenbaum and Cable (1997) and American Cancer society (2014).

Cancer refers to a group of more than 200 diseases characterized by the uncontrollable growth and spread of cells in the body growing abnormally. Cells are the basic units of life. These cells can divide and produce new cells in an uncontrolled manner thus creating
more cells even when they are not needed. The unwanted cells can spread throughout the body and cause damage to essential organs. The spreading of cancer to other parts of the body is called *metastasis*. When cancer cells enter the blood stream or lymph system, circulate all over the body system, and allow cancer cells to travel- metastasis occur. Tumours are masses (or lumps) that can develop as abnormal cells and accumulate but not all tumours are cancerous. There are benign (non-malignant) tumours that do not spread to other body parts neither are they life threatening. There are four main types of cancers; carcinomas (cancers of the organs); sarcomas (cancers of the muscles, bone, cartilage and connective tissue); lymphomas (cancers of the lymphatic system) and leukaemia (cancers of the blood making system). Different cancers have different causes and are likely to have many risk factors. Certain cancers are more common than others are and chances of survival vary. Generally, cancers take time to develop into symptomatic elements say over 10 to 15 years and there are no known causes from a chemical, environmental, immunological or viral origin. Therefore, causes of cancers are complex involving both the cells and factors of the environment.

Most cancers are defined by stage of growth using a system developed by the American Joint Committee on Cancer for solid tumours. The stage is based on the size of the tumour and how much the cancer has spread. Proper staging is essential in assessing prognosis and determining the choice of therapy. Stage one is composed of a primary tumour only; stage two-primary tumour but larger than in stage one; stage 3-primary tumour and metastasis to lymph nodes; and stage 4- primary tumour and distant metastasis. To date there is no conclusive evidence of what generically causes cancers but mostly risk factors are cited. Risk factors include tobacco (ab)use, high fat diet and obesity, heredity, excessive exposure to sunlight, too much intake of alcohol; X-rays and other sources of radioactivity, chemicals and other substances in the environment (carcinogens). In addition, unsafe
sexual practices can lead one to acquiring infections such as hepatitis B virus (HBV), human papillomavirus (HPV), hepatitis C virus (HCV) human immunodeficiency virus (HIV) and helicobacter pylori (H.pylori) which predispose one to cancer of the reproductive organs. Common symptoms of cancer include thickening or lump in the body, cough or hoarseness that persists, obvious change in a wart (lump) or mole, changes in bowel or bladder habits, unexplained bleeding or discharge, sores that do not heal, unusual upset of stomach or having trouble in swallowing. Most cancers can be prevented by avoiding risk behaviours and lifestyles, by being physically active, taking a proper diet, behavioural changes and early screening. Screening allows for secondary prevention by detecting cancer early, before symptomatic elements develop and early detection generally results in better survival outcomes and less extensive treatment. Any person is at risk of developing cancer though the risk of being diagnosed with cancer increases with age. Cancer is diagnosed through physical examination, laboratory tests, magnetic resonance imaging (MRI) and biopsy. Biopsy is when a tissue is taken using a needle or a surgical procedure and is examined directly to see if it has the characteristics of cancer and it is the most effective and common method of diagnosis.

The treatment options of cancer depend on the stage and type of cancer and include surgery, radiation therapy, chemotherapy, biological therapy, hormone therapy and targeted therapy. If the tumour is in one place and can be removed, surgery is the most preferred option. Radiation therapy is whereby beams of x-rays or other high-energy rays are directed at the tumour site and this is done to shrink tumours or to make them disappear. Some of the side effects of radiation include fatigue, nausea and vomiting, skin inflammation, appetite loss, dry mouth and changes in the sense of taste. Chemotherapy is usually used to treat cancer that has spread. Some chemotherapy drugs are administered via the mouth or intravenously (into the blood through the veins). Some of the side effects
of chemotherapy include nausea and vomiting, fatigue, appetite loss, hair loss, sore mouth, changes in sense of taste, fever and infection. Biological therapies use treatments that help the immune system do its job of disease fighting in our bodies and can be effective on some cancers. Hormone therapy entails limiting the production of hormones through surgery or medication. Some people also use various complementary and alternative therapies.

1.7 Conclusion
This chapter discussed the conceptual and contextual issues that inform and permeate this study. The major intention of this study is to enhance indigenous understanding of cancer by advancing social science and phenomenological analysis in an area currently dominated by quantitative bio-medical scholarship. Such a thrust not only contributes to a holistic understanding of the existing knowledge on cancer but also extracts marginalised data from situated participants who live the phenomenon or the experience. The chapter gives a detailed picture of the nature and extent of the country’s cancer burden, and indicates what the existing policies are, and what services to people living with cancer are either available or unavailable. This enables the researcher and the readers to appreciate comprehensively the narratives of the participants. A recurring observation throughout the chapter is that the rising cancer morbidity and mortality rates in the country are not matched by a corresponding proactive government response. Thus, this chapter sought to bring the ‘research problem’ into sharper focus by presenting the overarching economic, political and socio-cultural contexts as well as the conceptual insights underlining the study.
2. CHAPTER TWO: REVIEW OF RELATED LITERATURE

2.0 Introduction

This chapter is a review of the literature at pre-analysis stage, related to the objectives and research questions of the study. It seeks to locate gaps in which to launch the thesis argument and familiarise with the phenomenon under study. Despite the abundance of literature on phenomenological and qualitative empirical studies on cancer in Western Europe, Western Australia, America and Asia, there is a research lacuna on similar lines in Zimbabwe. Since phenomenological studies focus on lived experience, they engender inimitable collective experiences, which though usually marginalised, are critical for our comprehensive understanding of ill health and its social impacts. The researcher could not find any single phenomenological study on people diagnosed with cancer in Zimbabwe at the time of the study. This chapter begins by discussing qualitative literature (including phenomenological studies) on perceptions and beliefs regarding the causes of cancer. Such a focus tends to elicit novel composite data that reflect the personalised and situated experiences of people diagnosed with cancer. The chapter then explores literature on the lived illness experience of people diagnosed with cancer. A focus on the lived experience is at the heart of interpretive hermeneutic phenomenology. However, as noted by Moen (2006:4) “as individuals are telling their stories, they are not isolated and independent of the context”. The chapter ends by reviewing literature on health-related, help-seeking behaviour and management of the cancer illness by people diagnosed with cancer.
2.1 Causal Attributions, Perceptions, Beliefs and Cultural Interpretations of the cancer illness

The review in this section addresses the question: What are the perceptions, beliefs, cultural interpretations on the causes of the cancer illness? 

It can be argued that the major limitation of most existing studies (on causal attribution of cancer) is an attempt to establish causal analysis or to streamline responses thereby distorting the reality of participants. Participants may not only give composite responses that blend various causal factors in a single narrative but also portray reality from their own frame of reference. The frames of reference thus portrayed may vary from scientific evidence.

Results from studies meant to establish the causal-attributions of women diagnosed with cancer of the breast, elicited various perceptions and beliefs, some of which were at variance with scientific evidence. In a survey to establish what female breast cancer survivors attribute their illness to; some participants attributed it to stress, some genetics, others to the environment, hormones, diet, breast trauma, with some professing ignorance (Stewart, Cheung, Duff et al, 2001). In the same study, a positive attitude, diet, healthy lifestyle, physical activity, prayer, complementary therapies, luck and tamoxifen, were credited with preventing a recurrence. Panjari, Davis, Fradkin et al (2011) used questionnaires to explore the beliefs held by 1 496, breast cancer survivors about the factors that contribute to breast cancer. Many cited stress followed by use of hormone therapy and family history. Women who thought it was stress were more likely to adopt strategies that reduced stress than those who did not. Of note, Stewart et al (2001) suggest that health care providers could consider the personal beliefs of people despite the likelihood of their being at variance with scientific evidence, when framing the management of illness among people with cancer, in personally meaningful ways. Such
views underscore the possible contribution of the *insider voice* in nurturing culturally sensitive nursing for people with cancer.

Narratives linking cancer to stressful events are not new, though the evidence is conflicting. Many studies on women diagnosed with cancer of the breast cited stress in their causal attribution narrative (Zhang, Fielding, Soong et al, 2015; Mellon, Gauthier, Cichon et al, 2012; Panjari et al, 2011; Stewart et al, 2001; AIHW, 2012; Kulik and Krofeld, 2005). Some studies have revealed no connection between stress and cancer of the breast (Nielsen, Stahlberg, Strandberg-Larsen et al, 2008; Michael, Carlson, Chlebowski et al, 2009; Surtees, Wainwright, Luben et al, 2009; Butow, Hiller, Price et al, 2000; Nielsen and Gronbaek, 2006 and Schraub, Sancho-Garnier and Velten, 2009). A few studies point to the contrary (Nielsen, Zhang, Kristensen et al, 2005). The major limitation of most studies of this nature is their attempt to establish causal analysis or to streamline responses in multifactor responses thereby distorting the perceived reality of the participants.

Zhang, Fielding, Soong et al (2015) administered a Brief illness Perception Questionnaire, among other quantitative instruments, to 1036 survivors of different cancers recruited within 6 months of completion of their adjuvant therapy from Hong Kong public hospitals. The objective was to document their illness perceptions. The attribution of the causes of cancer varied from stress-related, to lifestyle, environment, psychological/personality and health-related factors. Of interest to this study is the conclusion by Zhang et al (2015) indicating a similarity of illness perceptions across the different types of cancer. This position resonates well with my ontological assumption on the cancer illness conceived in its wholeness in everyday [lay] expressions rather than the various taxonomies conceived in clinical research.
Dumalaon-Canaria, Hutchinson, Prichard et al (2014) reviewed 22 articles published between 1982 and 2012 that examined the causal attributions of breast cancer among women previously diagnosed with breast cancer. Their findings indicated a consistent belief in the contribution of stress, fate or chance, environmental and family history, to breast cancer. Contrary to expert enunciation of lifestyle risk factors such as physical inactivity, diet and alcohol consumption, such explanations were less conspicuous over the past 30 years. Notwithstanding the affinities between this study and this review, it is evident that the review asks the same questions asked as the domain of medical science. My study demonstrates a departure from conventional medical research by undermining pre-set and preconceived cancer knowledge through privileging and listening to the narratives of the research participants regarding what they personally attribute their cancer illness to.

Lizama, Rogers, Thomson et al (2015) administered a questionnaire in a case-control study of 1 109 cases and 1 633 controls in Western Australia, to explore women’s beliefs about breast cancer risk factors and whether these differed by demographic factors and personal and family history. Significant variations were noted between cases and controls for 16 of the 37 exposures, with younger women and university-educated women more likely to correctly identify known breast cancer risk factors. The study also showed that women’s perceptions about the effect of alcohol consumption differed from that usually reported in literature. This study minimised the number of questions based on pre-set concepts that fit into the already existing medical knowledge of risk factors associated with cancer. The thrust is on documenting people’s narratives and what they attribute their cancer to, within their frame of reference and lived experiences beyond, or as part of, medical scientific knowledge. The understanding of such narratives is likely to be essential to culturally sensitive nursing and treatment and is likely to enhance illness-management as well as the
sharing and importing of intelligent messages in public health campaigns. Unlike Lizama et al (2015) who draw probabilistic statistical inferences using statistical models on the impacts of demographic characteristics, this study draws inferences from any such emergent associations from the narratives of the lived realities of people diagnosed with cancer. The researcher interprets any such association from the novel experiences related in conversational interviews in pursuit of validity rather than reliability. However, the catalogue of 37 exposes by Lizama et al (2015) thought to be associated with the risk of breast cancer is invaluable for comparison, though differences between the research settings or cultural tastes is germane.

Anorlu (2008) reviewed literature, which critically assesses the incidence, mortality, knowledge, prevention and treatment of cervical cancer in Sub-Saharan Africa. She notes the incidence rates in Uganda, Mali and Zimbabwe to be on the rise and that about 60-75% of women in Sub-Saharan Africa who develop cervical cancer, live in the rural areas and mortality is very high. Anorlu (2008) reviewed a combination of socio-cultural, biological and economic factors seen as drivers to high incidence of the cancer. Anorlu (2008) cautions that the true incidence of cervical cancer remains elusive because the figures quoted in the literature and in official statistics are hospital-based. This suggests that a small fraction of women die because they can neither afford nor access hospital care. Consequently, they die at home. This background offers ample scope from which to investigate the social experiences of people living with cancer in rural areas. It also makes it possible to investigate the alternative therapies they utilise in light of religious belief systems and inaccessibility of hospital care owing to cost and lack of de-centralised treatment infrastructure.

Most studies in Africa highlight low levels of basic knowledge on cancer among participants in surveys conducted. Mupepi, Sampselle and Johnson (2011) sought to
estimate the proportion of rural females who have received cervical screening and to assess knowledge, beliefs, attitudes and demographics that influence cervical screening in Zimbabwe. The key findings from their study were that 91% of the respondents had never had cervical cancer screening, 81% had no previous knowledge of cervical screening tests and 80% of the group expressed positive beliefs about cervical screening tests after an educational intervention. The current study utilises qualitative methods, which allow probing, and clarification. However, in line with Mupepi et al (2011), this study explores the social experiences on cancer including the impact, if any, of demographic factors like gender, age, marital status, religion, level of education and type of occupation. In a similar vein, Mangoma, Chirenje, Chimbari et al (2006) assessed rural women’s knowledge, constraints and perceptions on cervical cancer screening in the Mutoko and Shurugwi rural districts of Zimbabwe. Their study revealed that cervical cancer is of concern to women and health practitioners and 95.7% of women interviewed had never gone for screening. Mine is an intimate case study that seeks to reveal people’s understanding and experiences on the overall notion of cancer (gomarara) not from pre-set medical knowledge but from the understanding of participants.

Levy (1997) relives her personal experiences with Shona cancer patients at Parirenyatwa public hospital in Zimbabwe. Her key observations were that the Shona people in Zimbabwe are steeped into traditional religious beliefs including the embracing of traditional healers. According to Levy (1997), most Shona patients had little or no concept of cancer. Levy further attests that there is no word for cancer in Shona lexicon. Levy (1997) attests that a few people, showing some understanding of the nature of the disease, used words meaning a mole burrowing in the ground or parasitic mistletoe. This study interrogates such an observation in light of field evidence. It attempts in-depth research into the cultural understanding of cancer by conducting in-depth interviews and FGDs. The
study transcends individual detached observations similar to those of Levy. Nonetheless, Levy (1997) makes interesting observations with regard to Shona people diagnosed with cancer. Her observations emanate from her personal experiences, which this study subjects to scrutiny in light of field evidence.

Thomas (1989) analyzed the nature of Navajo causal reasoning about cancer through comparison of data between Navajo and Anglo-American cancer patients, based on Navajo patients’ episodic experiences with the illness and the concomitant social meanings assigned to the condition. Thomas (1989) justifies his focus on cancer “a disease for which the causes are uncertain and the symptomatic manifestations are multiple”. Thomas (ibid) addresses the problem of specificity in cause and concept by referring to the Navajos' common attribution of cancer to exposure to lightning. The methodological issues in this area of cultural analysis are summarized in terms of the conceptual distinctions between cause and symptom, between disease as entity or as process, between biomedical and traditional ethno-medical systems, and between body and mind. Such a holistic and pragmatic approach at both the epistemological and ontological levels is invaluable to this research.

At the conceptual level and for delineating the focus of this study, reference is made to Thomas (1989) who presents an emphatic argument that “requisite to the validity of cross-cultural comparison is determination of whether an indigenous concept exists parallel to that of cancer as a discrete type of illness”. Although oncologists technically regard each cancer as a separate disease, and in turn come up with a plethora of cancer types, local understanding can be to the contrary. Among the Shona in Zimbabwe, for instance, there are several terms for cancer, namely, gomarara, nhuta, nyamakazi and mhuka. Further distinction can then only be enunciated in terms of cancer site exemplified in gomarara rezamu (breast cancer), gomarara rechibereko (cervical cancer) et cetera. The overarching
term is *gomarara* (cancer). Similarly, Thomas (1989) recalls Werner’s (1965) observation that the Navajo language has never had a large list of named diseases, but rather a series of connotatively overlapping ways of referring to and describing sickness and pain. Although Navajos recognize that cancer can occur in different parts of the body and may affect different parts in men and women, this is not precisely, how they would understand the phrase ‘different cancers’. Instead, this phrase was described as a composite term in an etiological sense: cancer caused by snakes, by tornados, or by [sexually transmitted] bugs [germs]. All these combined together are known as ‘niAtdzid’ (Thomas, 1989). This discussion is instructive to this study in that it reiterates the point that everyday expressions used by people may not conceive cancer as a group of diseases, with the distinction made only on body site where the cancer is evident.

### 2.2 Illness Experiences among People Diagnosed with Cancer

*This review addresses the questions; what is the lived experience of people diagnosed with cancer?*

The body as a site of study and as an axis of power is a prominent element in illness experiences. Based on a phenomenological life-world perspective, Sekse, Gjendedal and Raheim (2013), sought to illuminate the experiences of 16 women living in changed women’s bodies after gynaecological cancer. The key findings were that learning to recognise and understand their bodies after treatment was a core issue for all the women. Feelings of unfamiliarity linked to bodily emptiness, changes in body temperature regulation, changes in sex life and a vulnerable and unpredictable body were the most significant challenges facing the women. The study by Seske et al (2013) does not only allow a comparative analysis against the experiences of the participants in this study, but also offers methodological insights, which enrich my study.
Chemotherapy-induced alopecia (hair loss) is one of the most pronounced side effects experienced by women, which interferes with their femininity and womanhood. Zannini, Gjendedal and Raheim (2012) qualitatively explored the perceived effects of an aesthetic wig programme involving 20 patients from the region of Sicily in Italy. The Zannini team used Interpretative Phenomenological Analysis on transcriptions of data gathered from semi-structured interviews. The study gave credence to the conclusion by many other studies that alopecia is a traumatic event that challenges a woman’s femininity. This is notwithstanding, the key finding, that the wig is a helpful ‘friend’ that conceals baldness and ameliorates the ‘sick label’ associated with alopecia. The study revealed that such aesthetic care/wig programmes could assist women affected by alopecia to cope with cancer-related stigma, especially in the rural areas where psychosocial programmes are too complicated to implement due to cultural barriers. This study inspects stigma-related experiences of cancer, which may emanate from the illness itself and/or side effects of medication among people living with cancer.

Hospital based enthnography of the cancer experience and cancer care, done in a longitudinal fashion usually yields to novel, multiple experiential, situated and habitualised lived experiences, rooted in the socio-cultural, moral and economic-political fabric. Julie Livingston (2012) conducted an extensive field study (from the year 2006 to 2010) in a small cancer ward in Princess Marina Hospital in Gaborone, Botswana’s Capital. She portrayed an intersubjective phenomenology of care (meanings, practices and politics of care) in the ward, involving suffering, pain, hope, disfigurement and death and daily routine involving patients, their families, nurses and the oncologist. Some of the findings of interest of my study are on embodied experience, the paradox of unpleasant biomedical practice (the pain that comes with radiotherapy and chemotherapy), all these, as a set of moral and interconnected technological challenges to oncology. Nevertheless, my study
may not exude the same ethnographic flur as hospital based ethnography, is however buoyed by such insights. However, an anaemic reference to the activities of local Tswana healers on cancer healing seem to limit Livingston’s illuminating study, a gap which my study exploit in its deliberate exploration of traditional healing of cancer by various traditional health practitioners.

Ahlberg, Ekmon and Gasten-Johansson (2005) describe how patients with uterine cancer and receiving radiotherapy in Sweden, experienced fatigue, poor quality of life (as defined by the World Health Organisation) and other symptoms. The key results were that fatigue increased significantly during therapy and the global quality of life decreased significantly during treatment. Couper (2006) conducted a review of the research literature on reports emanating from the partners of prostate cancer patients, using five databases for the decade 1994-2005. The literature reveals that partners report more distress than people with cancer report and yet still believe that people diagnosed with cancer are the more distressed. What seems to concern people with cancer most is that their sexual functions are compromised and that their partners do not share this concern to an equal degree. This further buttresses the importance of collecting the social experiences of ‘significant other’ as part of understanding the collective illness experience.

Treatment experiences and the impact of clinicians on client’s experiences are revealing and instructive. Egestad (2013) explored the encounter between radiation therapists and head and neck cancer clients’ experiences going through radiation therapy. The study employed a phenomenological-hermeneutic approach and carried qualitative interviews with eleven treated people with cancer. It showed that when the radiation therapist takes time to build rapport with patients, show demonstrable competence and undertakes responsibility for any unintended consequences, this, in turn, creates a feeling of security
and decreases the existential anxiety of the client. A thrust on examining the impacts of clinicians and/or patrons of different treatment regimens, is vital in our understanding of the whole illness experience and in turn may indicate possible areas requiring improvement in nursing.

2.2.1 Exploring Stigma [illness] Experiences among people with Cancer

A detailed focus on stigma as part of a review of the literature on illness and social experiences is befitting given the far-reaching impacts of health-related stigma on the concerned individuals, their families and the society. It is especially more illuminating to social science given the chronic nature of cancer and for a condition which is fatal, incurable and not easily understood. Such a particular focus enables us to explicate fringe and nuanced data. This is vital to our comprehensive understanding of the cancer illness, as experienced by people.

Since Erving Goffman’s (1963) classic taxonomy of stigmatized conditions, health-related stigma has received profusions of attention among social scientists and health policy advocates. Various literature and empirical studies have highlighted the profound negative effects of health-related stigma (Chapple, Ziebland and McPherson, 2004, Link and Phelan, 2001, 2006; Else-Quest and Jackson, 2014). Health-related stigma is associated with premature termination of treatment, lack of disclosure, poor quality of care, delayed presentation, amplification of psychological as well as social morbidity and loss of personal control (van Brakel, 2006; Chapple et al, 2004; Link and Phelan, 2006; Link, Struening, Rahav et al, 1997; Knapp, Maziliano and Moyer, 2014). Though overt discrimination has become less socially acceptable and less conspicuous, more subtle responses such as avoidance, isolation, enactment of barriers to treatment and the possibility of being ostracized, remain (Else-Quest and Jackson, 2014). Sontag (1978)
notes that negative images, myths and perceived or existing physical limitations, partly explain why people stigmatize illnesses.

### 2.2.2 Epistemological Debates on the notion of Stigma

Notwithstanding Susan Sontag’s (1978) seminal essay, *Illness as Metaphor* and Hippocrates who buttress the view of medicine as impersonal, studies on health-related stigma, serve to remind us of the salience of moral beliefs and the place of phenomenological sociology in studying the enterprise of illness and medicine. Stigma is a complex phenomenon that is variously defined and redefined and which manifests in various combinations. Stigma was originally perceived to happen when a “society labels someone as tainted and less desirable on the basis of an attribute that marks them as different” (Goffman 1963: 1). The literature is replete with attempts at revising and reconstructing definitions of stigma since Goffman (1963), to illuminate the context-specific, illness-specific and lived realities of the people. Notable works in this area include Link and Phelan (2001, 2006); Knapp et al (2014); Kleinman and Hall-Clifford (2009) Major and O’Brien (2005). Other scholars have criticized classic definitions of stigma as being too individualistic and narrow. Classic definitions are also thought to limit attention to micro level analysis too much while giving lacklustre attention to structural elements (Oliver 1992; Link and Phelan, 2001, 2006). Thus, the critical sociological issue is to determine how culturally created categories arise and how they are sustained as stigma, dependent upon social, economic and political power (Link and Phelan 2001, 2006; Kleinman and Hall-Clifford 2009). Fife and Wright (2000: 51) aptly capture the elusive and fluid manifestation of stigma as ‘a complex phenomenon expressed both subtly and overtly, and it is subjectively experienced in multiple ways that are partially dependent upon the nature of stigmatising condition and the social circumstances of the individual’.

To Major and O’Brien, (2005) it is now much more appropriate to examine the factors
surrounding cancer, such as type, visibility, and the likelihood that the disease will interfere with each individual’s abilities or function in social contexts. Conversely, past research focused on the disease itself as a stigma that affected all individuals in the same way.

This study contends that self-stigma and enacted stigma are a duality, which may not be separated as the two are mirrors and are, therefore, a reflection of each other. Self-stigma (also known as felt/perceived stigma) entails the tendency by afflicted individuals to internalise societal stigma scripts and feelings of shame, fear and vulnerability while enacted stigma spells out actual discrimination-actions, perceptions and behaviours by the public, directed at people living with the illness. Mac Donald and Anderson (1984:285) posit that, “stigma is the result of interaction between the individual and community values”. Edelen, Chandra and Stucky, (2014:1) note that “the framing of health-related stigma has begun to advance a more complex discussion of stigma, one that encompasses both the internalization of stigma by the individual and the public reaction and potential marginalization that may occur”. In addition, Schulte (2002) contrasts two models or theories about disease-related stigma. In this regard, the behavioural model assumes that stigma arises from the actions of the stigmatized and envisages consensus on defining stigma among observers while the cultural conflict model posits stigma as a social construction and predicts differences in interpretations amongst investigators. A common thread imbued in the aforementioned models is the supposed behaviour culpability of the afflicted in their own illness, as the most salient factor in the stigma arithmetic (Schulte, 2002). An interface of the two theoretical models is invaluable to an examination of self and enacted stigma.

Link and Phelan (2001: 365) assert that “people approach the stigma concept from different theoretical orientations that produce somewhat different visions of what should
be included in the concept”. Thus, different investigators can conceptualise stigma differently, based on their epistemological grounding and inductively inspired by the lived experiences of research participants as long as the meaning is explicit. Investigators are detached from the stigmatised and tend to otherise stigmatized groups in an *us versus them* situation and in the course of doing that uncritically introduce uninformed preconceived and pre-set definitions and constructs from the people under study and driven by their own theoretical inclinations (Link and Phelan 2001). Interpretive phenomenological sociology exhorts researchers to blend their own perspectives and interpretations with those of the research participants. van Brakel (2006) argues that notwithstanding variations in type of illness and cultures, personal and public health-related consequences of stigma are strikingly similar. Although stigma may share features across contexts, this study concurs with Kleinman and Hall-Clifford (2009) that understanding the unique social and cultural processes that create stigma in the lived worlds of the stigmatized should be the first focus of efforts at combating and studying stigma and that currently, surprisingly little about the moral processes that undergird stigma, is known.

### 2.2.3 Cancer Stigma

Around the world, cancer continues to carry a significant amount of stigma but there has been thin research on the phenomenon (Livestrong Report, 2007). Looking at evidence from the mid-20th century, cancer was not often discussed with people due to its association with death (Else-Quest and Jackson, 2014). According to Knapp et al (2014:5), “cancer fatalism is the belief that cancer will lead inevitably to death… and this can hinder engaging in cancer prevention practices and screening, stigmatizing others, and stigmatized individuals may also internalize these attributions”. Knapp et al (2014:1) indicate that cancer fits well into Goffman’s (1963) categorization of ‘abomination of the
body’ though new clinical knowledge continues to alter and shape perceptions. People living with cancer indicate a poor quality of life due to their appearance, particularly alopecia among women (hair loss) (Rosman, 2004) and elevated rates of anxiety, depression, and guilt as well as financial strain (Applebaum, Faran, Marziliano et al, 2014). Crocker, Major and Steele (1998) identify visibility as a salient factor of stigmatization that can affect psychosocial well-being and interpersonal interactions. Cancer can become visible as the disease progresses or treatment side effects become obvious (MacDonald and Anderson, 1984; Peters-Golden, 1982). Sontag (1978) notes that treatment leads to loss of hair, scars, bodily changes that add to the stigma.

Chambers, Dunn, Occhipinti et al (2012) did a systematic review of the influence of stigma and nihilism on lung cancer and the key results indicated pronounced stigma related to poor quality of life, high psychological distress in people with cancer and lack of empirical evidence on nihilism. The study by Bloom and Kessler (1994) indicated that breast cancer no longer carries any stigma, at least not to the extent of reducing the level of emotional support that accrues to the women. Mac Donald and Anderson (1984) noted in a community study of 420 people with rectal cancer that feelings of stigma were associated with poor health and disablement. Indications were that people who live with a colostomy confront multiple stigmata as follows: stigma emanating from the disease, a feeling of loss of a body member (physical deviance) and the intra-psychic challenge of incorporating a new body image in their self-concept (Mac Donald and Anderson, 1984). Stahly (1988) posits that cancer stigma is driven primarily by fear of the illness itself or the perception of a ‘just world’ and the idea that ‘it could also happen to me’.

Edelen et al (2014), note that specific types of cancer may also carry disease-specific stigma. For example, cervical and lung cancer are often cited because each is linked to
behaviour that may be deemed undesirable or marginal regardless of the actual disease pathway (Chapple et al, 2004; Chambers et al, 2012, Else-Quest and Jackson, 2014; Cataldo, Jahan, Pongquan, 2012). Quigley (1989) notes that as new relationships and issues of sexuality and sterility take centre stage for unmarried survivors disclosure becomes a daunting challenge. Nonetheless, there is evidence of a decline in cancer stigma research in the 1980s and 1990s (Knapp et al, 2014) or for specific cancer types like breast cancer (Bloom and Kessler, 1994) or when compared with HIV and AIDS (Fife and Wright, 2000; Idemudia and Matamela, 2012). The foregoing studies broaden comprehension of the manifestations of cancer, which enhance comparative analysis. However, context-specific studies yield more validity.

2.3 Health-related Help-seeking Behaviour, Pathways to Cancer Treatment and Management of the Illness

The question is; how can we characterise the help-seeking behaviour of people living with cancer?

The central argument is that qualitative and phenomenological analysis enables us to holistically study and comprehensively appreciate health-related help-seeking behaviour of people diagnosed with cancer. This study is well-positioned to illuminate the lived realities of participants and the various treatment modalities which are not covered in conventional health research. Interpretive phenomenology dictates a stance that is non-judgemental of other people’s beliefs and practices.

Pruitt, Mumuni, Raikhel et al (2015) carried out a qualitative study comprising 31 women with cancer of the breast and 5 physicians, to identify the social barriers to diagnosis and treatment. The study was done at University College Hospital Ibadan, Nigeria where the afflicted women presented. It identified lack of education, utilisation of non-physician
medical services like pharmacists, fear of unanticipated surgery and cost of treatment as key barriers. Marlow, Wardle and Waller (2015) qualitatively studied how facilitators and barriers help determine behaviour related to breast and cervical cancer. The study used 54 healthy women from an ethnically diverse population in the United Kingdom. The results showed that an assumption of symptomatic elements of cancer motivated one to seek help while prospects of a cancer diagnosis served as a deterrent. Positive benefits of early diagnosis such as improved survival rate and a sympathetic general practitioner encouraged help seeking. The study cited the incidence of an unsympathetic general practitioner, racism, language barriers and the utilisation of alternative therapies as first line strategies, as barriers. The labeling of certain health behaviours as ‘social barriers’ by Pruitt et al (2015) and Marlow et al (2015) serves to buttress the assumptions of biomedicine as the ‘mainstream’ or ‘official’ health care system in all societies and stigmatizing non-Western medicine systems and traditional health practitioners who are widely consulted and who may provide effective medicines. This study transcends such ideological inclinations.

Minimising the tendencies by people to present late and with the disease advanced is touted as one of the ways to improve survival among people diagnosed with cancer. Smith, Pope and Botha (2005) undertook a qualitative synthesis of 32 international publications spanning 1984-2004 on delay in cancer diagnosis and help-seeking experiences of at least 20 types of cancers. They sought to identify the relevant research and meta-ethnography and to identify common themes across the studies. The analysis of the results showed strong similarities among people diagnosed with cancer, with the recognition and interpretation of symptoms and the fear of consultation emerging as key issues. The fear of stigma or the fear of cancer (death, pain), or both, the social dimension of gender and the sanctioning of help seeking were important factors in early presentation. Such results from
an extensive review of literature are important for the comparative analysis of key results. Conversely, the results of such a review of the country case studies of developed countries, though limiting, provides a launch pad for this Zimbabwe-situated study. Moreover, the findings from the extensive review by Smith et al (2005) vindicates the position adopted in this study, to transcend various [medical] cancers by privileging local understandings of cancer, though various demographic characteristics shape experiences.

In seeking to understand the late presentation of lung cancer as well as, in particular, colorectal cancer which has high mortality rates in the United Kingdom, Mc Lachlan, Mansell, Sanders et al (2015) conducted semi-structured interviews with nine people and twenty people diagnosed with lung and colorectal cancer respectively within the previous 12 months. Participants were asked about their appraisal of symptoms in the period prior to diagnosis and decision-making for help seeking. The study revealed the complexity of patients’ reasoning, decision-making processes and the influence of interpersonal interactions, with some being proactive and others developing non-cancer explanations based on their knowledge and experience only to change them due to the persistence of symptoms. The decision-making process in seeking pathways to treatment and care is one of the key questions pursued in this study while at the same time studying symptom-interpretation prior to diagnosis. Typically, geographical and cultural differences always illuminate salient differences.

Medical pluralism is a well-pronounced health-related help-seeking behaviour among people faced with an incurable life-threatening ailment like cancer. Citrin, Bloom, Grutsch et al (2012) sought to understand the motivations that underlie the preference for alternative therapies to conventional treatment by women with breast cancer, despite the evidence of the effectiveness of early treatment via conventional protocol and poor health
outcomes on those who forgo conventional treatment. The key findings were that negative experiences at the hands of physicians after diagnosis, a belief in holistic therapy, perceived risks associated chemotherapy; radiotherapy and misinformation are some of the leading reasons why some women with breast cancer shun conventional treatment. Such scholarship enables a comparative analysis of the results with evidence from this study especially regarding the motivation behind the shunning of hospital cancer treatment in preference for traditional indigenous healing practices.

There are affinities between this study and Piret’s (2008) study that examined the attitudes of people with cancer towards the use of complementary and alternative medicine in Finland, from an ethno-medical perspective, based on cancer narratives. The current study is similar to Piret’s study, methodologically and conceptually (narratives of people with cancer and ethno medical knowledge). Piret (2008) transcends the biomedical and quantitative approach, thus attesting that cancer narratives form a good source for studying popular ideas about cancer and that these “texts mediate the human attitudes and behaviour in the particular socio-cultural context related with the illness discourse”.

Shahid, Bessarab, Thompson et al (2010) undertook a qualitative study that explored Aboriginal Australians’ perspectives and experiences with cancer, in Western Australia. The study examined contemporary meanings attached to use of bush medicine by cancer patients. The key findings were that, as part of their healing some Aboriginal Australians use traditional medicine for treating cancer. The major rationale for the use of traditional healing processes and medicine can be located in a people’s quest to reconnect with their heritage, land, culture and spiritual ancestry, and in the process, bring peace of mind during illness. This study has a similar thrust though it is not restricted to examining the practices of traditional healing. It pursues issues on aetiology, social experiences on cancer
illness including perceptions and experiences on non-hospital based remedies. There is a
dearth of research with such a research thrust in Zimbabwe. Using a social constructivist
framework and using NVivo 7 to manage and analyse data, the key findings by Shahid et
al (2010) were as follows: misunderstanding, fear of death, fatalism, shame, traditional
healing preferred and spiritual elements all influenced access to services.

For his doctoral thesis, Mulemi (2010) carried out a hospital ethnographic research on the
subjective experiences of adult cancer patients at Kenyatta National Hospital in Kenya, in
the wards and in the broader socio-economic milieu. His key findings point to the
insufficiency of cancer management in Kenyan health systems and the salience of socio-
political factors that shape the ‘life worlds’ of patient’s daily lives in and outside the
hospital setting. This study is not primarily centred on the hospital setting per se, although
it seeks to capture the experiences of both hospital care and life in the home and
community. Mulemi’s study, nonetheless, is invaluable for comparative purposes. Mac
Artney (2011) for his PhD studies combines his own subjective experiences with cancer
and the ‘stories’ of sixteen other cancer patients to capture their narratives on the use of
complementary medicines. A closer look shows that there are affinities between Artney’s
study and this study. The current study seeks to understand individual social experiences
with cancer and any non-hospital management initiatives on cancer.

In Zimbabwe, there is currently a dearth of research on the utilisation of traditional
indigenous health practices by people diagnosed with cancer. Such information is usually
sidelined in conventional medical research where there is focus and attention on hospital
treatment. Xu, Trowers, Li et al (2006) conducted a qualitative study to explore the
perspectives and experiences of Chinese cancer patients and traditional Chinese medicine
professionals. Their key findings were that the use of traditional Chinese medicine (TCM)
by cancer patients is premised more on the self-healing process deeply rooted in Chinese
cultural heritage and worldview. TCM cancer therapy focuses on mobilizing and activating the body’s natural resources to redress the balance and to help defeat the cancer and promote healing (Xu et al, 2006). Corner (2004) explored the use of Complementary and Alternative Medicine (CAM) by people living with cancer and notes that CAMs are in widespread use yet little information exists as to how such therapies are used or what the people’s motivation for using them is. Corner (2004) observed distinct explanations on the use of CAM among patients with cancer: therapies are meant to either cure cancer or reduce the tumour burden as ‘alternative treatments’ and as an addition to hospital cancer treatment. Secondly, the therapies are designed to help maximize the quality of life. Similarly, this study deliberately focuses on the treatment and healing philosophies behind traditional indigenous healing practices of traditional health practitioners who attend to people with cancer in Zimbabwe. Currently there is a research lacuna on such elements in Zimbabwe.

2.3.1 The Role of Spirituality among People Diagnosed with Cancer

This review section attempts to address the question: how do people with cancer manage their illness?

It is imperative to review literature and scholarship on the role of spirituality (understood both in a secular and religious sense) among people diagnosed and living with cancer in attaining an understanding of health-seeking behaviours and individual management of the illness. Such a focus is befitting to a terminal illness like cancer, which demands the mind, body and soul, both in terms of manifestation of the illness and in terms of aggressive treatment regimens. Interpretive phenomenological analysis, offers analytical equipment to explore those spiritual elements sidelined in clinical studies but which facilitate a holistic comprehension of the cancer illness as it is experienced by people. Of note, Bury (1991)
challenges sociologists to not only focus on human problems but also on how people address those problems.

Moberg (2008:101) defines spirituality as having a ‘more existential and experiential focus upon an individual’s internalized faith, values, and beliefs along with their consequences in daily behaviour’, whereas religion usually refers to someone maintaining membership and participation in rituals, beliefs and organised activities of religious faith like Judaism, Hinduism, Islam or Christianity (Moberg, 2008). Most studies on spirituality and health care have been what Puchalski (2010) termed ‘association studies’ which drew our attention to correlates between religious/spiritual beliefs, practices and [optimal] health care outcomes. Some of the studies examined the connection between spiritual well-being and better quality of life (Cohen, Mount, Tomas et al, 1996), and the provision of psychosocial support (Levin, Larson, and Puchalski, 1997; Tuck, McCain and Elswick, 2001). Spiritual and religious practices are also central to decision-making within treatment modalities (Roberts, Brown, Elkins et al, 1997).

The contribution of spiritual elements to the coping resources and management of illness is well-documented (Halstead and Fernsler, 1994; Baider, Russak, Perry et al, 1999; Roberts et al., 1997; Koenig, McCullough and Larson, 2001). Instructive to this study, is how religiosity and spirituality offer resources to people confronted with an illness like cancer, to get inner healing and grapple with existential questions, in search of meaning and life purpose (Puchalski, 2010). In addition, various studies have demonstrated how religious beliefs can promote healthy life styles (Koenig et al, 2001; Powell, Shahabi and Thoresen, 2003). Other studies illustrate how certain religiosity can promote disenchantment with treatment modalities (Pargament, Tarakeshwar, Ellison et al, 2001; McConnell, Pargament, Ellison et al, 2006). Meraviglia (2006) examined the effects of spirituality on a sense of well-being among women who had breast cancer in central Texas (sample from
both rural and urban settings) using a questionnaire. The key results were that meaning in life is positively related to psychological responses and negatively related to physical responses. Prayer was found to be positively related to psychological well-being.

After reviewing several studies, Khamechian, Alizargar and Mazoochi (2013) concluded that the prevalence of depression among people diagnosed with cancer was higher than in the general population. For people with cancer, a diagnosis of depression, if not adequately treated, can further reduce their chances of survival and may contribute to a poor quality of life (Irving and Lloyd-Williams, 2010; Pinquart and Duberstein, 2010).

There is now a growing body of evidence demonstrating the importance of spirituality and religion among people experiencing physical (Strada, Homel, Tennstedt et al, 2013), psychological or emotional distress (Harvey and Silverman, 2007; Nolan, McEvoy, Koenig et al, 2012); and cultural or spiritual crises including suicide attempts (Garroutte, Goldberg, Beals et al, 2003). Studies show the benefits and effectiveness of spiritual and religious coping in stressful situations (Pargament, 1997; Pargament and Lomax, 2013). Questions about the meaning of life and death often occupy the minds of those experiencing an illness such as cancer.

In sub-Saharan Africa, the practice of consulting traditional and/or faith healers is common practice. It is estimated that 60-80% of people in Africa rely on African traditional medicine for their primary health care (Mhame, Busia, Kasilo et al, 2010; WHO, 2002). The religious question in Zimbabwe, especially the sudden upsurge in Pentecostal and prophetic activities in Harare, the capital, is not only rich qualitatively, but it testifies to the imperative of conducting context-specific and situation-based studies. Chitando (2009) traces the religious epiphenomenon that has gripped the country to the people’s way of managing economic-politico and socio-cultural uncertainty and to how prophets seem to
offer some certitude in the everyday lives of people. The uncertainty that comes with incurable ailments like gomarara (cancer) is one such conspicuous case in point.

2.4 Conclusion

This chapter reviewed the literature related to the objectives and research questions of the study in order to familiarise with the phenomenon at pre-analysis stage. It is apparent that so far, there is no single phenomenological study exploring the lived experiences of people diagnosed with cancer in the country. To compound the problem further, there is a paucity of qualitative analysis on cancer in the country. Most of the reviewed literature on phenomenological studies on cancer is from Western Europe, Western Australian, America and a little from Asia and Africa. Thus, this study had a launch pad from which to embark. The major concern throughout the review was to illustrate the invaluable insights reposed in qualitative and interpretive phenomenological analysis with a view to extracting hitherto marginalised and novel data on cancer from people who live the experience. The studies reviewed were intended to help attain insights on methodology, theories and data in order to facilitate a comparative analysis for broadening our readership of the salient issues.
3. CHAPTER THREE: ORIENTING THEORETICAL STRATEGY FOR THE STUDY

3.0 Introduction

The central argument inspiring this study is that qualitative analysis engendered in interpretive hermeneutic phenomenology offers a sound vantage from which to study indigenous knowledge and social experiences on cancer. This is so because it elucidates novel marginalised data and aids to our holistic comprehension of the phenomenon of living with cancer. My aim in this chapter is neither to rewrite a long *article on the tradition of interpretive hermeneutic phenomenology*, which serves as my theoretical framework, nor to give a review, but rather to highlight and adapt aspects of the phenomenological tradition and related ideas, which guide my study. I first briefly trace and highlight the cardinal ideas of the broad tradition of phenomenology. I then elucidate the hermeneutic phenomenology of Heidegger, which serves as the main analytical framework to my interpretation of the key study findings that inspire the whole research process. The point is to harness or adapt the tenets of theory to the current study and to discuss any evident limitations of the theoretical framework. A theoretical framework in this study is a *Weltanschauung*, that is, a general perspective from which one sees and interprets the world (Abend, 2008). To Abend (2008: 179) “Theory focus on our conceptual and linguistic equipment-the nature of the location from which we look at the social world, the lexicon and syntax by means of which we talk about it, the nature of conceptual scheme, the categories into which we group things, and the logical relations that can be between concepts”. If someone is not situated or positioned, not only is it a challenge to carry out a meaningful study, but such a study is difficult to make sense of.
3.1 Mapping out the Tradition of Phenomenology

This research is grounded in the tradition of phenomenology, considered as both a philosophical discipline and a research method (Le Vasseur, 2003; Lopez and Willis, 2004), and pivotal to the interpretive paradigm (Denzin and Lincoln, 1998). According to Moran (2000: 4), “Phenomenology is best understood as a radical, anti-traditional style of philosophising, which emphasises the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experience”. The thrust is to pay more “attention to the nature of consciousness as actually experienced, not as is pictured by common sense or by the philosophical tradition” (Moran, 2000: 6).

The Encyclopaedia of Phenomenology goes on to identify seven distinct perspectives under phenomenology namely; descriptive (transcendental constitutive) phenomenology, naturalistic constitutive phenomenology, existential phenomenology, generative historicist phenomenology, hermeneutic (interpretive) phenomenology, genetic phenomenology and realistic phenomenology (Moran, 2000). Inherent in all these taxonomies of phenomenology, is the central idea that all reality is socially constructed, that society is a fragile human construction and social products are humanly meaningful acts that appear as supra-human entities (Laverty, 2003). In essence, phenomenology is politically neutral and non-judgemental. The phenomenological tradition is rooted in the seminal works of Edmund Husserl, Martin Heidegger, Jean-Paul Satre and Merleau Maurice Ponty amongst various others. Loosely defined, phenomenology is the study of structures of consciousness or things as they appear in our experiences, or in the way, we experience things from the first-person point of view. Immanuel Kant (1724-1804) is one of the precursors to social phenomenology and his ideas enhance our understanding of phenomenology. In his seminal work titled “Critique of Pure Reason”, Kant makes a
distinction between “phenomenon” which connotes human sensibility and understanding and *noumena*, which connotes objects as things-in-themselves which humans cannot directly experience (Moran, 2000). Hicks cited in Moran (2005) puts nineteenth century Kantianism into two: structural linguistics and phenomenologists with the former seeking subjective *noumenal* categories while phenomenologists were content with describing the phenomena without asking what connection to an external reality those experiences might have. This captures the thrust of phenomenology in sociological theorizing-individual descriptions and meaning they attach to social phenomena.

A broadened scope of phenomenology will have to include human knowledge and behaviour generated based on inherited tradition (Miettinen, 2013). Indeed a particular community create and transform culture and tradition and it is appropriation of these, that we become members of a community in the first place. Husserl (1962) talks of what he calls “the paradox of subjectivity” - the idea that we constitute the world as well as belonging to the world as constituted. This idea by Husserl is reminiscent of structure-agency paradigms, which underscore the conditioning of human behaviour by structure and on the other hand, human agency constituting and recreating the very structure.

In light of this study, aspects of inherited tradition find expression in narratives of people living with cancer with reference to the cultural belief systems in disease causation and treatment. This knowledge is generated from oral knowledge passed from generation to generation, knowledge generated from the families of people living with cancer, from support groups, from patrons of traditional/alternative medicine and from personal search for new knowledge by participants. It is imperative to note the distinction between tradition, which is more solid and static, and culture, which is created and recreated every day. This implores us to avoid a primordial view of culture or to treat anthropology as the study of the past alone but the present as well. This persuades me to see a very thin line
separating anthropology and sociology considering that both utilise similar qualitative methods and as we become a more cosmopolitan society in shrinking time and space.

3.2 What Phenomenology Aims at

Phenomenology aims at giving a deeper understanding of the nature or meaning of our everyday experiences. It asks, “What is this kind or that kind of experience like?” (Moran, 2000). It differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world, pre-reflectively, without taxonomizing, or abstracting it. It is the study of essences—the systematic attempt to uncover and describe the structures, the internal meanings of structures, of lived experiences (van Manem, 1990). Phenomenological research is the description of the experiential meanings we live as we live them (Moran, 2000; Mapp, 2008). It differs from other human sciences, which do not give primary focus to meanings but on statistical relationships among variables. Rather it attempts to explicate the meanings as we live them in our everyday existence, our life world.

Phenomenology is a human scientific study of phenomena, systematic, explicit, self-critical, inter-subjective, and attentive practice of thoughtfulness (van Manem, 1990). Phenomenological research is the explication of phenomena as they present themselves to consciousness and it is by virtue of being conscious that we are related to the world. To be conscious is to be aware, in some sense, of some aspect of the world. Phenomenological reflection is retrospective rather than introspective (van Manem, 1997). Reflection on lived experience is always recollective, it is a reflection on experience that is already passed or lived through (Moran, 2000). It, therefore, follows that in my study; people diagnosed with cancer were asked to relive their experiences about the onset of symptomatic elements of the illness, early reactions upon news of results of a cancer diagnosis, illness and pain experiences as well as relating the help-seeking journey among other salient issues.
According to Patton (1990: 71) "…a phenomenological study…is one that focuses on descriptions of what people experience and how it is that they experience what they experience”. Of note, one can employ a general phenomenological perspective to elucidate the importance of using methods that capture people's experience of the world without conducting a phenomenological study that focuses on the essence of shared experience. (Norlyk and Harder, 2010). Rossman and Rallis (1998: 72) state that “Phenomenology is a tradition in German philosophy with a focus on the essence of lived experience”. Those engaged in phenomenological research focus in depth on the meaning of a particular aspect of experience, assuming that through dialogue and reflection, the quintessential meaning of the experience will be revealed. Language is viewed as the primary symbol system through which meaning is both constructed and conveyed (Holstein and Gubrium, 1994). My use of the Shona language as the medium in the personal interviews (all of the participants are Shona speaking though some can also speak English or Ndebele) with participants with cancer, in consent forms, in conceptualising key concepts of the study and in direct verbatim quotation of determinative statements has both epistemological and ontological significance. It was crucial for me to conceptualise the notion of cancer or gomarara, from the frame of reference of participants and their everyday use in our society and communities, thereby transcending expert or scientific (clinical) knowledge of cancer. Understanding the cancer illness from the frame of reference of participants makes this study distinct and resonates well with cardinal ideas of interpretive hermeneutic phenomenology.

Phenomenological inquiry is particularly appropriate to address meanings and perspectives of research participants. The major concern of phenomenological analysis is to understand "how the everyday, inter-subjective world is constituted" (Schwandt, 2000) from participants' perspective. The basic philosophical assumption underlying this inquiry is
epitomised by Husserl's (1962) statement - "we can only know what we experience". Thus, any inquiry cannot engage in 'sciences of facts' because there are no absolute facts; we only can establish 'knowledge of essences' (Moran, 2005). The essence is the central underlying meaning of the experience shared within the different lived experiences (Kendall, 2006; Notter and Burnard, 2006). Nonetheless, contrary to Husserl, personal narratives may not reflect just the unique experiences of the participant but ‘the voice is overpopulated with other voices, with the intentions, expectations and attitudes of others in history and culture’ (Moen, 2006:3).

The researcher should first look into the individual point of view, to get to understand human phenomena as lived and experienced, which Giorgi (1985) pointed out as the major characteristics of a phenomenological psychological method. There should be two perspectives of phenomenological analysis of the perception of lived experience: from the people who are living through the phenomenon, and from the researcher, who has great interest in the phenomenon. This sums up Heidegger’s (1962) ‘double hermeneutics’.

3.3 ‘Lived Experience’ and ‘Understanding’ Explained

According to van Manem (1997) phenomenology essentially examines the study of lived experience or the life world, the world as lived by a person, and the world not separable from the person. The term understanding invites some openness on the part of the investigator to let the unexpected meanings and interpretations emerge as meaning is generated and transformed and not conceived in some hard facts (Lopez and Willis, 2004; Giorgi, 2011). Drawing from the phenomenological notion of bracketing, the researcher is implored to hold in abeyance and deliberately set aside one’s own beliefs, values, knowledge and experiences about the phenomenon under investigation in order to validly describe participants’ experiences (Carpenter, 2007).
Despite the plausibility of bracketing, the process cannot be conceived in absolute terms but in relative terms only, drawing some kind of continuum-like the extent to which one has exercised bracketing. Neutrality and being non-judgemental are virtues of doing research phenomenologically. Heidegger’s interpretive hermeneutic phenomenology undermines the notion of bracketing arguing that it is impractical and disingenuous. To Heidegger (1962), researchers should in fact be open about how their beliefs and values may have affected the research, which aid our understanding of one’s interpretations of data. Some scholars have noted that it is impossible to do bracketing (Johansson and Ekebergh, 2006) with some emphasizing reflexivity (Friberg et al, 2007; Wilson, 2007).

3.4 Adapting Heidegger’s Hermeneutic Interpretive Phenomenology to this study and the Sociological Connection

Following Heidegger’s hermeneutic interpretive phenomenology, it is important to elaborate on the idea of hermeneutics. The word comes from the Greek word *heuresis* meaning power of invention or discovery with Plato and Socrates presenting the mythical Greek god *Hermes* as the ‘messenger’ or ‘interpreter’ (Jost and Hyde, 1997). The term was developed in the works of German thinkers like Schleiermacher (1977); Dilthey (1991), Gadamer (1975) and Habermas (1984). Hermeneutics is involved in understanding in all its various forms including the technological understanding of language, vocabulary, grammar and guide jurisdiction. The goal of hermeneutic investigation is *understanding* in which linguistic and historical frameworks are part of the process. Scientific replication for interpretation is not a goal as Heidegger called it ‘extra scientific’ knowledge. Gadamer (1975) cited in Sikka, (2008: 235) states that “the task of hermeneutics is entering into dialogue with a text. To understand something is to reach an understanding with one another about it, and that can only be achieved through a conversation that sustains the interplay of question and answer”.

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Heidegger’s phenomenology gives central concern to the situatedness of research participants in relation to their location in the broader socio-cultural and economic-politico context (unlike Husserl who gave context peripheral significance) (Mapp, 2008; Moran, 2000). In other words, we cannot study people in isolation of their culture, family traditions, community values or the historical period in which they live.

Heidegger (1962) coined the term dasein (the human way of being in the world) to reiterate that individuals cannot be held in ‘constant’ from various contexts that influence their choices and that assign meanings to their lived realities. On dasein and situatedness, Heidegger (1962) cited in Kumar (2012:795) goes on to enunciate what he calls a ‘forestructure of understanding’ which comprises fore-having (practical background from individual own world that make interpretation possible); foresight (socio-cultural milieu that condition view-point from which to make an interpretation) and fore-conception (socio-cultural background may mirror results of the investigation). In sum, Heidegger assumes how forestructure is inextricably interwoven with how an individual perceives the world and how he/she interprets reality. According to Kumar (2012: 795), therefore, hermeneutic inquiry attempts to identify research participants’ meanings from a merger of the researcher’s understanding of the phenomenon, participant-generated information, and the data obtained from other relevant sources.

My research problem, study objectives, research questions and the composition of my participants, readily weigh in the salience of ‘context’ and ‘situatedness, thus the utility of Heideggerian hermeneutic inquiry. My first objective seeks to describe local causal- attribution of cancer among people diagnosed with cancer in Zimbabwe. Traditional Health Practitioners (THPs) who treat illnesses and act as ‘moral entrepreneurs’ and cultural curators, espouse indigenous interpretations. The other study objectives include thick descriptions of lived illness experiences, help-seeking behaviour and existential
challenges faced by people diagnosed with cancer in Zimbabwe. I could not isolate my participants from their socio-cultural arrangements, from their family traditions, the obtaining socio-political atmosphere or historical period in which they live. In my recruitment and selection criterion, I deliberately factored in various cross-cutting demographic characteristics of participants (see appendix 7 and 8 on pages 334-339) to include both rural and urban experiences, the male and the female genders, participants living with cancer on different body sites and participants utilising varying treatment modalities. This arrangement not only weighs in the importance of context, but it offers a holistic, a wholeness picture of the phenomenon under study. In addition, I had to engage in reflexive sociology by acknowledging the impact of my worldview, my subjectivities in the whole research process.

There is something, which strikes an interesting chord between the cancer illness and Heideggerian hermeneutic inquiry that gives weight to ‘context’ and ‘situatedness’. Though Western scientific medicine has made great strides in discovering evidence on cancer aetiology and concomitant treatments, it is an axiom that cancer is incurable. An incurable and a partially knowable ailment creates a kind of vacuity and fertile ground for various philosophies, theories, perspectives, treatment modalities, beliefs and cultural repertoires to advance own understanding. In essence, discourses on the duality of culture and health have a long tradition (Kleinman, Eisenberg and Good, 1978; Airihihenbuwa, 1995).

In essence, people are likely to actively construct reality of what may have caused their cancer illness or that of their relative. In a similar vein, people, families and communities have seen, heard and witnessed individuals who have had their legs amputated or who had mastectomy to remove the cancer gangrene only to be told that the cancer had spread. In other words, to some extent, hospital treatment has not always been successful in saving
lives from cancer in as much as some clients receive treatment from several THPs to no avail. Despite the idea that late presentation with advanced disease, may be a plausible explanation for a poor survival rate in hospital cancer treatment, people are likely to construct their own plausible explanations which may sometimes implicate certain modern cancer treatments (like radiotherapy) as leading to fatalities.

On the other hand, faced with a life-threatening ailment, people are likely to swing into some kind of medical syncretism in an attempt to salvage their lives or that of their loved ones. Thus, family histories and lived experiences may serve as information repositories or vital texts on which people base their decisions, whether they are judicious or not. For example, families may read and match from previous experiences of relatives who went for surgery or radiation therapy and the resultant outcome. In addition, an appreciation of the salience and centrality of context and situation in hermeneutic phenomenology can be noted in the self-evident truth that human beings are composed of various facets of life, which include the physical being, the spiritual being and the social/cultural being. As individuals, we do not live in a vacuum but in essence, we may render our loyalties to various figures like pastors, prophets, husbands, parents, traditional healers, spirit mediums, family doctors, friends, work mates and so on and so forth. Various scholarship ventures and studies have underscored the centrality of the religious or spiritual world in informing health philosophies, lifestyles, health decisions, attitudes, knowledge, beliefs and practices (Ellison and Levin, 1998; Levin, 1994; Powell et al, 2003). It is imperative to locate participants’ narratives from the spiritual vantage point- in a non-secular and a secular sense.

The World Health Organisation (WHO) Commission on Social Determinants of Health (CSDH) defines the social determinants of health as those conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the
conditions of daily life (CSDH, 2008). These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems. A greater appreciation of the situated actor or in another expression *experiences or narratives of a Zimbabwean diagnosed with cancer in Zimbabwe today* comes with an appreciation of the impacts of the prevailing socio-cultural, economic and political environment in the country. It suffices to say, such an environment not only shapes the lived experiences of people diagnosed with cancer. It is also likely to shape their stories as related in interviews. It is likely to inform and shape the pathways followed by people diagnosed with cancer in seeking treatment and the decision making process on choice of treatment modalities.

Heidegger (1962) emphasized historicity, or the facticity of humans, to temporality, or concrete living in time. He claimed that all description involves interpretation, that is, description was only a derivative of interpretation. The pure description of Husserl needed to be situated inside a radically historicised hermeneutics. Martin Heidegger (1889-1976) refuted idealism. *Being and Time* is one of the strongest anti-Cartesian, anti-subjectivist, anti-dualist, and anti-intellectualist explorations of what it is to be human, and how it is that humans encounter the world in concernful dealings which are bound up in situations yet project forward from those situations (Moran, 2000; Mapp, 2008). Human existence is not a given entity ‘out there’ but rather some specific person’s existence (Mapp, 2008). It also follows that the interpretation of human existence cannot be a dispassionate, neutral exercise but it must take into account the participation of the investigator in the undertaking as well (Laverty, 2003).

In *Being or Dasein and Time*, Heidegger aimed to give an existential analysis of a human being and his relation to time as human existence essentially takes place in time spread out between past and future, limited by death and therefore incomplete (Laverty, 2003).
Hermeneutic phenomenology captures illuminating details and seemingly trivial aspects within experience with a goal of creating meaning and achieving a sense of understanding. While Husserl focussed on understanding beings or phenomena, Heidegger focussed on ‘Dasein’—the mode of being human or the situated meaning of a human in the world’ (Laverty, 2003). Heidegger emphasized historicality, a person’s history or background though one’s background cannot be made completely explicit. Meaning is found as we are constructed by the world while simultaneously we are constructing this world from our background and experiences (Laverty, 2003).

Quintessentially, Martin Heidegger the philosopher espouses and inspires the sociological work of sociologists like Berger and Luckmann’s (1966) social construction of reality and Antony Giddens structuration theory (1984). The cardinal idea shared among them is that social reality is not a social fact in its own reality, but is something produced and communicated, its meaning derived in and through these systems of communication (Berger and Luckmann, 1966). In essence, humans are a product of society in as much as the very individuals constitute society. This sociology of knowledge that privileges everything that passes as knowledge in society (knowledge engendered from lived experience) is the common thread that connects the whole body of knowledge generated in this thesis. Gidden’s structuration theory is a bold framework, which emphasize this macro and microanalysis as the hallmark of social life—the idea that individuals are created and recreate society. In addition, by evading an overly deterministic view of society, Giddens’ (1984) structuration theory offer prudent analytical lens with which to emphasis the agentic behaviour of human beings, the tenacity and great ingenuity by people with cancer to confront a life threatening ailment in a constraining environment as shown in Chapter 8 (section on coping mechanisms and management of illness).
3.5 Limitations and Delimitations of Interpretive Hermeneutic Phenomenology as a Theoretical Framework to this Study

The critique of phenomenology in general came from positivism and from members of the Vienna circle (Moran, 2000). Carnap criticised Heidegger for promoting a meaningless pseudo-metaphysics while Marxism, saw phenomenology as the apotheosis of bourgeois individualism (Moran, 2000). One of the major limitations of hermeneutic phenomenology as a theoretical framework is that its research philosophies emphasize depth on a small sample of cases, which precludes replicability and generalizability, typical of large samples. However, the main goal of my study is to illuminate on the chosen cases with an emphasis on validity and novelty of individual subjective experiences and not to generalise. Nonetheless, the rigor with which individual cases are scrutinised can be emblematic of people experiencing the same phenomena (the cancer illness) outside the research study (vertical generalisability). In addition, proponents of positivism submit that Heidegger’s phenomenology offers weak causal explanations. Conversely, the main rationale of this study is not to streamline issues or experiences by seeking to establish some correlations or statistical significance. The major rationale is to give thick descriptions, valid interpretations of the cases, cases which are people, people of whom are inimitable, who think, act, and who are influenced by many confounding variables at the same time. The goal in qualitative methodologies is not to establish a causal link but rather offer meanings interpretation of relations and understanding of ways in which perceptions of causality are interpreted.

To protagonists of structuralist thinking, hermeneutic phenomenology is limited in proffering a robust analysis of structural factors of social phenomena while restricting to microscopic elements and subjectivities. Contrariwise, Heidegger’s prominent emphasis
on context and situatedness of individuals permits an analysis of macro elements for instance the conditioning impact of the socio-cultural, political and economic environment on individual dispositions or idiosyncrasies.

Lastly, interpretive hermeneutic phenomenology stands accused of propping up a pseudo-science through its emphasis on individual subjectivities and lived experiences using ‘soft’ data collection methods, rather than emphasizing objective reality of quantitative measures. The emphasis of Heidegger’s phenomenology is to get closer to essences of lived experiences, emphasizing on validity rather than reliability. It suffices as well to argue that it is disingenuous to claim complete detachment from the researched as our values, preferences, discipline orientation and social environment stand to influence the research process. In any case, the main goal of this thesis is to fill in the knowledge gaps, evident in existing cancer research and scholarship, which promoted a reductionist and mechanist view of the cancer illness while marginalizing the lived experience of people diagnosed with cancer in Zimbabwe.

3.6 Conclusion

In this chapter, the whole array of theoretical underpinnings, which inspire and permeate the whole study were highlighted and discussed. The rationale of a theoretical framework was advanced as that of proffering a general perspective from which one sees and interprets the world. The theoretical equipment enunciated the position or situatedness of the researcher, which helps readers to make sense of the thesis arguments. The general tradition of phenomenology, which served as the overarching framework, was discussed, building on the central idea that reality is socially constructed. The specific interpretive hermeneutic phenomenology of Heidegger (1962) which served as the analytical lens used in this study was highlighted; his emphasis on lived experiences, his notion of Dasein and ‘double hermeneutics’. The ideas by Heidegger accentuate on deeper understanding of the
nature and meaning of our everyday experiences. Taken as a whole, Heidegger’s approach, which is defined as both a theory and method inspired this study, with its ability to extract fringe data on cancer, currently missing in existing scholarship and aiding to our holistic appreciation of the cancer illness.
4.0 Introduction

The central and recurring argument in this thesis is that qualitative methodology embodied in interpretive phenomenology is well positioned to illuminate the indigenous (local) knowledge and social experiences of people diagnosed with cancer; in the end, giving new insights and aiding to our comprehensive appreciation of the phenomenon (living with a cancer diagnosis). Moreover, it is evident that the tradition of interpretive phenomenology which is adopted in this study as a theoretical framework, has strong pointers on how a researcher goes about to study phenomena (methodology) and epistemology (how knowledge is produced or the theory behind knowledge). This chapter outlines and discusses (in the order given); the methodological orientation of the study (ontology, epistemology, methodology and Heideggerian methodological insights), the research design, scope of the study, ethical considerations, the sampling and recruitment process of research participants, the strategies for data collection, the process of data analysis and interpretation and lastly, the challenges encountered and lessons learnt from the research process. The focus is on detailing how the researcher went about collecting the data and not so much on how one ought to carry out a study as contained in Research Methods textbooks. Thus, use of the first person narrative where it is in evidence is deliberate and meant to identify with the intimate process, befitting of a sensitive [health] research. Accordingly, I had to be reflexive and empathetic throughout.

4.1 Ontology, Epistemology and Methodology

Following Lincoln and Guba (1985), it is important to have an appreciation of the distinction among the terms, ontology, epistemology and methodology. Ontology denotes the form and nature of reality and what can be known about it; epistemology spells out the nature of the relationship between the knower and what can be known about it and
methodology is how the researcher goes about finding out what they believe can be known (Lincoln and Guba, 1985).

For the interpretivist (which applies to this study), at ontological level there is not one but many realities that are constructed and altered by the investigator. Epistemologically, this framework sees an ensuing relationship between the knower and the known. The notion of value free research is challenged and such a stance may be responsible for loss of certain kinds of knowledge about human experience such as meaning making (Cotterill and Letherby, 1993). Denzin and Lincoln (2000) observe that the researcher and the researched are inextricably connected, with the investigator as a passionate participant. Methodologically, the thrust is on understanding and on the reconstruction of experience and knowledge. Reminiscent of Weber’s *Verstehen*, the researcher’s own subjectivity is enlisted as a resource for the study, engendering an empathetic liaison between the researcher and the participants. The underlying strategy is for the investigator to try to identify with the actor and to view the course of conduct via the actor’s eyes rather than the outsider’s eye.

Principally, phenomenological methodology and qualitative methodology are synonymous. Given the sensitivity and personal nature of health matters and the quest to capture the lived realities of participants, qualitative methods were the most appropriate. Qualitative research methodology does not only effectively address the broad research questions of this study. It further attempts, emphatically, to address knowledge discrepancies in the cancer medical discourse in the country. The few cancer studies utilising qualitative methodologies in Zimbabwe, tend to inadvertently extend and buttress the imprint of quantitative analysis by eulogising ‘medical facts’, whilst trivialising and shunning personal narratives. David Hufford attests that “ordinary people tend to be underestimated and their knowledge tends to be discredited by authorities” (Adler, 1991). In this study,
research participants were afforded a chance to relate and delineate their perceptions, social interpretations, beliefs and experiences with the illness in their own terminology and logic.

A strong case for advocating a strong presence of qualitative insights in this study, finds justification given the pragmatic and holistic nature of qualitative inquiry. This blends well with the manifold, complex models of help-seeking behaviour of terminally ill persons. Phenomenological methodologies put a thrust on the *emic*, insider voice. Motivation for the use of and the impact of adopted health-seeking strategies was appraised in relation to the outcomes that individuals themselves expect, rather than in relation to pre-conceived, researcher-generated measures of outcome.

**4.1.1 Methodological Insights derived from Heidegger**

To Heidegger, there is no dividing line between the individual and experience. The two are regarded as co-constituting each other (Gavin, 2008). Hermeneutic research is interpretive and focuses on the historical meanings of experience and their developmental and cumulative effects at the individual and social levels. To hermeneutic research, any personal biases and presuppositions of the researcher are not bracketed or set aside, but being embedded, they therefore, become essential to the interpretive process (Moran, 2000).

The interview process is one of a relationship where safety, trust and care are critical and where, ultimately, a relationship develops and is sustained (Heidegger, 1962). I designed specific questions to document data on demographic characteristics. The rest of the questions were open-ended and the participant related his/her story with minimum interjections. The major rationale is to encourage the interview process to remain as close to the lived experience as possible. Geertz (1973) described the process as getting at what
participants really experienced, from the inside out, instead of simulating what they think they experienced. Kvale (1996) further advises, however, that it is important to look for not only what is said, but also for what is said between the lines. Hence, verbatim or word for word transcriptions are not exhaustive on their own but are further enhanced by the researcher’s interpretations (Wilcke, 2002).

Heidegger introduced hermeneutics into the study of phenomena as he reasoned that pure description in Husserl’s descriptive phenomenology was limited in its ability to reveal meaning (Osborne, 1994). Originally, the term “hermeneutics” referred to the study and interpretation of biblical texts, but now means “the theory and practice of interpretation and understanding or verstehen in different kinds of human contexts (Odman, 1988). Heidegger (1962) conceived of existence, that is Dasein or being-in-the-world as taking place in a world that is already given and which we take for granted. Many of the elements that shape our being-in-the-world are hidden and require interpretation for existence to be understood. Therefore, Heidegger’s concern was to uncover these hidden phenomena of our lives as well as their meanings (Spiegelberg, 1982).

4.2 Research Design

This study is a cross-sectional, multiple cases, interpretive study grounded in qualitative methodology and interpretive hermeneutic phenomenology. Methodology grounded in hermeneutic phenomenology is congruent with the purpose of this research- to understand and interpret the contextualised lived experiences of people living with cancer. In carrying out this study, the thrust was to get access to the individual embodied experience, the life-world. The perspective allowed a search for commonalities across persons, in relation to the phenomenon of living with a cancer diagnosis.
According to Kumar (2012: 795-6) hermeneutic phenomenology “is a methodology useful for describing human experience of caring, healing, and wholeness in relation to historical, social, and political forces that shape the meanings of wellness, illness and personhood”. The assumption is that the researcher and “participants bring with them fore- structures of understanding to the research process, shaped in part, by their social background and in the process of interaction and interpretation, they cogenerate an understanding of the phenomenon being studied” (Kumar, 2012:796). It is ‘through a close examination of individual experience that the phenomenological analyst captures the meaning and common features or essences of an experience or event’ (Starks and Trinidad, 2007:1374). van Manem (1990) notes that phenomenologists ask questions about lived experiences as contrasted with abstract interpretation of experience or opinions about them.

### 4.2.1 Research Site and Scope of Study

My initial scheme was to have Harare, the capital, as the case of the study or research site. The reality on the ground and the research process dictated the de-territorialisation of Harare. Though Harare remained the catchment area for the recruitment of participants diagnosed with cancer, it became apparent that participants recruited via Parirenyatwa Hospitals Radiotherapy Centre, the main referral centre for cancer in the country, came from various corners of the country. All participants recruited via institutions came from in and out of the capital, bringing with them a variety of rich experiences. In addition, I discovered that many people diagnosed with cancer, who reside out of Harare, come to adopt the physical addresses of their relatives in Harare, for use in official hospital documents. The oncologist, a key informant, confirmed the same observation. As a result, it is difficult to classify the geophysical location of a person who may reside temporarily in Harare, during the period of receiving treatment and later retire to rural areas or other towns and cities. During the period of this study, people with cancer were very mobile.
the end, as illustrated in appendix 7 (page 339-341) and appendix 8 (pages 342-344), the final sample comprised a diversity of experiences of participants from all corners of the country, who enhanced the heterogeneity of the sample. From in-depth personal interviews, I managed to establish the actual geo-physical location of all the participants, where they spent most of their time with the cancer illness.

As stated in the justification of the study in Chapter One, the study sought to understand the whole notion of cancer, a disease known as *gomarara* in local Shona dialect (it is also known as *nhuta, mhuka, nyamakazi*). According to Smith (2000) language is a major and often distinctive, source of information for social and behavioural scientists. It facilitates and reveals the development of persons and cultures. Language permits inferences regarding subjective experiences, intentions and internal structures that influence overt behaviour. Language often tells more about people than they want to disclose, or than they know about themselves, and it can bring into light things a researcher might not think to ask about (Smith, 2000).

The master concept was cancer itself and not the several medically defined typologies. Although local understanding of cancer and everyday usage of the term recognise the different body sites where people are affected by cancer, ordinary people do not necessarily define or express the cancer illness as a group of diseases and do not describe their social experiences using a multiplicity of medical categories and jargon. My perspective is shared by Thomas (1989), who conducted an ethnographic study on cancer amongst the Navajo in which he compared them with Anglo-Americans diagnosed with cancer. Thomas (1989) recalls Werner’s (1965) observation that the Navajo language has never had a large list of named diseases, but rather had a series of connotatively overlapping ways of referring to and describing sickness and pain. Similarly, in everyday
expressions in the Shona language, people use a composite term in an etiological sense, *gomarara* and they only distinguish it in terms of the body site it has manifested.

The salient distinctions that my study makes are based on the gender dimension because it may be imprudent to generalise men and women’s experiences if we factor in biology. It follows that, anatomically, cancer can manifest in reproductive organs unique to the male and female sex. For instance, we find cancer of the cervix and cancer of the breast in women and prostate and testicular cancer in men (cancer of the breast can be unisex though very rare in men).

**4.3 Ethical Approval and Rights of Participants**

Ethics generally spell out our responsibility to research participants and the scientific community and this ought to percolate in the complete scholarly practice (Laws, Harper and Marcus, 2003). To Neuman (2000) ethics define what moral research procedure involves, what is legitimate to do or not and Gokah (2006) adds that one has to be sensitive to the cultural environment and not just be preoccupied with managing participants. Kvale (2005) implores researchers to be accountable to both participants and the scientific community. Largely, I concur with Baarts (2009: 423), who observes that, “…the type of subject matter determines the nature of the ethically sensitive situations that occur during the research process and the kinds of ethical decisions taken by the researcher”. In essence, ethical considerations are, besides our comprehension of prior knowledge of informed consent, privacy and confidentiality, as spelt out in professional codes of ethics, contingent upon the situations that confront the researcher in the field and prompt swift decisions.
4.3.1 Approval

The student confirmation letter from the Department of Sociology, which communicated the academic purpose of my research, enabled me to start formal interactions with institutions like the Zimbabwe National Cancer Registry (ZNCR) and the Cancer Association of Zimbabwe (CAZ) also known as the Cancer Centre. A permission letter from the Ministry of Health and Child Welfare (see appendix 2 on page 333) enabled me to start engaging with the ministry departments as well as facilitating my clearance with the city of Harare and health care institutions.

I lodged my application with the Medical Research Council of Zimbabwe (MRCZ) (see appendix 1 on page 332), a statutory body which clears all health research in the country, comprising a completed application form, research protocol, research instruments in Shona and English and informed consent forms covering all respondents in the two languages. After 3 months, my study was given full board approval (MRCZ/A/1834) having completed the due process including incorporating specified recommendations. In addition, at the Parirenyatwa Group of Hospitals in Harare, the Clinical Director granted me a letter of permission into the Radiotherapy Centre and the Sister-in-Charge was instrumental in my getting smooth access to clients and the premises. The Parirenyatwa Radiotherapy Centre is the major referral centre for all cancer cases in the country.

4.3.2 Individual Informed Consent

According to Burns (1997), it is a requirement that participants must get to understand the nature and purpose of the research without any undue influence, prior to participation. Upon initial contacts with every potential respondent, I took them through the MRCZ approved informed consent form. The form introduced the researcher, outlined the purpose of the study, why the particular participant was selected, how the research was to be
executed, the rights of participants to privacy and confidentiality, voluntary participation, right to withdraw any time and possible (minimum) risks involved like emotional content. After the participant had understood and consented, he/she, plus a witness and I would append our signatures, with the respondent retaining an extra copy. As informed consent is not an event but a process, I repeated myself to get the consent of the participants in every research or interview encounter. Sometimes this included the consent of the ‘significant others’ especially family caregivers or guardians or spouses who may reserve the same rights on behalf of the individual. Since all my participants were adults (above 18 years of age) the consent of the participant was adequate. There were no unlettered participants.

### 4.3.3 Dealing with the sick and those in pain during Interviews

I halted interviews during moments when a participant was sick, in pain or was overwhelmed emotionally. I had four of such incidences where a male participant with advanced cancer was in agonizing pain and where three of the female participants were overwhelmed emotionally. I had to proceed later with their consent. The researcher observed the rights of people with cancer to rest when in pain and any such other requirements in line with the doctor’s, traditional healers’ or family attendants’ directives. According to de Vaus (1995) there is a need for the researcher to point out any potential harm or risks involved for participants. I took full responsibility to ensure that no harm was instigated on the research participants, whether physical or emotional. I stopped interviews when a respondent indicated fatigue. However, given that one of my study objectives invited an in-depth insight into illness experiences, I had to witness certain episodes of pain experiences. Thus, I constantly had to weigh ethical duties to the sick and the scientific value of the data elicited, as spelt out in the study objectives and research questions. I paid home visits to check on sick participants as a moral duty and as part of ongoing research.
4.3.4 Guaranteeing Privacy and Confidentiality of Research Participants

To de Vaus (1995:337) “Confidentiality means that the researcher can match names with responses but ensures that no one else will have access to them”. Anonymity and confidentiality are maintained to enhance the nature and veracity of responses; to enhance the sample size and its representation of the overall study population, to ensure that the participants’ privacy is not compromised and to encourage involvement (de Vaus, 1995:337)

The privacy and confidentiality of the participants was guaranteed upon signing a document to that effect and by the use of pseudonyms instead of real identities. Documents or records bearing real names of participants were safely kept for the researcher’s records alone and name identification was removed from all interview transcriptions. To guarantee privacy, I requested the audience of the participant alone for personal interviews in a secure room or open space unless the participant requested the presence of a family caregiver to assist with more information mostly in the case of married couples. I conducted three interview sessions with different participants, where a caregiver was present. For participants whom I had to interview at the premises of Traditional Health Practitioners (THPs), again a one-on-one audience was sought in order to guarantee privacy. Public figures like the registrar of the Zimbabwe National Cancer Registry, the Sister-in-charge at the Radiotherapy Centre and the information officer with CAZ agreed to be identified by their designations and not real names. On certain questions, they wanted to separate their own opinions from their institutional positions (I needed their personal insights most, as experts, unmediated by protocol, which masks novel data).
4.3.5 Dealing with the Issue of Empathy, going native and Objectivity

Given the nature of my study, I was to grapple with the risk of going native, in the process of empathising with people living with cancer. During interviews with people diagnosed with cancer, I empathised repeatedly as a humane trait. I was quick to learn that, despite my position as a researcher, I was a son to all of the older female and male participants, and a brother to the relatively young. I empathized during interviews, in times of pain and under stressful situations. The practice of ethics is connected to the morality of the particular researcher (Denzin and Lincoln, 2000). In a case of a woman with cancer of the breast recuperating in the park area of the Radiotherapy Centre, after a chemotherapy session, hungry but without money to buy lunch, I had to make a choice to press on with the interview or to buy her lunch first and do the interview later. I chose the latter, because I thought it was the right thing to do. I chose to help first. I went to the funerals of some of my participants who passed on after data collection, to pass my condolences. I visited some of my participants or their friends upon admission at hospital. Indeed, a relationship ensued the moment I met my participants, a relationship, which had to be watered by goodwill in order to access the life world of my participants. I quickly realised that in doing cancer research, I gathered more data and insights from informal visits and engagements, sometimes deeper than in a formal interview! Nonetheless, when we communicate evidence through writing, there is some degree of detachment between the researcher and the data, which ensures some semblance of objectivity. As noted by Dahlberg et al (2008) writing distances us from the life-world, and makes it possible for us to reach a level of abstraction.

4.3.6 Limited Deception

There were scenarios, which did put me in an intercalary position where I had to weigh the cost of declining to assume a certain vantage position and carrying my studentship status
traced from the University, Sociology Department. Island Hospice facilitated my initial contact with participants diagnosed with cancer who were their clients in palliative care. The senior community sister contacted the participants and informed them of my impending visit as a research student attached with the hospice. This created a great deal of rapport, ensuring warm relations full of trust and goodwill. Some participants took me for a ‘doctor’, a ‘social worker’ or ‘counsellor’. I had to clarify that I was not a medical doctor and I was not in a position to do a prognosis when a participant needed clarification on some ill health experience. I would reaffirm my identity as a social science student, though my being introduced, as an incumbent member of the hospice ensured smooth access to participants and a great deal of goodwill. However, the tag or identity of a counsellor was to pervade my whole interview processes as all people diagnosed with cancer perceived me to be a willing listener, to them, where many may no longer see their value and some of whom now lived solitary lives.

4.3.7 Commitment to the Scientific Community and Research Participants

Admittedly, one of the ethical dilemmas I faced throughout the study was when participants asked about some basic information on cancer and any knowledge of organisations or health practitioners who could assist. I must say, during the start of fieldwork, I was not in a position to share my little knowledge about available services or basic knowledge on cancer, a position that shifted as I gathered more experience from my interactions with oncologists, the sister-in-charge and officials from cancer service organisations. As a civil and moral citizen, I had to inform new clients about the Cancer Association of Zimbabwe (CAZ) and the services they offer, the processes done to get a letter from the social welfare department and basic knowledge on hospital cancer treatment. A letter from social welfare confirms the vulnerability of the bearer and thus
his/her eligibility to getting preferential treatment. I was supposed to show that I empathize and I care about the welfare of my participants and not just be obsessed with my PhD!

On another note, as a researcher, I had an obligation to the scientific community to produce valid data/knowledge. With my study grounded in a phenomenological episteme, I was aware that I was not going to satisfy certain benchmarks like representativeness, randomness and coverage, which allow generalisations to be made. Nonetheless, this is befitting to a study, which is qualitative, context-specific, situation-based and experiential. My study stands to contribute new knowledge emanating from the qualitative paradigm; it is the intensity, rigor, and systematic way that the research was carried that is the hallmark of its scientificity. I share the same observation with Baarts (2009) that “research ethics are ‘political’ in that scientific knowledge is used strategically to support specific knowledge interests”. In essence, all knowledge is politically interested.

4.4 Sampling and Recruitment Process

In a phenomenological research, participants are selected not based on meeting some statistical requirements but participants who have lived experience are the focus of the study (Gibbs, 2007). Such participants are willing to talk about their experiences and are diverse enough from one another, to enhance the possibilities of rich and unique stories of the particular experience (Polkinghorne, 1988; van Manem, 1997; Woodgate, 2006). Variation was in terms of demographic characteristics (Shattell, McAllister, Hogan et al, 2006) and variations in both demographics and experiences (Esbensen, Swane, Hallberg et al, 2008). The researcher continued with recruitment until some kind of saturation, in which a clearer understanding of the experience could no longer be found through further discussion with participants (Kendall, 2006).
Generally health issues are sensitive and private and purposive sampling was the most feasible and suited way of selecting the research participants. Kumar (2012) observes that the issue of [large] sample size in qualitative research is less important but what is critical is to collect data which fully addresses study objectives and which provides information-rich cases with experience of the phenomenon. To Starks and Trinidad (2007), diverse samples provide a broader range from which to distil the essence of the phenomenon, and rich data from detailed individual accounts might suffice to uncover its core elements. The sampling frame is comprised of a “list of the units of the population from which the units that will be enumerated in the sample are selected” (Casley and Lury, 1987:52). I obtained names of hospital-supplied participants from a huge list of registered cases of cancer at the registration office at Parirenyatwa Radiotherapy Centre. Cases were purposively selected to ensure heterogeneity and diversity in terms of different demographic and cancer variables (see appendix 7 and 8 on pages 339-344). A focus on upper ages (50 years+) sufficed as information reservoirs with requisite experiential memory.

4.4.1 Sources of Recruitment

Several institutions and sources mediated the recruitment of the 30 participants for the life histories and semi-structured interviews. This served practical and external validity reasons. Given the individual and terminal nature of the cancer illness, access to people with cancer and cancer survivors is generally facilitated by hospice services, cancer service organisations and support groups. The initial contacts I made enabled me to snowball a couple more cases. A triangulation of sources of recruitment of participants tended to strengthen the external validity of the main cases as ‘voices’ came from various sources. Various sources of recruitment enhanced the heterogeneity of the final sample across various experiences and treatment modalities.
4.4.2 Island Hospice and Bereavement Centre

I recruited my initial cases through the facilitation of Island Hospice and Bereavement Services, in Harare- an organisation that has offered palliative care to people with terminal conditions, including cancer, since 1979. I was introduced to the senior community sister who contacted the would-be participants first before I could secure interview appointments. My introduction by the senior community sister did help a lot in terms of being assured of good rapport and retaining the confidence and trust of my participants. I got my first five participants with the facilitation of the hospice. All such participants were now receiving palliative care.

4.4.3 Cancer Association of Zimbabwe

The second institutionalised mode of recruitment was through the Cancer Association of Zimbabwe (CAZ), also known as the Cancer Centre. Since the beginning of my study in 2012, I had become associated with the Cancer Centre. I began to attend their public lectures from January 2014, and more consistently from May 2014 soon after the approval of my study by the MRCZ. The Cancer Centre hosts a seminar series/public lecture every last Thursday of every month between 12:45 pm and 14:00 pm, where various facilitators ranging from oncologists, dieticians, complementary medicine therapists, medical doctors, health ministry officials, people living with cancer amongst many others give papers on various topics. From such a platform, I recruited five people living with cancer who then linked with more cases from support groups.

4.4.4 Parirenyatwa Radiotherapy Centre

The third recruitment platform was the Parirenyatwa Radiotherapy Centre in Harare, the major referral centre in the country. Armed with a letter of permission, I visited the reception/registry section of the radiotherapy centre to see the details of clients coming for
reviews on the day. Review days were done every Thursday of the week. New clients were attended to on Wednesdays. I would arrange with the nurses to talk to diagnosed clients soon after they were through with consultations. For some I booked appointments for a later date or for a home visit on a day they were free. For others, I would move to conduct the first interview, which on average would last for 30 to 40 minutes. The sister-in-charge assigned a small room, which I used to conduct interviews.

4.4.5 Recruitment via the Traditional Health Practitioners (THPs)

My meeting with registered THPs, facilitated by the Traditional Medical Practitioners Council, a unit under the parent Ministry of Health and Child Care, facilitated my meeting with a faith healer/herbalist who was attending mainly to people diagnosed with cancer. The faith healer who doubled as a herbalist, Sekuru N.C, a Seventh Day Adventist and his female ‘nurse’, spoke passionately about the social impacts of cancer. I visited his premises located in a low income housing scheme in the outskirts of Harare. I developed a sustained father-son relationship with him. He facilitated my interviews with several of his clients, some new and others he had attended to since the year 2011. I managed to interview 8 people he treated to recovery in the past years and some he was currently attending to. Three of those I interviewed later died.

4.4.7 Snowballing and Support Groups

The rest of the participants were recruited via networks of informal support groups and friendship networks among women diagnosed with cancer. All participants in the women only Focus Group Discussion (FGD) in Harare were recruited from networks of two women, one diagnosed with cancer of the thyroid and another with cancer of the breast who had been visiting new people diagnosed with cancer, giving them psychosocial support and taking part in outreach education programmes.
4.5 Data Collection Strategies

4.5.1 Life Histories

As noted by Williamson et al (1992) cited in Burgess (1982), on life history reports, the focus is on tracing and analysing critical life events, responsible for shaping research participant’s perspectives. In these, more open and extensive descriptions of past events, illness experiences were elicited and clarifications were requested. Through life history interviews, social biographies of the cases of people living with cancer were obtained and these covered the following: their upbringing, family history and health history, social, economic, religious life and educational background. The interviews (see guide on appendix 4, page 335) involved chosen participants diagnosed with cancer cases chronicling their personal life experiences with cancer especially life changing and life threatening experiences, turning points and unforgettable memories with the illness.

4.5.2 Semi-structured interviews with people living with cancer and the illness narrative

Interviewing participants is one of the preferred techniques of eliciting responses from research participants in phenomenological research. Patton (1990) states the purpose of interviewing as "to find out what is in and on someone else's mind", that is the perception of lived experience. Smith and Eatough (2006) indicate how semi-structured interviews are a versatile information-gathering technique, which gives a thrust to understanding individual experiences and meanings while not losing sight of the influence of the interview context. Semi-structured, open-ended interviews (Morgan, 2006) were conducted with cases of people diagnosed with cancer at their homes to get a nuanced understanding of their perceptions and beliefs on the causes of their cancer, their daily social experiences with the illness, their pathways to treatment and suggestions to the
government. This form of interview allowed dialogical engagement between the researcher and participant and allowed modification of questions in light of a participant’s responses. All interviews with the participants diagnosed with cancer were conducted in either Shona or English.

Semi-structured interviews ensured the establishment of rapport and allowed the interview to pursue novel issues. My role in a semi-structured interview was to facilitate and guide discussion rather than dictate questions. The interview guide mainly indicated areas of interest and provided cues (see guide on appendix 5, page 336). The process of interview itself instructed the sequence of questions. The number of interview sessions, which ranged from 2 to 4 sessions was contingent upon the following factors: the level of openness and depth a participant exuded in an interview and whether all the issues addressing study objectives and research questions were covered to my satisfaction. I must say with regard to participants who were not keen to share much, my home visits (without scheduling a formal interview) provided vital additional data on their experiences. In most scenarios of home visits, for couples (with one diagnosed with cancer) and in the case of present home caregivers, a lot of data were gathered in one session with caregivers and the partner sharing further details. I however, need to reiterate that the presence of a caregiver during the interview or a partner was only with the consent of the participant. The main advantages of having a family caregiver or spouse contributing to the interview was that, one could cross check the validity of the responses with another party elucidating further. In this way, a lot of data were gathered in a single session. A limiting factor in the context of co-presence was that the participant could not feel comfortable in discussing certain issues for instance any emergent stigma experiences in the family. However, it was apparent that all the discussions were open and frank in the presence or absence of family members and the benefits far outweighed the limitations. The interviews were digitally
recorded (with permission from participants) using a voice recorder and later fully transcribed.

In addition, the use of interviews as a phenomenological tool of research, as a method to collect a subjective, personalised story has been popularised as illness narrative. As noted by Atkinson (2009) oftentimes, the illness narrative method is valourised as the window for researchers to gain access to authentic personal experience, to the subjective or individualised aspects of illness. Individual narrators are presented and celebrated as an itomised subject, a de-socialised patient, who narrates in a social vacuum, and in the process, stripping the inquiry of any sociological thrust (Atkinson, 2009). Thus, Atkinson (2009) calls for more analytical strategies that treat illness narratives as a speech act, based on socially shared resources and conventions. In the context of the study, and notwithstanding the importance of concerns raised by Atkinson (2009), the very epistemologies of interpretive hermeneutic phenomenology delimit such flaws inherent in the illness narrative. Interpretive hermeneutic phenomenology espouses the sociological imagination with its emphasis on the situatedness of participants, the salience of the prevailing social milieu in shaping and mediating narratives. Throughout the study, the researcher demonstrated awareness to the cultural distribution of discursive resources and conventions.

4.5.3 Key informant interviews

According to William Foot Whyte cited in Burgess (1982), as the study progresses, one can think of collaborators who can give expert guidance on some research issue. Whyte observes that not all informants are of equal value to the research, and that the “best informants are those in a position to have observed significant events, and who are quite perceptive or reflective about them”. Key informants in this study were enlisted to reflect
and relate their experiences of interactions with people diagnosed with cancer, to feed into the narratives of people diagnosed with cancer who were the main protagonists in this study. This is notwithstanding their vantage point as experts in their areas of competency where they assisted with putting explanatory frameworks on the illness and social experiences and in recruiting participants. The key informants in this study (see appendix 3 showing list of key informants on page 334) are presented below:

4.5.4 Registrar: Zimbabwe National Cancer Registry (ZNCR)

An interview with the registrar, who has been with the registry since its formation in 1985, was important to relate the cancer burden, get the interpretation of the trends from the perspective of the registry as well as discussing possible limitations of the data collection strategies. I was put on the mailing list to get the latest cancer annual reports and any updates on upcoming reports.

4.5.5 Monitoring and Evaluation Officer: Cancer Association of Zimbabwe

I also moved quickly to establish contacts with the Cancer Association of Zimbabwe (CAZ), the oldest non-state cancer service organisation in the country. I conducted interviews with the Information, Monitoring and Evaluation Officer to get to know the kinds of services offered by the organisation to people diagnosed with cancer, to find out the organisation’s experiences in serving clients diagnosed with cancer and the experiences encountered by people with cancer from the perspective of the organisation.

4.5.6 Senior Community Sister: Island Hospice and Bereavement Centre

At the Island Hospice and Bereavement Services, one of the few organisations offering palliative care to people with terminal illnesses like cancer, I met the senior community sister. Having been with the organisation over a period spanning 25 years, she was instrumental in facilitating my contact with the first five participants of my life history
cases. I conducted two interviews with the senior community sister and as a gesture of goodwill; I gave a small donation to the hospice.

4.5.7 Sister-in Charge: Parirenyatwa Radiotherapy Centre

The sister-in-charge at the Parirenyatwa Radiotherapy Centre was not only instrumental in facilitating my entry and access to the Centre but gave useful insights on the role of nursing as well as her experiences with cancer clients. The sister-in-charge gave insights into the costs of treatment and assigned a room for my interviews.

4.5.8 Radiation Oncologist

The radiation oncologist elucidated on the bio-medical narrative on cancer, touching on the manifestation of the illness, hospital treatment and associated side effects. Our interviews dwelt more on her experiences interacting with cancer clients, touching on myths associated with the cancer illness and hospital treatment and on the doctor-client relationship in hospital cancer treatment. The differences between the practices of scientific medicine and those of traditional medicine or healing came into sharper focus.

4.5.9 Traditional Health Practitioners (THPs)

The Ministry of Health and Child Welfare through the Traditional Medical Practitioners Council (TMPC) facilitated my contact with four THPs for a group interview. The four comprised a herbalist trained in India who attends to various ailments including cancer, a traditional healer who used spirit possession and attends to various ailments, a herbalist by experience who used indigenous medicinal plants to treat various ailments including cancer and a faith healer who uses prayer and herbs attending mainly to cancer clients. I was to pursue the faith healer (Sekuru N.C) who uses herbs and prayer and who mainly attends to cancer clients unlike others who were not specializing.
One of my participants, whom I recruited at Parirenyatwa Radiotherapy from the rural areas of Chiweshe, referred me to a well-known traditional male herbalist who treats cancer in the area of Chiweshe. The herbalist (Sekuru M.B) later assisted me in mobilising participants for a focus group discussion held at Howard Mission Hospital. In addition, he referred me to a female traditional herbalist in the Chiweshe area. The two THPs were initially hesitant to have interviews with me, suspecting that I could be a law officer incognito, as they were not formally registered.

I managed to have a key informant interview with a registered herbalist, Sekuru Muc who specialised in cancer of the wounds, *a wound that does not heal*, in Chitungwiza city near Harare. Since my study had somehow become *de-territorialised*, I conducted an interview with a 71-year-old village elder (Sekuru M.T.) in my home community (Msengezi Area) who shared ethnological knowledge of cancer based on his experience.

With the help of a friend who used to teach in the rural areas of Mount Darwin, I contacted a 76-year-old traditional healer, Sekuru Pasi who had been popular in the area between 1980 and the 1990s. He shared novel ethnological accounts of why in his opinion; the cancer illness was on the rise in the country now and also spoke about his treatment and healing philosophies. His age and vast work experience spanning decades acted as a repository of cultural dynamics in lifestyles and illness interpretation.

**4.6.0 Semi-detached Unobtrusive Observations at Different Research Sites**

Following Spradley’s (1980) classical method of ‘participant observation’, I engaged in semi-detached unobtrusive creative observation exuding a high sense of alertness and a wide-angle lens during interviews and social interactions with research participants. This enabled me as the researcher to observe and grasp some taken-for-granted actions and
speech, which in turn lead to the unravelling of instructive data. Notes on observations were taken on spot.

Inevitably, I found myself frequenting the Parirenyatwa Radiotherapy Centre, the main referral and treatment centre in the country over a sustained period of time (9 months). At the Radiotherapy Centre, I had access to clients coming from all corners of the country including rural folk and urban dwellers. I visited the radiotherapy centre on Wednesdays and Thursdays from 9 am to 12 noon. Sometimes I arrived early around 7 am to listen to local pastors ministering to old and new clients at the Centre. Thereafter the nurses on duty took the clients through the hospital protocol and basic knowledge on cancer and hospital cancer treatment.

In the Radiotherapy Centre Waiting Area, I would sit, observe, and listen attentively to ensuing conversations among people with cancer and family caregivers or relatives as they waited for their turn to consult a doctor. There was a park area outside where some clients rested or where family caregivers waited for their loved ones and a rendezvous for siblings and relatives some of who were meeting for the first time. In the park area, I conducted unobtrusive observations, chatted, participated in informal group conversations and made appointments for further personal interviews.

My second prominent observations research site was the residence and premises of a known local faith healer, Sekuru N.C who used herbal concoctions and prayer to treat clients with cancer. The premises were located on the periphery of Harare the capital. The premises comprise a two-roomed structure, with one space, which acted as a consultation room and another room, which was occasionally used to admit very sick clients.
4.6.1 Focus Group Discussions (FGDs) and Informal Group Conversations

According to Wilson (2007), FGDs come after one-on-one interviews to validate personal interviews and generate deeper insights on the phenomenon. After life history interviews and one-on-one semi-structured interviews, I conducted two FGDs; one in the Chiweshe rural area in Mazoe District and another one in Harare with each going for 2 hours 30 minutes. The question guide (see guide on appendix 6, page 338) was tailor made to address the five objectives of the study. FGDs elicited other insights which individual people diagnosed with cancer did not share in personal interviews for instance stigma experiences. In this regard, the seemingly therapeutic latent function of the group discussion was evident, with the women observing that it was a day well spent as they reflected on their journeys with cancer. Oftentimes, they could have been alone stressing, as some of them were widows.

The Focus Group Discussions (FGD) in rural Chiweshe comprised 12 participants who included some people diagnosed with cancer (who are not part of the 30 life histories participants), relatives/family caregivers of people diagnosed with cancer and the herbalist who joined later. With the help of the community health officer, a convenient room was provided at Howard Mission Hospital for the group interview with ages of participants ranging from 30 to 68. The FGD explored the rural experiences of the cancer illness, beliefs and knowledge on the cancer illness among the rural folk. Most of the participants of the FGD gave novel data on the cancer illness, not coloured much with exposure to knowledge from support groups, cancer service organisations and hospitals. The diversity of participants added more value to the data.

The second FGD in Harare was comprised of eight women of whom four were diagnosed with cancer. Three of these are part of my 30 case participants; others a widow of one of
my deceased participant with prostate cancer, then a cancer activist and two accompanying friends of people diagnosed with cancer. The diversity of participants in the group discussions ensured diversity of experience sharing. My role in the FGDs was mainly to facilitate and guide the discussion with participants having an open floor to talk and even distress. The FGD in Harare, though originally meant to be a mixed one, managed to capture women’s experiences in an urban set up.

The reality on the ground forced me to change some of my initial proposals-for instance to have a men-only FGD. One recurring aspect throughout the study was the difficulty of getting male participants to enrol. The male participants that I managed to get on board were upon mediation of institutions and not personal networks as in the case of female participants. I did not come across a men-only cancer support group. Females diagnosed with cancer belonged to support groups where they exchanged notes and helped each other cope with the illness, in contrast to men who were so secretive about the ailment. Similarly, Merckaert, Libert, Messin et al (2009) found that more women had a desire for psychosocial support than men did.

4.6.2 Field Notes in Red and Black Cancer Diaries

Upon the commencement of my fieldwork in March 2014, I secured two 2014 red and black diaries, exclusively for research purposes. I jotted down notes during and after interviews, and after observations, notes during and after FGDs and during seminar presentations at the CAZ. Field notes were taken alongside the use of the voice recorder to capture those elements, which the voice gadget could not capture like visual observations. At the end, I compiled all the panorama of bits and pieces of information into a typed write-up for my comprehension during thesis writing on findings. Additionally, diaries
tended to be inventories of contact details of participants I scheduled to interview. In the
diaries, I outlined my to-do-list.

4.6.3 Home visits, Hospital visits and Funerals

Along the course of the research, there emerged other serendipitous sources of rich data,
which I had not previously planned for. The kind of empathy embodied in my study led
most of my participants and their family caregivers to construe interviews as counselling
sessions, which engendered a possible cathartic effect in participants, diagnosed with
cancer. This empathy meant that I was in constant touch with some of my participants and
I received updates on their health for those in Harare where I live. It meant that I attended
funerals or passed my messages of condolences on some of my research participants who
unfortunately passed on at the end of my fieldwork or before I submitted the thesis. It
meant that I visited some of my participants who were admitted at the hospital upon cancer
related sickness or other non-cancer related ailments. My home visits illuminated further
the kind of life styles or social relationships of some of my participants. Nonetheless,
during all the visits I did not lose focus of getting more and more relevant insights. At
funerals, I listened to people’s comment on the death, gossip and jokes.

4.7. How the Data were Interpreted and Analysed

My overarching tools of analysis comprised the theoretical framework, thematic analysis
and literature review. The principles of Heideggerian interpretative phenomenology and
‘double hermeneutics’ which serve as the theoretical gridiron of this study, permeate the
whole thesis and inform the scope, form and substance of this manuscript. A cardinal point
in Heideggerian epistemology is that human existence is entirely and indissolubly
cemented in the world, a world comprising of relationships, things, people, language and
culture (Larkin, Watts and Clifton, 2006; Moran, 2000). In keeping with the practicalities
of phenomenological analysis, I found myself engaging the data, the moment I had my first interview or from initial general observations of the study’s phenomenon. Data analysis was an ongoing enterprise, undertaken concurrently with data collection (Callister and Cox, 2006; Woodgate, 2006).

Largely, this study exploited the basic philosophies of Interpretative Phenomenological Analysis (IPA) in analysing field data. According to Smith and Osborn (2008), IPA undertakes to explore in detail how participants assign meaning to particular experiences, events and states, how they make sense of their personal and social world. Thus, rather than trying to find causal explanation for events, IPA is an inductive approach concerned with understanding an individuals’ personal or shared account of a particular experience of a phenomenon (Smith and Osborn, 2008). Thematic analysis as a process of making explicit the structures of meaning embodied by participants and the researcher in a text was done reflexively, in a circular fashion back and forth, rather than as a linear activity (Gavin, 2008). The appreciation of literature in light of data transcriptions was undertaken at post-analysis stage (that is after phenomenological and thematic analysis), to reduce influence on the intimate interpretation of phenomena, in keeping with tenets of phenomenology (Kendall, 2006).

Having stated the overarching framework underlining my data analysis, I now relate the practical steps or the actual process of data interpretation and analysis pursued in this study. During fieldwork, analysis was ongoing. The moment I stepped into the Radiotherapy Centre waiting area, at Parirenyatwa Hospitals I jotted down ‘reflective notes’ on any striking observation of people diagnosed with cancer as well as during FGDs and interviews. Later, I expanded the reflective notes in continuous prose.
During the data collection, I positioned myself to note any points of convergence and divergence on data from personal interviews conducted with people diagnosed and living with cancer. In the case of seven of the participants diagnosed with cancer, recruited via a faith healer/herbalist who attended to them, I confirmed their illness accounts with those of the herbalist, noting any divergences or further details. Joint interviews of married couples where one spouse had cancer enabled me to confirm evidence of it. In some instances, the researcher would probe and prod issues with key informants to help with interpretations on issues raised during interviews with participants diagnosed with cancer.

With printed data transcripts (direct verbatim), I applied steps enunciated by Smith and Osborne (1998, 2008); Diekelmann, Allen and Tanner, (1989); Cresswell (1998); Moustakas, (1994); van Manem, (1997). Notably, these steps were not enacted linearly, but in a cyclic, discontinuous fashion, going back and forth. I read and re-read data transcripts noting down comments on the transcript in line with my study objectives and research questions. I underlined metaphors, definitive statements, and statements with emotional appeal—some of which I quoted as direct verbatim in text. I noted down similar lived experiences among and between participants diagnosed with cancer and from key informants. Diekelmann, Allen and Tanner (1989) formulated IPA, a seven steps analysis package, which I exploited. The first step entailed reading several times recorded interviews to obtain an overall understanding and noting comments on any striking, similarities, differences, echoes and contradictions in person’s narratives. The second step involves writing interpretive summaries and coding emerging themes, treating the entire transcript as data. The third step, analysing bunched selected transcripts to derive themes, revisiting texts and/or participants to clarify any discrepancies in interpretation and writing composite analysis for each text being the forth step. The fifth step compares texts to identify and delineate shared experiences and common meanings, identifying patterns that
not only link the themes but also decipher differences in participants’ accounts being the sixth step and lastly enlisting suggestions on final draft from the interpretive team, in my case my two supervisors. Superordinate themes were translated into a narrative account, where they were explained, illustrated and nuanced. The whole activity engendered ‘double hermeneutics’ where the participants’ interpretations where blended with that of the researcher.

Smith (1996) notes that the term ‘theme’ is used in phenomenology instead of ‘coding’.

My study objectives and research questions served as flags to pigeonhole my case specific data into themes. Data across the 30 cases of people diagnosed with cancer and key informants was grouped in line with study objectives and research questions. With grouped data, further sub-grouping was done in line with commonalities and patterns that emerged from data from interview transcriptions and focus group discussions. Themes were derived from dominant messages generated from cross-case analysis.

According to Gibbs (2007) narration or story telling is one of fundamental ways in which research participants organize their understanding of the world. The stories in Chapter 5 were developed into logical, unfolding accounts from life stories of participants. The stories are compiled in such a way as to address the five study objectives as issues are presented cross cuttingly. The ten chosen stories in Chapter Five are the most elaborate, chosen to depict varying experiences according to age, marital status, cancer site, source of recruitment and peculiarity of lived experiences. The case presentations compiled in a systematic way, are meant to make explicit the phenomenon-in this case, living with a cancer diagnosis in Zimbabwe. In addition, case presentations are meant to illustrate the particular life world of participants who have recounted their experiences. On the same note, cross-case analysis meant moving from the particular to the general or to shared experiences among people diagnosed with cancer, which is one of the cornerstones of IPA.
(Smith and Eatough, 2006; Smith and Osborne, 2008). The richness of personal narratives were systematically analysed so that important commonalities were not masked by the individual variability that they emphasized.

I kept in mind the scientific benchmarks proposed by Lincoln and Guba (1985), namely, credibility, dependability, confirmability and transferability throughout the research process. To meet credibility, I sought clarification from participants whenever I encountered a mix up or some distortion in life histories and chronicling of events and experiences. Joint interviews at homes of participants with spouses or a family carer helped in enhancing credibility. Interpretations were constantly cross-checked with original transcripts to ground interpretations in data. Discussions with supervisors and a fieldwork companion also ensured dependability and confirmability of results. On transferability or generalizability, the distinction made by Stephen (1982) cited in Gavin (2008) between horizontal and vertical generalizability is useful. Horizontal generalizability where findings are meant to be applicable across settings was peripheral to this study while vertical generalizability, which is meant to enhance our understanding, to enlarge insight and contribute to existing theories and the generation of hypothesis, was sought (Johnson, 1997; Kearney, 2001; Yardley, 2008).

The last stage of analysis involved appreciation of existing empirical studies related to study objectives in relation to my data and interpretations. This was done, post-analysis in line with the phenomenological logic of limiting colouring of original research with extant literature (Kendall, 2006). Some of the literature related to the study objectives, meant to help locate study gaps was reviewed prior to analysis (Esbensen et al, 2008). Literature was exploited either to confirm results of my original research or to note points of divergence and explain them. In the end, the final account proffered a layered analysis of lived experiences of people diagnosed with cancer in Zimbabwe. First, there was a
descriptive level, which demonstrated a robust understanding of the experience and the second and final, a more critical analysis, based on deeper interpretative work of the researcher (Eatough and Smith, 2006; Larkin et al, 2006; Smith, Flowers and Larkin, 2009)

4.8 Challenges Encountered from the Research Process and Lessons Learnt

One of the challenging yet valuable research experiences, was abandoning initial plans specified in the proposal in light of the reality of fieldwork. Initially, I had envisaged having a proportional representation of participants according to age and gender in the research sample. However, it proved difficult to secure the participation of more young unmarried adults (including adolescents) and men diagnosed and living with cancer (despite that some would initially agree). I learnt that the general apathy by younger participants and males was due to the sensitivity of health issues and stigma attached to cancer. Unlike middle-aged and older females who were actively involved in support groups and cancer programmes, males were conspicuously absent and, therefore, difficult to recruit. However, given the qualitative nature of my study, the final sample managed to address the primary aim of the study.

Moreover, though the title of the study indicates the City of Harare, the country’s capital, as the main case of the study, the final sample comprised participants from various corners of the country (as shown in the table of the demographic characteristics of the participants in appendix 7 page 339). From the experience, I came to learn of the scenario where a number of people diagnosed with cancer who come from out of Harare, come to be registered under Harare in Cancer statistics from the Zimbabwe National Cancer Registry. This was because they usually submit the physical address in Harare of a relative whom they come to reside with during the course of the illness or hospital treatment. Nonetheless, from the recruitment exercise, I ended up having a very rich cross-sectional
sample and experience of people from rural and urban areas (from a personal interview, it was easy to get a valid response of where a participant resides permanently).

In a related matter, I came to acknowledge the ambiguous nature of the term indigenous (as it applies to my study) included in the title during the research process (without being drawn into wider debates on the notion in literature). The term, which from my initial and current literal applications is synonymous with ‘local’, was meant to draw attention to the localised nature of the study (a study of cancer from the perspective of selected Black African participants residing in Zimbabwe). It was apparent (during and after data collection and analysis) from the narratives of people diagnosed with cancer in this study that indigenous, as denoting traditional, pristine, or giving connotations of a static cultural viewpoint or a fixed geo-physical location, was only an ideal type devoid of lived realities. The projection of indigenous as fixed and unchanging has been questioned as people assume global identity and as knowledge involves appropriation of both the local and global (Airihihenbuwa, 2007a). Thus, it is not prudent to elucidate experiences shared by a Zimbabwean as simply local perceptions as an American or Australian can also share the same perceptions. During interviews, participants (including traditional health practitioners who may be perceived as cultural curators) gave cosmopolitan narratives on understanding the cancer illness, which in essence illustrated the influence of knowledge from various sources. However, the fact that the responses were from local resident black Zimbabweans still applied to the sense of indigenous as local. In the end without having any bearing on collected data, the primary aim of the study and the initial approved study focus, I intended to amend the title to be more precise and elaborate of the final thesis manuscript; to read as

“The Lived Experience of Selected People Diagnosed with Cancer in Zimbabwe: An Interpretive Phenomenological View”.
The title amendment, which was to come two months before final submission, was barred at Faculty level. I was advised that the Academic Committee was not likely to approve the amendment given the short time frame left from final submission. Thus, my application to amend the title, though it was approved at department level and was agreed by my thesis supervisors, could not pass the Faculty level. Change of title is provided for in the regulations governing DPhil studies at the University of Zimbabwe and is sanctioned by the Academic Committee. After consultation with my supervisors, we [gudgingly] agreed to stick to the initially approved title (as it reads on this thesis manuscript), as it would not nullify the content of the whole manuscript including study objectives and key thesis contributions. I must say, this was one of the most challenging moments of my studies and which reminded me of the contested nature of doing a DPhil! Personally, I had hoped to fine-tune the title in the end (in line with international practice), when one has a good feel of the final product and where the initial title is conceived as a working title! The lack of flexibility on the part of the Faculty and Academic Committee (or is it wrong interpretation of regulations!) illuminates the struggle with overcoming an intellectual hegemony inscribed in our policies to privilege the Western cultural logic and hard sciences (or quantitative methodologies) in ways that dislocate the cultural logic of ordinary people, in this case. It is within the framework of quantitative research, to frame the direction of research before data collection commences—hence apriori conceiving of the title. However, with qualitative research (which applies to my study), one would finalise the title of the research after completing data collection and analysis. It is an irony that the very premise and central contribution of this cancer research serves to interrogate the very logocentric and intellectual hegemony that pervades knowledge production. Therefore, I would like my readers to be familiar with the foregoing contestations, how institutional
policy could undermine a key basic message of authenticity to participant voices as the hallmark of this study.

Lastly, in doing cancer research I came to realise that one had to be empathetic throughout, show concern for the welfare of some of the participants in need, and not just to be preoccupied with the research process. I must say, it was a life-changing research, where I came to be more health conscious (I changed my diet and became disciplined with physical exercise upon being reminded of my own vulnerability as well) and more passionate about areas which need redress for people diagnosed and living the cancer, taking the role of an advocate.

4.9 Conclusion

This methodological chapter firstly discussed the ontological, epistemological and methodological orientation of the study. The chapter drew from chapter three to elucidate Heidegger’s methodological underpinnings as theory informs method. Secondly, the study design was construed and discussed as a cross-sectional multiple cases, interpretive study grounded in Heidegger’s methodological insights, chief among them being his emphasis on contextuality and situatedness as well as ‘double hermeneutics’. The scope of the study, which was derivative of the interpretive hermeneutic tradition, was enunciated. A common thread running throughout the study was the need for practising reflexive sociology, inevitable of a study, which invited the researcher to be empathetic throughout the fieldwork. The chapter then discussed the ethics that were observed contingent upon the realities of fieldwork. The triangulation of sampling and recruitment processes as well as data sources was meant to enhance the density, heterogeneity and external validity of the findings. This ensured a holistic and comprehensive study of the phenomenon. The chapter went to enunciate how data were interpreted and analysed in processes that saw the application of multi-layered analyses and ‘double hermeneutics’ which coalesced the
researcher’s and participants’ interpretations. In essence, the data analysis was an ongoing exercise. Lastly, the chapter presented the challenges encountered by the researcher, typical of the nature of the study but not limiting the overall scientific value of the study and instead offering invaluable lessons. In the end, the central argument emanating from this methodology chapter is that phenomenology offers an ensemble of research philosophies and novel data capturing strategies, which enable us to extract new and fringe data (limited with quantitative methodologies) for our holistic understanding of the cancer illness.
5. CHAPTER 5: PRESENTATION OF CASES

5.0 Introduction

This chapter presents a selection of ten stories from the collection of the thirty cases emanating from participants diagnosed and living with cancer all of whom took part in this study. The systematic compilation of the stories embodies a structure and thick descriptions reminiscent of Geertz (1973). The narratives are first order constructs by participants’, expressed in their own words and capturing precisely what they said, which then constitutes another level of analysis (Ajawi and Higgs, 2007; Gibbs, 2007). The stories fit into Frank’s (1995) notion of quest narrative about the teller’s story where the teller is in control of things and relates his/her experiences in a personal way. The ten stories are elaborate examples of authentic experiences, representative of the salient issues captured cross-cuttingly in line with the research questions of the study. In this chapter, I do not attempt to interpret any of the stories. This enables me to avoid duplication and redundancy given the comprehensive analysis in Chapters 6-10 in line with the five objectives and corresponding research questions of the study. The study uses the cases partly to illustrate the arguments on shared experiences in the ensuing discussion chapters. It is important to portray the diverse but connected experiences of people diagnosed and living with cancer in Zimbabwe in keeping with how they related and relived their experiences. The stories of this study’s participants are in unadulterated narrative form free of interpretations by me as the researcher, and free from the influence of literature that could turn out to be intrusive. This is in line with the overarching principles of phenomenology, which emphasize studying the lived experience in order to understand a phenomenon (Mapp, 2008).
5.1 CASES
(All the interviews with participants diagnosed with cancer were conducted at their homes, except for Ms. Bee and Mr M.M who were interviewed at the premises of the traditional health practitioner who attended to them and Mr S.M who was interviewed in the central business district at a convenient venue. The interview sessions lasted between 30 minutes to 60 minutes for each session out of three or four sessions, between May 2014 and December 2014)

5.1.0 Case 1
Mrs. P.M. is a fifty-four year old Christian mother of four who served as a soldier and retired in 2005. She lives with her husband in a middle density suburb in Harare and was diagnosed with cancer of the thyroid, stage four, in March 2010. Currently she is on remission (the cancer is dormant, but not gone). Mrs P.M. grew up a healthy person but later became hypertensive and diabetic when her first husband died in 1997. Her illness started as a terrible cough in the 1990s and the army doctors diagnosed asthma. During her visit to South Africa in 2010, her daughter discovered an abnormal growth on her throat. After this discovery, she had a thyroidectomy to remove the ‘goitre’ or tumour. During the removal of the tumour, the doctors found a mass of suspicious grey matter. The body tissues sent for biopsy tests confirmed cancer at stage four. Upon hearing the news, Mrs P.M. had an emotional breakdown. She saw her world ending. The news of her cancer diagnosis devastated her family. Many people who came to visit her were negative about the hospital treatment she was receiving. She had to be positive and that helped her to fight on. After some time, she picked herself up and was ready to fight the cancer. Mrs P.M. went on to research into thyroid cancer with the support of her family and her oncologist.

The radioactive iodine therapy Mrs. P.M. received, as the main treatment was overwhelming and complicated. The drugs were flown from South Africa within a stipulated period. She then began to receive treatment at the Parirenyatwa Nuclear Medicine arena where the thick walls for the radioactive treatment are located. After taking the radioactive pills, Mrs.P.M. routinely went into quarantine for about six days at
the hospital with no one allowed near her. This was because technically she was a ‘moving X-ray’.

She relived her experiences during radioactive iodine therapy in a novel way,

“What used to happen with radioactive iodine was that; she [female oncologist] gave it to me twice a year, like every 6 months. She would put me on a very low salt diet, in fact on a no salt diet for two weeks before the treatment and that was the worst thing because the less salt you take in, everything, your whole body breaks down. It breaks down completely and you become so forgetful, you cannot drive, you can’t do anything. One day, I remember I went shopping with my husband when I was on these low salt things. I was in a supermarket and all of a sudden, my feet just jammed. My husband had to hug me and take me slowly, out. He made me sit and I laughed and he said, “Why are you laughing?” and I said, “you know the way you are holding me and taking me, people are saying, “Oh my God, these people are just in love” they don’t even know I can’t walk you know”.

“Then I would go to Parirenyatwa get admitted, all the admission procedures, get a drip put into my hand because I am diabetic and the oncologist didn’t want to take chances to say nothing happens to you when you are alone. They taught me that once you get the tablet we are out, we do not come and see you. Only the physicians were gonna be coming and measure my radiation level you know. The doctor would come and stand far away by the door to say, “How are you today?” When I had taken the tablet, I really felt nothing. I would swallow it, get water and everyone would practically runaway from the room you know radioactive, radiation is not good for other people so when I took the tablet I would sit and relax and just be detoxifying myself as it comes out”.

I used to remain in the hospital for 5-6 days. The people who used to visit me were not allowed in. It had to be proper isolation. Straight after that, in the evening you can start
reacting with salts. You can just feel the rush of blood like hey its abnormal, you feel nauseous, you feel like vomiting and you go through so much. It is something going through your body which I can’t explain you know, but I had to do my blood pressure readings, my sugar levels and report to the reception and tell them exactly what it is. If someone visits you, they would phone from the reception area. When you go to the toilet you have to flash between 3-4 times and clean your seat and everything. When you bath, you use different towels repeatedly because radiation is coming out. Your nightdresses, you have to wash them, your cutlery does not come out of your room. You wash it, keep it clean then they would phone, “Put your plates by the door” a distance away from your door. You go and take food, you eat, and you wash up. You know, you are just so busy. The first time I was depressed, I cried a lot because you know; I just did not stand the fact of being all alone. Even the Television you know, lucky enough my daughter had bought me a little boom box TV, it just did not take away the loneliness. But you know, the second time a lady visited me and said “You know Pau, when you are going for radiation do you know you got somebody else with you?” I said, “Who?” and she said, “You know, your God. Jesus is with you”. I never became lonely again because I knew my Lord was with me, that fear of being alone in my room was gone because I never liked being alone in a room.

I had a schedule that in the morning I would get up and bath. After my bath, I would dress up; 6 o’clock I would do my prayers, my bible reading, my meditation, my rosary. So by the time I looked up it will already be 10 O’clock, time, for breakfast. After my breakfast, I would take in a bit of TV and sleep. Then lunch time. After my lunch, I read a bit and then TV and it was time for supper. After supper, it is that time again; thanking my Lord for the day and to me those days flew. When I went for my 3rd session, I never suffered from loneliness. The only medicine I had was the radioactive tablet and the anti-nausea tablets.
My medication for diabetes, umm sugar and high blood pressure, your diabetes, and your temperature- you report to the reception.

When I come back home, my husband would have to be out of the bedroom and umm it was just, “Hi, hi, bye” My sister would come in sometimes and speak with me for a few minutes and I would say, “Hey, go now? We were to keep a distance of about 2 meters apart from each other. When you are going to the toilet, you tell people you are going to the toilet and everybody clears the passage, you go to the toilet. When you finish you shank shank, clean, wipe up you know, back to your room because you know the radiation will still be active at home until you save, say up to 15 days”

Mrs. P.M. had to take in many Chinese supplements to aid the radioactive pills and to restore worn out body tissues because of the aggressive therapy. She received many complementary therapies from the Cancer Centre such as Shiatsu, reflexology to help her cope and ease the pain. Mrs P.M. utilised various treatment modalities, both Western and non-Western for curative and complementary purposes. She cannot credit any single mode of treatment as having solely been responsible for her state of remission

The unwavering support of her husband and her sister was critical in reaching the remission state she is in right now. Mrs P.M. has learned that cancer is caused by a multiplicity of factors ranging from the food people eat, their stressful life styles as well as hereditary factors. Her father died of oesophageal cancer. Her child in South Africa had also been diagnosed with cancer, but had had it eliminated at a very early stage. All that explained her hereditary cancer.

For Mrs P.M. her cancer diagnosis was a life-changing occurrence. Below I reproduce her interview with only some minor editing.
“Honestly, it is very interesting. You know cancer changed my life. How? I was a hard woman, carefree you know, someone who enjoyed life with my kids and family but you know I never looked at life from a positive side you know, even a Christian side. I was what you call a churchgoer. Sometimes the reading would touch you, sometimes nothing you know, so long as I am in church. Now with cancer, I am looking at life from a different perspective. To me cancer was a calling, a born-again experience. If you listen to the Pentecostal churches, saying you are born again, born again and I have always refused. However, with cancer I have agreed because here is illness you think is gonna take you and then the Lord gives you life. Even now, sometimes when I go to funerals, you find I cry so much because I’m thinking so much, “Why did that person have to die? Lord, what went wrong...?” I have always had my thought that people should be helped. You know even a diabetic, you know when a diabetic person dies, sometimes it is a simple thing, the sugar levels went down nobody knew you know. I love being with people now. I used to love being alone-you know, as a soldier, but now I just love to be with people and umm, positivity, I love positivity. Wherever I go I talk positivity because I know that with cancer if you tell yourself I am going to die, you are dead. But if you are positive ..., “that you not gonna die of cancer” you never die.

So you know, cancer has really changed my whole life completely. It brought me close to family, very close to family. I am someone who never used to cry between issues, but now I get so touched, that’s my biggest problem. I now get so touched even with little things whereas I’ve to tell myself, “But you are the mother of the family, all these problems and issues have got to come to you, you have got to solve them: But it has made me so soft. Long time ago whenever I received a call from my child that she had been bullied, I would be ready to go fight. Right now I can ask my child what happened. I tell her that you were wrong; you should not have done that. Even like in marriage, it has brought my husband
and me so close, very close because I am sure he also got to a stage where he said that, “What if my partner dies?” Then I got to a stage where I was a bit selfish. I once got to a stage where I said now I want a divorce. “Why would you want to divorce me? “I don’t want you to be a widower.” It is better you go and I stay away while I die. But he stood the test of time and said, “Never, I will be with you. You not dying, you will live” and it helped me so much”.

5.1.1 Case 2

Mr. M.M. is a thirty-eight year old married man diagnosed with cancer of the leg in 2010 at Parirenyatwa Hospital, having started to feel the pain in the year 2006. He went up to form two and trained for a course in building, his profession to date. He has five children and goes to an Apostolic Church.

He recalled vividly that one night while lying in bed, he suddenly felt piercing pain on his right foot. He could not help but scream as he fell off the bed. The following morning, he could not walk properly on the swollen foot. He went to a local clinic where he received pills to stop the pain. The assumption was that he had an abscess or mota that would soon be ready for treatment. It was not long before the spot turned blackish and many people in the community urged him to consult traditional Shona healing practices or chivanhu. In the same year, in 2007, a traditional health practitioner (herbalist) drained a lot of pus or hurwa from his foot because at the hospital they were only going to attend to him when the inflamed leg had subsided.

A friend advised him that his sickness resembled cancer and he was diagnosed with cancer in 2010, after a biopsy. He enrolled for chemotherapy at the Parirenyatwa Radiotherapy Centre. He recalled the excruciating pain he felt whenever they injected him with chemotherapy drugs. In the aftermath of the chemotherapy, he was usually bed-ridden with
pain for one and a half weeks. Owing to lack of finances, he would skip some of the chemotherapy sessions, as some of the drugs for his prescribed injections were very expensive.

He went on to meet Sekuru N.C, a faith healer and herbalist at his younger brother’s residence where he spent most of the time in bed with excruciating pain. In the end, he had to discontinue chemotherapy, as his body could no longer sustain the remaining two sessions. He was ‘admitted’ by the faith healer/herbalist for three months and registered great recovery as he could now walk and resume his construction trade.

At one point, some of his relatives began to think it would be expedient if they reserved some money for his possible death. Throughout this trying time, his wife remained a pillar of strength and support. His legs had turned blackish and were oozing a watery substance.

At the time of the interview, he had experienced great improvement, unlike earlier on when his legs were overly swollen. In his words, *makumbo angu anga atova maturi chaiwo* (my legs had become so swollen that they resembled a traditional mortar).

During the peak of the illness, he could no longer fit into a pair of trousers and had to be dressed in open clothing. He had to be carried to the rest rooms and had to be bathed by his wife. He said he wished God to take his soul.

Mr. M.M. had not been told the stage of the cancer at the time of diagnosis but he presumed it to have reached an advanced stage, given that his prescription comprised more than two different drugs whose total effect was only a bit of short-lived relief before the pain returned. At the time of the interview, he had not stopped to get X-rays and scans once every year, to ascertain if the cancer had not spread. He is somehow content with the reality that he is now able to resume work as a builder and has energy in his body unlike at the peak of the illness.
Asked what he attributed his cancer illness to, Mr. M.M. had this to say,

“I ni gomarara rangu ndichiritsanangura ndinoona zviri zve ropa nekuti baba vangu vakafa ne gomarara”

(I attribute my cancer to heredity because my father succumbed to cancer).

He went on to note that an uncle of his diagnosed with cancer of the leg, while his mother succumbed to cancer of the breast. In general, he also attributed cancer to the super-refined foods so popular in many homes these days.

On the question of the pathways that he followed in seeking help, Mr. M.M. went on a spree-consulting prophets and faith healers. One traditional healer pierced his legs until blood oozed and then applied a poisonous substance, rogor (a rat poison) and lemon on his sores, the assumption being that the rogor would kill the internalised gangrene. A spirit-type church prophet who assisted him to neutralise the poison then attended him. Another traditional healer used a razor to cut his feet and administer medicines via the incisions, a practice known among the Shona as kutemera nyora, to no avail. Basing on his experience so far, he notes that the cancer illness requires a lot of patience, whether one is receiving hospital treatment or traditional Shona healing.

Relating his stigma experiences, Mr. M.M. noted that friends and relatives shunned him and his colleagues at work were no longer comfortable in sharing a bathroom with him. At one point, some of his relatives accused him of practising witchcraft or kuromba as they wondered why his illness was incurable and not subsiding despite treatment. At one point, before the cancer illness, Mr M.M. was a well-up person with various assets and properties, most of which he sold to meet the growing bills of treatment costs. Some of his relatives then alleged some avenging spirits had consumed his ‘ill-gotten’ fortune. In a
case of self-stigma, at one point, he ‘freed’ his wife to move out and consider remarrying, as his situation became hopeless. His children accepted his condition, though they were traumatised.

Asked what government can do to ameliorate the negative impacts of cancer, he weighed in on the need to make accommodation available during treatment as people with cancer who stay with relatives face profound stigma. Consequently, some people with cancer may not recover due to stress. He urged the government to consider issuing travel warrant documents, to enable those out of the city to meet treatment costs minus transport costs. For people with advanced disease and those too incapacitated to fend for themselves, food handouts would go a long way in providing relief. Commenting on Traditional Health Practitioners (THPs) attending to people with cancer, Mr. M.M. noted that government needed to support THPs with a proven record of accomplishment of assisting people with cancer, so that they can get the ancillary resources they need to treat and care for clients. Such resources could include food handouts to bed- ridden clients. Sekuru N.C. who attended to Mr. M.M. and saw him to recovery credited the hand of God.

5.1.2 Case 3

Ms. M.V. is a 66-year-old Christian woman and a former primary school teacher diagnosed with cancer of the breast in the year 1993. She retired from teaching on medical grounds in the year 1994. She never had children and her husband had passed on from cancer of the pancreas in the year 2005. She relived her husband’s sickness as follows: it was as if you were seeing someone drowning and you cannot swim and you cannot rescue. Her journey with cancer commenced in April 1993, when she felt a lump in her right breast, which in her words was as big and hard as an unripe mango. She felt the pain at night and was gripped with fear instilled by the general talk in her community that with
cancer was a death sentence. A cousin of hers was diagnosed with cancer of the cervix and died at the age of 40. Her elder sister was diagnosed with cancer of the breast in 1987 (at the time of the interview the elder sister reported a recurrence on her other breast after 27 years and was admitted at a major government Hospital). Ms. M.V. reported to her General Practitioner who took her for mammogram tests and was then referred to a specialist surgeon. The surgeon removed the bigger lump on the right breast, which turned out to be cancerous, and the smaller lump on the left, which was not cancerous. She went for a second surgery after her oncologist had recommended the removal of more flesh as the cancer had affected the surrounding body parts. The radiotherapy treatment she received for 25 days signalled the start of the enormous health challenges she experiences to today because of her breast-conserving surgery when she started on radiation therapy. Her doctor explained to her that she was feeling a lot of pain because of the bad sores on flesh surrounding the breast whilst with others it was mainly bone and skin. The sisters at Island Hospice encouraged her to request to be put on morphine but the surgeon was adamant arguing that morphine was addictive and had side effects. It took the head oncologist, Mr. H.O. to convince Mr S.B. (the surgeon) to put her on morphine. Mr M.M. taught them about cancer and one of his most important points was about being able to manage pain.

Ten months down the line Ms. M.V had a recurrence with the cancer spreading to her lymphatic glands. The surgeon, Mr.H.O. had conducted breast-conserving surgery because she “wanted to save her breast”. Recalling the excruciating pain she went through during radiotherapy, Ms. M.V. was hesitant to be referred back to the surgeon. In the interim, the oncologist went on to put Ms. M.V. on antibiotics for two weeks. During the two weeks a close friend came to advise Ms. M.V., of a new church leader who was performing healing miracles. When she finally attended the church service, Ms. M.V. recalled that during a
prayer session a painful laser flash of lightning had hit her. Surprisingly, thereafter, her pain subsided and when she returned for a mastectomy for the recurrent cancer in the lymphatic glands, the surgeon was greatly surprised and wondered what had really transpired with Ms. M.V. because he could not feel the lump anymore; neither could he detect the tumour on the mammogram. Ms. M.V. was so happy that she told any interested listener about her healing. The doctor then noted that the tumour was evident on the mammogram machine but he could not feel it by hand and suddenly, Ms M.V was so angry with God and wished to die. She grudgingly accepted to be sent back to Mr S.B for a mastectomy and was admitted for 17 days at a private hospital. The nurses measured the amount of fluids Ms. M.V. was discharging from the wound every day and she spent 17 days in the hospital without catching any glimpse of the outside. In addition, Ms. M.V. was put on anti-hormone therapy based on tamoxefin, to starve breast cancer cells for 5 years. She, however, noted that the anti-hormones do not waste away such that even to today she feels the side effects. Sometimes when she felt pain she would shiver and feel cold, but on other days, she would feel hot. At some points in time, she would be warming herself at the heater and on other occasions; she would be cooling herself with a fan. Thus, during treatment, she reported an incident when she had experienced a blackout on her way to the hospital. A nurse accusingly shouted at her, asking why she was walking unaccompanied and one of the nurses inquired about her mother. She wept hysterically, thinking about her sick mother whom, because of dementia, was losing her memory and was erroneously now referring her daughter, Ms. M.V. as her sister. She received massage therapy at the Cancer Centre. She received reflexology, relaxation and many other complementary therapies. The picture of ailing people with advanced cancer, the picture of some clients dying while on the floor at the Radiotherapy Centre and the picture of ailing people at the Cancer Centre was an unpleasant experience for her.
Relating her experiences of pain caused by the cancer illness, Ms. M.V. observed that it was difficult to put it down in words. It was agonizing. All she could say was that, what she used to do on her own, she could no longer do and she was even struggling just to get up. If she did not take her medication on time, the pain would ‘remind her’, and spill out of control. She became confused with pain, in a case of traumatic stress disorder. To Ms. M.V., the traumatic stress disorder does not have any prescription so the concerned individual had to be positive.

As some of the side effects of the drugs, she related how she had now become weak and frail and that, therefore, she was no longer able to perform her household chores with the same vigour and energy as of old. She now takes several hours to make a meal. Three years ago, she contemplated moving into an institutionalised home where the sick and elderly are accommodated until death. She feels her body energies dissipating every day.

Ms M.V. has learned over the years that some of the pain we feel is because of a certain deficiency of certain vitamins or supplements in the food we take. Asked what she attributed the absence of cancer recurrence in the past 2 decades, she gave all credit to the grace of God. She also firmly believes that it is not disease, which causes death but time, the time of God. To her, pain is what requires management as it results in unwanted discomfort and human suffering.

In terms of available social support, Ms. M.V. has never had a child of her own in her whole life. There was no relative to accompany her to the radiotherapy centre. Her solitary life causes her stress. However, she has since accepted the reality with newfound friends at the church and in the neighbourhood. Mrs. M.V. implored government to consider providing accommodation, financial support and rehabilitation services to people with cancer and in need of such assistance.
5.1.3 Case 4

Mr. S.M. is a 32-year-old single unmarried man who is a holder of a Diploma in photography with a local polytechnic college. He resides in the town of Marondera approximately 70 kilometres from Harare, the country’s capital city. He was diagnosed with cancer of the colon in June 2011, and now lives with a permanent stoma. It all started when he felt sharp pain in the abdomen and backache, and often passed stool with bloodstains. While growing up he experienced a problem of piles (haemorrhoids) which eventually disappeared. In the years 2005 to 2007, the problem of passing stools with bloodstains persisted, but he thought it less serious than previously. Whenever he felt stomach pain, he took home-made remedies like ginger or tsangamidzi and pills from a local clinic.

The year 2011 in the middle of the month of June signalled the start of a big health challenge. One Monday, the pain became unbearable and he struggled to defecate. At the same time he began to vomit a substance stained with blood. He was subsequently, hospitalized for a week at a local hospital. At the hospital, the medical officers gave several prognoses on his condition, with some talking of gastrointestinal obstruction. Seeing no change in his condition family members pressed to have him referred to a General Hospital. In consequence, a 27-centimetre long perforated colon was removed, with the lymph nodes testing cancerous after a biopsy.

Mr. S.M. only attended one session of chemotherapy. He then got advice from some clients who had a similar condition and shifted to herbal medicine. He used to get herbs sent to him from the rural areas and another consignment of herbs from a friend’s brother working for the Red Cross in Pakistan. The herbs served the role of cleaning the system,
detoxification and alleviating pain. Probed further on why he disengaged from chemotherapy, he had this to say,

“The side effects were profound and another pressing issue was lack of finances to purchase the required drugs as the letter from Social Welfare could not enable me to procure all drugs. It was also in the midst of a biting economic crisis and my unemployed parents were not in a position to assist. I had to go for readily-available options”.

Mr S.M. mixed water with unspecified herbal concoctions brought for him from the rural areas. Since 2011, he had also been using Aloe Vera or gavakava, which he has since planted, in his garden. He either crushed the aloe vera, and mixed it with water to take as a drink or cut it into pieces taking it as a tablet. From the Ileostomy and Colostomy Trust (ILCO) he gets a month’s supply of colostomy bags upon payment of a nominal fee of 10 United State Dollars.

Mr. S.M. managed to put together a write-up, which chronicled his life with the cancer illness. I reproduce the write-up below (with minimum grammar editing),

“I would say my life has changed a great deal ever since I discovered that I had colon cancer. First and foremost the fact that I live with a condition known as Ostomy, I could not accept the new life, since the condition meant that I had to depend on colostomy appliance bags which I wear at all times. This condition has affected me emotionally such that whenever I am running out of the bags I get stressed which sometimes leads me to take in alcohol.

The other thing is that I am no longer comfortable being around strangers, because my stomach can produce some embarrassing sounds and in the end I will have to explain my condition to people. In the end, I get mixed reactions. At times people tend to be
judgmental which leaves me with a deep feeling of rejection and self-blame. It is now hard for me to start a relationship because I will have to explain to every prospective girlfriend about my condition. From experience, with most women that I have met before, everything changes the moment that they start knowing my condition, which depresses me.

In as far as my family is concerned, they have learnt to accept me. They help me sometimes by paying towards the cost of any medical requirement that I might want and when they cannot, I get help from well-wishers. My friend assists me with 10.00 USD, which I require every month to get access to the bags from a non-governmental organisation. My support group friends help me with moral support and emotional support; they always encourage me to keep it real since there is more life than just spending time regretting and wishing if things were different.

This illness has really altered my self-image because I am constantly being reminded of the pain and suffering that I went through before and after the operation, the sores and stoma are a constant reminder. My lifestyle has had to go through change. I had to change the food that I used to eat. I no longer take gas-forming foods. I now depend on light meals, which may be expensive, but I am managing through God’s grace.

In terms of stigma experiences, I had some incidences whereby you overhear people talking about my condition behind my back, saying a lot of hurtful stuff about how I got ill and how I got in this situation. For example, some blamed it on excessive alcohol I used to take. Before, it really used to affect me a lot such that I would spend days depressed and in isolation, but thanks to support group meetings that I attended. I have now learnt how to deal with stigma and rejection and how to let go.

As far as my future is concerned, I have made a vow to myself that I will fight this disease to the end. I will not lose hope that easily because I believe there is light at the end of the
tunnel. In addition, people in my situation should have faith and be emotionally strong since it really plays a big part in getting healing from the disease.

As for the quality of service at the hospitals, I really feel that there are many issues that need to be addressed, especially with reference to people who will be seeking treatment. Firstly, I wish government would improve the quality of service for cancer patients in public health institutions. Many cannot afford to get treatment at private hospitals, which are better equipped. In public hospitals, the same people who are supposed to be assisting you sometimes mock us.

Cheaper and affordable cancer treatment medicines are not readily available and if available, it costs an arm and a leg. Unfortunately, most cancer patients cannot afford to pay for the treatment and most of them simply go back home and die a slow painful death. I really feel that the government should introduce a system whereby the cancer patients will end up receiving monthly doses of cancer treatment drugs just like people living with HIV are benefitting.

My unforgettable memory is having to wake up in the intensive care unit hospital with a very sore tummy from stitches of the operation and then later on realising that I was never going to use the toilet the normal way. I would say that was one of my saddest moments in my whole life. And the painful injections that I had before and after the operation, I would never forget that stinging pain on my hands. It was so unbearable that sometimes I have nightmares”.

5.1.4 Case 5

Ms. J.M. is a 56-year-old widowed Christian woman who lives in the rural area of Chipinge in Zimbabwe. Her husband died in 1994. She was diagnosed with cancer of the cervix on 28 December 2013. Before the cancer illness, she used to earn a living from 115
market gardening and horticulture projects funded by non-governmental organisations in the area.

Relating her early life, she explained that her family was poor and her father was in a polygamous marriage. In terms of family health history, many in her family were infected with HIV and died of AIDS. Two of her female siblings died of bleeding in the uterus and when they presented at the hospital it was too late. She recalls now, that it could have been cervical cancer but no one knew then. In as far as her personal health history is concerned she enjoyed good health from a tender age up to when she got married. In 1994, she started experiencing leg pain when she gave birth to her last child.

The onset of symptoms all started as she was coming from the fields and found herself, all of a sudden, struggling to walk to reach her home. When she got home, she saw blood in her under garments and saw that she was bleeding. She went to a local clinic where she was referred to a major hospital and then to a General Hospital. At the hospital, she was asked to fork out 600 United States Dollars (USD) in order to receive treatment.

She was compelled to try South Africa in the hope that she could get affordable treatment. At the time she left for South Africa, the doctor had not informed her of her cancer diagnosis. She spent seven months in South Africa and her bleeding persisted. To her the issue was simple; “South Africans hate foreigners”. The medical staff there kept changing the dates for her surgical operation.

When she came back to Zimbabwe, she presented at the Parirenyatwa Radiotherapy Centre where she was officially told that she had advanced cancer of the cervix. She was not told the stage of her cancer though she had expected to be given a full briefing. Ms. J.M. accepted her fate without sadness or anxiety as she had suffered for long. Her children were disturbed by results of the diagnosis.
When she started to undergo radiotherapy, she went for 10 days without passing stool even though she was taking food. During radiotherapy, they were discouraged from bathing the ‘marked area’ (female genitalia). As a woman, it was a difficult decision to people who are used to such personal hygiene. At one point, she defied the directive not to apply water to the marked area and she developed painful blisters. At the time of the interview, she kept worrying about the state of affairs at her rural home as the roof of her hut had collapsed. It also appeared that she was going to miss land cultivation for the incoming agricultural season.

Her major challenge was money for bus fares and for purchasing drugs. However, treatment seemed to give her hope of recovery though she always worried about recurrence. In the end, I learnt of Ms. J.M.’s death on 13 August 2015 and I must say I was depressed.

5.1.5 Case 6

Mr. F.M. is a 69-year-old married man diagnosed with advanced cancer of the prostate in the year 2010. At the onset of symptoms, Mr. F.M. was experiencing pain and great difficulty in passing urine. He presented at a local clinic, which referred him to the mission hospital of Karanda. Doctors at Karanda inserted Paul’s tubing to enable him to pass urine. A biopsy confirmed advanced cancer. Initially the wife suspected HIV and AIDS but that was nullified by medical tests.

With advanced cancer, Mr. F.M. would vomit blood. Medical doctors could not do much since he declined surgical removal of his testicles citing cultural reasons. During that time, water was a challenge at Parirenyatwa hospital and his children had to purchase water for cleaning cloths. He failed to raise the USD300 required to procure drugs, which could stop the bleeding. During that time, Mr. F.M. could no longer get up and so his wife advised
their children to procure pampers for stool collection. At the hospice, the wife was assisted with more pampers. The Island Hospice assisted with pain-stopping drugs like morphine and also did home visits to see him.

At one point, the elder sister to Mr. F.M. enlisted the services of a traditional healer. Medicines from traditional healers were used concurrently with hospital drugs and *Tiens* products to no avail. Mr. F.M. would insist on a traditional herbal root *tsangamidzi* or ginger herb touted for helping to heal various ailments.

Throughout my second home interview session, Mr F.M. kept on calling his wife while giving her contradictory instructions. Sometimes he would request a blanket or have it removed. Relating her experiences with the illness of her husband, the wife noted that she had come to accept his illness and condition. Regarding her husband’s illness and experiences during the night, she had this to say,


(Like these days during bedtime, he [Mr F.M] beats me out of anger. He sometimes digs into my skin with his fingernails. The pain can be very bad and sometimes I get really annoyed and move over to the sofa, only later to feel compassion and return in case he may not be covered with blankets. I am now used to it and my children empathize with me).
Asked about the day-to-day pain experiences of Mr. F.M., her husband, she had this to say.

“At this stage of the illness, my husband feels pain all over and he is starting to lose his sanity because his virility is gone, something which prompts bad temper in him. Do you understand, my child? However, as his wife I accepted it because Dr. Stevenson warned me in advance that that might happen. He said this was one of the things that could happen).

The main challenge according to the wife is loss of eyesight, which has complicated the illness. The wife wished there was money to purchase a wheelchair so that she could take him outside to feel a fresh breath of air.

In terms of bodily changes, the wife to Mr F.M had this to say,

“I am watching my husband losing more and more weight by the day. However, his voice has not changed. What is changing is his physical stature because of the sickness).

Mr F.M. passed on in October 2014 and I attended the funeral.
5.1.6 Case 7

Mr C.M is a 64-year-old married man with six children and lives in a high-density suburb in Harare. He was diagnosed with advanced cancer of the prostate in mid-2012. In terms of family health history, his father was diagnosed with appendicitis and the same condition was to be found in four more family members. The wife who was present during the interviews noted that she accepted her husband’s illness as a plan from God because anyone can be diagnosed with cancer.

It had all started while he was working in the fields in his rural home when he collapsed with excruciating back pain. He received surgery in July 2012 at Harare Hospital and the doctor noted that his cancer was very much at an advanced stage. His prostate gland and testicles were removed in a surgical operation. Part of his back borne had been eaten away.

At the time of the interview, he was receiving palliative care from Island Hospice. He did not receive any further treatment like radiotherapy or chemotherapy. He went for reviews at the hospital whenever he experienced great pain.

It was his wife and his younger brother who came to know first of his cancer diagnosis. At one point, relatives disputed the diagnosis of cancer and the elder sister to Mr. C.M. called in a female traditional healer who gave a different diagnosis and treatment which relieved pain for just a week. The wife and children, however, stuck with the advice of the medical doctors.

The wife related the agonising pain that her husband sometimes experienced and which worried the whole family, leaving everyone at a loss as to what could be done. He experienced great pain, which filtered through the whole leg, and at the peak of the pain, he could neither walk nor stand on his own. He would resort to crying. He experienced
insomnia oftentimes and that despite taking two tablets of morphine every 4 hours. Commenting on his general quality of life, Mr. C.M. had this to say,

“Saka kurwadziwa ndiko kwandava kurarama nako saka nekurwadziwa chaungatarisire ndechipi? Nokuti wapama tablets zvekuti after every 2-3 days warwadziwa pamwe washaya mishonga ungatarisire kuti uri kugara zvakanaka?

(Pain is what now defines my life. With this kind of pain, how can anyone possibly be hopeful about anything? I am now so dependent on these tablets that I often find difficult to last every 2 to 3 days without pain. At times, I can’t get any at all. With that, can I talk of a quality life?).

Asked about how he sees the future he had this to say,

“Tinoona ranhasi nokuti kuti titaure nezveramangwa tinenge tiri kunyepa. Tinongotenda hapenyu hwanhasi chete.

(We go through each day when it comes. When we talk about tomorrow we fool ourselves. We can only live a day at a time. Tomorrow may never come).

The wife bemoaned the situation that due to ill health; Mr. C.M. was no longer in a position to fend for his family and his many dependants. The wife was very appreciative of the family especially the children who gave material and emotional support. I learnt of Mr. C.M.’s death in December 2014 and I visited his wife to express my condolences.

5.1.7 Case 8

Ms. M.S.G. is a 42-year-old divorced woman diagnosed with stage 2B cancer of the cervix. In terms of personal health history, Ms. M.S.G was diagnosed with TB when she was five years old. In terms of her family health history, tuberculosis was the common disease among her family members. Notably, her grandmother died of cancer of the cervix. 121
Back then, the grandmother would jokingly tell Ms. M.S.G. and fellow young female family members *kuti nhazi ndageza kunge musikana* (today I have had my menstrual period just like a girl). When she finally visited the hospital she was told that she was too old to be surgically operated. With such a background at the back of her mind, Ms M.S.G. was swift to visit a doctor when she started bleeding.

At the onset of symptoms, she experienced bleeding which she initially thought to be an ordinary menstrual cycle. One day in October 2013, when the bleeding intensified she found it necessary to seek medical help. She went to a local clinic where the medical staff said they suspected hormonal imbalance. She was given some tablets but the situation did not get any better. Her estranged husband advised her to seek further medical advice. The cancer diagnosis caused her a lot of emotional distress. She delayed by a whole month, as she was afraid of radiotherapy.

She did not disclose to her mother because she was afraid that she could suffer a heart attack. At her workplace, she just mentioned that she had a problem of bleeding without elaborating. Ms. M.S.G. did not disclose her diagnosis to her two boys because she feared the news could disturb them in their examination year. She never faced any form of discrimination or even heard of others’ experiences. She highlighted that most people were ignorant about cancer regardless of the awareness campaigns on radio programmes. She noted that many women in the communities experience the problem of bleeding but may not know its root causes and many continue to get basic treatment in anticipation that the problem will end. Some women think that it is caused by the contraceptive injection-*Depo-Provera.* She has since been advising her friends with the problem of bleeding to go for further medical examinations.
Asked what she attributes her cancer to, she professed ignorance, noting that she may give a personal view unique to her. She however, went on to note that, at one point she learnt from a radio programme that sexual intercourse and childbirth increase a woman’s chances of getting cancer. She was done a caesarean assisted birth when she gave birth to her first child. The stitched area was where the tumour developed.

By the time of the interview Ms. M.S.G. had not used any non-hospital treatment mainly because she was yet to get any advice to that effect. However, she believed that *chivanhu* (traditional Shona healing practices) does not help as most of the people diagnosed with cancer ultimately come to the hospital.

Asked what challenges she was experienced so far due to the cancer illness, Ms. M.S.G. noted that there are many costs involved. The transition from the use of a Zimbabwean currency to a multi-currency regime rendered her old medical insurance cover problematic with some service providers.

The major change to her body due to the illness was weight loss. Ms. M.S.G. had to suspend her monthly contributions to a low-income housing scheme in order to meet the costs of her medical treatment.

### 5.1.8 Case 9

Mrs. R.G. is a 46-year-old married woman diagnosed with cancer of the breast. She suspects that her cancer may be genetic since her maternal grandmother’s sister died of cancer of the breast. One night, when coming from night school, she was wearing a white dress top and some fellow male students advised her that there was some blood on her top. Her white employer advised her to immediately call and book to go and see a doctor. A friend accompanied her for the biopsy and the results came out after two weeks confirming stage one cancer or *ductal carcinoma* on the nipple.
When the doctor confirmed the biopsy results of cancer, she went down and cried uncontrollably and she hated the doctor. She saw her eventual death coming. The very same day, the doctor referred her to a cancer service organisation the Cancer Centre. She was given an elderly counsellor and from the entire counselling session, nothing sank into her mind during that moment. In her mind, it was easy for the counsellor to say whatever she deemed fit because she was not in the same situation.

She disclosed her condition to her husband whose sister happened to have succumbed to cancer of the breast. Her husband and daughter encouraged her to get hospital treatment. When she disclosed to her father, he pleaded with her not to have a mastectomy as he had heard about, “many people who have died at the hands of doctors when they had their breasts removed”. She had to go it alone without advising her father when she went for a mastectomy. At the Cancer Centre, they gave her demonstrations including watching video clips, which helped dispel her fears. When she returned home in preparation to go to the theatre, she sought to make all necessary plans with her family, lest she dies.

A drug called tamoxifen was prescribed for her and she took it every day for 5 years (2007-2012). She now goes to review clinics, for tests and scans, chest X rays, blood tests and liver function tests (secondary recurrence of breast cancer can go to the liver). For her surviving breast, she undergoes mammograms in case it gets affected as well. By the time of the interview, she had just done all the tests on the 31st of July 2014.

Her cancer diagnosis and mastectomy has changed her life. She has started to love herself. She no longer holds grudges and now seeks peace with all people.

5.1.9 Case 10

Ms. Bee is a young divorced woman aged twenty-three with a six-year-old male child. She is HIV positive (these details were shared by the ‘nurse’ to the herbalist whom she
disclosed her status to). Her biological mother died while she was still young and her father went on to marry another woman. She was married at the age of seventeen. Ms. Bee was healthy, until she developed blisters on her private parts (vulva) in 2009.

Ms. Bee was diagnosed cancer of the vulva in the year 2014. In 2009, she developed a wart or *mhopo* on her private parts and the warts went on to multiply. The warts then developed into wounds in the year 2014. Initially she thought the vaginal warts would disappear but when the symptoms multiplied, she had to seek medical help at the hospital. However, the treatment she received made no significant positive impact on her health.

She started to attend the hospital in 2011. The doctors at the hospital did not indicate the exact name of the disease even though they were giving her treatment. She also thought she was infected with a sexually transmitted infection. She however, was diagnosed with cancer of the vulva in March 2014 at the Parirenyatwa Radiotherapy Centre.

In terms of treatment, she received liquid medicine to spread on the warts and received injections as well, whereupon the warts would temporarily heal before resurging. In the year 2014, family friends advised her father about Sekuru N.C., a herbalist who could assist her.

After receiving treatment from Sekuru N.C., Ms. Bee has recovered in a profound way. She no longer produces odour and she no longer has the excruciating pain she used to suffer before. The warts have disappeared though they tend to resurface whenever she stops taking the traditional herbal medicine. At one point, her father took her to a traditional healer where she stayed for a month and her condition deteriorated. In the end, the traditional healer ended up proposing marriage to her, regardless of her ill health and she had to run away.
Ms. Bee reported stigma experiences connected to her illness. Because of the strong stench she used to produce, many relatives and friends isolated her. Her stepmother would instruct her to remain in her room until visitors had left. At the personal level, it was difficult to accept the bad smell that emanated from her warts and it affected her mood. She experienced a lot of discomfort when aboard public transportation vehicles. This was due to the odour that emanated from her person. On one occasion, her own father questioned if she was truly his daughter. At the peak of the illness, her father wished her to die since he had other children. She said,

“...to suffer from cancer is a very serious challenge. You lose friends and very few people accept you. Even your relatives think you are now a burden. For example, last week my daddy told me to go and work because the bill from Sekuru N.C. was now very high”

Ms. Bee reported an incident, during the peak of her illness, whereupon her father invited relatives to come and attend to her impending death and another incident when he invited relatives back after phenomenal recovery. Then, Ms. Bee wished it were better for her to die.

After recovery, Ms. Bee got into a relationship but the boyfriend disappeared after she disclosed her health condition. The incident affected her emotionally and she vowed to remain single. Additional narration on Ms. Bee’s story came from Sekuru N.C. and his ‘nurse’ who attended to her and witnessed her recovery. The ‘nurse’ indicated that when Ms. Bee arrived, her illness was serious and strange. One woman, who saw Bee’s condition, commented that the severity of her illness was fit for an adult person not a young person of her age. Her stomach was swollen and she could not pass stool.
Sekuru N.C. highlighted that the challenge facing clients like Ms. Bee was stigma and discrimination emanating from the families. Her father and other relatives at one point labelled her a prostitute given the site of her cancer. She was now unable to care for her child, something that had a potential to cause her mental distress and in some cases generate suicidal tendencies.

5.3 Conclusion

This chapter presented ten elaborate stories out of the recollections of the thirty core participants of this thesis study. The stories comprising four males and six females were meant to be representative of the major experiences of the two genders, ages, geophysical location, various cancer sites and time lapses since diagnosis. The issues highlighted were presented cross-cuttingly in order to address the research questions of the study. Story telling is one of the ways in which participants organise their understanding of their experiences and the world (Moen, 2006). In essence, these thick descriptions logically developed by the researcher constituted a certain level of analysis. The stories gave direct access to the voices of participants, undiluted by literature and my interpretations as the researcher, thereby illuminating the essences of beings in line with Heidegger’s Dasein or the study of being-in-the-world. The stories together with the data from other participants are enlisted in the subsequent discussion chapters to decorate and illustrate arguments. On reflecting upon the stories, I find perspicacity in Moen’s (2006:4) submission that “as individuals are telling their stories, they are not isolated and independent of the context”. I concur with Moen (2006:8) that “the life is told by the person who lived and experienced it, and it is then retold when the story teller and researcher collaborate to produce an inter-subjective understanding of the narrative”. Thus, this chapter constitutes robust and insightful empirical evidence of living with a cancer in Zimbabwe as in the selected cases of this study.
6. CHAPTER 6: INDIGENOUS KNOWLEDGE AND NARRATIVES ON CANCER CAUSATION BY PEOPLE DIAGNOSED WITH CANCER AND KEY INFORMANTS

6.0 Introduction
One of the major contributions of this phenomenological study on cancer is to share the indigenous understanding of cancer (given cursory attention in clinical and quantitative studies). The questions addressed in this chapter are; What are the indigenous [local] perceptions, beliefs, cultural interpretations and assignments of the cancer illness in Zimbabwe? How do people living with cancer account for their cancer illness? How do people living with cancer account for the general rise in the cancer illness in Zimbabwe?

In this chapter, I present and analyse thematised data, drawn from the thirty research participants diagnosed with cancer, from key informants, from group interview participants and from family carers. The evidence which may expectedly be at variance with ‘scientific’ or ‘expert’ knowledge on cancer is instructive to nursing practice, to awareness and educational programming as well as research and policy making (Panjari, Davis, Fradkin et al, 2011; Dumalaon-Canaria, Hutchinson, Prichard et al, 2014).

In the interviews, participants with cancer were asked what they specifically attributed their cancer to. In order to elicit generalised shared realities, the participants were asked to what they attribute the rise in cancer incidences in the country. These narratives are analysed in a non-judgmental way, capturing the novel insights in their contextuality and situatedness rather than to derive some ‘gabled version of responses’ which distort the valid meanings and interpretations. Thus, even though the causal narratives are categorised under specific themes, it was crucial to present the actual narratives of participants, which may point to multi-causal factors, a departure from conventional medical research, which is engrossed in aggregating factors. It is pertinent to acknowledge the situatedness of
participants in the broader economic political, socio-cultural and religious context as well as the personal circumstances, which shape their realities. Throughout the discussions, the researcher is well aware of the idea that personal narratives are influenced by the cultural convention of telling, by the audience and by the context, following Bruner (1984) cited in Moen (2006); and that a story is retold when the storyteller and the researcher collaborate to produce an inter-subjective understanding of the narrative (Moen, 2006).

6.1 Indigenous Knowledge and Cultural Interpretations on the origins and causes of cancer

The thesis argument envisions the extraction of marginalised data and the lived realities of the research participants, for attaining a holistic understanding of the phenomenon under study. In a context where traditional health practitioners (THPs) are widely consulted by people diagnosed with cancer and their families and given that THPs come to play the role of cultural curators or are viewed as such, it is vital to understand their narratives which filter into the world views of many. THPs shared cultural insights on the cancer illness in the country and these derive from indigenous philosophies of health and illness. One traditional herbalist summed up a seminal view shared in a group interview with six THPs, who attend to people diagnosed with cancer,

(We, in traditional Shona ethnology, believe cancer is a disease, which emanates from the earth. We do not express it as they do in Western traditions, where they single out a [definite] cause of cancer. We say it originates from the earth. What it means is that, we believe in the role played by our ancestral spirits whom we believe reside inside the earth. Hence, when we err or wrong them, we can receive cancer as a punishment or curse).

From the above narrative, it is noteworthy that there is no tangible or definitive factor that is taken to cause cancer. The attribution is a metaphysical one, which fits into Kleinman’s (1988) explanatory models of disease. The above statement espouses a classic cultural belief on disease causation, among autochthonous people, especially the Shona, rooted in the belief on the role of the dead and ancestors in the spiritual realm, (Bourdillon, 1990; Chavunduka, 1986, 1994; Mararik, 2011; Gelfand, 1962, 1959; Crawford, 1963). The narratives suffice as a symbolic explanation of a mysterious illness that is too complicated to understand and treat as well. The statement can also be viewed as a tacit admission by THPs that they do not possess the diagnostic means of detecting and staging cancer as in biopsy and pathology. Nonetheless, experiential knowledge of symptomatic elements can be utilised in ‘traditional’ cancer diagnosis. In addition, the implied meaning in the above-mentioned view is that cancer is a natural illness, and is not caused by other people or some vector. Sekuru Muc, a traditional healer who specialises in wounds that do not heal, reaffirmed this sense,


(Cancer is a natural disease originating from this earth. It cannot be attributed to witchcraft or related explanations. It is a natural disease and it just came).
The gist of the foregoing narrative by the herbalist, traced from the frame of reference in which it was raised, is that cancer just like other fatal and incurable [at least medically] ailments, can be considered as some sort of punishment or curse from the ancestors who are believed to be connected to the living (Mararike, 2011; Bourdillon, 1990). It is noteworthy that such explanations as the foregoing confirm the omnipresent connection between health and culture (Airhihenbuwa, 1989, 1995). The narrative is discordant with the much cited ‘scientific’ or ‘expert’ knowledge, which emphasizes tangible proof as the criterion for measuring cause-effect. It was apparent in the cases of people diagnosed with cancer in this study that no one cited a view identical to the foregoing though a number insinuated the same and consulted THPs. It is argued that this ensuing narrative or explanatory model is a generic one, which can be cited in the case of other illnesses besides cancer. This has the effect of diluting its explanatory power. Nevertheless, it constitutes the worldview of those who espouse it.

6.2 Moral Explanations and invoking of Judeo-Christian Dogma

Regarding the marked rise of cancer cases in the country, traditional health practitioners attending to some participants diagnosed with cancer gave a number of philosophical explanations of cancer that invoke cultural, moral and ecological viewpoints. Thus, Sekuru Pasi, a 76-year old traditional healer, attested that in the past, the cancer illness was not as widespread as it is today, as it was restricted mainly to certain lines of descent. He had this to say,

“chaiva nemadzinza aibatwa nechirwere chacho ichocho. Iye zvino chaye kunetsera kuti pose pose chavepo”

(In the past, the cancer illness was restricted to certain clans, unlike today where it is widespread).
The traditional healer attributed the high incidence of cancer to the huge influx and growth of human populations from different social, cultural and nationality backgrounds, a kind of cosmopolitan society, which comes with a loosening of cultural mores and traditions. The argument is that in the past, people lived in close physical and social units governed by specific family traditions and mores governing sexual relations, unlike today where there is unguarded cross fertilisation of cultures. The traditional healer had this to say,

“Zvirikowo zvimwe but zvirikubva pakuwanda kwedu vanhu hatichagona kuzvibata”
(Besides various other causal factors, one of the main factors is promiscuity in a cosmopolitan and permissive society).

Furthermore, some THPs and participants diagnosed with cancer invoked Deuteronomic traditions in Judeo-Christian dogma in cancer causal attributions, to account for the swelling numbers of cancer incidence in the country. The responses showed a penchant for citing narratives from the biblical Deuteronomy tradition underpinned by the proclamation ‘if you do not obey my commandments...’ as well as some cultural nostalgia of a people alienated from their traditions. Sekuru N.C., a Seventh Day Adventist, practising traditional herbalist and faith healer made a strong allusion to scriptures in explaining the cancer illness. He alluded to the example of the Israelites who were punished by God for having forsaken his commandments, with some of the punishment coming in the form of incurable diseases. Thus, cancer is viewed as a punishment from God, though one that may not necessarily be targeted at the afflicted individuals, but on families or generations. A similar view was given by Ms M.V., a 66-year old widow diagnosed with cancer of the breast and who goes to a Pentecostal church. She noted that pastors regard diseases like cancer as a curse, but that, however, people can be delivered through the grace of God.
What can be deduced from the foregoing expositions is an affirmation that definitive causes of the cancer illness whether clinically or ethno-medically are an enigma. This metaphysical explanation, which appeals to the role of some transcendental Being like God, may give a compromise explanation to sceptics of both local people’s worldviews and the biomedical view. Nonetheless, this does not have to overlook the long-standing beliefs, shared by the Shona and Ndebele people in Zimbabwe on the active role played by ancestors in the spiritual realm, the spirits and God or Musikavanhu in all spectrums of people’s lives including people’s [ill] health (Levy, 1997; Bourdillon, 1990; Chavunduka, 1994; Mararike, 2011; Crawford, 1963). Furthermore, embodying some cultural rhetoric and nostalgia, Sekuru N.C. went on to single out the practice of intermarriages as one such example of ‘cultural rape’ which digresses from the teachings of our forefathers who implored people to marry within their clans, communities, race or nationality. He noted that intermarriages do not just signal a union between two people but cross-fertilization of spirits whereupon some nationalities thrive on bad spirits. He said,

“Kuparara kwechivanhu chedu unogona kunge utori iwo mudzi muku tisati tamboenda kune zvimwe nekuti mwana anozodya adzidza kubva kuvabereki vake”

(Loss of respect for our cultural traditions, mores, norms and values may be the root cause before we attribute other factors, just like an infant who learns to eat from emulating its parents). Such sentiments are part of moralist arguments, which oftentimes are not palatable in biomedicine and sociology. Furthermore, such moral explanations were dogged by people diagnosed with cancer during the interviews, as they tend to point to personality attributes, life styles and individual accountability (Lykins, Graue, Brechting et al, 2008). The narratives underlie windmills of stigma and moral blameworthiness that people diagnosed with cancer may come to experience and confront (Lebel and Devin,
2008). Even though these narratives are not supported by scientific evidence, it is imperative to factor them in as part of learning culturally sensitive knowledge.

6.3 The Sociology of Witchcraft and Cancer

This theme fits into, what are the indigenous [local] perceptions, beliefs, cultural interpretations and assignments of the cancer illness in Zimbabwe?

Witchcraft accusations and sorcery are some of the prominent metaphysical narratives in disease attribution and misfortune especially in Africa (Chavunduka, 1986, 1994; Crawford, 1963; Evans-Pritchard, 1935; Middleton and Winter, 1963). In our society, witchcraft is believed to cause unnatural death, misfortune or ill health (Chavunduka, 1986, 1994). Though two or three cases of people diagnosed with cancer in this study alluded to the practice of witchcraft in their illness causal narratives, it is noteworthy, that the narrative was cited less often and that when cited it was an ancillary causal factor. This can be explained in two scenarios. Firstly, the status of the researcher, a university person, in a typical fashion of interviewer bias, may have unknowingly influenced respondents to dodge such narratives which they felt, could be adjudged unsophisticated and anti-science. The other scenario is that the narratives of most of participants may already have been shaped by acquired knowledge on cancer from support groups, doctors and friends, from own reading or experiential knowledge from a family history of cancer.

The point, however, is not to be judgmental, but to privilege the knowledge of participants. Nevertheless, if culture is not static and cancer is new (at least to the concerned individuals), one could argue that the absence of the witchcraft narrative may be well understood rather that it being an issue of interviewer bias. Historically in almost every society (including the so-called developed countries), there has been evidence of supernatural explanations in disease causation, by family members and community especially for terminal illnesses (Airhihenbuwa, 1995). Thus, if one were to get beyond the
question of hegemonic discourse on health and medicine as with witchcraft, the subordination of medical of medical logic to supernatural one, this may not interpreted as ignorance per se on the part of a country or specific population or person. It is global and cuts across different educational and economic status (Airihihenbuwa, 1995).

An elaborate case of the witchcraft narrative in the study though, was of Mrs. L.K, a 53-year-old married woman with cancer on the leg, the wound that does not heal. She traced the emergence of her cancer illness to her father whom she believed might have practised some witchcraft on her. She reported an incident which raised her suspicion when one day, while asleep and after intensive praying, she heard a voice [purported to be from God] calling on her to stand and walk (at the time she could not walk). The following morning she managed to get up and walk. Surprisingly her own father became sad and could not return a salutation from her. Similarly, Mrs L.M, a 35-year-old woman diagnosed with cancer of the breast, who lives in the rural areas of Chiweshe suspected some malevolent behaviour by her mother-in-law, who could not check on her during hospital admission or return salutations. Mary (pseudonym), a woman diagnosed with cancer of the breast shared the belief that her cancer could be attributed to some unnatural causes in a possible case of chitsinga or sorcery that can only be treated with traditional medicines, or chivanhu. To a 38-year-old male participant in a focus group discussion (FGD), the role of witchcraft in causing cancer is hard to reconcile. The critical point in interpreting these narratives is not to question whether witchcraft exists or not but to appreciate what people believe to be true, which can be true in its consequences (Mandizadza and Chavunduka, 2013). The sociology of witchcraft has taught us that witchcraft accusations tend to highlight fissures and tensions in family relations and can serve as form of social control. Witchcraft is usually cited to attempt explaining the inexplicable; in this case the incurable ailment-cancer. A major point to note though, in all narratives, which invoked the practice of
witchcraft, is that it was not a primary causal explanation of cancer among all participants but tended to provide ancillary explanations to other factors. In addition, Mararike (2011) made a key observation that ordinary people in the villages group illness into two broad categories: normal and abnormal; or illnesses with impersonal causes (zvirwere zvaMwari), and illnesses with interpersonal causes (zvirwere zvavanhu). Thus, illnesses believed to be caused by witchcraft fall under abnormal diseases and people usually consult a traditional or faith healer.

Although it is difficult to reconcile witchcraft as a definitive cause of the cancer illness, the practice of witchcraft is believed to negatively affect a person by precluding the effectiveness of cancer treatment. A traditional herbalist/faith healer elaborated that prayer becomes essential in a scenario where evil spirits invoked by witchcraft can prevent the effectiveness of treatment whether from clinical care or traditional healing. Mrs Mut, a 59-year-old woman diagnosed with cancer of the cervix, succinctly submitted such an interpretation. She feared witchcraft in as far as her adversaries might take advantage of her cancer diagnosis to cast a bad spell on her, (kusundidzirwa mhepo). It is a common practice among the Shona that news of someone’s ill health should be kept secret for a while, in case enemies take advantage and practise witchcraft, which can hinder the effectiveness of treatment or lead to death. These interpretations embody Shona world views and are put into perspective by Chavunduka (1986, 1994) who attests that in Africa, medicine is used to address both controllable (natural) and uncontrollable (unnatural) forces. It follows that biomedical doctors do not have the competences to treat or to attend to uncontrollable or spiritual aspects of ill health given their schooling. Faith healers and traditional healers, who use spirit possession and prophets, attend to these spiritual or magical elements.
6.4 Desertion or Laxity in Practising Traditional Ill-health Preventive Lifestyles as a Causal Factor

A dominant indirect causal-attribution narrative shared by all Traditional Health Practitioners (THPs) and older people diagnosed with cancer, centred on laxity in practising traditional inoculation and prevention of disease and illness, done in the past. This is perceived to have provided fertile ground for the conspicuous and rampant manifestation of rare and hidden ill-health conditions like cancer. Traditionally, parents and elders used to ‘vaccinate’ newborn babies and the young from any emergent disease and dormant, hereditary health conditions. One of the practices was characterised by parents who took traditional herbal roots, tubers or leaves and chewed them on behalf of the newly born babies until the baby’s umbilical cord or rukuvhute dropped, a process known among the Shona as kutsengera. Similar practices included dissolving traditional medicines in harvested water, where babies or toddlers (or grown-ups) had to absorb some of the medicines via the anal opening. Alternatively, on a certain day in a year, all children were made to take certain medicines which would trigger vomiting, thereby cleaning the body system. These practices have been abandoned. Thus, borrowing from the scientific explanations of cancer cells as dead or unwanted cells that keep piling in the human body without being ejected out of the system, the traditional vaccination practices were meant to either disable or deracinate such bad elements in the human body, at the earliest possible stage. As one elderly woman diagnosed with cancer of the cervix observed,

“...mukatarira makuriro atakaita pachivanhu maiti mukapihwa porridge raiiswa mushonga, mu tea maiswa mushonga, gare gare mopiwa mimwe mishonga yekusimbisa muviri neku suppresser kuti zvisatombomuke, zvotofira imomo”
(When we were growing up, rooted in our Shona traditions and practices, there were days when we would take traditional medicines together with porridge or tea, meant to prevent diseases, strengthen our bodies and suppress symptoms before they manifest).

Thus, this *error of omission* or *commission* is part of the proffered explanation for the pronounced growth in cancer incidences among children, the old, and a general upsurge in ill health conditions. Shona tradition, therefore, placed emphasis on preventive measures as opposed to the current emphasis on curative medicines as espoused in ‘trending’ cancer treatment discourses and interventions. The views also indicate the points of divergence between Western medicine, which embodies principles of the germ theory of curative medicine, and traditional medicine meant to prevent and treat both controllable and uncontrollable causes of illness in a case of holistic care (Mararike, 2011; Chavunduka, 1986, 1994). The foregoing evidence is not only novel data, sidelined in conventional clinical studies but is also evidence of a comprehensive and holistic understanding of cancer embodied in such indigenous worldviews.

### 6.5 HIV as a Major Risk Factor

The attribution of cancer or its association with HIV as part of the biomedical discourse, was common among some key informants. The Zimbabwe National Cancer Registry (ZNCR) 2005 Annual Report revealed that 60% of cancers in the country are HIV related (Chokunonga, Borok, Chirenje et al, 2009, MoHCW, 2014). Asked about what she considers as the main drivers behind a seeming upsurge of new cancer incidences in the country, the senior community sister with Island Hospice gave a multifactorial viewpoint,

“In my opinion, I think the cancer has come with HIV and AIDS. I have been with Island Hospice for quite a number of years, since 1992 to date, but it has suddenly shot up. Then you find many of the cancers have to do with HIV and AIDS. You might find a few patients
who have cancer without HIV, but most of the patients with cancer are HIV positive especially the young ones. I think the diet too has changed. Maybe people moving from rural areas and coming into urban areas are eating refined foods. Because we are getting a lot of cancer of the colon in young people, whether it has also to do with water pollution and you know our environment is not clean as it used to be, that can also drive the number of cancer cases. You also find that there is a lot of braaing of red meat here in Harare. Drinking also, many people are drinking, also the young people are starting to drink alcohol early, and this may lead to cancer of the mouth.

The Monitoring and Evaluation Officer with the Cancer Association of Zimbabwe (CAZ) weighed in on the HIV connection, which has actually distorted the age pattern of cancer. Unlike in the past where cancer was a disease mainly found among the old, today, many children who are born HIV positive are likely to be diagnosed with HIV-related cancer like Hodgkins.

One of the striking observations and recurring features in this study was the open efforts shown by most participants diagnosed with cancer to deny any HIV connection. In a comparative study between HIV stigma and cancer stigma, individuals with HIV reported stronger feelings of stigma than those with cancer though many other variables weighed in (Fife and Wright, 2000: 63). Noteworthy, Lykins et al (2008) posit that people diagnosed with cancer hardly cite personality and lifestyle factors in cancer causation as a way to preserve self-esteem.

### 6.6 Heredity in Cancer Causal Narratives

Causal narratives by participants diagnosed with cancer that attributed cancer to hereditary factors seemed to point towards learned narratives. Participants blended knowledge acquired from counselling sessions with that obtained from health care professionals.
Evidence on the ground shows hereditary factors (also referred to as family history or genetic factors), associated with cancer incidence cases worldwide, account for 10-15% of the total share (AIHW, 2012; Newcomb, 2010). These statistics on cancer attribution can be misleading in the context of multifactor answers or responses. Of the 30 people diagnosed with cancer who participated in this study, 10 traced their cancer along family lines while the researcher deduced six more cases from an assessment of family health history (from life histories). Three elaborate cases of the family history narrative in this study are represented in the cases of Mrs. P.M., Ms. M.W. and Ms. M.V. Mrs. P.M., a well-read woman diagnosed with cancer of the thyroid, attributed her cancer to family blood (hereditary). On her paternal side, an uncle of hers was diagnosed with a cancerous tumour in the brain, her biological father died of oesophageal cancer, her two siblings died of cervical and lung cancer and only recently, her daughter based in South Africa had a cancerous tumour detected in the throat. Luckily, for her daughter, the tumour was attended to just on time. Mrs. P.M. gave an interesting qualification of hereditary factors and the effects of not sharing and imparting knowledge of cancer among family members. She remarked, 

“...its heredity because now I have got cancer today, if I don’t explain to my grandchildren to say this is what cancer looks like, they would be at risk. However, if we do that, those children grow up knowing the symptoms and signs of cancer so that they are treated early and it is detected early. There will be no this whole talk about heredity wiping families”.

The case of Ms. M.W., a widowed woman diagnosed with cancer of the breast in the year 2001 emphatically confirmed genetic causes of cancer. The prior knowledge of cancer she earned while working as a driver at a private hospital, enabled her to trace her cancer diagnosis to family history. Her two aunts, both of whom were born with albinism died of...
skin cancer. Of note, as I have maintained contact with my core respondents to the present, Ms M.W updated me that only recently; her eldest brother had been diagnosed with cancer of the lungs.

Reluctance by some people diagnosed with cancer to attribute inheritance factors despite a family history of cancer may have been due to the perception that any illness is unique to persons and may be due to fate. There is a gamut of literature on cancer illness narratives pointing to inherited factors of cancer. Ferruci, Cartmel and Turkman (2011) revealed the salience of family history narrative in a study of 10 most common cancers. Mellon, Gauthier, Cichon et al (2012) highlighted a high level of secrecy about cancer within Arab-American families. Several studies on women diagnosed with cancer of the breast confirmed the family history narrative (Taylor, Lichtman and Wood, 1984; Willcox, Stewart and Sit, 2011; Kulik and Kronfeld 2005; Dulmalaon-Canaria et al, 2014). Genetic factors have also been cited in general studies on knowledge, beliefs and perceptions on the causes of cancer among people living with cancer (Panjar et al, 2011; Zhang, Fielding, Soong et al, 2015). In light of the evidence from field data, I am persuaded to posit the salience of family history in the cancer burden of the country beyond the ‘less than 10%’ narrative at a global level. It would seem that experts might be reluctant to create ‘moral panics’ on family histories of cancer. Emphasis on heredity and on genetic counselling and testing may signal a breakthrough with regard to breaching the high levels of secrecy about cancer in Zimbabwean families.

6.7 Stress

Stress is one of the most prominent and widely cited factors in cancer causal narratives, though ‘scientific’ evidence has not decisively confirmed it (Dumalaon-Canaria et al, 2014; Panjar et al, 2011). I argue that narratives on stress espoused the cultural milieu or life worlds of the participants. It could be that among some people, stress is taken to be a
normal part of life for every normal person. Thus, stress may not be perceived to pose the
danger of causing grievous harm or an incurable illness like cancer. Nonetheless, many
people now appreciate the dangers of stress in the context of high incidences of
hypertension. It can also be argued that the widely read and those who have attained higher
levels of education as well as participants diagnosed with cancer have been exposed to new
knowledge from counselling drills and from seminars, at conferences and during cancer
*teas* and luncheons. Expectedly, such groups cited the possible role of stress in causing
cancer.

Of significance to this study is the fact that only two or three women alluded to stress,
either in a generic way or as a secondary causal factor, which can trigger cancer recurrence
for those on remission. Nonetheless, several participants on remission and those who
responded well to treatment, tended to credit non-recurrence to the absence of stress and to
positive thinking. Mrs. P.M., a 54-year-old woman, diagnosed with stage four cancer of
the thyroid remarked,

“*I have always told myself Pau (not real name) do not stress, because worry and stress can
trigger your cancer again. Do you know so many different things, the foods we eat, the
stressful lives we lead, can bring in cancer. Sometimes cancer can be brought in by
memories of the past, because of bitterness, the non acceptance of something you know*”.  

Several studies confirm my findings, especially among people who believe that lifestyle
and personality have a say in one’s health (Ashing-Giwa, Padilla and Tejero, 2004; Mellon

Mrs. P.M. also had this to say,

“* I grew up a very strong girl...I was never really sick but after my first husband died in 1997, I went into depression and that’s when I was diagnosed with high blood pressure*
and diabetes. And then it was illness after illness but I really find that all these things, started because of that depression.... It really sort of awakened all these illnesses which I never had when I was a girl”.


6.8 ‘I just cannot attribute it to anything’

Two or three participants could not attribute any factor to their cancer diagnosis in this study. A 56-year-old widowed woman, Mrs M.D, diagnosed and living with cancer of the cervix could not attribute her cancer to some cause or risk factor. She had this to say, “Ipapo panondinetsa mufunge kuti nditi pane zvekudya here kuti nditi pane chii zvinondinetsa”. (The issue of what I may attribute my cancer to really puzzles me. For me to attribute to diet or anything, it continues to be a mystery to me).

A 56-year woman, Ms. D.Z., diagnosed with cancer of the colon could not attribute her cancer illness to any known factor given that she had never taken alcohol or smoked cigarettes. A 23-year-old girl, Ms. V.V. diagnosed with cancer of the leg could not attribute her cancer to any factor. The ‘I do not know answer’ was confirmed as well in studies by Ferruci et al (2011); Willcox et al (2011) as well as a sizeable number in large scale survey studies by Zhang et al (2015) among 1 036 cancer survivors in Hong Kong.
From the findings of Dumalaon-Canaria et al (2014: 783) indications are that the ‘I do not know answer’ speaks of a lack of awareness about basic cancer knowledge or that someone is confused. The answer can also be interpreted to mean that the participant is saying that she does not want to think about it. In addition, I argue that the ‘no’ answer implies attribution to a natural cause, to the idea that everyone can just fall ill in life regardless of whether one expected it or not. The idea emanates from the belief in fate or the uncontrollable forces in life. I argue as well that some participants may feel hesitant to share an opinion for which they have no scientific proof of. This scenario can be underlined by some kind of ‘interviewer bias’, given the educational level of the researcher, despite reassuring participants that their opinions were the most sought after. Nonetheless, we should not be tempted to fall into a potential trap of university hegemony over community, which is very common globally among ‘experts’and ‘intellectuals’. The three participants who could not attribute their cancer diagnosis to anything may not be interpreted as ignorance but that they gave candid responses. Suffice to say, there is not a single cancer-causing agent to which everyone must be aware. Of note, interpretive hermeneutic phenomenology exhorts us to be non-judgemental.

6.9 Invoking Previous Health History in Causal Attribution of Cancer

Personal interpretation of past [ill] health experiences became vital ‘stocks of knowledge’ and espoused life worlds from which some participants diagnosed with cancer drew from, to make sense of their illness. Mrs. L.C., a 57-year-old woman diagnosed with cancer of the liver, pointed to a previous snakebite as a possible predisposing causal factor to her cancer of the liver. The side of the spot where she received the snakebite was the very side she felt the pain in her liver. She recalled that although she had received treatment at a local clinic for the snake bite, no one then, attempted kubvisa mazino enyoka (to remove the venom of the snake) and she did not go on to take traditional medicines for a snake
bite. In addition, Mrs L.C. went on to note that her two uncles from her maternal side died of chiropia or liver related disease, a history which enabled her to make sense of her illness. In the case of Mrs L.C., the experience of snakebite illustrates her rural environment and local perceptions on snake bites which are believed to continue posing a danger if the venom of the snake is not removed. Many people in the rural areas have, just like her, a strong faith in indigenous medicines for snakebites. Therefore, her causal attribution, though at odds with scientific knowledge, illuminates her life world/her world of familiars.

A 32-year-old single male diagnosed and living with cancer of the colon Mr S.M., traced the onset of his cancer illness to the problem of piles (haemorrhoids) that he experienced as a young boy. According to him, the problem was never rectified. He perceived that to have sown the seeds to his subsequent ill health, to present as cancer of the colon years later. In addition, he used to take a lot of alcohol and his parents perceived that to be a possible cause of his cancer. Ms. M.S.G., a 42-year-old woman diagnosed with cancer of the cervix, though initially hesitant about the plausibility of her opinion, went on to connect her cancer diagnosis to a caesarean section operation she had had when she gave birth to her first child. She noted that the very site where her wound stitches were lined up was the very lining where the tumour emerged. A 47-year-old woman from Seke rural, diagnosed with cancer of the oesophagus perceived her history of tonsils and treatment to have triggered her cancer. At the onset of symptoms, when she experienced great difficulties in swallowing food, she thought it was due to the surgical operation of tonsils gone wrong.

The narratives above made sense to participants who reflect on how a certain health history could provide clues for a cancer diagnosis. The narratives demonstrate how people diagnosed with cancer socially construct their reality, which may be at variance with
expert views. The foregoing findings augur well with Mechanic (1961:189), classic definition of illness behaviour as the “ways in which given symptoms may be differently perceived, evaluated and cited upon, by different kinds of persons”. In a similar vein, Kleinman’s (1988) Explanatory Model captures how people use culture and past experiences as resources in symptom interpretation to inform their choice of treatment. The results of my research affirm Zola’s (1966, 1973) emphasis that the interpretation of bodily sensations as symptoms is embedded within the socio-cultural reality. For Angela Alonzo’s situational approach, symptoms are not necessarily related to the individual, but they evolve and come to be defined in specific contexts and situations (Alonzo, 1984)

6.10 My mother died of it; then it was my wife and then a sister to my wife: Cancer

Seen as Infectious!

Scientific evidence has so far shown that cancer is not contagious and a healthy person cannot get cancer from physical contact or from kissing or air breath (AIHW, 2012). However, in the case of a village elder, Sekuru M.T who lost three family members to cancer, cancer could be passed on through contact. In line with phenomenological thinking, it is important that I present his narrative without being judgmental. His narrative constitutes vital data capable of inspiring a process of educational programming on cancer. He had this to say,

(The way I see it, the increasing incidence of cases of cancer these days indicates that cancer is being passed on through contact. My mother died of cancer, as did my wife who attended to my mother, and then it was the younger sister to my wife who has passed on due to cancer. Therefore, three people have now died in my family. My mother and wife died from cancer of the colon while the younger sister to my wife had cancer of the breast).

A key argument in view of the foregoing is that the frequent occurrence of events or experiences, in time assumes relevance among people in communities. The more an experience repeats itself the more it warrants serious attention. This applies in the case of Sekuru M.T. Whether the discrimination can be understood in the context of lack of awareness or heightened fear—it is vital that the perceptions of people like Sekuru M.T be comprehended as lived realities and lived experiences of people.

**6.11 Age as a Risk Factor**

Advanced age is taken to be one of the predisposing factors of cancer from expert knowledge and scientific evidence (Dumalaon-Canaria et al, 2014; Newcomb, 2010). My observations at the Parirenyatwa Radiotherapy Centre showed the advanced age of most clients to be a striking feature whenever I visited. The majority tended to be women in their 60’s and the men tended to be older than 60 (from observations). From a perusal of the register of cancer cases of both old and new clients at the reception centre at the Parirenyatwa Radiotherapy centre-advanced age was a conspicuous feature. Sekuru Pasi, a traditional healer observed that cancer of the prostate was likely to be diagnosed among men of advanced age (from 50 years going up) because as one grows older, the body systems, specifically the flow of blood becomes less efficient, as veins and arteries grow tired, resulting in difficulties with passing urine. Embodying, bio medical knowledge, the Monitoring and Evaluation Officer with CAZ explained that,
“You will find out that as you grow old the tendency for the prostate gland to develop abnormalities, increases with age though a very small fraction from risk families can be diagnosed with cancer of the prostate at the age of 30 or so”.

Mr C.M. and Mr F.M. both in their 60’s and both diagnosed with cancer of the prostate concurred that with age, one’s body system becomes prone to diseases associated with old age. However, since many older people of both genders can go on to live without cancer, age was not a convincing explanation to most participants diagnosed with cancer. They rather looked for familiar explanations elsewhere. It is interesting to note that the presence of child cancers tend to dilute the advanced age narrative in as much as HIV related cancers have come to distort the age patterns, with more younger people getting diagnosed of cancer.

6.12 Diet and Food Consumption as a major Predisposing Factor of Cancer

Diet was the most frequently cited life style factor in cancer causing narratives in this study, in order to account for increasing incidences of cancer cases in the country today. The same results are corroborated in many studies on perceptions and beliefs on the causes of cancer (Stewart et al, 2001; Panjari et al, 2011, Zhang et al, 2015; Dumalaon-Canaria et al, 2014). It is estimated that 30% of cancers in Zimbabwe, especially those related to the bowel and gastro intestinal parts are related to diet (MoHCW, 2014). In most of Sub-Saharan Africa, there is talk of diet transition where many people are moving more towards Western foods and dishes (MoHCW, 2014). This ‘globalisation of food’ found expression in the MacDonaldisation of life. Fat, highly refined foods, low in fibre are taken to be a major risk factor of cancer (ALHW, 2012; Newcomb, 2010). Other commonsensical views shared in the study came from sceptics of food aid and genetically modified foods, which are perceived to contain harmful substances, which may cause cancer (KII, P.I, FGDs).
The explanation of foods as a possible risk factor in cancer cases featured prominently in a focus group discussion in a rural area. A local traditional herbalist, Sekuru M.B. who took part in a FGD in rural Chiweshe, summed up the view,

“E-ee chirwere ichi semafungire andava nawo ndisingataure zvakare, ini ndiri kuti sei chirwere ichi chawanda? Asi zviripo here zvatava kudya zviri kukonzeresa, dzava pfungwa dzangu manje idzo. Hanti mese muri muno makambonzwa kuti mafreezits aya ari kuuya arikukonzera cancer? [all nodded in agreement]. Zvimwe zvezvandakambonzwawo nachiremba, saka ini zvava mupfungwa dzangu ndezvekuti zvimwe zvinhu zvatinodya zvava kukonzera”.

(From my own opinion, I am wondering why cancer incidences have increased these days and I am tempted to think that the foods that we are now consuming could be behind the cancer. I think all of you who are in this room; you once heard that certain soft drinks that are on the market are causing cancer [all nodded in agreement]. Some of this, I heard from a medical doctor which prompted me to attribute cancer to unhealthy foods).

In addition, the narrative on diet observed how people today have negated traditional foods like millet, rapoko/zviyo and wild fruits like nhunguru (sour plum), tsambatsi (wild grape) which are thought to constitute food medicine. A female herbalist, Mai Bridget attributed cancer to the kinds of food that many are consuming these days with most fresh foods being glutted with fertilizers and various chemicals. Buttressing the same view, a herbalist trained in India elaborated (in a group interview) the diet narrative by borrowing from biomedicine, noting that since we are born with cancer cells in our bodies, synthetic chemicals inherent in some foods we consume tend to activate dormant cancer cells in our bodies-leading one to get cancer.
Significantly, none of the participants diagnosed with cancer attributed own cancer to food or dietary issues as a primary or definite cause. Many participants tended to highlight the ‘diet factor’ in generic terms. This is because it is hard for individuals to pin down specific foods and specific time lines for one to see the direct impact of food on one’s health. Anderson, Steele and Coyle (2013) confirmed the same kind of scepticism in a study among colorectal cancer survivors, partly because people believed their diets to be healthy before the onset of the cancer illness. The general lack of attribution to unhealthy diet to own cancer could be a way by cancer survivors to salvage their self-esteem (Lykins et al, 2008). In a sense, admitting to personal culpability in cancer causation can predispose someone to double stigmatization by the experience of cancer and own contribution to causation (Lebel and Devin, 2008).

In light of the discourses in the foregoing sections, it is utopian to envision pure traditional oral accounts of cultural assignment of health, disease and medicine untouched by pervasive biomedical knowledge of [ill] health. The ‘food or diet explanation’ of cancer can be read in three contexts or scenarios. The first scenario is to account for huge numbers of people being diagnosed with cancer, just as we all consume food and ‘wrong diet’ may come to affect many. The second scenario is the actual constitution of food, mostly of Western diet, which has pervaded nation borders, the rural-urban divide as well age boundaries, perceived to be high in fat, low in fibre and, therefore, carcinogenic. The third scenario where seemingly more young people who are fond of the Western diet are coming to be diagnosed with cancer associated with the digestive tract (this was confirmed as well by the senior sister with Island Hospice). Another scenario where diet featured prominently was in the managing of the illness and in preventing recurrences especially when an individual believed that life style choice played a role in the development of their cancer (Costanzo, Lutgendorf and Roeder, 2011).
6.13 Of Reproductive History, Sexuality and Family Planning Methods in Cancer causing Narratives

Cancer causing narratives on cancer situated in the reproductive organs tended to focus on issues of sexual life, biology and morality. Almost all women diagnosed with cancer of the cervix initially interpreted constant bleeding and abnormal discharge as being typical of reaching the post-menopausal stage or a menstrual cycle gone wrong but which will mend (Panjari et al, 2011). A 46-year-old woman, Mrs R.W. diagnosed with cancer of the cervix, reported to a clinic after an abnormal discharge of fluids which she thought was a sexually transmitted infection from her husband. After two months, she started bleeding and she thought it was as a result of family planning pills which she requested to be changed. She said,

“Ah ini chandinoona sekuti chakakonzera cancer iyi ma tablets andainwa e family planning. Ndozvandotofunga nokuti kubvira nokubvira ini handina kumbochinja system. Saka ndaingogara ndichianwa kunyange padainge ndisina murume”

(I attribute my cancer to family planning tablets, which I have consistently taken even when I was not seeing my husband).

The attribution narrative serves to embody the general suspicions that many hold concerning family planning methods and associated side effects. Lavery and Clarke (1996) outline their findings on attribution to contraceptive pills. An elderly woman from the rural areas who was diagnosed with cancer of the cervix suspected the use of condoms. She said: “Iwo matube anongotaurwa iwaya, zvinozoonekwa pava pava” (I believe it could be condoms whose negative impact is only realised later). These sentiments are typical of the scepticism and conspiracy theories associated with condoms in Africa (Zimbabwe Human Development Report, 2003).
The sentiments by the traditional healer in the foregoing tend to give credence to the idea that traditional healers also serve as cultural custodians of morals and values in societies in Africa in addition to their healing function. The sentiments by women in the preceding paragraph indicate the common interpretations of women towards problems of constant bleeding and abnormal discharge. These interpretations in turn influence their decisions to seek help and the kind of treatment they are likely to get from nurses and doctors (Shiloh, Rashuk-Rosenthal and Benyamini, 2002; Abad, Tan, Baluyot et al, 2014). Indeed these interpretations, which can be taken as self-evident truths even by general practitioners and gynaecologists, become a contributory factor in late presentation or diagnosis.

6.14 Work Life and the Work Environment as a Risk Factor

The young, the educated and those with exposure to media, tended to zoom in on environmental factors that are thought to be risk factors to cancer, in line with expert knowledge. A 33-year-old participant in a FGD, who worked for several years in the Heavy Industries of Harare, attributed some cancers to hazardous chemical substances used and produced in industries. These toxins build in someone’s body upon inhaling, risking one to develop cancer of the lungs or liver. Buttressing the biomedical view, the Information Officer with the Cancer Association of Zimbabwe (CAZ) related exposure to carcinogens in the manufacturing industry and many people using mercury without protective clothing in informal gold mining/panning activities in the country.

There was no participant who attributed own cancer specifically to these environmental factors. However, environmental factors salient in urban areas like air pollution, contaminated water and unhealthy environments were cited as causal factors in a FGD in Harare with women participants. Such narratives tend to be shaped by media exposure and education. In Zimbabwe, rural life and rurality is associated with clean environments, authenticity (a virtue of tourism) and a quiet life away from the hustle and bustle of urban
life-hence rural participants did not cite much on environmental factors. Literature in the Western world tends to cite attribution of environmental factors and smoking among people diagnosed with cancer of the lungs (Zhang et al, 2015)

6.15 Is it more Cancer Cases or Improved Help Seeking Behaviour?

A female oncologist with the Parirenyatwa Radiotherapy Centre emphatically underscored the salience of the prevailing environment to our understanding of cancer incidence cases in line with Heideggerian (1962) emphasis on contextuality and situatedness. She remarked,

“Well, cancer in Zimbabwe, it is one of those areas that have also been affected by the economic situation. You find that in the early 90’s or early 2000 when things were relatively okay, we had quite a number of cancer cases, and then you find when things were going down economically, cancer cases went down. So it gives like a seemingly increase in numbers but the situation is also dependent on what is happening to the rest of the people in the country.

The Knowledge Manager with the Cancer Association of Zimbabwe concurred with the female oncologist on the question why there seems to a sharp rise in reported cancer cases in the country, positing that it could be attributed to improved data collection and help-seeking behaviour and is not necessarily indicative of a marked increase in incidence, morbidity and mortality rates. He argued that it could be that in the early 1990s and early 2000, the country had a limited capacity to diagnose and treat cancer and many could have been dying at home without diagnosis in as much as capturing of statistics could have been limited.

Despite the fact that the views expressed by the key informants of this study (cited above) offer plausible explanations, to a certain extent their observations are found wanting when
looked at in the context of apparent new trends. In this regard, we find that more, younger people are getting diagnosed with HIV-related cancers and there is also anecdotal evidence of more cancer deaths and morbidity rates in the country. There is also every reason to believe in the ‘dark figure’ of possible cancer cases which are attended to by THPs and very low utilisation of biomedical health facilities by men with reproductive health-related problems (Subedi, 1989; Onokerhoraye, 1999; Bourne et al, 2010; Zambezi et al, 2011). In Zimbabwe, studies established that despite the availability of modern health care facilities in the country at primary, secondary, tertiary and quaternary levels, the number of men utilising such facilities was very low (Bourne et al, 2010).

6.16 Views of Experts on Causal Attribution of Cancer in the Country

The experts reaffirmed the much-cited risk factors on cancer, from a biomedical view adapted to localised contexts. Of note, the experts frequently cited life-style-related risk factors not cited in personal attribution by participants diagnosed and living with cancer. The female oncologist highlighted the consumption of fried food and fatty foods taken over a long period and braaing of red meat or gochi gochi, popular in Zimbabwean townships, as factors likely to increase the risk of one developing cancer. There is widespread smoking of tobacco and high alcohol intake among younger men in Zimbabwe as increasing incidences of lung and liver cancer testify. In addition, many people in urban areas have begun to live sedentary lives lacking in physical fitness. Consequently, many people have a disproportionate weight-height ratio or body mass index-while increasing the risk of obesity and cancer (oncologist). Similarly, the Monitoring and Evaluation Officer with the Cancer Association of Zimbabwe (CAZ), singled out some kind of transition in diet that came with Westernisation, in contrast to life before colonisation, when local people consumed more plant-based food that, willy-nilly, prevented or reduced the risk of developing cancer.
Specifically, for cancer in the reproductive organs like cancer of the breast and cervix in females, the oncologist attributed the larger part of afflictions to sexual activity—particularly early sexual debut among girls. Traditionally such cancer used to affect older postmenopausal women (60 years and above). She elaborated that when one acquires the HPV virus earlier on in life like 12, 13 years of age, the cervix would not have matured yet to clear the virus. The virus would then sit in the cervix for a long time and cause damage or it will show up 10 or 15 years later as cancer of the cervix.

More in line with the phenomenological stance of this thesis, the oncologist was asked, based on her experience of interacting with clients with cancer, to relate what their clients attribute their cancer illness to. The oncologist noted that, instead of attributing, many clients diagnosed with cancer were puzzled and would ask her why they have developed cancer. Some clients query the genetic connection; others blame themselves for consuming the wrong foods. There was also a number that blamed their smoking habits. Some blamed their promiscuous behaviour or their sexual partners.

6.17 Understanding the Variance in causal attribution narratives between Experts and Participants diagnosed with cancer

The major variance on perceptions of the causes (risk factors) of cancer, evident between ‘experts’ and participants diagnosed with cancer is the emphasis on life-style-related factors by the former and attribution by the latter to natural and environmental factors. I found the observations by Lykins et al (2008), to be plausible that people diagnosed with cancer hardly cite personality and lifestyle factors in cancer causation. That is a deliberate act for preserving their self-esteem. Thus, people with cancer tended to avoid taking responsibility, which in essence is instrumental action to manage the psychosocial burden that comes with the cancer illness. Significantly, the narratives between experts and participants diagnosed with cancer tended to overlap on generic attributions of the cancer
illness inherent in empirical literature, but salient to our context. Interestingly, all the participants came to espouse a potpourri of local discourses on cancer causation, drawn from a blend of experiential knowledge, commonsensical views, indigenous knowledge, biomedical knowledge and life worlds. This corroborates Denzin’s (1989) idea of thick descriptions/narratives that present both the context and the web of social relationships.

6.18 Conclusion

The chapter presented an analysis of the key findings of the first study objective meant to identify the causal attribution narratives of selected people diagnosed and living with cancer in the country. The chapter addressed the following three questions: 1) what are the indigenous [local] perceptions, beliefs, cultural interpretations and assignments of the cancer illness in Zimbabwe? 2) How do people living with cancer account for their cancer illness? 3) How do people living with cancer account for the general rise in cancer illness in Zimbabwe? As can be expected, most of the perceptions on causes of cancer espoused by participants diagnosed with cancer departed from the often cited ‘scientific’ risk factors associated with cancer, with some very comparable with similar studies carried outside the country boarders. However, the narratives reflected and espoused the aura of localised reality and situatedness, some distinct to individuals and country’s cancer ethnology. It was apparent as well that individual narratives showed traces of newly-acquired knowledge from counselling drills, from nurses’ induction exercises and other media. The analysis, however, was such that the richness of individual narratives was systematically coalesced with that of others so that important similarities did not remain obscured by individual variability, which they emphasized. In the end, the evidence presented in this chapter illuminated rich fringe data, conspicuously absent in the existing corpus of knowledge in canonized form. The perceptions on causes of cancer may likely have strong
pointers in possible shaping of health-seeking behaviours and on how individuals with a cancer diagnosis experience the illness.
7. CHAPTER 7: THE LIVED EXPERIENCE OF PEOPLE DIAGNOSED WITH CANCER

7.0 Introduction

This chapter is the linchpin of this study that coalesce theory and data to illuminate an interpretive hermeneutic phenomenological study of cancer in Zimbabwe. The chapter addresses the key question: *What is the lived experience of people living with cancer in Zimbabwe?* The chapter captures one of the central ideas of interpretive hermeneutic phenomenology-studying life as lived. The emphasis is on studying or understanding phenomena from those who experienced the phenomena under study (Mapp, 2008). Giorgi (1985) and Kvale (1996) remind us that the most important reality is what one perceives. The focus is on not only how individuals experience the cancer disease, *per se*, but is also on their treatment experiences and more importantly the social impacts of the cancer illness in different contexts involving the concerned individuals. Such an approach enables the explication of thick descriptions of fringe data, which in turn is an aid to our comprehensive understanding of the phenomenon under study. The chapter begins with a discussion of early experiences prior to and soon after a cancer diagnosis including early reactions to the news of a cancer diagnosis. Throughout the discussions, keen interest is shown on streamlining gendered experiences. The chapter then discusses treatment experiences; family experiences, embodied experiences and pain experiences. In addition, the chapter examines how the cancer illness reconfigures the self and social relations with the ‘significant other’ and sometimes the ‘generalised other’. The chapter then presents a detailed examination of cancer stigma as one of the prominent areas of lived illness experiences, befitting of a condition that is dreaded, incurable and fatal. In addition and lastly, in this chapter, I found myself intrigued by the insights from Bury’s (1991) work: *The Sociology of Chronic Illness: A Review of Research and Prospects*, particularly his
notion of ‘biographical disruption’ and Little, Jordens, Paul et al (1998) in Liminality: A Major Category of the Experience of Cancer Illness. These and related ideas are exploited and embedded in the chapter discussions.

7.1 Descriptions of Onset of Symptoms and Early Reactions to a Cancer Diagnosis

I concur with Molen (2000: 49) who posits that, “For most people, the experience of cancer does not start the minute they are given their diagnosis. It starts earlier with some having suspicions”. Though the participants presented at different times and stages, many recounted vividly the day they were given their results, although they could no longer chronicle all the events in sequence (Molen, 2000; Akyuz, Guvenc, Ustunsoz et al, 2008; Saegrov and Halding, 2004). Despite the examination of help-seeking behaviour being the core issue in Chapter 8, it suffices to say, all people diagnosed with cancer who participated in this study were propelled into seeking help after the onset of overt symptomatic elements which heralded the manifestations of their cancer illness. For many, illness symptoms (despite lack of insight that it could be cancer) had been building up or had been evident for years or several months, while they hoped that the symptoms would disappear or be kept under control.

7.2 Males Experience of the Onset of Cancer Symptoms and Early Reactions to Diagnosis

Seven male participants diagnosed with cancer took part in this study (see appendix 7 and 8 on pages 339-344). Generally, the male participants presented late for diagnosis after experiencing serious symptoms, which became hard to ignore given that they interfered with their daily bodily functions. Poor help-seeking behaviour among males compared to women is well-documented (Nathanson, 1975; Mechanic, 1976). It was only upon experiencing physical disruption and severe pain that men sought help as illustrated in the cases of Mr. C.M., Mr. F.M. and Mr M.M. in Chapter 5 (pages 105-121).
Mr S.M, a 32-year-old single man diagnosed with cancer of the colon and living with a permanent stoma experienced sharp pain in the abdomen. His stomach had become swollen and he would pass stool with great difficulty, which prompted him to seek medical help. News of his cancer diagnosis and the reality that he was now going to live with a permanent stoma caused him a great deal of stress that triggered suicidal thoughts in him. Mr. G.M., a married man diagnosed with cancer of the oesophagus received the news of cancer diagnosis philosophically, having suffered for a rather long time (For detailed stories of Mr. C.M., Mr. F.M., Mr. M.M. and Mr. S.M. refer to Chapter 5).

From the cases of cancer of the prostate, we can see that men tend to go for a long time without disclosing their health challenges probably due to fear of stigma. Only when symptoms begin to interfere with bodily functions do men seek help. Of note, the males presented a brave picture, highlighting that they received well the news of their cancer diagnosis. Generally, men have a tendency not to share their weakest points, where they cried, screamed, moaned, where they shuddered in great trepidation especially at the thought of cancer as a potentially fatal ailment. Charmaz (2002), implores us not just to focus on words that participants use but also to pay attention to silences. What is not said is that men generally may not know how to recount their emotions. This deduction is predicated on the embodiment of traditional masculinities, that is, on the idea that real men do not cry. It is difficult to avoid concluding that in the cases cited in this study, the men tended to make covert their fears, anxieties and emotional breakdown to the researcher, to their spouses and to their children. This probably finds explanation in the embodiment of the traditional, hegemonic masculinities of men which portray them as being fit, having a lot of strength and a virility that renders them incapable of being fallible when it comes to reproductive health. The case of Mr F.M. is reflective of hegemonic masculinities traceable back to traditional Shona beliefs. This explains why he declined to have his
testicles removed arguing that it was against tradition and asserting that he preferred to die with his organs intact. According to Korda (1998: 3), “prostate cancer specifically has been considered in terms of fears that it brings with it that go to the very core of masculinity”. It could also be that in a gerontocracy, the older people are not expected to show the emotion of ‘weakness’ overtly, hence the absence of novel experiences by older men. However, younger men, as in the case of Mr. S.M. and Mr. M.M., overtly spoke about and described their reactions, fears and anxiety.

7.3 Women’s Illness Experiences of Early Reactions upon Cancer Diagnosis

The majority of female participants diagnosed with cancer in this study, reacted strongly to the results of a cancer diagnosis. Relieving her early experiences Mrs. P.M. diagnosed with stage four cancer of the thyroid had this to say,

“I really cried; I just broke down completely. To me I thought this is the end of the world, Why Lord? Why me? I have got diabetes, I have got hypertension, now you are there telling me I have got cancer. Why me? That was my question, why me? And umm that went on for a long time, even when I walked I said to my husband why me? My doctor actually broke down with me because they did not believe a person could cry so much in just a matter of time. That is why I have always described the day I was told- you have got cancer; I have always looked at it as that bright and shining sunflower wilting and closing up”.

For Mrs M.W., the previous experience of family members diagnosed with cancer was both scary and pacifying. However, it was during the solitary moments that the sad reality of cancer would re appear. In her words,

“Asi ndaiti ndakarara ndikatanga kufunga nedikita rinobuda. Ndinana tete vangu two vakafa ne cancer”.

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(My nights were particularly troublesome because sleep eluded me and the anxiety was so great that I sometimes caught myself sweating profusely. I have two aunts who succumbed to cancer of the skin).

Some saw their imminent death upon diagnosis. Mrs. M.G. diagnosed with cancer of the breast had this to say,

“Ndakanyatsoona rufu rwangu because ka unongoziva munhu akanzi ane cancer vanhu vanofunga kuti waakuita sei waakufa. Plus mukungonzwawo zvinenge zvichitaurowa nevanhu mukugara unenge uchinzwa kuti cancer hairapike chii chi”

(I saw my death coming because as you know when you’re told you have cancer, the people out there think you are dying. Moreover, there is all this talk about how cancer is not treatable).

There were cases where some got angry with the doctor and could not absorb anything in their first counselling session. A 46-year-old woman diagnosed with cancer of the breast, stage one said,

“Nguva iyoyo ndakabatikana ndikachema stereki ndakatoshatirwa kana iye doctor ndakabva ndatomuvenga. ...Bva ndazopihwa counsellor...Bva vataura neni but pavaitaura neni hapana chandaimbonzwa. Ndakangoti haa vari kungotaura nokuti hazvisi pavari”

(That very moment, I was greatly distressed and I cried a lot. I was so angry. I even hated the surgeon as if it was a personal thing. Then they gave me a counsellor. I hardly heard what she was saying, convinced as I was that she was just saying these things. After all, it wasn’t her with the cancer)

Some women were shocked that for a while they did not know what step to take next. Mrs. M.S.G., a 42-year-old woman diagnosed with cancer of the cervix said,
“Paakauya ndichiudzwa kuti ndine cancer, ipapo ndopabaya manje. Ndakafunga zvakawandisisa ndikatomboita one month ndisina kudzokera kuchipatara nyangwe dai mari ndaiva nayo”.

(When the biopsy results finally confirmed cancer, I was shocked. Many thoughts flooded my mind and I went quiet for one month before I decided on seeking further medical help).

Some readily accepted their new reality (especially those who had experienced great pain for prolonged periods with no diagnosis). Ms J.M a widowed woman diagnosed with cancer of the cervix had this to say,

“Ndakazvigamuchira ndisina kana kugumbuka kana kurohwa nehana. Ndakange ndarwadziwa kwenguva yakareba. Ndakazviziva kuti ndikaramba ndichibuda ropa, mhedzisiro yacho ndaizonzi ndine cancer”

(I accepted the results of the cancer diagnosis with relief rather than anxiety or sadness. I had suffered for long. Somehow, I knew that if I continued to experience continuous bleeding, the result was going to be cancer).

Women diagnosed with cancer, who shared their early reaction experiences in a focus group discussion in Harare, used the following words in describing their feelings: ‘cried uncontrollably’, ‘was devastated’, ‘was shocked’ ‘was traumatized’ ‘went down’ ‘was greatly distressed’, ‘was angry’ ‘sought answers from God’ ‘got depressed’ ‘got anxious’ ‘was depressed’ ‘became frightened’ ‘was at a loss’ among others.

In view of the foregoing, most females diagnosed with cancer, had strong initial reactions that included fear of imminent death, worry and distress. The narrative by Mrs. P.M. in the foregoing is replete with her own interpretation of her feelings and reactions- an interpretation that is informing to a ‘double hermeneutic’ understanding of the episode.
Unlike males diagnosed with cancer, most females recounted their feelings openly. It would seem to most women that sharing their stories of how they received the news of their cancer diagnosis has a cathartic effect to many who are grateful to God that they are still surviving (Benzein, Norberg and Saveman, 2001; Barnett, 2001). Such stories resemble Arthur Frank’s *Wounded Storyteller* (1995) typology of the *quest narrative*—a narrative, which is owned by the storyteller and where he/she is in control of things. This is distinct from *restitution narrative* favoured by medical practitioners, which focuses on restoring health and *chaos* narrative, where a storyteller does not give a sequence of events, lacks control and focuses on dark experiences (Frank, 1995). Most women considered themselves ‘survivors’ and shared their stories in support groups with the newly diagnosed. Similarly Barnett (2001), noted evidence of the positive effects of involvement in research by people diagnosed and living with a chronic condition as their participation tended to restore a sense of purpose in them. Indeed the majority of [female] participants diagnosed with cancer registered their delight in participating and were grateful to the researcher ‘who reminded them of the old memories’ early upon diagnosis.

Several studies confirm the findings of my study on ‘early reaction experiences’ among women. Akyuz et al (2008) in a study of 19 Turkish women with gynaecological cancers, revealed that the time during diagnosis is a ‘difficult and stressful one’ ‘associated with ‘death’, ‘big shock’ fuelled by the doctors’ expression when breaking the news. Halldorsdottir and Hamrin (1996) talked of an ‘existential crisis’ revolving around life, death and disease. In Bury’s (1991) language, the news of a cancer diagnosis results in ‘biographical disruption’, the idea that the illness would affect personal meaning and create a disruption to one’s expected life trajectory, *life world* and biography. In a study of six cancer narratives, Molen (2000) noted that all participants recounted vividly the day they received their results and all talked of the fear of death and dying. In a typical case
confirming the case of Mrs. R.G. who could not pay attention to anything that was said after the doctor revealed her results, Molen (2000: 49) reported that “many people find that once they hear the word ‘cancer’ they forget anything else that has been said”. In their study of lived experiences of ten Norwegian women diagnosed with cancer of the breast, Landmark and Wahl (2002) pigeonholed ‘emotional chaos’ as a theme to characterise the ‘trauma’, ‘acute emotional imbalance’ and ‘shock’ immediately after the news. The same feelings of stress and ‘biographical disruption’ were found in a study of 10 women diagnosed with cancer of the breast among Lebanese women (Doumit, Saghir, Hijer et al, 2009) and among 12 people diagnosed with cancer located on different body sites in Norway (Saegrov and Halding, 2004).

Most reactions by the women in this study embodied popular views in the communities especially the view that cancer is equal to imminent death and cannot be treated. This view emphatically points to the salience of prevailing myths, perceptions, attitudes, knowledge and beliefs about cancer in shaping the illness experiences of people with cancer in Zimbabwe. In addition, it can be argued that some women who indicated indifference to news of their cancer diagnosis or who ‘accepted it as the new reality’ may have already weathered through the trauma such that they needed not recount the experiences or they had internalised despair and resigned to fate. In the final analysis, reactions to the news of the diagnosis and the likely impact on the personal meanings of life can boil down to personalities, with some choosing to fight and reconfigure their self and others choosing to ‘live each day as it comes’ in a sign of capitulation and general despondency.
7.4 Early Illness Experiences among women diagnosed with Cancer of the Breast prior to and Immediately after Diagnosis

N.B (a detailed discussion of help seeking behaviour is presented in chapter 8. Here, the onset of early symptoms is discussed as part of early illness experiences just before a cancer diagnosis).

The combination of the discovery of early symptoms and subsequent associated experiences was dramatic for some women. For Mrs. R.G, male colleagues in whose company she was walking from a night school observed some blood on her white top and pointed it out to her. Following this incident, she went to seek medical advice. Ms. M.W. felt like there were things moving inside her breast and so ended up scratching the whole breast. Sometimes her right breast would be lactated, as if she was breast-feeding. She felt a lump one morning. Mary (pseudonym) experienced breast discharge for four years, but thought it would heal one day. Contrary to her expectations she was diagnosed with stage 3 cancer of the breast when her right breast became ‘swollen, hard as rock, painful and shiny.’ Ms M.V likened the ‘big thing’ she felt on her right breast, to an unripe mango fruit—a lump, painless during the day and painful during the night. Ms. M.G. felt a piercing ripple of pain in her nipple and beneath the nipple there developed a small lump. Her nipple had been eaten away and she had maggots in the inside. (For detailed stories of Mrs R.G (pages 123-124) and Ms. M.V. (pages 108-111) refer to Chapter 5)

What can be discerned from the foregoing narratives is that, it is only after a recurrence of symptoms, irritation and pain that the women sought medical help leading to their diagnosis. A majority of the women initially tended to interpret symptomatic elements as ‘normal’ functioning or reaction of the woman’s body. For Ms. M.V. and Ms. M.W., fear was fuelled by a history of family members and friends who had died of cancer. It is worth noting that in all the foregoing cases, it was not necessarily the severity of the disease
symptoms *per se* but the interpretation of the symptoms based on uninformed popular views shared by the public together with experiential knowledge, which underlie the women’s experiences. The fears were heightened thoughts of whether or not the treatment was going to succeed, and worry about the possibility of the cancer having spread. The doctor’s demeanor, especially his expression, also assumed critical levels of importance. Such findings are well supported in the literature (Landmark and Wahl, 2002; Molen, 2000, Andreason, Randers, Na˚slund et al, 2006; Akyuz et al, 2008). It can also be argued that the level of social support from the immediate family and ‘generalised other’ people did shape the experiences, with lack of support darkening the experiences and more positive support making the psychosocial burden bearable.

7.5 Onset of Symptoms among Females Diagnosed with Cancer of the Cervix and Vulva

The major symptomatic elements for women diagnosed with cancer of the cervix in this study were sustained bleeding and vaginal discharge, an area that is symbolic of the very core of womanhood and femininity. Mrs R.W. attributed her vaginal discharge to a sexually transmitted infection (STI) from her husband. Later she began to experience bleeding which she attributed to family planning pills. Similarly, to a degree, a woman from a rural area, Mrs Mut, experienced excessive bleeding well beyond her normal menstrual cycle. In her words,

“*ndai bleeder zvekuzadza ma jug ndikasara ndachenuruka, ndapera muviri, tsinga dzese dzasviba kuti ndoo*”

(I bled so excessively as to fill up jugs. Consequently, I became anaemic, lost considerable body weight and became pale. My veins turned frighteningly dark).
One afternoon, Ms. J.M. was unable to walk from her fields because of the great pain coursing through her body. When eventually she arrived back home she was bleeding profusely. The bleeding lasted several months. One year later, her diagnosis confirmed she was at stage three cancer of the cervix. An elderly woman, Ms. L.M., suffered bleeding coupled with difficulty in passing urine. This condition prompted her to seek medical advice. Ms. Bee, a single young mother of one, experienced inexplicable pain as she went on a whirlwind trip consulting among Traditional Health Practitioners (THPs) to no avail. Doctors unsuccesshfully tried several treatment and medication regimens before a diagnosis confirmed cancer of the vulva.

In view of the foregoing, it is evident that irregular and sustained bleeding coupled with vaginal discharge was the major symptomatic element of cancer of the cervix among the women in this study. Most women, in my study, tended to relate their excessive bleeding to their menstrual cycles. Panjari et al (2011) and Zhang et al (2015) observed this same pattern in the studies they undertook. The women’s experiences were underlined by excruciating pain and fear of diagnosis. The majority of women diagnosed with cancer of the cervix who participated in this study were either widowed or divorced. Conversely, Ms. Bee diagnosed with cancer of the vulva was single. The majority of the women were older and no longer of childbearing age. The [single] marital statuses and advanced ages of the majority of female participants did not allow the revealing of rich experiences related to sexual matters. Based on a study of 19 Turkish women diagnosed with gynaecological cancers, Akyuz et al (2008) observed that gynaecological cancers pose special challenges because they involve organs related to femininity, sexual life and fertility. Both the diagnosis and treatment tended to be stressful to women (Costanzo et al, 2006). The stigma attached probably explains why most women experience the symptoms for a considerable length of time before they seek medical help.
7.6 Early Illness Experiences of Women with Cancer situated on Non-reproductive Body Organs

Two women, Mrs. N.Y. and Ms. S.W, were diagnosed with cancer of the oesophagus in this study. Their early symptoms included great difficulty in swallowing, vomiting blood, loss of weight and feeling that there was a thing, in their throats, blocking the passage of food. In the end, both women had to have a keystone tube inserted to allow the passage of food. Andreassen et al (2006) found the same early symptoms in a study of people living with oesophageal cancer in Sweden in addition to sore throat, heartburn, chest pain and fatigue. Similarly, Andreassen et al (2006) highlighted existential threats to individuals who lose the pleasure of eating. The inability to eat constitutes an acute ‘biographical disruption’ to a normal, basic routine of eating without which one cannot survive.

The case of Mrs. P.M. (story in Chapter 5, pages 100-105) illustrates a dramatic discovery. For two female participants diagnosed with cancer of the leg, it started as a wound that would not heal causing difficulty in walking. Ms V.V. a 25-year-old unmarried girl diagnosed with cancer of the leg experienced discrimination from family and friends due to the odour she produced from the wound and due to her stunted growth. Mrs L.C., a 57-year-old woman diagnosed with cancer of the liver, experienced pain in the ribcage or mabayo. She shared illness experiences prior to her cancer diagnosis,

(I lost weight and became bedridden. In those days, I spent more time at the gate there because I did not want to catch the smell of cooking fat. Even the smell of chicken manure upset me. It was very easy for me to vomit. While at my rural home, I could not do anything and people in the neighbourhood brought me food since my husband was away at his place of work). For Mrs. A.C., what started as a severe toothache during pregnancy with her fourth child in the year 2000 was to be diagnosed as cancer of the mouth 13 years later. A hard lump full of pus was discovered in her mouth and she sought help from local clinics as well as from traditional health practitioners, and did that quite early.

The case of Mrs. L.C. illustrates some of the existential challenges faced by people diagnosed with cancer. She was forced into self-induced isolation, and self-blame that came with a lot of emotional distress. Such an experience can affect one’s self-image, including how individuals think others view them (Cayless, Forbat, Illingworth et al, 2009). Instructive to the experience is the observation by Ohman, Soderberg and Lundman (2003) that chronic illness means living a life hovering between enduring and suffering, including a process of reformation of the self, what Bury (1982, 1991) referred to as, ‘renegotiation of identity’.

7.7 Treatment Experiences: Reliving Moments in the Theatre Room

Surgery is a procedure that invokes near-death experiences among many. For some participants who went through surgical procedures, the theatre room was perceived as a ‘death room’ where life could possibly end. For her mastectomy, Ms. M.G. requested time from the surgeon to allow her to go and finalise her plans with her family in case in the end she did not come out of the theatre room alive. On the day of her operation, she placed her new special dress on top of her head so that her relatives could dress her up in it inside her coffin! Similarly, after getting chilling hearsay accounts from her father who recounted the popular views among the public that few can survive after breast surgery; Mrs. R.G. went
home to plan for her possible death before reporting for theatre. For Ms M.G., her negative experiences were worsened by conversations held by some of her relatives about ‘burial arrangements’ for her. They were well within hearing range and she could hear them clearly from where she lay in recovery following surgery.

7.8 Women’s experiences with Radiation Therapy Treatment and Chemotherapy

Though most women who received radiotherapy reported that their earlier fears of being ‘burnt’ (the local Shona term for radiotherapy is kupiswa, which literally translated, means ‘to be burnt’) were dispelled, some of the clinical guidelines made the whole experience unpleasant. As a clinical guideline, all women were outlawed from bathing the ‘marked area’ (the target of radiation rays during radiation therapy) with water during the whole period which on average would go for 23 days. It was an unpopular experience among women used to personal hygiene, as part of their femininity and womanhood. As aptly put by Ms J.M,


(We were instructed not to apply water to our private parts- the marked area for radiotherapy. It was of great concern to imagine how we could afford not to attend to the marked area, being women and, therefore, being sensitive about that kind of personal hygiene. This, obviously, was asking too much. How could we possibly open our legs for the doctors at the radiotherapy machine without giving an odour? As women, we are used
to personal hygiene of the private parts and it was a hard choice. I once defied the directive and went for one week before anything happened and before I began feeling any pain. When I developed blisters, I opened up to the nurses who taught us alternative ways of maintaining personal hygiene around the area). Such an experience indicates the medicalisation of women’s lives during radiation treatment to the extent of colonising the life world of their femininity in Habermasian language. In the end, during the treatment period, women sometimes become alienated from their bodies, lose self-esteem and carry a psychosocial burden (Landmark and Wahl, 2002)

Some dark experiences during radiation therapy were doctor-induced in cases of ‘breast conserving surgery’. For Ms. M.V., going to the theatre for a second time after breast-conserving surgery was a reminder of the dark experiences of going with a fresh wound to the radiotherapy machine, which caused her untold suffering and pain. The same experience applied to Ms. M.W. who had to go for a mastectomy after two weeks from the initial lumpectomy. Thus, in an endeavour to ‘save women’s breasts, most surgeons inadvertently increased their physical and psychosocial burden. Of note, Landmark and Wahl (2002) did not see any significant difference in psychological outcomes between mastectomy and breast-conserving surgery. Other side effects of radiotherapy experienced by women (side effects could differ with each individual) in the study include loss of skin colour (sometimes the skin turned blackish), loss of appetite, going for several days without passing stool, loss of taste, loss of skin on the ‘targeted area’, dehydration and general fatigue.

In the case of chemotherapy, most women submitted that chemotherapy was a painful and demanding treatment. In my observations, I witnessed some women vomiting soon after leaving the clinic rooms. Many reported that chemotherapy triggered diarrhoea, fatigue, pain, loss of white blood cells, alopecia (hair loss), vomiting, loss of weight and a general
poor state of health. One woman, Ms. M.W. described her experiences with chemotherapy, and said,

“Ndichipedza session yangu ye chemo, ndasvika kumba chekutanga kugeza nokuti unenge waakunhuwa zvisingaite...kwakutsvaga pane mhepo pekurara. First day zvinenge zviri right. Second day unomuka uri chimwe chinhu. Aah unombofunga kuti handidzokere futi. Third day worse. Saka pandaienda kubasa munhu akakubvunza kuti uri kurwara here unenge uchitorwara ne kuti unenge uri weak. Kunyatsokutsanangurira zvainzwa handigoni asi kungoti zvinorwadza”

(Once I finish my chemotherapy session for the day, the first thing I do when I got home is to take a bath because the whole body will smell chemotherapy drugs. After the bath I find somewhere to lie down, a place with a lot of air circulating. The first day after a chemotherapy session, you feel ok. The second day you are not quite yourself. The third is bad. When people at work ask if I am sick, indeed I will be sick. I cannot explain to you exactly how it feels with chemotherapy. Let’s just say that it is very painful indeed).

7.9 Family Experiences upon a Cancer Diagnosis

It is imperative to note that some consequences of cancer are experienced well beyond the individual and that they extend to the family and sometimes to the society. Research has highlighted the psychological and mental distress of family members, family carers and children caused by the cancer illness. Wideheim, Edvardsson, Påhlson et al (2002) found that family members, especially carers, can experience greater distress, fear and anxiety more than people with cancer can. The impact of the cancer illness on children is contingent upon their developmental stage and age (De Groot, Mah, Fyles et al 2005). Some adults with cancer were reluctant to disclose to their young children the cancer diagnosis- to avoid their children being emotionally traumatised! It was evident that the
cancer illness of an individual who could be a father or mother, husband or wife, son or daughter, nephew or niece— took a toll on family members. During interviews, the spouses of Mr. C.M. and Mr. F.M. noted how the cancer illness derailed all family plans including projects and family livelihoods. Similarly, Harden, Schafenacker, Northouse et al (2002) noted that the cancer illness tended to disrupt family members’ daily lives, routines and life plans. In this study, Ms. M.S.G. had to suspend her monthly contributions to a low income housing scheme in order to be able to meet the cost of chemotherapy. Most of the participants reported sadness, panic, fear and emotional stress that gripped their family members upon the news of their cancer diagnosis.

The wife to Mr. C.M. who was diagnosed with cancer of the prostate noted in a joint interview that,

“Imwe pain yavanombonzwa tinosvika pakudzamirwa semhuri nokuti vanomborwadziwa zvinoshungurudza”

(Sometimes the profound pain he experiences troubles and leaves the whole family shaken and distressed).

The case of Mrs. P.M. in Chapter 5 (pages 100-105) illustrates strong novel family reaction to the news of a cancer diagnosis. Her daughters cried and went down. Thus, the news of cancer diagnosis in Zimbabwe can have a great impact on families let alone communities because of the dominant view of associating cancer with death. This in turn, negatively affects the mental health of both the person diagnosed and family members.

7.10 How Levels of Support shape Experiences

One of the key findings in this study is the influence of levels of social support on the experiences of people diagnosed with cancer. From a look at the demographic
characteristics of the thirty participants diagnosed with cancer (refer to appendix 7 and 8 on pages 339-344), it is worth noting that the majority of participants were not gainfully employed and due to illness they were out of employment. Thus, the majority came to rely on support from children and siblings be it financial or psychosocial support. Two prominent cases stood in contradistinction in this study. Ms. M.V. is a widow who never had a child, who did not receive significant family support throughout her journey with cancer and Mrs. P.M., a married woman who received overwhelming support from her husband and family (refer to chapter 5 for detailed stories of Mrs. P.M. and Ms. M.V.). With overwhelming psychosocial support from her family and a good medical insurance cover from her husband, Mrs. P.M. mobilised against stage four cancer of the thyroid up to her current state of remission. On the other hand, the two decades long journey with cancer of the breast for Ms. M.V. since 1993 has been a strenuous one, full of scars and ugly memories, which have left her to contemplate to move into an old people’s home.

Benzein et al (2001) notes the importance of support including support from other people diagnosed and living with cancer, in their study of hope among people with cancer in palliative home care. Adrykowski, Carpenter and Munn (2003) noted social support as one of the key variables associated with good adjustment to cancer, including support from family and friends. I argue that strong reactions by spouses, relatives and children upon news of cancer diagnosis, paradoxically shores up massive social support for people with cancer, be it psycho social, spiritual, material and financial support.

7.11 Body Disfigurement and Impairment among people with Cancer

The bio-physicist paradigm views the body as a kind of biological machine, a laboratory site for experiments and clinical examination. As noted by Little, Jordens, Paul et al (1998:1485) “Because of its reductionist tendencies, conventional medical understanding also typically fails to capture the embodied experience of illness”. The social science
perspective echoes Michel Foucault’s ideas on the social construction of the human body as the axis of ubiquitous power relations. Cancer and its hospital treatment can have disfiguring effects on the human body, which result in profound socio-cultural and personal consequences.

I observed the disfiguring effects of cancer at the Radiotherapy Centre and at the Oral Health Centre. Mrs. A.C. diagnosed with cancer of the mouth in 2013, presented with a disfigured face, having defaulted on radiotherapy after surgery. Her disfigured face caught the attention of every passerby. She reported a traumatic incident when she took a look at her face in a mirror. She was haunted by her appearance. Some people diagnosed with cancer of the eye would put on sunglasses or cover their faces with a cloth to conceal the disfigured facial area (*observations*). Such concealing is a way to manage possible stigma from a ‘spoiled identity’ by ‘passing as normal’ (Goffman, 1963). I saw a man with a huge hole on the neck (cancer of the neck), who carried with him a small mirror to look at his wound. Such an act may indicate heightened ‘felt stigma’ whereupon the wound becomes the focus of attention for the individual. In the waiting area at the Radiotherapy Centre, I chatted with a young woman diagnosed with a brain tumour 5 years ago. She was happy to be alive despite going blind and losing hair, which never renewed due to chemotherapy and radiotherapy. This case illustrates how human beings may come to value life and look beyond a ‘spoiled identity’, albeit with huge physical and psychosocial costs.

### 7.12 The Case of Mastectomy and Alopecia: Femininity under Threat

Mastectomy resulted in women losing their body shape and chemotherapy resulted in alopecia (hair loss) among women. In order to manage disfigurement, women would improvise with prostheses (artificial breasts). All the women reported feeling ‘out of shape’ during the days soon after mastectomy- a feeling that bothered them. Mrs. R.G. reported feeling alienated from her body where every morning she had to reach out for
another ‘breast’ in the wardrobe and remove it during sleep time. Nonetheless, I found one’s age and marital status influencing women’s experiences of losing a breast with the older, widowed women who had been living with cancer for years not being bothered much compared to younger, married women who worried much about their appearance. Thus, the 64-year old widow, Ms. M.G, was not bothered by a ‘small mistake’ of forgetting to put on her prosthesis before going to a church service.

In a similar vein, Doumit et al (2009) talk of living with losses; ‘loss of body part’, ‘loss of normal life’, ‘loss of hair’ in a study of experiences of 10 Lebanese women. Halldorsdottir and Hamrin (1996) talk of discomfort that came with side effects of chemotherapy and mastectomy among women. Molen (2000:50) reports that mastectomy dents the chances of a young woman in future relationships and strips ‘her’ of womanhood, of which a breast is an integral part. In their study of the lived experiences of 10 women diagnosed with cancer of the breast in Norway, Landmark and Wahl (2002) report that the women in their study became alienated from their bodies. The ‘body broken and torn’ is another thematic description offered by Landmark and Wahl (2002) in their study, which is contradicted by older women in my study, who gladly opted for mastectomy as long as it ensured their wellness and successful treatment. Doumit et al, (2009) reported alopecia as shocking among the women. Besides the high value placed by women on hair as their symbol of femininity and beauty and in a country which experienced initial overt ugly scenes due to HIV and AIDS, hair loss was liable to be stigmatised as one symptom of sero positivity. Several studies established that alopecia ranked the top most distressing side effects of adjuvant and metastatic chemotherapy regimens in self-reported studies among women (Kiebert, Hanneke, de Haes et al, 1990; Sitzia and Huggins, 1998; Sitzia and Dikken, 1997; Carelle, Piotto, Bellanger et al, 2002, Duric, Stockler, Heritier et al, 2005).
7.13 Masculinities and Femininities under Stress

Surgical removal of testicles on men with cancer of the prostate and uterus removal in the case of women with cancer of the cervix interfered with masculinities and femininities for men and women respectively. Concerned men felt the loss of their manhood, their self-worth especially the fact they now stood before their sexual partners as ‘harmless’ and impotent beings. Mr. F.M. resisted having his testicles removed citing traditional beliefs though he went on to lose his virility due to advanced illness. The wife to Mr F.M highlighted her husband’s aggressive behaviour due to loss of virility (see story in Chapter 5, pages 117-119).

For women, the uterus and the breast are some of the most important reproductive organs and part of their femininity contributing especially to what it means to be a woman (Akyuz et al, 2008; Landmark and Wahl, 2002; Doumit et al, 2009). Hence, loss of such organs comes with great personal difficulty and a feeling of loss of self-worth. Ms. Rose, a 67-year-old woman diagnosed with cancer of the colon, confronted the shock of her life when she learnt from the surgeon that her uterus had been removed in previous surgeries. Since the surgery was done without her knowledge, she cried uncontrollably. For young women who are still sexually active and are of childbearing age, it was a hard choice, more so for those who hope to get married (FGDs) (Molen, 2000). This probably partly explains the difficulty I had in recruiting young women in this study. In my study, the majority of women had reached menopause stage, had finished giving birth and had become less sexually active-hence they suffered less personal and social impact. For cancer of the reproductive organs, some reported dampening of sexual life among the married, explained by fear of instigating harm on a partner or due to years of taking chemotherapy drugs (Mrs. R.G.). Though women in the study noted that loss of their reproductive organs dealt a dent to their self-identity or self worth, it was secondary to the health imperative.
7.14 **Living with a Permanent Stoma**

“My unforgettable memory was having to wake up in the intensive care unit hospital with a very sore tummy from stitches of the operation and also to then later on realise that I was never going to use the toilet the normal way. I would say that was the saddest moment of my whole life” (Mr S.M, a 32-year-old man diagnosed with cancer of the colon now living with a permanent stoma)

The above is one of the most illuminating experiences of the impacts of losing a body member, a finding confirmed by Briggs, 1977 and Little et al (1998). It illustrates a kind of alienation from one’s body in the aftermath of a life-changing surgical operation- a feeling that could persist for the rest of one’s life. Indeed, it was a life-changing procedure, which came to shape his diet, and sports he could do. It influenced whether he could embark on a journey without enough stock of colostomy bags, whether to attend a party and decline taking some food and disclosing to a potential girl friend and face the consequences. A similar experience was evident among participants with cancer of the prostate and cancer of the oesophagus, who resorted to Paul’s tubing and Livingstone tube respectively. In their studies, Briggs (1977) and Little et al (1998) revealed that the introduction of an alien body member had a tendency to cause discomfort or to make people feel alienated from their bodies.

7.15 **The Predicament of a Mother in Choosing between Double Amputation and the Welfare of her Children**

Malterud (1999) cited in Kralik, Brown and Kock (2001: 600) attests that “medicine maintains a distinction between the patient's 'subjective' experience and expression, and the 'objective' findings observable by the doctor, dismissing the former and emphasizing the latter”. Mrs. L.K., who was diagnosed with cancer of the leg back in 1992, was recommended for double amputation. She knew that once she was amputated she would
become dependent, restricted for life and incapacitated to fend for her children. She also risked losing her husband. She had to make a decision between a medical imperative and a social imperative. She chose the latter. To date she has been treating her legs with a combination of various medicines from THPs and modern medicine. During FGDs, many stories were shared of people with a wound that does not heal who ran away from hospital upon being recommended for amputation and got treated from traditional Shona healing systems, or chivanhu which ‘saved their legs’. The experiences of Mrs. L.K. illustrates how people weigh the social costs that come with medical interventions which medical practice on its own does not pay attention to. Malterud (1999) cited in Kralik et al (2001) concluded that “a medical diagnosis is seldom a biological fact, but the outcome of a process where biological, cultural and social elements are interwoven”. Assigning validity to the voice of the woman might broaden our understanding of women's health, illness and disease.

7.16 Men and Women’s Experiences of Physical Pain

Pain continues to be a major source of suffering on people with advanced cancer, with detrimental effects on individual’s quality of life and with a potential of causing emotional distress in families and on family caregivers (Portenoy and Lesage, 1999; Thomas-Maclean, 2004). A recurring and striking lived experience in this study was the agonising pain that sometimes characterised the cancer illness and its clinical treatment. I must admit that it was the graphic accounts of pain experiences that I heard from people diagnosed and living with cancer, that I witnessed, that has reconstructed my self, my views on cancer and my own [health] lifestyle. In one incident, my field companion was emotionally affected by the graphical pain accounts to the extent that he became hysterical about a small painless lump on his tongue, which had been there since birth, and he sought herbal medicine from one traditional herbalist as a precautionary measure!
Based on field experiences, I argue that ontologically, it is impractical to separate pain emanating from the disease from pain that comes with hospital cancer treatment, for those receiving treatment. However, with advanced cancer under palliative care, we have a better prognosis of cancer pain independent of treatment. It is also prudent to assess cancer pain from initial symptoms before diagnosis and treatment. Advanced cancer illness was experienced with agonising pain while radiation therapy and chemotherapy can add a huge burden of pain and discomfort. From the cases of Mr. F.M. and Mr. C.M. both of whom had advanced cancer of the prostate, pain was the dominant lived experience (refer to stories of Mr C.M and Mr F.M in Chapter 5 (pages 117-121). In one of the home visits, the researcher witnessed the profound pain experiences of Mr F.M. The most striking highlight of pain experiences by Mr C.M. came from the wife, a few months after Mr C.M’s death, when the wife volunteered to take part in any future cancer outreach programmes so that (in her words) ‘I would explain to men who refuse cancer treatment, about the pain experiences my husband went through’. Whenever she sat on the sofa, her late husband used to sit on, she would somehow feel his pain incarnated in her. The case story of Mr. M.M. (story in chapter 5 page 105-108) illustrates the agonising pain he went through during chemotherapy.

Women with advanced cancer of the cervix tended to experience profound pain just like men with advanced cancer of the prostate. An elderly woman diagnosed with advanced cancer of the cervix Ms. L.M., attempted to illustrate her pain experiences diagrammatically noting the severity of pain. She testified that in her whole life she had never experienced great pain like the cancer illness pain. In a typical sense of Husserls’s (1962) seminal statement that, “we can only know what we experience’, Ms. L.M. observed that ‘urwere huri pane mumwe idombo kune mumwe’ (illness/pain as experienced by someone is hard to explain to someone who does not experience the same). In our
society, it is rare for the elderly especially women as mothers or aunts to shed tears of pain but they always seek to conceal pain for fear of causing emotional distress to children and family. However, when they cry openly and uncontrollably—it testifies to great pain. Ms L.M. reported crying at the height of pain.

7.17 A tale of how the Cancer Illness Reconfigures the ‘self’ and Transforms Social Relations

One of the questions pursued in this study was how the cancer illness trajectory possibly signified the reconstruction of the ‘self’ among people with cancer and transformed social relations. This was expressed in the question: how has cancer changed your life? Admittedly, this was a cognitive and intimate focus and responses hinged upon the ability of the participant to assign and relate the meaning of the cancer journey and illustrate how the whole experience has been life changing. Greenstein and Breitbart (2000) highlight that, for existentialist thinkers like Frankl, suffering is a potential springboard both for having a need for meaning and for finding it. Elaborate narratives came from participants who have been living with the ailment for sometime. Along the way, they had come to embody positivity, were actively involved in counselling the newly-diagnosed and were active in educational outreach programmes. Park and Folkman cited in Greenstein and Breitbart (2000: 492) state that “advocacy is a common route of finding meaning for people suffering from traumatic loss or an illness”. Such participants like Ms. M.V., Mrs P.M. and Mrs. R.G. became cancer ambassadors who had mastered the art of testifying their stories openly during research, in support groups, seminars, fundraising dinner campaigns, international conferences and during World Cancer Day commemorations. Thus, such prior experience may have come to influence their stories. Such women tended to embody hope, an element which Benzein et al, (2001) also found in a study aimed to illuminate the meaning of lived experience of hope in people with cancer who were under
palliative care. Of note, older men who in the first instance were reluctant to come out in the open and who did not belong to support groups like women, tended to give restricted reflections.

Mrs. P.M. a married woman diagnosed with stage four cancer of the thyroid in the year 2010 gave a novel and illuminating narrative of how cancer changed her life (the self) and transformed her relations (refer to chapter 5, pages 97-101 for the detailed narrative). The cancer diagnosis and life with cancer heralded a brand new life. The narrative by Mrs. P.M. resembles how cancer has altered the lives of most women. The major point is that, cancer tended to make most women with cancer become more spiritual in both secular and religious ways. Mrs. P.M. chronicled how cancer made her softer, more tolerant, forgiving, sentimental, more Christianised and more willing to help and care for others. Indeed her cancer diagnosis has been a watershed in her life by changing her worldview, her social relations and her relationship with God.

For another life story case of my study, Mrs. R.G. who was diagnosed with cancer of the breast in November 2006, I got additional insights into how cancer changed her life from her testimony included in the first edition of a cancer exclusive magazine; Cancer Zim published by the Cancer Awareness Survivor’s Trust, October 2013.

Part of Mrs R.G.’s testimony read; “After mastectomy, my life changed. I started to love myself, following a period when I have been afraid of rejection. I have conquered my fear of cancer. I have no regrets. I have to admit that this cancer can cause some emotional stress: you may feel angry or cross with everyone around you” (Cancer Zim, 2013: 4)

In a semi-structured interview, Mrs. R.G. noted that after cancer diagnosis, she was now very careful in everything she does in her life. She no longer holds grudges but she has learnt to confront a person whom she feels has crossed her path head-on. She now avoids
hanging around with people who speak negativity especially on cancer. For Mr. S.M., a 33-year-old single man who was diagnosed with cancer of the colon, his life after a cancer diagnosis witnessed a rupture. He experienced an emotional breakdown and reconfiguration of his relations with strangers, prospective female lovers and downed his level of engagement in outdoor life activities (refer to a detailed account in chapter 5 pages 108-112).

7.18 The Lived Experience from Bury’s (1991) notion of ‘Biographical Disruption’

To Bury (1982, 1991) the onset of chronic illness illuminates a ‘biographical disruption’, and biography suggests that meaning and context are intertwined, an idea emphatically affirmed by Heideggers’ Dasein. Chronic illness creates a disruption of one’s expected life trajectory and biography especially during the acute stage and during treatment (Bury, 1991). Soon after diagnosis, the majority of the participants found themselves having to abandon their daily routine. In Parsonian language, they transposed into the sick role status where their families expected them to demonstrate willingness to want to be well. Many had to quit formal employment and withdraw from many social life activities with family and friends. More so, the very mentioning of the word ‘cancer’ upon diagnosis signalled a rupture in the lives of many who started to worry about death, treatment side effects, life and family.

It is from hospital treatment that the conspicuous ‘disruption of biographies’ was witnessed. For clients from rural areas and out of Harare, it meant being alienated from their families and work-related activities for sometime while they receive treatment. The 23 days of receiving radiotherapy (on average) and 6 months of chemotherapy was tough an experience for elderly women from the rural areas, who became unsettled and insecure about the welfare of their families and state of affairs in their agriculturally- related work. In fact, many such participants tended to develop or suffer from further stress related
health complications like hypertension. In addition, some clinical guidelines signalled ‘biographical disruption; whereupon during radiotherapy, women were instructed to restrict their contact with water on the marked parts where high-energy rays are focussed-a scenario that many women found hard to fathom.

Cancer treatment [side] effects, ‘disruptions’ and potential outcomes of the disease among men include incontinence, impotence, erectile dysfunction and urinary flow disruptions (Cayless et al, 2009). This was evident in the cases of Mr. C.M. and Mr F.M. These disruptions in turn affect self-image. According to Bury (1991) treatment may become part of a problem and a solution. In the case of cancer, besides the positive benefits, aggressive cancer treatment was received with a huge social cost to individuals with cancer and families. Alopecia, loss of weight, diarrhoea and loss of skin colour led to a *legitimation crisis* or in the language of Bury (1991) ‘a situation of meanings at risk’. Traditionally, such symptoms were associated with the scourge of HIV and AIDS. One of the recurring observations throughout the study was the spirited effort by people diagnosed with cancer to dissociate their sickness from HIV sero positivity. Thus, for many people, cancer diagnosis was an official validation that one has cancer and not HIV. However, as Bury (1991) noted, individual perception of reality is not guaranteed to be accepted and those seeking sympathy run the risk of being rejected. Thus, uncertainty tended to be a key aspect of the illness experience, an observation confirmed by several studies (Molen, 2000; Landmark and Wahl, 2002; Halldorsdottir and Hamrin, 1996; Benzein et al, 2001; Akyuz et al, 2008)

**7.19 A Heightened Case of Biographical Disruption: The Case of Radioactive Iodine Therapy**

I found experiences with radioactive iodine therapy treatment in the case of cancer of the thyroid (Mrs. P.M.) to be a heightened case of ‘biographical disruption’ to both the
individual and her family (refer to the detailed case story presentation in chapter 5, pp 100-105). The treatment process was not only a ‘biographical disruption’ of daily life but was also a strenuous process that affected her, and her family, physically, socially, emotionally and psychologically. She was alienated from her body, from her sexual life, from her family and friends and from her belongings. In essence, she was under quarantine. Such a scenario comes with a lot of traumatic stress. Understanding such experiences is important for the nursing practice to help prepare clients and their families psychologically prior to and after hospital admission including family counselling. Nonetheless, Bury (1991) reminds us that people are not helpless and neither are they ‘victims’. By contrast, they mobilise human agency to manage the situation (such elements are discussed in-depth in chapter 8).

7.20 Stigma Experiences of People Diagnosed and Living with Cancer in Zimbabwe

This analysis of cancer-related stigmata is typical of a localised, situated, and context-specific study underlined by a penchant for reflexivity and microanalysis of macro elements. Kleinman and Hall-Clifford, (2009) posit that understanding the unique social and cultural processes that create stigma in the lived worlds of the stigmatised should be the first focus of our efforts in combating and studying stigma. A consistent argument is that at an ontological level, self-stigma mirrors enacted stigma in as much as enacted stigma gives rise to self-stigma. Furthermore, it is prudent to consider a juxtaposition of investigators and participants’ interpretation of reality in line with Heidegger’s ‘double hermeneutics’.

7.21 The Dread of Cancer and Internalised Fear

One of the most conspicuous indicators that underlie the stigmatisation of cancer in this study is the dread of the illness emanating from its association with imminent death. The ‘news’ that someone has been diagnosed with cancer was greeted with immense
trepidation in families and communities in rural and urban communities. Rosman (2003), Else-Quest and Jackson (2014), note that from the mid-20th century, cancer was often not discussed with people due to its association with death. A 63-year-old woman who had a mastectomy on her right breast in 2001 recalled her early days after diagnosis,

“When you hear the word ‘cancer’ eish. It is very scary! That word cancer I think is what kills a lot of people as they stress and sometimes fail to confront reality.”

Similarly Karl Menninger cited in Sontag (1978:6) observed that "the very word 'cancer' is said to kill some patients who would not have succumbed (so quickly) to the malignancy from which they suffer." A familiar picture at a radiotherapy centre was of distraught sad faces, moments before the commencement of doctor consultations (from observations). Lack of concrete assurance from a doctor, on chances of successful treatment, heightened fear. Owing to fear, some individuals, spouses and families chose not to disclose to outsiders or some family members. Relatedly, Knapp et al (2014:5) highlight of “cancer fatalism, the belief that cancer will lead inevitably to death… and this can hinder engaging in cancer prevention practices and screening, stigmatizing others, and stigmatized individuals may also internalize these attributions”.

7.22 The Dread of Radiotherapy and Therapeutic Nihilism

A related striking and recurring observation in this thesis is the tendency by a number of people in communities to associate hospital cancer treatment with imminent and eventual death, in a typical fashion of ‘therapeutic nihilism’. According to Starr (1982) cited in Chambers et al (2012:2) “Therapeutic nihilism as a concept first arose in the 19th century as a belief that medical science was limited to treat disease that was considered best left to the healing powers of nature”. On surgery, the phobia is that ‘cancer does not want to be disturbed; hence any surgical operation can trigger the gangrene!’ Of note, on radiation treatment, the local term in use for radiotherapy treatment, kupiswa (literally translated it 187
means to be ‘burnt’) was in itself culpable in instilling fear in most people. A layperson would visualize live electrical rods connected to a human body during radiotherapy! The common mantra in some (rural) communities is that, *ukapiswa wafa* (radiotherapy equals death). In a similar vein, Susan Sontag’s (1978) *Illness as Metaphor*, famed for her central claim to strip illness of metaphor, she highlighted the military flavour inherent in the metaphors of aerial warfare; patients being "bombarded" with toxic rays associated with radiotherapy. Another widespread view was that, once one receives radiotherapy, the cancer can no longer be treated successfully by traditional Shona healing practices or *chivanhu*. Thus, some traditional health practitioners tended to discourage clients to utilise hospital cancer treatment in favour of ‘natural healing’ from traditional medicines and God.

My argument is that it is imperative to delineate stigma that emanates from the disease itself and stigma that is associated with cancer treatment; an act worthwhile for analytical purposes but hard to pigeonhole at practice level. This is a key observation, which needs to be taken into cognisance when discussing cancer stigma in Zimbabwe and it may be the single most important reason why some people diagnosed with cancer present late or shun hospital treatment.

**7.23 Interposing Culture, Financial Strain and Self-Stigma**

The prevailing harsh economic environment, high costs of hospital cancer treatment, high levels of lived poverty and the very patterning of society help us to appreciate internalisation of stress, depression and anxiety among people diagnosed with cancer. Interpretive phenomenology underscores the salience of contextuality in understanding phenomena (Norlyk and Harder, 2010). My study findings revealed that it was not only the disease which came to bother people with cancer, but stress over where to get finances for the next chemotherapy or radiotherapy session or where to get the next bus fare. A woman
with cancer of the oesophagus, Ms. S.W. reported how she lapsed into depression whenever she received a letter of warning over her unpaid hospital bills from debt collectors. A notable case of internalised stigma was reported; of a woman with cancer of the oesophagus who was now refusing food and medicines because her relatives were now viewing and treating her as a financial burden and she ‘would now wish to rest, to spare them of more trouble’.

For the elderly women from the rural areas, the prolonged nature of hospital cancer treatment alienated them from their homes, which was equally distressing as it came to colonise their life world. From the gossip at the Radiotherapy Centre waiting area, some family caregivers faced a challenge of controlling their older mothers who were ready to dodge treatment or review clinics and retire to their rural homes to oversee land cultivation and reunite with family or mhuri. Thus, they lapsed into depression. In Shona culture, a home or musha is of high significance to women. Thus, it is imperative to understand some contexts in which depression (one of the indicators of self-stigma) occurs among people diagnosed with cancer rather than cite it in generic terms.

7.24 Labelling and Name Calling

Enacted stigma from labelling and name-calling tended to target external manifestations of the illness. A 53-year-old woman with cancer on the leg, Mrs. L.K. was name-called by some relatives due to wounds that do not heal. The father and stepmother to Ms. Bee, a 23-year-old single, unmarried woman, diagnosed with cancer of the vulva, labelled her a slut. Chambers et al (2012), Else-Quest and Jackson (2014), Cataldo, Jahan and Pongquan (2012) highlighted the moral blameworthiness associated with cancer related to reproductive organs like the cervix, prostate and vulva because they are linked to behaviour that may be deemed undesirable or marginal regardless of the actual disease pathway. Age and marital status were salient factors in shaping stigmatization, with older
women (50 years and above) sometimes not being bothered by the small ‘mistake’ of forgetting to put on prosthesis (artificial breasts) in public. The experience was not the same with young women who were still dating and who were married who worried about their body image (from observations). Similarly, Quigley (1989) noted that as new relationships and issues of sexuality and sterility take centre stage for unmarried survivors, disclosure was a daunting challenge.

7.25 Cancer Stigma and Straining of Family Relations

A recurring sentiment during conversational interviews was how the cancer illness may result in strain in family relations. The cancer tended to shake the moral fabric of families and led to a breakdown in human relations, or ubuntu. Several cases of either husband or wife running away from an ailing partner were highlighted (FGDs). In one incident, a woman skipped out of the country because her husband who was diagnosed with cancer of the blood “was taking long to heal”. Such incidences of naked stigma took a toll on people with cancer as they were stressed upon the realisation that, ‘their loved ones were dumping them at their point of weakness, when they needed them most’. Some family ties were severed due to financial strain and the burden of care that comes with [advanced] the cancer illness. In what can be viewed as a heightened case of self-stigma, some elderly persons with cancer would wish to die to spare their children the ‘trouble’ of spending their hard-earned financial resources. On the contrary, in some cases, the cancer illness brought some couples together. Interestingly, not all men or women in this study show the audacity to withdraw from their sick wives.

7.26 Narratives of stigma by Single, Young Unmarried Persons with Cancer

Single, young people had peculiar stigma experiences, informed, in part, by their age, gender, marital status, socio-economic position and family living arrangements. Single, young, dependent people diagnosed with cancer are easily accused, may have their power
to make decisions emasculated and can experience harrowing discrimination in families. In some context, self-stigma was not triggered by the cancer illness itself but the lifestyle one adopts as part of managing the illness. Mr. S.M. diagnosed with cancer of the colon and now living with a permanent stoma had this to say,

“I am slowly losing confidence in dating women because I will have to explain my condition time and again. The sores and stoma is a constant reminder of the suffering and pain I went through before and after the surgical operation”.

Charmaz (1983) cited in Bury (1991: 453) posited that “the onset of chronic illness represents an assault not only on the person’s physical self, but also on the person’s sense of identity calling into doubt the person’s self worth”. Notably, Briggs et al (1977) observed that people who live with a colostomy are not always successful to pass as ‘normal’ as supposed by Goffman (1963) as the bags can burst, and can produce odour and noise.

7.27 Incidences and Episodes of Blatant Discrimination, Rejection and Isolation in Homes and Communities

In the absence of institutionalised care and hospital accommodation, family living arrangements, nature of illness and socio-economic circumstances tended to shape the nature and process of stigmatization. Reminiscent of the early days of HIV and AIDS, some participants diagnosed with cancer who came to temporarily stay with relatives in the city while they received hospital treatment, were not allowed to touch a plate, jug or feed a baby because their cancer was perceived to be infectious. Ms. M.G., a 64-year-old woman with cancer of the breast had this to say of her relative,

“She separated utensils I used and the bucket I use for bathing, from items used by the rest of family members and any of my food remains were to be disposed of right away”.

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Such acts which were reported widely about some families and in communities can find fertile ground from egoistic personalities and already existing strained family relations and may not be applied to wholesale cases. As a result, some persons with cancer would opt to sleep on the floors of hospitals to avoid such unpleasant experiences.

7.28 Non-Disclosure

According to Sontag (1978:8) “Since getting cancer can be a scandal that jeopardizes one's love life, one's chance of promotion, even one's job, patients who know what they have tend to be extremely prudish, if not outright secretive, about their disease”. In a case of non-disclosure (internalised stigma) of the cancer illness in communities and lack of knowledge sharing, Mrs Mut, a woman with cervical cancer [knowledge by hindsight] now recalls how in her community men diagnosed with prostate cancer and inserted with Paul’s tubing, kept it a secret. She said,

“We used to hear about men in our communities who were said to be using tubes to pass urine and we had no knowledge that it was prostate cancer till we came here at the Radiotherapy Centre”.

Similarly, from retrospection, Mrs P.M. now familiar with the odour associated cancer, had every reason to believe that her father possibly died of cancer of the oesophagus, though their mother managed to hide it from them, then. Lack of knowledge of cancer combined with non-disclosure; prevents the sharing of family health history, which can help improve help seeking behaviour.

7.29 Intra-stigmatization

The study revealed cases and episodes of what can be referred to as intra-stigmatization were people with cancer can stigmatize other people with the illness just like people in the public. A woman diagnosed with cancer of the breast commented on a friend with
pancreatic cancer “*who was definitely slowly dying*” while a single young man with cancer of the colon was sometimes teased by fellow support group members as ‘*bag boy*’. Another woman with cancer teased people diagnosed with both cancer and HIV positive telling them that they were ‘*wearing two coats*’. The point is not to view people with cancer as not fit to comment on other people just like people without cancer. The point is to note some subtle, minute manifestations of internalized stigma, which may not be wholly negative but is part of the differential mobilisation of resources by people living with cancer to manage and cope with the illness. Ironically, such acts are tantamount to stigmatisation!

**7.30 Futuristic outlook**

Internalisation of stigma was discerned in a limited projection of futuristic plans and the mind-set that comes to dominate the *life world* of some people diagnosed with cancer. Some participants diagnosed with cancer, who recovered from initial ugly scenes of the disease, expressed an interesting perception of the future and death. They observed that even if they were to die now, at least they are grateful to God that they got a chance to live and have been relieved from excruciating pain. This was notwithstanding the fear of cancer recurrence that lives with many of the people diagnosed with cancer.

In the final analysis, in certain contexts, stigma experiences need to be read as ‘incidences’, ‘episodes’, ‘events’, ‘processes’ and in certain instances taking habitualised, enduring character (like the dread of cancer). Pinel (1999) and Major and O’Brien (2005) add interesting dimensions by their notion of *stigma consciousness*—the tendency by individuals who are susceptible to being stigmatised to differ in their responses and expectations of being stigmatised. Furthermore, the over-romanticised view which needs debunking, is that stigma is overly negative and that the stigmatised are ‘victims’, ‘passive actors’ and helpless. Notwithstanding the validity of such a standpoint, it can be noted that

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people with cancer not only fight the negative views of selves whether felt or external stigma but some actively participate in productive activities like advocacy and counselling of the newly diagnosed. Some behaviours and actions, which have been pigeonholed as manifestations of self-stigma in literature and stigma tool kits (for instance social withdrawal, non-disclosure, isolation, self-blame) (Eba, 2008) in fact, demonstrate a feisty mobilisation of tact and great ingenuity by the stigmatised, in managing their stigmatization.

7.31 Liminality as Illness Experience: A Tale of Life with Cancer

I found the conceptions and analysis by Little, Jordens, Paul et al (1998), in their study of 10 participants diagnosed with colorectal cancer, titled: Liminality: A Major Category of the Experience of Cancer Illness- to be an informing synopsis of the whole illness trajectory of people with cancer. Though rooted in various traditions, the notion of liminality is adapted from social anthropology particularly the works of Van Gennep in 1909, in his study of rites of passage with stages of separation, transition and aggregation (Little et al, 1998). The point is to capture the trajectory of a chronic illness as a subjective process that progresses in stages, though in a multidirectional and discontinuous fashion.

In the context of cancer, Little et al (1998: 1490) refer to acute liminality, some kind of ‘black box’ to outsiders, a state wherein people diagnosed with cancer upon receiving the news of a cancer diagnosis, they experience the existential threat of its dread; then sustained liminality where they begin to reassert control by the small acts of independence. “Experiences of liminality are expressed in three themes; cancer patientness which illuminates boundedness, communicative alienation which reinforces patientness and boundedness in terms of social context, space, time and an alienation from the self. These themes thus overlap, shift and elide in a process which begins in the high drama of acute liminality but which persists life-long in the repeated re-writing and reordering of the
illness narrative” (Little et al, 1998: 1490). For the purpose of my study, I elucidate the theme of cancer patientness, which seems to encapsulate the other two themes of communicative alienation and boundedness by Little et al (1998).

7.32 Cancer Patientness

I have resisted the use of the term ‘patient’ in this study as a major identifying category of people diagnosed and living with cancer, as somehow a misnomer in its insinuation of a perpetual state of sickness despite lapses of time between diagnosis and treatment, an issue which Little et al. (1998) also admonish. Even though people with cancer are expected to present during review clinics at set periods, they are normal, active people; they are mothers, fathers, husbands, wives, aunts and nieces. In contextualising the notion of cancer patientness, I discerned some affinities with the medicalisation of social life thesis associated with the works of Conrad (1975) and-the idea on the pervasiveness of biomedical power in covering the non-medical elements in people’s lives. Similar ideas include the idea of medicine as an institution of social control by Zola (1972, 1983, 1991) and the notion of bio power and medical gaze associated with Foucaudian medical sociology (Focault, 1975).

According to Little et al (1998: 1486), the theme of cancer patientness, “encompasses the immediate impact of cancer diagnosis, and persistent identification as a cancer patient regardless of the time since treatment, and of the presence or absence of recurrence or persistent disease”. In light of my study, it is particularly striking to note, the long hospital treatment regimens, which maintain the sick role status of people diagnosed with cancer long after initial diagnoses and completion of treatment. The state of patientness was underlined by the long period of hospital treatment regimens for clients with cancer. Someone who completes the recommended treatment is usually required to attend review clinics and pass various medical tests to confirm non-recurrence, commencing monthly
and returning every three months, every six months, then yearly, bi-annually, tri-annually, and after 5 years et cetera. Ms M.G. was diagnosed with cancer of the breast stage 2B in 1997. She underwent radiotherapy for 8 weeks followed by six months of chemotherapy and had to take tamoxifen for five years. Since then to date, she is monitored by Island Hospice, which sometimes provides her with pain-stopping drugs to control and manage pain. During all this period, people with cancer would seem to be affirming and legitimising their cancer patientness and sick role status.

Family carers and relatives or friends reinforced the identity of patientness. Since 1999, Ms. M.G. has been residing at her sister’s two-roomed house in a high-density location ‘because she was now a sick person who needed constant care’. Her church leader once asked why she was troubling herself in performing church work since she was a sick person. In the case of Mr. S.M., now living with a permanent stoma, it was apparent that there was sustained liminality whereupon in his words, “I am constantly being reminded of the pain and suffering that I went through before and after the operation—the sores and the stoma are a constant reminder”. This concern was also evident among male participants in a study by Little et al (1998).

Participation by some people diagnosed and living with cancer in awareness and outreach programmes can be defined as a state of sustained liminality. Some women in the study became passionate about advocacy around cancer issues. They counselled the newly diagnosed, participated in support groups, gave a talk in churches and at funerals and even travelled to speak at international conferences. Through such activities, people diagnosed and living with cancer engage in a perpetual search for meaning in life. Furthermore, liminality as an illness experience of people diagnosed and living with cancer was emphatically expressed through the adoption or holding of certain lifestyles which are shaped by the cancer illness. One major conditioning factor is that medically, it may not be
possible to declare one cancer-free after diagnosis and treatment. Medical protagonists talk of a state of remission, which implies that the cancer is lying dormant and unforeseeably it can recur in the future. Thus, people diagnosed with cancer adopt an active health-seeking behaviour by constantly presenting for liver function tests, blood tests, scans, bone tests among other clinical tests to declare them free of any possible recurrence. Those on palliative care keep taking their pain control drugs like morphine even when they do not feel any pain. Borrowing Foucault’s (1975) language, people diagnosed with cancer remain under the medical gaze for a prolonged period.

In a case of life style liminality (my own taxonomy) people living with cancer were prescribed a certain diet-using diets with no highly-refined foods and so on. Many who undergo surgery, radiation therapy and chemotherapy were encouraged to do light work, carry light loads and to avoid direct sunrays. In addition, it can be argued that the spirituality and religiousness that most people diagnosed with cancer in the study came to embody can be categorised as sustained liminality-a life style of coming to look up to and rely on God on issues of life, death, disease and human fate. The state of liminality persists until life ends in a ‘remission society’. In a similar vein, Foucault’s notion of bio power is espoused in the ability of medicine to coerce people into a kind of self-surveillance and self-discipline. In this process, they subjugate themselves (Pylypa, 1998). However, this seemingly essentialist and logo centric view submitted by Little et al (1998), invaluable though it is, should not be applied in an overly deterministic manner. Neither should it be taken to suggest that people diagnosed and living with cancer become cogs in a machine or come to live in a perpetual state of physical, social and psychological ‘boundedness’. On the contrary, I found some people diagnosed with cancer to have returned into full participation in normal daily activities and that they were fulfilling societal roles and expectations.
7.33 Conclusion

This chapter sought to analyse the diversity of the shared experiences of those living with cancer from the onset of initial symptoms right through the treatment process to the present circumstances of the core participants. There was evidence of unique elements in the gendered experiences and the different cancer sites. It was apparent that women with cancer on their reproductive organs tended to ‘normalise’ initial symptoms to their anatomical and biological make-up and most women had a strong reaction upon news confirming cancer, with many experiencing high levels of distress. Severe physical pain was a major highlight of hospital treatment experiences for most participants including agonizing pain among participants with advanced cancer. Harsh treatment side effects on body image were recorded among women and this, in their view, tended to interfere with their notions of femininity. The males, by contrast, were partly engrossed in their notions of hegemonic masculinities (virility, lack of emotion, lack of weakness). It was apparent that cancer was a life-changing condition, which made many more spiritual in both the religious and secular ways. The chapter confirmed pronounced self and enacted cancer stigma experiences, with a far-reaching impact on individuals and families. Bury’s (1991) notion of ‘biographical disruption’ and that by Little et al (1998) when they talk of liminality as a category of cancer illness experiences were useful in illuminating shared and recurring experiences among participants in the study. The novel experiences discussed in the foregoing sections testify to the robustness of an interpretive hermeneutic phenomenology to extract fringe data that not only humanize discourses on cancer but also engender a holistic study of the impact of cancer to individuals, families and communities. True to the principles of Heidegger’s phenomenology, the experiences shared by participants with cancer and their stories reflected their situatedness and the salience of context in shaping experiences and stories.
8. CHAPTER 8: HEALTH-RELATED HELP-SEEKING BEHAVIOUR AND ILLNESS MANAGEMENT OF PEOPLE DIAGNOSED WITH CANCER

8.0 Introduction

This chapter pursues one of the major focal areas of the sociology of health and illness-health-related help-seeking behaviour. The chapter addresses the following questions: 1) what are the trajectories followed by people living with cancer in their quest to become well, to manage the pain and the debilitating impact of the illness in Zimbabwe? 2) How can we characterise the help-seeking behaviour of people living with cancer in Zimbabwe?

The central argument is that a phenomenological analysis enables us to unpack and explicate the complexity that characterises both the decision-making process informing the choice of treatment modalities by participants diagnosed with cancer and the philosophies underlying healing and treatment modalities from non-hospital care systems. A focus on traditional indigenous healing practices is at worst ignored and at best trivialised. Given the current paucity of research on traditional indigenous treatment and healing modalities in the context of cancer in the country, a focus on these is one of the major contributions of this thesis. The chapter begins by highlighting help seeking prior to a cancer diagnosis. It then establishes how (or where) people get a cancer diagnosis. The chapter then discusses the sociology of symptom interpretation, a focus that underlies health-seeking behaviour. The chapter then traces and discusses the pathways to seeking treatment and draws these from the narratives of the participants. The experiences of the participants at the hands of traditional health practitioners (THPs) and in seeking treatment outside the country’s borders then come under focus. The factors influencing the decision-making process on choice of treatment modality are scrutinised. It then traces the point at which participants, in the treatment trajectory, consult THPs and why they do so. The chapter moves on to address the following question: why do people present with advanced cancer disease?
Discussions on the activities of THPs and philosophies informing their medicines and therapies, then ensues. The chapter ends by illustrating the tenacity of the human spirit faced with a life-threatening ailment, in managing and coping with the negative impacts of illness.

8.1 Seeking help on Illness Symptoms Prior to Cancer Diagnosis

Molen (2000) attests that the experiences of cancer do not commence soon after the announcing of the results, but before, when individuals experience the onset of symptoms. The symptoms make some of the individuals suspicious that something might be amiss. When participants were confronted with unusual symptoms at the onset of cancer symptoms (even though they were not aware), many first sought help at medical health institutions dotted in and around the country. In both rural and urban areas, the seemingly less severe conditions were reported at primary health care centres or council-run health centres in urban areas. This preceded the reporting of severe cases at hospitals at district, provincial and ultimately central hospital levels.

For some of the afflicted, the first port of call was a visit to a general practitioner (GP) or a family doctor. Depending on the severity or peculiarity of the condition and the illness narrative of the client, the GP would either refer the client to a physician or attend to the client and prescribe some medication. Thus, when Mrs R.G. discovered blood on her right breast, she went to a GP who was swift in recommending a mammogram. Ms M.V. presented to her G.P when, upon discovering a lump on her right breast, she began to suspect cancer.

The oncologist had this to say regarding GPs,

“A lot of women will tell me that they have been going to their GPs [General Practitioners] and they said this is an infection and they will treat it with antibiotics, this
and that for a year before they decide later to go see a specialist on their own. After biopsy, they are told it’s cancer, and they would wonder why the GP was sitting on this. But most of the time, the GPs also in their minds do not want their patients whom they have been attached to for so long to be diagnosed with cancer”.

The foregoing comments by the oncologist were confirmed in a focus group discussion (FGD) in Harare, where women raised the same concerns with GPs. Their comments make apparent the pitfalls inherent in a long-standing jurisdiction of Western medicine, where one consults a general practitioner first then a surgeon or physician and ultimately an oncologist as a cancer specialist, in that order. This scenario partly accounts for why people oftentimes present late with advanced cancer disease. Various works have confirmed the ‘doctor delay’ among GPs (Facione, 1993; Facione, Dodd, Holzemer et al, 1997; Andreassen et al, 2006).

8.1.2 Where do people get diagnosed of cancer in Zimbabwe and Why?

As a subsequent question on exploring pathways to seeking treatment, I sought to establish where selected people with cancer are diagnosed. It is noteworthy that 29 of the 30 research participants in this study had their cancer diagnosed via biopsy (a body tissue is taken for laboratory tests) in a clinical set up while a magnetic resonance imaging (MRI) was done on one female participant diagnosed with cancer of the liver. In a group interview, all Traditional Health Practitioners (THPs) confirmed that almost all of their clients had their individual cancer diagnosis confirmed by clinical methods prior to receiving treatment because they themselves lack diagnostic infrastructure. The cancer diagnostic paraphernalia in the country is currently centralised in the two major cities of Bulawayo and Harare.
THPs often use experiential and traditional knowledge in reading symptomatic elements and in obtaining clues from the illness narrative of the clients, to ‘diagnose’ cancer in their clients. For instance, Sekuru M.B., a traditional healer who, by the time of this study, had been attending to people with cancer for the past three decades in the Chiweshe rural area, claims to do a prognosis of cancer based on how the client elucidates the illness symptoms. Sekuru N.C. uses his liquid herbal concoction or drug to ‘diagnose’ cancer from skin reactions, 3 days after an ill person takes it. THPs have traditionally relied on *indigenous diagnostic apparatus* namely spirit possession, dreams, bone setting and bone throwing or *hakata* (though such experiences were not shared in this study) (Chavunduka, 1986, 1994; Gelfand, 1962). The elusive and severe way in which most cancer cases present themselves to unknowing individuals, compels many to get diagnosis in a hospital set-up first, before they decide on how to go about seeking treatment.

**8.2 The Sociology of Cancer Symptom Interpretation**

Examining symptom interpretation is instructive to our appreciation of health-seeking behaviours among people with cancer. Mechanic (1961: 189) coined the phrase *illness behaviour* which denotes the “ways in which given symptoms may be differently perceived, evaluated and acted upon by different kinds of persons”. In a similar vein, Kleinman’s (1988) Explanatory Models captures how people use cultural experience in symptom interpretation, which may inform choice of treatment. As presented in Chapter 6, people diagnosed with cancer in this study shared a variety of beliefs, perceptions and interpretations on illness causes and on initial symptoms.

In this study, of the women diagnosed with cancer of the cervix, many who experienced bleeding and vaginal discharge tended, in their symptom interpretation, to attribute the processes of menopause and menstrual cycles (biology and female anatomy). Some women read the occurrences in the processes of giving birth and caesarean section
operations. Of note, Mrs Mut a 59-year-old woman with cervical cancer blended a biological explanation with a cultural belief in malevolent acts by enemies who can temper with a woman’s undergarments to cause the menstrual process to extend indefinitely. Of note, amongst sexually active married women, the initial symptoms of cancer of the cervix were interpreted as either a sexually transmitted infection or the side effects of family planning pills.

For women diagnosed with cancer of the breast, symptom interpretation varied from attributing a painful nipple to a previous bite from a suckling baby, the belching from a breast-feeding infant or *kudzyoverwa nemwana*, to a belief in witchcraft practices evidenced by strained veins or *rutsinga* in the case of Mary. For Ms M.V., drawing from previous experiences with a family history of breast cancer, she correctly suspected cancer, though due to fear she delayed in seeking medical help.

Men diagnosed with cancer of the prostate, namely Mr. C.M, Mr. R.W. and Mr. F.M., interpreted difficulty in passing urine as a sign of old age. They concealed their predicament for a long time until the discomfort became unbearable. Mr. M.M. interpreted his pain and swollen feet as an abscess, as did Mr. B.M., diagnosed with cancer of the rectum. Ms. S.W. and Mrs. N.Y., diagnosed with cancer of the oesophagus, initially attributed difficulty they had in swallowing as symptoms of a previous history with tonsils. In addition, it is imperative to note that the enterprise of interpreting initial symptoms tended to involve general practitioners and medical personnel stationed at primary health care centres. This class of personnel sometimes gave a misdiagnosis. In the case of Mrs. P. M., her cough problem and sore throat, which started in the 1990s, was treated by the GPs as asthma or bronchitis until a proper diagnosis confirmed cancer of the thyroid in the year 2010. Mrs. L.C., diagnosed with cancer of the liver, for a long time received piecemeal medication at health care centres where treatment for ribcage pain or *mabayo* was
prescribed. For Mrs A.C who in the year 2013 was diagnosed with cancer of the mouth, the initial symptoms of what started as a toothache in the year 2000 were interpreted as a boil for several years.

In view of the foregoing, Malterud (1999) cited in Kralik et al (2001: 600) concluded that, “a medical diagnosis is seldom a biological fact but the outcome of a process where biological, cultural and social elements are interwoven”. Due to asymmetrical power relations, bio medical doctors oftentimes sideline clients’ subjective accounts. My study results affirm Zola’s (1966, 1973) submission that the interpretation of bodily sensations as symptoms is embedded within the socio-cultural reality. Alonzo’s notion of containment illustrates how bodily sensations may not be defined as [serious] symptoms as long as they can be integrated within the individual’s normal daily life (Alonzo, 1984). Most women in the study embodied containment in interpreting bleeding, vaginal discharge and breast sensations as ‘normal biological processes’. Pruitt et al (2015) found the dismissal of symptoms as one of the barriers to diagnosis and treatment among women diagnosed with breast cancer in Nigeria. The fact that cancer symptoms may build up for years and present as silent symptoms, further compounds symptom interpretation. Rothwell, Feehan, Reid et al (1997) noted that silent symptoms, for instance a painless lump, cause delays.

8.3 Tracing the Pathways to Health-Related Help-Seeking Behavior and Treatment Experiences in People Diagnosed with Cancer

This sub-section gives the major highlights and analytical synopses of specific treatment trajectories followed by participants diagnosed with cancer in this study. Such a focus combines symptom-interpretation, decision-making, the parties involved and actual treatment experiences.
8.4 Treatment Pathways by Male participants

This study had seven male participants. Mr. R.W. is a married man diagnosed with cancer of the prostate in the year 2006. One morning he realised he could not pass urine and he visited a mine doctor. The problem had been with him for some seven months prior to this incident, but he had assumed that the condition would disappear with time. At the mine, the urine was drained and a Paul’s tubing was inserted to address the problem of passing urine. The mine doctor then referred him to a colleague doctor at a private hospital in Harare for further tests. The results of the biopsy confirmed cancer of the prostate. Mr. R.W. was not told about the stage of the disease up to the time of our interview. The procedures used to collect samples of his prostate gland for biopsy signalled the start of pain and more of the health complications he faces. An oncologist enrolled him on a drug for one year and when the PSA (Prostate Specific Antigen) level results were not good, he was referred to a senior oncologist. At the time of the interview, he had just come for a second chemotherapy session and he was dismayed that despite initial assurance from the oncologist that the cancer had not spread, there were now suggestions to the contrary. This is one case (Mr. R.W.’s) marred by poor doctor-client communication as well as poor doctor-to-doctor communication. This subject has received a lot of attention in the literature (Larsen and Smith, 1981; Stewart, 1984; Ong, De Haes, Hoos et al, 1995). The case further demonstrates that the initial treatment received or the very first practitioner who attends to a client tends to shape the treatment journey of the client in times ahead (Thongsuksai, Chongsuvivatwong and Sriplung, 2000) The character of a client makes a difference as well in terms of treatment pathways as well as the whole experience. A more inquisitive and assertive character would seek clarification with the doctor on every procedure, stage of the illness and regarding the side effects.
The second case is that of Mr. S.M. (full story in Chapter 5, pages 112-115) a 33-year-old single man diagnosed with cancer of the colon in the year 2011, and now lives with a permanent stoma. The case indicates how the individual and parents ignore initial onset of symptoms, which may come to present as cancer later. It was the severity and advanced nature of symptoms that prompted his seeking of help at a major hospital. Zola (1973) posits that people accommodate symptoms and it is not until something critical occurs that medical help is sought. More so, this was a case of declining treatment (chemotherapy) due to the pronounced side effects associated with it. Similar behaviour is confirmed elsewhere (Pruit et al, 2015). The choice of resorting to herbal medicine was made upon recommendation from people with a similar condition. The availability of and easy access to herbs in combination with a lack of finances for chemotherapy dictated the chosen pathway. His utilisation of homemade remedies like Aloe Vera or gavakava, planted in a home garden, demonstrates industry and strategic action by people with cancer to manage their conditions.

Mr. M.M. (full story in Chapter 5, pages 105-108) had cancer diagnosed on his leg in the year 2010. The case of Mr. M.M. shows late presentation for hospital treatment given the onset of symptoms in the year 2007 and actual diagnosis in the year 2010. Late presentation is partly explained by misdiagnosis by General Practitioners as well as THPs who treated symptoms as a case of an abscess, results which have been confirmed in the literature (Facione, 1993). The case of medical pluralism, such as this one is, where people utilise various treatments sequentially or concurrently, is confirmed by Shahid, Finn, Bessarab et al (2009) among the Aboriginal people of Western Australia. The participant was compelled to consult chivanhu or traditional health practitioners because the hospital had to wait for symptoms (the abscess) to mature in order to take any action. Thus, when people cannot find ready assistance in a health care system, they are likely to look for
interim relief or help in alternative treatment systems. When a similar symptom keeps recurring with no effective treatment in sight, people tend to seek further tests and examination in order to get to the root cause of the problem. In addition, the lack of finances and the worsening of a health condition in the middle of hospital treatment (possibly due to side effects) lead clients diagnosed with cancer to seek alternative treatment (Pruit et al, 2015).

Mr. G.M. is a 48-year-old man diagnosed with cancer of the oesophagus who came to utilise both hospital treatment (surgery, chemotherapy) and herbal medicine from Sekuru N.C. and another female herbalist to whom he was referred by relatives. In his case, when some relatives saw that his problem was persisting, they then suggested THPs in addition to biomedicine.

Mr. B.M., a married, HIV positive man diagnosed with cancer in the rectum was treated of an abscess in the anus when he presented at a hospital in 2012. He received an injection and pills and the boil disappeared only to reappear in 2014, now cancerous. At the time of the interview, he had utilised hospital treatment (radiotherapy) alone in addition to prayer. The case of Mr B.M is one among many whereupon General Practitioners only treat the external manifestations of disease symptoms and do not usually refer clients for further examination. As a result, he presented late with advanced cancer.

Mr. C.M. (full story in Chapter 5, pages 120-121) presented late with advanced cancer of the prostate after years of ‘normalising’ leg and back pain only to seek medical help after a major disruption of bodily functions (Arndt et al, 2002). The decision by relatives to seek help from a traditional healer indicates how beliefs about metaphysical causes of ill health are inherent among Shona-speaking people (Chavunduka, 1994; Mararike, 2011) and how the extended family influences treatment decisions. Shahid et al (2009) found similar
observations among Aboriginal people. In addition, when people continue to experience pain—they open up to various treatment modalities in order to halt or manage pain. Of note, the case demonstrates the pervasiveness of masculinities whereupon Mr. C.M. initially declined to take his wife into the consultation room with the doctor, due to the link of the condition with male anatomy and possible sexual dysfunction (Courtenay, 2000; Chapple Ziebland and McPherson, 2004). Another case of advanced cancer of the prostate was that of Mr. F.M. (full story in Chapter 5, pages 117-119). This is a typical case of declining surgery on cultural grounds. On the same note, I further argue a case of hegemonic masculinities where the participant declined to have his testicles removed. Again, the influential role of an aunt or tete, or elder sister to Mr. F.M. was demonstrated when she brought a traditional healer. Typical of a traditionalist, the participant used traditional herbs like ginger or tsangamidzi in managing constipation.

In relation to the health-related help seeking behaviour of men diagnosed with cancer or men’s health-seeking behaviour in general, various studies have submitted several theoretical explanations in comparison with women. These studies suggest that generally men are reluctant to seek help from medical professionals and to utilise modern health care facilities (Merckaert, Finn, Bessarab et al, 2009; Addis and Mahalik, 2003; Subedi, 1989; Onokerhoraye, 1999). Many explanations to account for such behaviour in men are often sought in gender notions of hegemonic masculinities, the general tendency by men to deny weakness and their rejecting help as key practices of masculinity (Courtenay, 2000; Addis and Mahalik, 2003). In relation to cancer of the prostate, men were found to be reluctant to consult a doctor (Chapple and Ziebland, 2002). In addition, Chapple et al (2004) found that men delayed seeking help because they did not recognise the symptoms of testicular cancer and feared lacking masculinity and appearing weak. However, it is imperative to note that the notion of masculinity is a contested one, and is relative and fluid (Connell,
1995). In addition, studies have also shown that old age (the case of Mr F.M) was associated with general apathy to seek medical help as old people ‘normalise’ health challenges to old age (Arndt et al, 2002)

8.5 Pathways to treatment Followed by Women Diagnosed with Cancer

Most women who were diagnosed with cancer of the cervix, who experienced bleeding at the onset of the illness tended to ignore or ‘normalise’ the symptoms. It was apparent as well that many women experience bleeding and some go on to die due to excessive bleeding without any medical assistance due to lack of knowledge (FGDs, KII). The uncharacteristic nature of illness symptoms prompted some people with cancer to visit the hospital for diagnosis. The case of Mrs. Mut a married woman diagnosed with cancer of the cervix reflects the process of decision-making in a typical Shona family and indicates the fluid nature of choice making in a particular illness context. It is interesting to note that the father to Mrs. Mut, who had come to visit his daughter at the hospital, took to task his son-in-law to explain why he had arranged to have his daughter, Mrs. Mut to undergo surgery without the knowledge and consent of her father. Mrs. Mut jumped to the defense of her husband,


(I said, father do not trouble my husband. I want to tell all without any timidity. I became very sick and I was bleeding, the amount of blood which could fill several jars. I could not pass urine. Do you think I could go for 2 days without passing urine? This is what
prompted us to act with haste. My father understood and it was fortunate that I was alive and speaking for myself).

The foregoing incident demonstrates how complicated the decision-making process on a major illness requiring major treatment can be in families. Among the Shona, married women continue to be viewed as aliens or *vatorwa* in their husband’s families and their maiden family wield and retain control over them. The incident also demonstrates how the severity of the illness and the urgency it demands can prompt quick decisions without reaching collective decisions.

**8.6 Treatment Experiences at the Hands of Traditional Health practitioners**

Not all people had good experiences at the hands of traditional health practitioners. Mbuya C.C., a 68-year-old widow diagnosed with cancer of the cervix shared rich negative experiences at the hands of THPs who attended to her soon after she was suspected of cancer at a local hospital before actual diagnosis,


(In my case, I have a real experience to tell. At the onset of illness symptoms, I first presented to traditional health practitioners, where I experienced even more damage and worsening of my condition as I was no longer able to pass stool or urine and the pain was increasing. I then went to the hospital. So if you ask me, there is no good from traditional healing practices).
Ms. Bee, a 23-year-old single mother of one diagnosed with cancer of the vulva after years of misdiagnosis reported an incident with a traditional healer who ended up asking for her hand in marriage despite her poor health condition. Such an experience just goes to indicate some of the gendered experiences women go through with traditional health practitioners when they have sexual and reproductive health conditions.

8.7 Seeking treatment outside the country borders

For some people with cancer in Zimbabwe, the high cost of hospital cancer treatment and the prospects of high quality treatment infrastructure and optimal outcomes took some people with cancer out of Zimbabwe to neighbouring South Africa or even as far as India. The case of Ms. J.M. (pages 115-117 in Chapter 5) illustrated dark experiences, while seeking treatment in South Africa. Ms. Rose, a 57-year-old woman diagnosed with cancer of the colon, narrated a series of not-so-good experiences in South African health institutions as well. Again, the propensity by some medical officers to decline to disclose a client’s real disease and condition was illustrated, something, so it seems, which is motivated by a desire not to instil further psychological distress. However, doctors’ non-disclosure that clients are suffering from cancer becomes one of the prime reasons why people present late. To Sontag (1978:7) “The solution is hardly to stop telling cancer patients the truth, but to rectify the conception of the disease, to de-mythicize it”.

8.8 Doctor-inflicted Injuries

Most quantitative clinical studies do not pay attention to doctor-induced injuries among people receiving hospital cancer treatment. For Ms. M.D. a 64-year-old woman diagnosed with cancer of the cervix, the third surgery which in her view was done hurriedly (possibly, by junior doctors who lacked experience, as she perceived it), left a huge scar which accidentally combined the urinary tract and anal opening. The tube she was inserted to redirect the urine and allow the wound to heal caused her much pain that she could not
sit. She ended up visiting Sekuru N.C. whose herbs eased her pain and healed the wound while the tube continued to cause her discomfort. In addition, other cases in point were those of Ms. M.V. and Ms. M.W., both of whom initially had breast-conserving surgery and ended up experiencing a recurrence, causing a lot more pain and psychological distress. Writing within a Marxist tradition, Illich (1976), a staunch critic of Western medicine posited his notion of clinical iatrogenesis, a reference to the pain, dysfunction, disability and anguish resulting from technical medical intervention errors by doctors on defenceless clients. According to Illich (ibid) such cases are rising to rival morbidity due to traffic and industrial accidents, making medicine, one of the most rapidly spreading epidemics of our time.

8.9 Decision making in choosing Treatment Modality

Understanding the decision-making processes in the choice of treatment modalities after diagnosis and parties involved is vital for nursing and clinical practice and in tailor-making culturally sensitive and appropriate educational programmes-as this can help in the identification of gatekeepers and influential actors (Ahmed et al, 2001; Airhihenbuwa, 1995; Shahid et al, 2009). It is noteworthy that many participants utilised various treatment modalities simultaneously or side by side with biomedicine, what I refer to as medical syncretism.

The results from this study reveal the role of various socio demographic factors (as illustrated in Appendix 7, pages 339-341) in shaping and mediating the decision-making process. It is imperative though, to note the fluid nature of the decision-making process, which was contingent upon the interplay of various factors at a particular time in a particular context. In terms of marital status, for the divorced or widowed, the decision was usually reached between the widower/widow and his/her children (biological or social) who usually stood to provide financial support. In the case of no children, siblings tended
to weigh in. Equally important the concerned [able] individual had leeway to make an independent decision on his/her own. For some like Ms. M.V. and Ms M.W. who had a strong familiarity with hospital care prior to diagnosis, the decision was largely independent, with some involvement of the children along the way. This was the case with most of the participants diagnosed with cancer on various body sites in this study.

For the married couples, the two spouses and their adult children usually made the decisions on choice of treatment. More urban families tended to resemble the nuclear family in the Murdock’s (1951) sense involving husband, wife and children born of the union. The spouse and children were more influential in a context where they provided financial and social support. In such an arrangement, a family chose whether to consult members of the extended family or not on important decisions. This arrangement applied to the majority of cases in the study, in such family units.

In rural set-ups, a family usually had an obligation to reach big decisions on treatment modalities in consultation with the extended family especially the parents of the person diagnosed with cancer. Typically, among the Shona, a male partner whose wife is diagnosed with an ailment like cancer, has to get the consent of his in-laws before any surgery could be done as a gesture of respect and protocol. For Mrs. A.C., a married woman who was diagnosed with cancer of the mouth, parents from the husband’s side and her side where influential in dissuading her from enrolling on radiotherapy.

For the more educated and inquisitive people who strongly believed in the abilities of Western medicine, like Mrs. P.M. and Ms. M.V., independent decisions informed by personal research tended to be predominant, albeit with support from family. For example, when Mrs. P.M. was diagnosed with cancer of the thyroid in 2010, she researched on her condition on the internet and in textbooks. The result was that whenever she went for
doctor consultations she would ask questions on various therapies or prescriptions before she adopted them. To Mrs. P.M. it was crucial for people with cancer to acquire more knowledge on the possible treatment regimens for their particular condition, so that they could ask the doctor the right questions.

From a close analysis of many cases involved in this study, the financial position or a poor financial status proved to be one of the most important factors shaping and mediating on choice of treatment regimen. A strong financial position tended to cut across all other factors like age, gender et cetera to hold sway on influencing choice of treatment. In the case of Mary, her brothers funded her treatment by THPs only because they could not trust hospital treatment when it comes to cancer.

There were certain contexts where cancer service organisations namely the Cancer Centre and Island Hospice exerted influence in choice of treatment procedure by people diagnosed with cancer—where they had a formalised and active engagement with major referral hospitals. Such organisations used sapiential power (knowledge power) based on their experiences of attending to people with cancer. Ms. M.W. was persuaded to demand full mastectomy after getting breast-conserving surgery— to avoid any eventuality of possible recurrence. Medical doctors, just like THPs, wielded considerable power in shaping the help-seeking behaviour of their clients. A doctor advised Ms. J.M. never to attempt any medicines from traditional healers, warning that she would die. However, not all people diagnosed with cancer adhered to doctors’ instructions as many tried a number of remedies concurrently with hospital treatment in order to fight the ‘incurable’ cancer.

In relation to the influence of the demographic characteristics of participants with cancer in shaping health-related help-seeking behaviour, the literature confirms the associations though many such studies are from developed countries. Such studies include Tipping and
Segall (1995); Leventhal and Prohaska (1986) who found that widowed and divorced women had a higher risk of delay. In this regard, Facione (1993) cites the lack of support as the reason. In my study, the marital status factor was salient in swift decision-making on the choice of treatment due to women’s independence from the clutches of patriarchy. In tandem with my study findings, Arndt et al (2002) found older women to be more prone to procrastinate on early detection of cancer of the breast and older women tended to ‘normalise’ the symptoms to normal ageing (Facione, 1993; Ramirez et al, 1999). Such empirical evidence is corroborated by my study.

8.10 At What point were People Diagnosed with Cancer Consulting Traditional Heath Practitioners and Why?

As a subsequent question on examining the pathways to seeking treatment, I sought to establish when participants with cancer consulted traditional health practitioners. As illustrated in Appendix 8, page 342, of the 30 participants with cancer; 10 or 33% had used some form of complementary or alternative medicine (at the time of the interview); 25 or 83.3% had utilised some spiritual therapy and 8 or 26.7% had utilised traditional healing. People faced with a life-threatening ailment like cancer practise what can be termed *medical syncretism* or medical pluralism whereupon they try various remedies in search of a cure (Bury, 1982, 1991; Chavunduka, 1994, Zola, 1966, 1973; Shahid et al, 2009). The World Health Organisation (2002) observed wide use of traditional medicine especially in Africa where it estimates that between 60 to 80% of the people utilise traditional medicine in both primary care and in secondary care. Of note, Levy (1997) reliving her personal experiences with Shona cancer clients at Parirenyatwa public hospital in Zimbabwe, observed that the Shona people in Zimbabwe are strongly embedded in their traditional religious beliefs including faith in traditional healers. Below (section 8.10.1 to
8.10.8) I attempt to draw taxonomies of the interactions between THPs and participants diagnosed with cancer in this study.

8.10.1 Cultural Beliefs or Myths?

First, there was a group which I term *cancer culturalist-nihilists* which comprised of people who put faith in indigenous [Shona] healing practices or *chivanhu* in cancer treatment and who declined hospital cancer treatment altogether. Thus, they only went to the hospital for a diagnosis, but were then treated by THPs (this group may be treated of other ailments and health conditions other than cancer at the hospital). The rallying point for such people was the cultural belief or myth that cancer was meant to be treated through traditional healing means and that hospital treatment often failed. The other twin *cultural belief* or myth was that once one received hospital cancer treatment that would render *chivanhu* impotent if not incapable of treating one’s cancer. Of the 30 participants, I found the case of Mary (pseudonym) falling in such a category. Mary, a 51-year-old married woman from a rural farm was diagnosed with cancer in the year 2013 after experiencing pain and breast discharge since 2009. Initially she perceived it was *rutsinga* or a strained vein (witchcraft related illness). She told her story,

“Ndine hanzvadzi dzangu dziri muno mutown saka takaungana tichida kuona kuti toirapira kuchipatara here kana kuchivanhu, ndokubva pataurwa kuti chirwere che cancer chakangogara chataurwa kuti kuchipatara hachisi kuzorapika. Saka zvayangobatwa chete kuti icancer tochitsvaka kuchivanhu tichiziva kuti tiri kurwisana nechirwere chakati...”

(We assembled together with my brothers here in the city to decide on possible treatment I could get after a cancer diagnosis; whether hospital treatment or traditional healing methods. It was then noted that traditionally cancer was not treated successfully at the hospital or curable bio medically. So now that we now knew that it was cancer from the
hospital diagnosis, we needed to look for THPs who treat cancer). Three months down the line, I learnt of Mary’s death. She was also HIV positive. In addition, similar sentiments akin to this group came from FGDs and key informant interviews with THPs.

Confirming the findings in the foregoing, Petersen, Soucar, and Sherman-Slate (2004) highlighted that health, health practice and care seeking are culturally bound while Lees and Papadopoulous (2000), Dein, (2004) and Yeo, Meiser, Barlow-Stewart et al (2005) noted the influence of culture on cancer in decision-making around care-seeking and accessing of services. It can also be argued that people in the same category with Mary, were characterised by fear of hospital cancer treatment and lack of education in basic information on biomedical cancer treatment. Of note, in the context of the case raised, traditional medicines and indigenous healing actually become the main form of treatment modality and not ‘complementary’ treatment.

8.10.2 Money and Treatment Choices

Another group of cancer culturalists by default comprised a group of people who could afford to pay for diagnosis, not mainstream treatment costs, and hence end up resorting to traditional indigenous healing as the main treatment modality. Data from the various sources provided evidence that due to poverty and lack of income in a subdued economy, many people get diagnosed but do not go on to access treatment. Thus, instead of becoming despondent and wait for death or leave the gangrene to ravage them, they would seek help and treatment from THPs especially those with a proven record of accomplishment in their communities or outside. For some who respond well, who witness a wound that could not heal healing and for women who stop bleeding-traditional medicine and healing became their major treatment modality and some may not see themselves visiting the hospital (unless to verify the status of the tumour). In my 30 core cases, several
participants confirmed challenges with finances which forced them to discontinue hospital treatment indefinitely or which led them to attend chemotherapy and radiotherapy sessions inconsistently. Pruitt et al (2015) in their study of barriers to diagnosis and treatment among women with breast cancer in Nigeria, revealed that financial challenges were a salient factor. In view of the foregoing, it is pertinent to highlight and assess the flexible modes of payment offered by some THPs who were attending to people with cancer in this study—a pull factor. In the case of Sekuru M.B., a well-known traditional herbalist in the Chiweshe Rural Areas did not charge a specific amount of money for treatment neither would he turn away someone who did not bring cash. He though, expected a nominal fee to compensate for the labour and pain he endures in the forests while looking for the treatment herbs. He said,

“...ini zvangu munhu akauya achiti handina mari handirege kumubatsira asi ndinongoti ndipoo huku yako, ndipo mari yekutsvaga kwandaita musango, kana wabatsirikawo unozouya uchitenda nezvaunoda”.

(The way I operate, when someone seeks help without money, I do not turn them away and instead they could pay me even with a chick-bird to compensate for my labours. When they get satisfied with the effectiveness of the medicines, they could later decide a substantial compensation of their choice). The same method also applied to Mai Bridget, a female herbalist in the same area. In fact, I found the practice common among most THPs in the rural areas. When compared with hospital practice, the model by THPs tended to be flexible, welcoming payments in kind and giving room for negotiation. Of note, payment was tied to satisfaction with service, which is not the case with biomedicine, whether there is treatment failure, or not. With Western medical institutions, one may not necessarily get services without paying while with THPs not only were the costs cheaper but the payment systems were flexible in addition to being tied to treatment success.
8.10.3 Cancer Medical Syncretism

Furthermore, there was a group of people who can be referred to as cancer medical syncretists who were the majority of participants and may likely be the majority in the wider population. This comprised a group of people who in light of the lack of a cure for cancer, acknowledging the fatal nature of cancer, recognising their advanced cancer illness and upon treatment failure-they take cancer as a battle and they mobilise every possible therapy at their disposal against the gangrene! They tended to harness the best that could be realised from biomedicine and the best from indigenous traditional healing practices including complementary medicines. Thus, for instance, after receiving radioactive iodine therapy and surgery for her stage four cancer of the thyroid, Mrs. P.M. went on a ‘medicines shopping spree’ where she tried traditional herbs and Chinese medicines; she also consulted a faith healer and assembled her own home-made remedies drawn from her research reading. In the end, Mrs P.M. cannot credit one treatment modality to her current state of remission. Mr. S.M. came to rely on traditional herbs and a consignment of herbs from Pakistan after a major surgery, which left him with a permanent stoma. Ms. L.M. used traditional herbs sent from her rural home together with morphine during her palliative care with cervical cancer. Mr F.M. consulted traditional healers and used traditional herbs during his sickness due to his traditionalist worldview. This group is an epitome of the tenacity of the human spirit in the face of adversity and possible death. This group did not heed calls by proponents of Western medicine who warned of the possible backlash effects of non-standardized traditional medicines like renal failure. Maher (1999) and Shahid et al (2009) found rampant use of bush medicine and Traditional Aboriginal Healing practices among the majority of people with cancer either sequentially or concurrently with Western medicines in Western Australia.
8.10.4 ‘Having nothing to lose’: Palliative Care and choice of Treatment

In addition, there was a group of people under palliative care either due to advanced cancer where no radiotherapy, chemotherapy or surgery could be administered or due to treatment failure. Sekuru N.C. noted that the majority of people diagnosed with cancer that he and others come to attend to would have gone through all hospital treatment regimens without any marked improvement to their health, in a typical medical merry-go-round noted by Robinson (1988) cited in Bury (1991). Mr. C.M., who was diagnosed with advanced cancer of the prostate, was put under palliative care, after surgery where no radiotherapy and chemotherapy could help any more. For Ms. S.W., a woman diagnosed with cancer of the oesophagus, traditional medicine and healing was the last option having been discharged from hospital due to treatment failure. Similarly, for Mrs L.C., a married woman diagnosed with cancer of the liver, which had metastasized, with all major hospital treatments regimens ruled out, there was every reason to try traditional healing and traditional medicines. Thus, in this scenario, utilisation of traditional healing practices and non-hospital remedies was the major option where major hospital treatment regimens were ruled out.

8.10.5 Declined Hospital Treatment

For people diagnosed with cancer who decline hospital treatment due to cultural beliefs, fears of adverse hospital treatment, side effects or pressure from family members, THPs and various complementary therapies were the major if not the sole available option. When Mrs. L.K., a married woman diagnosed with cancer of the leg in the year 1992, declined double amputation (surgery) she came to rely on spiritual therapy, traditional herbs and homemade remedies. Effectively, what she did was blend Western medicines and traditional Zimbabwean medicines and thus stayed alive to the present. To her, the welfare
of her children, which stood to be jeopardized from amputation, was primary compared to the possible consequences of defaulting on surgery.

Mrs. A.C., who together with her family declined radiotherapy treatment as a follow-up treatment after surgery in 2013 due to myths and family history ‘stories’, went on to consult several THPs in and around the country (including Mozambique) for a possible cure for the cancer in her mouth, all to no avail. When she resurfaced two years, later the tumour had spread to her face. Consequently, she had become agreeable to radiotherapy. Of note in the context of the cases raised, traditional medicines and indigenous healing actually became the main form of treatment modality and not alternative or complementary as evidenced in the cases of Mrs. A.C., Mrs. L.K. and Mary.

8.10.6 Restorative Medicine

This study found that people diagnosed with cancer turned to THPs in order to manage some of the grave side effects of hospital cancer treatment. Bury (1991) makes an important observation that expectations of treatment change at different points in an illness trajectory. In light of the demanding radioactive iodine therapy that she received, Mrs. P.M. experienced numerous side effects. As a result, she started taking Chinese supplements to help her body recover together with traditional herbs and massage. Elderly female participants who underwent mastectomy or surgery and then radiotherapy, used traditional herbs to help expedite the healing process of the wound. Most people diagnosed with cancer came to share these practices during chats at review clinics and in support groups for women. Thus, for Bury (1991) medicine will have addressed both instrumental (shrinking of the tumour) and affective (repairing worn out tissues for quality of life and personal re imaging) needs of a person.
8.10.7 The Sisyphus Syndrome

There were cases where participants diagnosed with cancer could go for some time experiencing harsh side effects of aggressive cancer treatment without seeing any evidence of marked improvement in their health. According to Jobling (1988), cited in Bury (1991), such people find themselves in a *sisyphus syndrome*. Jobling (ibid) observes that they are “Like Sysyphus who was condemned by the gods to roll a boulder up to the hill, only to see it roll back down again, so clients go through many procedures of treatment regimens and may not see marked change” (Jobling 1988, cited in Bury 1991: 459). Mr. M.M., a married man diagnosed with cancer of the leg had to endure excruciating pain during chemotherapy, which relegated him to the bed, and the next session would start whilst he was in great pain. He finally reached a point where he felt his body could not sustain another session. He went to seek help from Sekuru N.C. a faith healer who used prayer and herbs where he got some relief. As a result, traditional medicines and indigenous healing practices became a respite, in a *medical-merry-go-round*.

8.10.8 Waiting Period

In addition to being a psychological burden, the *waiting period*, while people wait to enrol hospital cancer treatment, became a ‘window’ or *launchpad* for some to kick start their ‘battle’ with cancer. Long queues on the radiotherapy waiting list, extended dates given to some people diagnosed with cancer due for surgery and waiting for *new treatment* after treatment failure, led some people diagnosed with cancer to enlist the services of THPs. In addition, the shortage of treatment infrastructure and increasing demand, led some people to go for several months before being initiated on treatment. For surgeons in public hospitals with a high doctor-patient ratio, this resulted in continuous postponements. Some *waiting* was prompted by the status of symptoms, which bio medical personnel could not handle but had to wait until the symptoms matured. For instance in the case of Mr. M.M.
who presented with a boil on the leg, the hospital surgeons declined to attend to him before the boil ‘matured’ and that was the case for some time. As a result, Mr. M.M. could only be treated of the abscess in the indigenous traditional healing sector. He went for 3 years before actual cancer diagnosis while he consulted amongst many THPs. The literature is replete with incidences and evidence of such provider-initiated delays and the possible consequences (Montezari et al, 2003; Ramirez et al, 1999; Arndt et al, 2002; Andersen et al, 2009).

8.11 Why do People present late with advanced Cancer Illness: Field Results

The question regarding why people with cancer present late for diagnosis and treatment is one of the prominent issues in trying to understand health-seeking behaviours by the same. Below (sections 8.11.2 to 8.11.10), I address this question based on empirical evidence from the field. But firstly, I highlight the conceptual problems associated with the phenomenon (late presentation) and analysis of statistics at hand.

8.11.1 The Conceptual Problematics

‘Patient’ delay in getting a cancer diagnosis and ultimately treatment, is one area that has received a lot of attention from scholars (Facione 1993; Ramirez et al, 1999; Andersen et al, 2009). Many benefits associated with early presentation of cancer are cited in the literature. These include improved survival rates, reduced morbidity and disfigurement and reduced treatment costs, while late presentation leads to low survival rates and progression of the disease (Cockburn, Paul, Tzelepis et al, 2003; Thongsuksai et al, 2000; Ramirez et al, 1999; Richards, Smith, Ramirez et al, 1999; Facione 1993). Studies in cancer diagnosis indicate that it is possible to improve the prognosis and reduce the need for aggressive and extensive treatment upon early presentation (Hansen, 2008; Jensen, Mainz and Overgaard, 2002). Delay in these matters is divisible into two: patient delay viewed as the time lapse
since symptom recognition to initial medical consultation and systems delay conceived as
time lapse from the first medical consultation to commencement of treatment (Andersen et al, 2009). Yet conceptualisation of the phenomenon is not without problems. Firstly, it becomes an ideological issue when studies emphasize the ‘end-point’ utilisation of the formal or official medical channels of Western medicine while visits to THPs and other unofficial channels are perceived as subterranean and as something, which should be prevented (Ahamed, Sobhan, Islam et al, 2001). Thus, when issues of delay are raised, reference is often made to the uptake of official health care systems that are predominantly bio medical. Yet according to Rahman, (2000) many studies on health care seeking behaviour in developing countries conclude that THPs need to be recognised as the main providers of care. In addition, as noted by Andersen et al, (2009) extant studies on patient delay fall short of factoring in existing theories on symptom interpretation. Many studies illustrate how the interpretation of bodily sensations as illness symptoms is embedded within a social and cultural context (Zola, 1966, 1973; Chavunduka, 1994; Alonzo, 1984; Airhihenbuwa, 1995; Petersen et al, 2004; Shahid et al, 2009). It follows that if research participants embody different symptomatic interpretations, they would not define delays in identical ways. In the end, I agree with Andersen et al (2009) that with studies on patient delay, validity will always be a matter of degree and that, in essence, we measure differences in response to bodily sensation, symptoms and the link to specific cancer sites. Nonetheless, despite these conceptual and theoretical ambiguities points can be raised on processes that obstructed participants in this study getting early cancer diagnosis and hospital treatment.

**National Statistics on stage of disease at presentation**

Of note, Jemal et al (2012:9) noted, “About 80% of cancer patients in Africa are thought to be diagnosed at advanced stages of disease, when pain relief is often the only choice of
treatment”. Chirenje et al (2000) established that 80% of women diagnosed with cervical cancer, presented with advanced disease at Parirenyatwa Hospitals in Harare, Zimbabwe. “Information on stage is important for cancer management and is also important in determining survival” (Chokunonga et al, 2015:26). For the first time in years the ZNCR presented data on the stages of the disease at diagnosis, in their annual report for the year 2013. Accordingly Table 1 below shows the number of cases of cancer in Harare (the capital city) and Zimbabwe, disaggregated according to stage of diagnosis.

Table 1: Current Statistics on Stage of Disease

<table>
<thead>
<tr>
<th>Stage of Diagnosis</th>
<th>Stage I</th>
<th>Stage II</th>
<th>Stage III</th>
<th>Stage IV</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harare</td>
<td>0.5%</td>
<td>3.4%</td>
<td>17.5%</td>
<td>5.3%</td>
<td>73.3%</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>0.7%</td>
<td>3.6%</td>
<td>14.8%</td>
<td>4.3%</td>
<td>76.6%</td>
</tr>
</tbody>
</table>

Adapted from the 2013 Zimbabwe National Cancer Registry (ZNCR) Annual Report

Regarding the contents of Table 1 above, the ZNCR went on to add that although the stage of disease for most of the cases registered in 2013 was not recorded, for those that were staged (23.4%), most of the cases (81%) presented with stage III and IV diseases. 18% of the cases presented with stage I and II diseases and only 3% had stage I disease (Chokunonga et al, 2015:25). Data presented on Table 1, adapted from the 2013 Zimbabwe National Cancer Registry Annual Report from a total of 2 459 recorded cancer cases for Harare City shows that 0.5% presented at stage one, 3.4% stage two, 17.5% stage 3, 5.3% stage four while 73.3% was not known. For Zimbabwe, from a total of 6 548, 0.7% presented at stage one, 3.6% stage two, 14.8% stage three, 4.3% stage four and 76.6% was not known. On my sample of 30 cases constituted in this study, it is striking to note that the results on stage at presentation also showed the same trends as that of the
national picture (shown in Table 1) where only 3.3% presented at stage one; 20% at stage 2a, 6.7% at stage 2b, 13.3% stage 3, 16.7% stage 4 and 40% not known as shown in appendix 8 on page 342. In my study, it was apparent though, judging from the illness narratives of participants and observable symptoms of the 40% not known, that the majority presented with advanced disease at either stage 3 or 4 and some were receiving palliative care.

I attribute the not known percentage on my sample to lack of effective doctor-client communication, a recurring observation throughout the study. Either the health professionals were too modest with information (probably to prevent causing alarm in their clients) or they did not make intelligible, medical reports for easy comprehension by clients diagnosed with cancer. It is interesting to note that the ZNCR in their annual report exhorted clinicians to consistently stage the disease, given the high number of cases that were not staged.

8.11.2 Lack of Basic Knowledge of Cancer Symptomatic Elements and Complacency by People in the absence of Pain and Discomfort

On the question why people present late, the oncologist attributed the phenomenon to lack of requisite knowledge about possible manifestations of cancer symptoms by most people in our communities. This is what she referred to as lack of cancer awareness. She pointed out that based on her experiences interacting with clients, most people can ignore a painless lump for 3 to 5 years only to seek treatment when it causes pain and is advanced. Similar sentiments were echoed by a senior sister with Island Hospice who observed that, “they don’t seek any medical attention until there is a complication and that poses a challenge for us”. Similar sentiments were apparent in the life histories and FGDs. de Nooijer et al (2001) and Ramirez (1999) found that patients who do not initially attribute their symptoms to cancer are more likely to delay seeking help compared to those who
believe their symptoms are indicative of cancer. In a similar vein, Rothwell et al, (1997) and Zola (1973) noted that silent symptoms cause delays.

8.11.3 Misdiagnosis and Late Referral by General Practitioners for Cancer Diagnosis and Treatment

A related scenario was that in which family doctors or General Practitioners to whom clients first presented did a misdiagnosis. The oncologist elaborated that when one is coughing doctors can treat for Tuberculosis when it can possibly be cancer of the lung; when one has challenges in eating they will treat ulcers before they think it could be cancer of the stomach or oesophagus. Several female respondents in the study confirmed this kind of systems delay. Andreassen et al, (2006) found similar cases of misdiagnosis among respondents with oesophageal cancer. Pruitt et al (2015), highlighted ‘inappropriate care’ in the case women diagnosed with cancer of the breast in Nigeria at the hands of pharmacists and GPs. Data from Thailand suggested that the first doctor plays a very important role in determining the time lapse of system delay (Thongsuksai et al, 2000).

8.11.4 Fear of Diagnosis and Dread of Cancer

Despite possessing some basic knowledge from education, training or from experiences of a relative previously diagnosed and treated of cancer- some people may develop cold feet to get a diagnosis and would rather remain ignorant. As the oncologist put it, ‘some would say ah if they diagnose me with cancer, I am to go through the same harrowing experience, my grandmother went through with cancer. I would rather not be diagnosed’. The oncologist noted the irony and paradox that fear and apathy is actually rampant among most health care professionals who have elaborate knowledge of how cancer progresses and the ordeal one goes through in treatment. In the case of Nigeria, Pruitt et al (2015) expressed the same point as denial and the common word in Yoruba for cancer is jerere,
which literally means *something that devours you*—something that instils fear among the public and people suspecting cancer.

### 8.11.5 Declining Treatment

Some participants in the study tended to decline treatment altogether. For instance, in the case of Mr. F.M., he declined surgery by citing cultural issues. Paradoxically, he went on to die of advanced cancer. Mrs. A.C. declined radiotherapy as follow-up treatment after undergoing surgery due to fear and family pressure. Mr. S.M. declined chemotherapy due to adverse side effects from the first session. Similarly, in a study by Pruitt et al. (2015) women diagnosed with cancer of the breast declined mastectomy due to fear and some declined treatment because they felt that there were too many tests, the costs, frustration and fear of side effects. In the case of the Aboriginal people in Western Australia, treatment decline was due to perceived spiritual causes of illness (Shahid et al., 2009). However, such people could then present later with advanced disease.

### 8.11.6 Systems delay due to centralised treatment and Diagnostic Infrastructure

As highlighted in the background to the study in Chapter 1, cancer treatment and diagnostic infrastructure in the country is centralised in the two major cities. The oncologist noted that the current situation where rural health centres, mission hospitals and district hospitals send blood and body tissues for a biopsy to Harare the capital city tended to result in 6 months or one-year delay to get feedback on results from a biopsy or imaging. In some cases, some clients go on to die or get treatment late. This is typical of most resource-constrained African countries (Pruitt et al., 2015).

### 8.11.7 Poor Coordination as a Case of System Delay

In a case of systems delay, poor coordination and communication in multidisciplinary treatment and care of clients was apparent in the study. In the case of Mr. R.W., it was
poor communication in the referral system and poor doctor-client communication, which ultimately led to metastasis. The oncologist explained that stage one cancer is usually dealt with by surgeons, and may not reach oncologists. It was quite common that some clients got to be attended by surgeons who remove the seemingly localised cancer via surgery when the cancer may have spread to other parts of the body where it grows again. The case of Ms. L.M. indicated the poor communication of the surgeon with the client who became complacent after surgery and after assurance from the surgeon that the problem had been solved. Unfortunately, for her, there was a recurrence three years later.

8.11.8 Consulting Traditional Health Practitioners

As highlighted already, quite a number of clients in general and some participants in this study sought treatment from indigenous traditional healing systems and the experiences varied with some deteriorating further while others experienced treatment success. When traditional healing failed to work, the same clients would present late at the Radiotherapy Centre as in the case of Mrs. A.C. Confirming the findings is Pruitt et al (2015) who notes that participants return to hospital treatment when THP treatment fails and most physicians they interviewed attributed many delays to THPs activities. Shahid et al (2009) also noted the huge influence of THPs among the Aboriginal people of Western Australia diagnosed with cancer. Ahmed et al (2001) and Rahman (2000), generally highlight the high esteem with which THPs are regarded in most developing countries.

8.11.9 Fear of Radiation Therapy Treatment in Zimbabwe and Therapeutic Nihilism

As has been highlighted throughout the study, one of the most conspicuous and powerful, major highlights of help-seeking behaviour among people who come to be diagnosed with cancer in Zimbabwe is their dread of radiation therapy. The oncologist posited that most clients are enrolled by health professionals for radiotherapy not for curative treatment but
for palliative care, meant to reduce pain, manage symptoms, improve the quality of life and sustain life even for a short period. Conversely and erroneously, people come to associate ultimate death with radiotherapy.

8.11.10 The Religious Factor

The senior sister with Island Hospice noted that complete refusal of medical treatment for cancer especially by the young, even when the disease is still in its early stages in preference for traditional healing and faith healing is one of her striking experiences, in a negative sense though. This can partly be attributed to increasing Pentecostal activities in the country centred on influential charismatic prophets who tend to promote a kind of therapeutic nihilism where modern bio medicine is blacklisted for its side effects in preference for natural healing and alternative medicines. The senior sister had this to say,

“It is a big problem actually especially of late when those young people say they are going to the mountains to pray and come back when it is worse, which is very sad. People leave their medication to go to pray and come to rely on holy water. They disappear at times when they are at stage two and come back at stage four of the disease when the disease would have decimated their bodies.

Various studies have demonstrated how certain religiousness can promote disenchantment with treatment modalities (Pargament, Tarakeshwar, Ellison et al, 2001; McConnell, Pargament, Ellison et al, 2006)

8.12 Traditional Medicine, Indigenous [Shona] Healing Practices and Activities of Traditional Health Practitioners (THPs) in Cancer Treatment and Management

One of the major contributions of this study is the attention given to the role of indigenous [Shona] healing practices and activities of THPs in relation to the cancer illness. The researcher could not find a detailed study with such a focus. This focus illuminates issues
that reflect the lived realities of people with cancer in our society. The study also brings into focus a seemingly grey area in mainstream cancer research and policy thinking. Below I examine the empirical evidence (sections 8.12.1 to 8.12.11)

8.12.1 Etymology of Indigenous [Local] terms for Cancer and Cancer Illness

Metaphor

Beyond Shakespeare’s *nothing in a name*, it is critical for us understand the general etymology of local terms in use for cancer, as part of our discussion on how indigenous black people in Zimbabwe, conceive of cancer and how it is treated. In contradistinction with the dogmatic stance taken by Sontag (1978) in *Illness as Metaphor* and (1988) *AIDS as Metaphor*, the ensuing discussions illustrate the illness metaphor as a resource that espouses rich indigenous knowledge on cancer. Sontag (1978: 3) claimed that “...illness is not a metaphor, and that the most truthful way of regarding illness and the healthiest way of being ill-is one most purified of, most resistant to, metaphoric thinking”. Prudently, AirihiHenbuwa’s (1989, 1995) PEN-3 cultural model implores us to view culture as a positive resource rather than as an obstacle as with conventional health research.

The ensuing discussion was not done by consulting linguists or linguistics but came from interpretations of participants mainly key informants in the study and the participants in the FGDs, in keeping with the phenomenological tradition. The interpretive hermeneutic phenomenology of Heidegger emphasizes the centrality of language in our *understanding* and interpretation of phenomena (Moran, 2000). To Heidegger (1962) language is both a medium and an expression or outcome of culture.

8.12.2 Interpretations of cancer as ‘nhuta’, ‘mhuka’ and ‘imvukuzani’

From the field data, the following Shona terms for cancer were found; *gomarara, nhuta, mhuka* and *imvukuzani* in Ndebele. Shona is the major spoken language in Zimbabwe.
followed by Ndebele. In a group interview with Traditional Health Practitioners (THPs) who attend to people with cancer, they read differences in local terms of cancer as emerging from various dialects among ethnic groups even though all principally point to the same thing-cancer.

The three terms *nhuta*, *mhuka* and *imvukuzani* all raise the connotation of a small animal-a mole. Specifically *nhuta* is a Shona term for a mouse-like creature, a ‘golden’ mole, which makes various molehills, and various gateways underground such that it is very slippery and difficult to hunt down. The three terms are constituted as an allegory or cultural interpretation for the manifestation of the cancer illness-how cancer metastasizes [spreads from one part to other parts of the human body quickly] which in the end complicates its treatment. For example, a cancer can manifest as a wound on one leg and when treated it can recur on the other leg. Cancer can affect one breast and two years down the line, a recurrence can occur on the other breast, spreading to lymph nodes or armpits. In addition, the word *nhuta* can be broken down or re phrased as *kututa tuta*, which suggests mole hill-making in more than one place, which again insinuates how the cancer spreads from one organ to other parts of the human body.

*Mhuka* literally is a Shona term for [wild] animal. One elderly participant in an FGD elaborated that a wild animal not only resides in a secluded place but also is evasive and difficult to hunt down. The same attributes apply to cancer, which may hide for a long time, only to manifest later as advanced disease, difficult to contain or treat. A male participant in one of the FGDs observed that, some people in his area refer to cancer as *pfuke pfuke*, a phrase that implies that the cancer metastasizes from one area to another. Some believe that as the cancer moves, it would be looking for an outlet for instance a wound where it is treated successfully.
8.12.3 Gomarara explained

*Gomarara* is the most common Shona term in everyday use for cancer in the country including in health care centres. Sekuru Pasi, a 76-year-old [retired] traditional healer whose career spanned the years 1975 to 2014, noted that the term *gomarara* literally refers to an alien plant-growth, which invades a tree branch or trunk, a growth different from the parent tree. The very part of the tree where the alien plant growth invades, tend to waste away and if not removed promptly, it ultimately poisons the whole tree to death. As a result, a solution is found in the complete removal of the affected area so that the tree can sprout new budding again. When applied to cancer, the alien plant-growth implies a cancerous tumour, which can invade any part of the human body and cause harm. It may then require surgery to remove the affected part as seen in amputation of legs or mastectomy. *Gomarara* is viewed as a parasite, a thing which comes to feed on another living organism and ultimately causing it to die. Usually, *gomarara* presents in the exterior where it is observable and where it can be treated or removed. One older female participant noted that since *gomarara* is an unwanted thing that invades a tree, it is an allegory of cancer, which grows where it is not wanted or where it is not expected. A 65-year-old male participant in a FGD in rural Chiweshe noted that sometimes cancer presents initially as an abscess or *mota* that could ultimately disappear but when the boil recur three or more times, it is interpreted as *mhuka*, or cancer. In view of the foregoing, such cultural knowledge and assignment of the cancer illness, expressed in local terminology and metaphors can be a resource in nursing practice and in enhancing doctor-client communication especially with the elderly and rural dwellers. Of note, these findings jettison the observations by Levy (1997), that most Shona ‘patients’ have little or no concept of cancer and that there is no word in the Shona vocabulary for cancer. Indeed the observations by Levy (1997) indicate someone who did not fully explore the issue in
detail, local discourses on cancer imbued in the activities of THPs and in ethnomedical knowledge on cancer as illustrated in this study.

In addition, it becomes apparent that there seems to be convergence between indigenous ethnomedical knowledge of the cancer illness and some clinical methods of treating cancer. Just like an alien plant growth, cut to prevent death or further damage of a tree, it seems the same principle informs surgery in cancer treatment. Some THPs would go on to use a concoction made from the removed alien tree plant, *gomarara remuti*, either as dried powder or liquid to treat cancer in various combinations with portions of plant and animal parts known to be of medicinal value. This probably suggests and vindicates the need for collaboration between biomedical practitioners and THPs in pharmacovigilance, in search for new cancer medicines. In the end disputing the hard stance by Sontag (1978; 1988), I concur with Coulehan (2003: 94) that “Illness and healing are inextricably bound to narrative, meaning, and metaphor. To Coulehan (2003: 94) the "strip illness of metaphor" suggested by Susan Sontag, and embodied in contemporary medical practice, damages the patient, doctor, and healing relationship. It promotes detachment, objectivity, and autonomy to the exclusion of connection, subjectivity, and solidarity; and teaches patients and doctors to ignore the power of words and stories to harm, as well as to heal”.

8.12.4 What is cancer like?

To appreciate comprehensively, the cancer treatment and healing philosophies proffered by THPs, it was vital to understand how THPs conceive of and visualise cancer. Their contention had the potential to contradict biomedical knowledge. I too was keen to get to understand how people diagnosed with cancer conceived of the gangrene or how it felt in their bodies as they lived the experience. A striking and recurring narrative by people living with cancer and some THPs attending to clients diagnosed with cancer was constant
insinuations on cancer as a living thing- ‘a moving thing’. A 47-year-old rural woman diagnosed with cancer of the oesophagus constantly referred to cancer by saying she felt it, as a ‘thing’ which would ‘move away’, ‘open’ or ‘block’ the livingstone tube installed in her oesophagus to allow passage of food. To some it was something, which can bite like a mouse. The majority of women participants diagnosed with cancer of the breast reported feeling some moving things in their breasts at the onset of illness symptoms and during treatment at the hospital or by THPs.

One traditional herbalist summed up the belief in the living nature of cancer,


(What I learned about cancer is that it is a living worm-like thing. I have seen the worm three times so far in my lifetime and once that worm comes out, a person with cancer is healed. From way back, people diagnosed with cancer would at certain times report feeling some moving things in their bodies. If we all treat cancer in here, if you administer some medicine to a person with cancer, there are certain times when he/she report feeling some moving things in his/her body. For instance, if you apply some liquid medicine inside the hole of someone with cancer of the leg, you may later see the liquid mixed with pieces of flesh as the worm tries to block the medicine).
Furthermore, close scrutiny of the imagery or metaphors imbued in local language terms of cancer, *gomarara* or *mhuka* or *nhuta* or *Imvukuzani*, all project the image of cancer as a living thing or organism, which can move in the human body and manifest in more than one part of the body. The point is not to adjudge whether such observations as the foregoing are scientifically void or not. The point is to get to understand how people and THPs conceive of cancer as part of their lived realities, as the subject matter of a non-judgemental, Heideggerian hermeneutic interpretive phenomenology.

8.12.5 Indigenous Therapies and Healing Philosophies

It was vital to attempt to understand the philosophies behind the treatment and healing processes by THPs attending to people diagnosed with cancer. Such knowledge may fit into Foucault’s (1975) ‘*subjugated knowledge*’ and which is conspicuously absent in the extant corpus of canonised knowledge on cancer in the country. The actual identification of medicines or herbs or portions of plants or animals used may be ancillary. Most THPs were not at liberty to disclose their closely guarded prescriptions, which they obviously regarded as belonging to their private intellectual property (though some were free to disclose). The study revealed striking similarities between the medicines and treatment philosophies across traditional healers, traditional herbalists who are faith healers, trained herbalists and traditional herbalists who use spirit possession. All the practitioners made use of plant herbs with some claiming to have discovered specific medicinal plants through dreams, some from knowledge passed on from their relatives, and others from experiential knowledge and still others from trial and error (Chavunduka, 1994).

8.12.6 Use of animal portions

One of the medicines or therapies used to treat cancer came from the mole (the mouse-like animal) or *nhuta*. Sekuru Pasi, a 76-year-old traditional healer narrated that he would hunt
down the small animal, which is very slippery and difficult to capture, remove its fur with fire, roast it and dry it. When it dries, he would grind it into fine powder and mix it with other portions of plant medicine (leaves or roots or both). For a [cancer] wound that does not heal the concoction would be applied directly as powder on the wound or as a liquid concoction taken three times a day, or it can be taken in porridge in the morning. This was not a common therapy though with other THPs that I interviewed in this study. It is noteworthy and interesting to learn the philosophies behind the use of portions of nhuta, as part of cancer treatment. Sekuru Pasi explained that the animal creature was medicine in its own right given the diversity of plant foods it consumes. It keeps its food inside the mole and it does not appear outside in broad day light. It mainly feeds on stuff which is deep in earth which means it has healing abilities of illnesses like cancer which are hidden inside and which only emerge without prior warning later.

8.12.7 Herbs (Plant roots and leaves)

All the herbalists dried the leaves or roots of specific medicinal plants and ground them into powder medicine. This was then applied directly on the wound or taken in porridge or mixed with water to be taken as a drink. One herbalist who doubles as a faith healer, Sekuru N.C. would make a herbal concoction mixed in water from fresh leaves and roots and administer this as medicine in liquid form. A client with cancer would take a half teaspoon three times a day (the measurements can be altered depending on the level of pain). Some herbalists encouraged use of finger millet or zviyo one of the traditional small grains to make the porridge, which is mixed with the powder medicine. Finger millet is valued for being nutritious and was encouraged by nurses for consumption by people living with cancer. It is thought to have properties that mould things together- properties needed for a wound to heal.
8.12.8 The Rationale behind different methods of administering the medicines

Direct application of the powdered medicine on the wound heals the wound from the exterior. Taking the herbal concoction as powder medicine in porridge or as a drink/liquid is meant to cure the cancer from inside so that the treatment is holistic. Thus, it was an important healing philosophy that the cancer be treated both on the manifest outside symptom as a wound on any part of the body and internally targeting cancerous cells inside the blood stream or body tissues. It is noteworthy that the same medicines and healing philosophies applied to treatment of all cancer as it presented on different body sites. However, it is important to note a widely held view in society that indigenous healing practices or THPs can successfully treat cancer when it presents outwardly as a wound while it was difficult to heal when it is inside like cancer of the colon or leukemia (cancer of the blood). A traditional healer and herbalist Sekuru Muc, specialised in wounds that do not heal only while other forms of cancer which do not present as wounds were difficult to treat. However, there was a consensus that the same herbal concoctions applied on the wound, can fight cancerous cells in any part of our bodies.

8.12.9 ‘The wound that does not heal’: Experiences

Sekuru Muc was convinced that any wound could be treated and healed completely such that amputations of legs or hands were not necessary and could be avoided. From my home visits to see some people diagnosed with cancer, which manifested as a wound, indeed it seemed the THPs offered effective treatment shown by a wound healing and from the accounts of the healed. During a focus group discussion in Chiweshe, it was highlighted that the former chief medical superintendent, a trained medical doctor would refer some cancer cases especially those which presented as wounds that do not heal to Sekuru M.B a well known traditional herbalist in the area. During a FGD testimony, a man from a polygamous man who had stayed at Howard Hospital for 5 months without any
recovery from a deep wound diagnosed as cancer on the left leg spoke about how his leg was restored by medicines from Sekuru M.B.

8.12.10 Spiritual Therapy

Prayer, prophesy and spirituality played an essential role in the treatment and healing process of people with cancer who get to be attended to particularly faith healers. In this study, Sekuru N.C. used both prayer and herbs to treat clients diagnosed with cancer. I got to attend several of his consultation sessions with people diagnosed with cancer. After, introductions and notification regarding the purpose of visit by clients, he would start by opening the scriptures and sharing the Word of God with all who will attend. The faith healer would then invite everyone in the room to recite a prayer asking for God’s intervention for the sick person. The ‘nurse’ would then prepare the liquid and powder medicines: the liquid one was designated as the proper cancer medicine, while the other two medicines served the functions of stemming out any odour, healing wounds whether internal or external, easing pain and enhancing appetite.

It is interesting to note that prayer mainly served the function of fighting any emergent ‘background spiritual battles’ on the sick client that may work to hinder one’s good response to treatment. Thus, in this context, prayer did not assume a direct curative function but played a complementary and symbolic one to the actual [herbal] medicine. Similar analogies of unnatural causes include the notion of ‘chibhoyi’ (misfortune/bad spell cast by enemies), ngozi (angry spirits of the dead), ‘mhepo’ (evil spirits) and ‘mweya yemadzinza’ (unprogressive lineage spirits) (Chitando, 2009:44). Hence, any comprehensive, sustainable, responsive and effective prevention, treatment, support and care mechanisms have to take the metaphysical realm into consideration (Chitiga, 2008).
8.12.11 Proof of Treatment Effectiveness among Traditional Health Practitioners

With most THPs, proof of treatment effectiveness was on observable changes, disappearance of initial symptoms and competence to perform roles or physical tasks that were not possible before treatment. Thus, for a wound that could not heal the wound would clear, for someone who could not sit or walk, he/she would now be able to, for some who could not eat or pass stool, they would now the able to. Thus, usually after 7 days given by most THPs to see a change, indeed a number of people diagnosed with cancer would see an observable change. How far a client would experience healing, recovery and the overall survival rate, was a secondary issue, it would seem. In any case, in the context of this study, it was beyond scope, as it would have required a longitudinal study. Nonetheless, some testified that they experienced complete healing, which is problematic to assess in the context of medical pluralism.

Waldram (2013:191) made a key observation that studies on the efficacy of ‘traditional’ indigenous healing often fail to consider the epistemologies that underlie specific healing traditions, especially intrinsic notions of efficacy. He went on to elaborate that in ‘transformative’ healing processes, healing is conceptualized as a journey in which the outcome goal is a transformed individual. In ‘restorative’ healing processes, the goal is termination of the sickness and the restoration of health and treatment efficacy is conceptualized as a return to a pre sickness state. In view of the conceptions by THPs in this study, it can be argued that they conceived of the efficacy of their healing in restorative terms. There were ‘transformative aspects as well when they asked for patience and consistence on the part of their clients diagnosed with cancer in taking the medicine, in spite of the disappearance of primary symptoms and especially for conditions, which presented at advanced stages. It is also interesting to note that THPs highlighted the need for clients to present early at the onset of symptoms, as advanced cancer would be difficult
or impossible to treat, an observation also made by Shahid et al (2009) about the Aboriginal Healing practices where participants highlighted the need for early presentation for *bush* medicine to work.

### 8.13 Coping, Strategy and Style among People Diagnosed with Cancer

In line with the third study objective, this section (**8.13.1 to 8.13.10**) addresses the question: *how do participants diagnosed with cancer manage the negative impact of the cancer illness?* Interpretive sociology and structure agency perspectives like Giddens (1984) *Constitution of Society: Outline of the Theory of Structuration*, have taught us not to treat individuals as *tabula rasa* or *cogs in a machine*, who lack agency to think or act otherwise. Bury (1991) chastises sociologists who become obsessed with the constraints facing humanity more than an interest in people’s response in tackling challenges. Gerhardt (1989) cited in Bury (1991: 452) attests that phenomenological models of illness are explicated as a means of enhancing our understanding of the social basis of illness and the negotiated reality, people fashion in response to it.

In his study titled “*The Sociology of Chronic Illness: Review of Research and Prospects*”, Bury (1991: 460) distinguishes three terms namely **coping**: - which entail the cognitive processes whereby the individual learns to tolerate or put up with the effects of illness. It denotes a ‘normalisation’ act, ‘bracketing off’ the impact of illness so that its effects on the person’s identity remain relatively slight. Maintaining a sense of value and meaning in life in spite of the illness is part of coping. **Strategy** transcends attitude to point to actual actions taken to mobilise resources and maximise favourable outcomes (Bury, 1991: 462). **Style** captures the way individuals respond to and present important features of illness while they illuminate on variations, symbolic meanings and social practices within the negotiated cultural order. I found this taxonomy by Bury (1991) invaluable, though in
practice the three elements overlap and mirror each other in such a way that attempts at separating them can be ‘splitting of hairs’.

8.13.1 Support Group Membership and Cancer Service Organisations

Support groups for people diagnosed with cancer and links with cancer service organisations tended to provide psychosocial support and in some cases material support. Three of my participants diagnosed with cancer of the breast belonged to a support group called Reach for Recovery (exclusively for cancer of the breast) where they shared their stories, counselled each other, rendered advice to each other on managing side effects of treatment, maintaining body shape and general coping with some training as volunteer counsellors. They met every first Wednesday of every month for their ‘teas’ at the Cancer Centre. Women who associated with the Cancer Centre stood to get access to a library with material on cancer and related subjects. Clients had access to complementary therapies like massage, reflexology, Indian head massage, meditation, visualisation, Rife, Shiatsu among others. This helped them in managing stress and equipping the body to withstand pain and treatment. Five or six of my participants receiving palliative care had links with Island Hospice and Bereavement Centre where they had access to [death] counselling, home visits by community nurses and access to subsidised pain management drugs.

However, it is imperative to note that most people diagnosed with cancer in rural areas were not aware of the existence of such organisations, and are disadvantaged because of distance. Of note, there was no evidence of support groups for men diagnosed with cancer and men diagnosed with cancer were reluctant to seek social support from the organisations compared to women. Merchaert et al (2009) confirm the observation that more women had a desire for psychosocial support than men did, something which
Navaie-waliser, Spriggs and Feldman (2002) and Neal, Ingersoll-Dayton and Starrels (1997) trace to the process of socialisation and women’s care giving role.

8.13.2 Speaking Positivity

Another striking coping measure and style was embodied in affirming positivity by some participants diagnosed with cancer to ‘bracket off’ negativity and ‘normalise’ the cancer illness. It was mostly women who received counselling and who actively participated in outreach programmes, who tended to affirm positivity. Such women like Mrs R.G, Ms M.W, Ms M.G, Ms M.V and Mrs P.M recognised the power of words and were wary of a possible recurrence triggered by stress. Of note, Mrs P.M a former army captain tapping from her employment history, came to conceive her cancer in war language as a battle she was determined to win. In her words,

“Being a retired soldier I said bring it on! This is a battle I was gonna fight and win”.

Such positivity was grounded in a firm belief in the power of God to heal and in a supportive environment of family members and friends. Personality attributes also mattered like in the case of Mrs P.M who invoked her combative traits to confront her cancer. Similarly, Benzein et al (2001) found that hope was a dominant component when terminally ill people described their experiences of health: hope of living as normal as possible, hope for life without pain and reconciliation with life and death.

8.13.3 Complementary Therapies as a Coping Mechanism and Strategy

As already highlighted in preceding discussions, some people diagnosed with cancer developed a penchant for utilising various homemade and institutionally provided therapies as complementary to their main treatment regimens. Some therapies were meant to manage and cope with the side effects of aggressive cancer treatment as in the case of
Mrs. P.M. who, to help her body cope, roped in Chinese supplements in addition to various spiritual and homemade therapies she discovered from her reading. In addition, it was striking to establish that clients diagnosed with cancer exchanged a lot of experiential information in the Radiotherapy Centre Waiting Area including information on complementary therapies to manage the side effects of hypertension and other associated adverse effects. By utilising a panorama of therapies at the same time, such actions had a cathartic and placebo effect that enabled participants to derive personal satisfaction from knowing that ‘at least they were doing something to fight an incurable disease and it could work’. Corner et al (1995) found the employment of complementary therapies as a coping strategy that could enhance quality of life.

8.13.4 A Passion to Work with People Diagnosed with Cancer

Some female participants went on to develop a passion for cancer-in advocacy education, policy lobbying and in counselling the newly diagnosed. As noted by Park and Folkman cited in Greenstein and Breibart (2000) advocacy is a common route of finding meaning for people suffering from a terminal illness or traumatic loss. From a ‘disrupted biography’ and ‘spoiled identity’, many people diagnosed with cancer may come to lose self-esteem and their belief in self-worth. In the study Mrs P.M, Mrs R.G, Ms M.W and Mrs M.V were actively involved in advocacy work in counselling the newly diagnosed.

8.13.5 Networks of Friends

In tandem with my findings, Benzein et al (2001) found social support from friends and family to be critical in managing cancer by individuals. Some people diagnosed with cancer in this study maintained strategic confirmative relationships and networks of strategic importance in managing their illness. Friendship cliques and networks were maintained among people diagnosed with cancer themselves who were able to advise each
other from actual lived experiences and not from mere speculation. Mr. S.M. maintained friendship with a colleague in Pakistan who supplied him with a consignment of herbs. Mrs. A.C. benefitted a lot from a consortium of church fellows who helped through fundraising activities for some of her treatment costs.

8.13.6 Social Withdrawal, Social Avoidance and Passing as Normal

Withdrawal from some social activities and ‘passing as normal’ and non-disclosure were some of the strategic actions and coping mechanisms by some participants diagnosed with cancer in this study. Due to his condition, living with a permanent stoma, Mr. S.M. withdrew from playing rugby, stopped attending social parties to avoid taking gas-forming foods and he avoided travelling long journeys without a good supply of colostomy bags. Most women who had a mastectomy acquired a prosthesis to ‘pass as normal’ without a disfigured shape. Some participants did not disclose their experience to all in order to manage possible stigma. Women participants with cancer of the breast who experienced alopecia (hair loss) as side effects of chemotherapy went on to put on hats, make-up and wigs to conceal the disfiguring element and to pass as normal. Similarly Kim et al, (2012) found that women wore make-up, wigs, scarves or hats when they went outside home and they tended to reduce outdoor social activities. Goffman (1963) coined the notion of ‘passing as normal’ a process whereby people with a disability or illness conceal their symptoms in order to manage their ‘spoiled identity’. Nonetheless, such acts as the foregoing have been pigeonholed as elements of self or internalised stigma in various literatures on health-related stigma (Eba, 2008; Parker and Aggleton, 2003). It is imperative to read in context how such acts are mobilised as resources by people diagnosed with cancer to manage the discrediting impact of their illness or to avoid more health complications.
8.13.7 Reading and Researching

Some participants developed great interest in researching to get more information about their condition as a strategy, coping measure and style. Notably such participants had an inquisitive character, were educated and younger. Mrs. P.M. was informed a lot about her condition from reading a book given to her by her oncologist, which aided her in strategizing on treatment and on how to manage the illness. Mr. S.M. researched a lot about living with a permanent stoma and stories from other persons living with the condition on internet restored his hope. Similarly Harris (1998) and Fallowfield and Jenkins (1999) noted that information tended to decrease anxiety and facilitate adjustment and coping.

8.13.8 Spirituality and Religiousness as a Coping Mechanism, Strategy and Style

The contribution of spiritual elements to coping resources and management of illness is well-documented (Halstead and Fernsler, 1994; Baider et al., 1999; Roberts et al., 1997; Koenig et al, 2001). Instructive to this study, is how religiousness and spirituality offer resources to people confronted with an illness like cancer, to get inner healing and grapple with existential questions, in search of meaning and life purpose (Puchalski, 2010). One of the striking observation and recurring behaviours amongst mostly women diagnosed with cancer in this study was to tap into spirituality in both secular and religious terms as a coping mechanism. All participants belonged to some religious grouping as illustrated in appendix 7 on pages 339-341. Of the 30 participants diagnosed with cancer; 4 or 13.4% were Catholic, 15 or 50% belonged to a Pentecostal church grouping, 10 or 33.3% belonged to an Apostolic church (Vapostori) and 1 person or 3.3% belonged to African Traditional Religion. Belonging to a church grouping was of strategic importance to some people diagnosed with cancer who in turn stood to get material, financial and psychosocial support. For women like Ms. M.G., a widow diagnosed with cancer of the breast,
affirming Bible verses and hope in God became a personal style. She would allude to scriptures and to God in almost every sentence and speech during interviews.

Another striking observation was a tendency by some participants diagnosed with cancer to practise religious syncretism, by belonging to more than one church grouping at the same time. Of note, some participants had joined recently formed Pentecostal churches led by young charismatic leaders with a penchant for miracle healing, gospel of prosperity and hope and use of symbols like wrist bands acclaimed to ‘protect’ followers from evil. This proved to be persuasive among some participants with cancer who needed ‘tangible hope’ to face a life-threatening ailment.

8.13.8 Embodied Spirituality: Personal Reflections and self-introspection

Spirituality and religion are important facets of life in present-day Zimbabwe, a largely Christianised nation. The study revealed how the majority of men and women with cancer embodied spirituality in their ‘journey with cancer’. One female respondent said,

‘So I have learnt to be humble, down to earth, a Christian who now understands what Christianity is all about because God is there to help no matter what medicine I took, God was there because you know, He is the one who guided me, He is the one who guided those people who treated me’.

It can be argued that spiritual elements are ever-present among people living with cancer in Zimbabwe. This is corroborated by evidence from similar studies in other countries. In their New York study, Stein, Kolidas and Moadel (2015) found that patients living with advanced cancer narrated that their spirituality and religious beliefs shaped their experiences and were important to them. The results from a study of a Canadian population in Ontario by Zaza and colleagues reported that most of the participants used prayer or attending religious activities as a coping strategy (Zaza, Sellick, and Hillier, 247
2005). Similarly, in their study of psychosocial needs amongst persons with cancer in England, McIlImurray et al (2003) extended the knowledge of the relationship between cancer and religious faith. Participants with a faith reported fewer unmet needs generally than those without a faith. In South Africa, Greeff and Loubser (2008) found that Xhosa families that had experienced a period of crisis and hardship depended on spirituality to help them stand strong and bounce back.

8.13.9 A Secular Understanding of Spirituality: The Case of a Hospice

A senior community sister with a local hospice gave a secular description of spirituality asserting that,

‘As an organisation, when we look at spirituality we are looking at patients opening up, patients talking about their own lives. How has my life been when I am sick? What am I hoping for in life? What am I here for? What have I done? Where am I to go to when I die? That is what spirituality is all about. Things like love, hope, and reconciliation with the family. We call that spirituality. It is inside! They have to vent them out. Talk about them’.

These statements resonate with similar findings by Young (2015) on people with severe mental illness who found that spirituality was considered an essential dimension of their recovery offering hope, meaning and a positive sense of self. In a study of how older adults use spirituality, Harvey and Silverman (2007) found that more African-Americans found hope and strength from God or a higher power.

8.13.10 The Role of Churches and Faith healing Among People with Cancer

One of the striking observations made at the major cancer referral centre in Zimbabwe, was the time given to local church pastors during the induction of new and old clients by nurses on duty every morning. The allocation of such time at the beginning of treatment
reviews is a key component of nursing. It is widely acknowledged those traditional health practitioners, among whom we include faith healers, exhibit considerable emotional intelligence which enables them to institute treatment adherence counselling, family counselling and social mobilisation in their communities (Mandizadza and Chavunduka, 2013, UN AIDS, 2006). A knowledge manager with the Cancer Association of Zimbabwe had this to say,

“We have realised that the majority of cancer patients get a lot of support from their church members and pastors. When people are told that they can be healed in churches, this helps create a positive mind. If you knock at a doctor’s door and you have a positive mind, the outcome will also likely be positive.’

Nonetheless, some studies suggest that negative religious coping, such as sentiments of divine punishment (the question of why me), being angry at God, or being disconnected from a spiritual community, were largely associated with an increased risk for suicidal ideation among patients with advanced cancer (Trevino, Balboni, Zollfrank et al, 2014). Winkelman, et al (2011) reported that spiritual concerns and struggles were related to the negative quality of life. Nonetheless, studies show the benefits and effectiveness of spiritual and religious coping in stressful situations (Pargament, 1997; Rammohan, Rao and Subbakrishna, 2002; Pargament and Lomax, 2013). Questions about the meaning of life and death often occupy the minds of those experiencing an illness such as cancer. In their study, Mohr, Brandt, Borras et al (2006) found that religion might help reduce feelings of anxiety, depression, and negative symptoms.

8.14 Conclusion

This chapter is an in-depth exploration of the health-related, help-seeking behaviour of selected people diagnosed with cancer. The chapter looks at all treatment regardless of
whether it is hospital or non-hospital. I was also interested in the treatment that the participants in this study were getting at the time of the interview. The major point recurring throughout the chapter was that the pathways to seeking treatment were informed by the beliefs held by the participants, the stigma and fear associated with different treatment modalities, the availability of financial resources and the influence of families and communities in choice of treatment. With regard to the results, I found the following things striking: all cancer diagnoses were obtained through clinical methods; clinical diagnoses did not correspond to preference for hospital cancer treatment; radiotherapy was dreaded and associated with death; and the majority of participants utilised more than one health care system or treatment modality.

A combination of myths, beliefs, lack of finances, previous history of experiences with hospital treatment and the influence of the family enticed some participants to seek treatment from traditional health practitioners. The salient question of why most people with cancer present late with advanced cancer was addressed with key factors pointing to both individual and system delays. One of the major contributions of the chapter was a discussion on the rich etymology of cancer, rooted in local terminology and the metaphorical expressions on cancer used by indigenous people. Following Bury’s (1991) admonishing that sociologists tend to be preoccupied more with challenges than abilities and capabilities of people to manage and cope with challenges, the chapter ended by discussing how people with cancer demonstrated feisty efforts and great ingenuity in fighting cancer and managing its negative impact.
9. CHAPTER 9: EXISTENTIAL CHALLENGES FACED BY PEOPLE DIAGNOSED WITH CANCER IN ZIMBABWE

9.0 Introduction

The central aim of this chapter is to explicitly present and make intelligible (to stakeholders) the dominant challenges reported by participants diagnosed with cancer and, therefore, quite distinct from the generic accounts shared in the public domain. The question being addressed is ‘what existential challenges do selected people diagnosed with cancer in Zimbabwe experience?’ In line with the thesis of the study, phenomenological analysis is capable of extracting non-medical elements of the illness experience, which are critical for our comprehensive understanding of the cancer illness. The philosophy of existentialism associated with figures like Sartre (1956, 1963), Kierkegaard (1957), Frankl (1969), and Heidegger (1962), shares affinities with my use of the term. I use the term ‘existential challenges’ to identify hitches that directly and tangibly interfere with or threaten the survival and day to day optimal functioning of people with cancer and their families. The challenges come to compromise the quality of life, with the possibility of physical death in certain instances, isolation and ‘social death’ (onslaught on the dignity, self-worth and inner person). A central proposition of existentialism as Sartre puts it is that [human] existence precedes essence. In essence, the focus is on environmental factors that impinge on health outcomes. Inevitably, these challenges are rooted in illness experiences hence some overlaps with discussions raised in Chapter 7. However, the thrust is to ground our understanding of the salient issues in the ‘voices of those who live the experience, which in turn inspires the last chapter (last study objective) of proferring suggestions for a possible plan of action.
Inexplicable Pain

As noted by Foley (2011) and Deandrea, Montanari, Moja et al (2008), worldwide, cancer pain continues to be undertreated, resulting in unnecessary distress to people and their families. One of the major existential challenges faced by participants diagnosed with [advanced] cancer was the excruciating pain, which became a way of life. Mc Caffery and Beebe (1989) who affirms that pain is what the patient says it is, espouse the argument of my thesis here. Such a view tends to be undermined by a belief among health care professionals that ‘real’ pain can only be verified via objective assessment (Luckett, Davidson and Green, 2013). The ensuing power relations are highlighted by Malterud (1999) cited in Kralik et al (2001: 600) that “medicine maintains a distinction between the patients’ ‘subjective’ experiences and expression and the ‘objective’ findings observable by the doctor, dismissing the former and emphasizing the latter”. Such an impersonal and reductionist stance illuminates a disconnection between the doctor’s version of reality and that of the client, the consequences of which pose an existential threat to people diagnosed with cancer.

Dy, Asch, Naeim et al (2008) proffered a crucial argument that stated that the formal assessment of pain, which is essential for follow-up time and for screening, needs to be augmented by more patient-centred care aimed at grounding pain severity within a holistic understanding of the patient and their everyday lived experience. In the case of Ms. M.V., her surgeon kept declining to put her on the morphine drug citing the side effects even though she was reeling with great pain. It took her oncologist to convince the surgeon to put her on morphine. The wife to Mr. C.M. had to improvise (outside the recommendations by the doctor) by adding paracetamol and other drugs to contain the runaway pain experienced by her husband who was no longer sensitive to morphine. To
Porter and Keefe (2011) cancer pain is a complex and multidimensional symptom influenced by social and psychological variables as well as the disease process itself. In addition, drawing from participants’ experiences, the existential threat was brought into sharper focus in the case of an erratic supply of pain stopping drugs, or when people diagnosed with cancer run out of money to procure another supply. The situation was even worse for many people in rural areas who do not have access to hospice care, who endure a prolonged agonizing death without any relief. Regrettably, all institutionalised cancer service organisations in the country including hospice services only rendered services upon recommendation by a registered [bio] medical doctor. This means that clients from traditional medical practitioners would not be considered by cancer service organisations in pain management. Similarly, Luckett et al (2013) noted with concern that despite growth in non-pharmacological strategies in pain management, biomedicine was not supportive. In the end, as noted by Cunnings, Olivo, Biondo et al (2011) unrelieved pain is associated with high levels of anxiety and depression, interferes with the daily functioning including general activity, mobility, active social relationships with others, sleep and enjoyment of life.

9.2 Doctor Induced Injury, Misdiagnosis, Miscommunication and Possible Treatment Failure as Existential Threats to People with Cancer

In line with the thesis of the study, interpretive phenomenology, which focuses on lived experiences, is well placed to extract fringe evidence on possible common medical errors and malpractices by doctors, which are hardly mentioned in conventional medical research. The same occurrences were reported of Traditional Health Practitioners, some of whom caused more damage to clients with cancer when they administered harmful/placebo medicines. Some THPs maintained a stranglehold over clients, even though there was no improvement and when a client’s symptoms could be addressed better in a hospital.
Though not exclusive to cancer, the study revealed cases of medical errors due to negligence or misdiagnosis by surgeons or oncologists, which posed serious existential threats to people with cancer. Ms. M.D., is a 65 year widow diagnosed with cervical cancer stage 2b, whose second surgery went wrong, resulting in the collapse of the urinary tract and anal opening, which upon her last visit, the doctors pronounced the mistake irreparable.

General practitioners (as reported in FGDs and KII) who do a misdiagnosis and hold on to clients while they administer piecemeal treatment to cancer symptoms thereby delaying clients in the process, it can also be argued, pose huge existential threats which threaten human survival. Writing within the Marxian tradition, Illich (1976) a critic of Western medicine highlights the doctor-induced injury, which results in pain, dysfunction, impairment or death, what he called clinical iatrogenesis. To Illich (1976), more damage is done when doctors avoid or prevent litigation and prosecution. In Zimbabwe, medical doctors have a strong association which wields formidable power and which enjoys some immunity from a Minister of Health, himself a practising medical doctor.

9.3 The Cost of Playing the ‘Sick Role’ and Loss of Livelihoods

Phenomenological analyses enable us to appreciate holistically, non-medical challenges associated with the cancer illness. Such a focus is usually neglected despite the huge impact on how an illness is experienced. Talcott Parson’s (1951) formulated the sick role thesis. In keeping with the tradition of functionalism, Parsons analysed illness and medicine in terms of its functional role to the social system. Thus, Parsons analysed the sick role in terms of rights and obligations on the part of individuals. As part of the obligations, individuals are expected to show willingness to want to be well by seeking medical help and they are exempted from normal duties. Literature has illustrated that the cancer illness can lead to entrapment due to financial drain, which combines with the
effect of disease to cause stress (Epstein and Street, 2007). The pronounced impact was felt in the case of breadwinners who had to leave employment or became so sick that they could no longer fend for their families. This then posed a huge existential challenge to the dependent children and spouses. The high cost of hospital treatment drained family resources and brought some to the brink of poverty as they mortgaged their assets to meet the costs of treatment. Sekuru C.N., a faith healer and herbalist, identified loss of livelihoods as one of the major challenges faced by people diagnosed with cancer and their dependents.

In the case of Mr C.M. with advanced cancer of the prostate illness, his wife had this to say,

“...In the good old days, he used to fend for his family. Our sons are out of employment and together with the daughter-in-law; they all look up to us. He is now sick. If it was possible, the government could intervene with assistance. The children here require schools fees, food and clothing from me, a stressful situation indeed”.

Gysels, Hugginson, Rasasekaran et al (2004) defined supportive care as care that helps a person with cancer and their family cope with the disease and its treatment, from pre-diagnosis through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement. In most low income countries in Africa where after treatment care, palliative care and end-of-life care is not a priority at all (Schaepe, Campbell and Bolmsjö, 2011; Stjernsward, 2002), people with cancer continue to live a poor quality of life as a result of unmet needs. Harrison, Young, Price et al (2009) highlight the following ‘unmet’ needs of people diagnosed with cancer: daily living domain, psychological, spiritual, communication and information. Currently, in the country there is little institutional, government or non-government support care in meeting such practical needs.
9.4 Severing of Cordial family Relations

Cancer is one such illness, which has had a far-reaching social impact on the family establishment, a scenario that prolongs the suffering of people with cancer. This compromises their quality of life and threatens their physical and social existence. There were cases of family discord due to lack of consensus on what type of treatment modality to pursue in light of the cancer illness. There was evidence of the breaking up of marriages in the context of stigma and discrimination. In an interview Sekuru C.N., a herbalist, from experience, cited family breakdown or strained family relations as one of the damaging effects cancer has had in communities, with cases of naked discrimination, abandonment, isolation, negligence being reported. These significant observations are usually not given attention in conventional medical research.

9.5 Existential Challenges Faced by Young adults Diagnosed with cancer

Phenomenological analysis and Heidegger’s emphasis on situatedness of participants helps us dissect rich unique experiences of data disaggregated by such demographic characteristics like age and gender. Young adults with cancer tend to focus on different issues and attach different levels of importance to different aspects of the experience depending on the time they were diagnosed (Zebrack, 2011). The cases of Mr. S.M., Ms. Bee and Ms. V.V., all illustrated the challenges with love relationships, dependence on guardians for resources and stigma experiences associated with moral blameworthiness and social identity; all these mediated and shaped by age, gender and socio economic position. Young adults diagnosed with cancer, get to face additional challenges based on the intersection of the cancer experiences with developmental tasks associated with that period (Zeltzer, 1993; Eiser and Kuperburg, 2007). It can be argued that the young adult participants experienced ‘social death’ when they saw their chances of getting into a love relationship dissipating, given their age-the very stage and period where dating is the
defining social enterprise especially because of what it means to be a young man or woman.

9.6 Money as the Password to Treatment: No Money No Access!

Drawing from the narratives of participants with cancer, I came to conclude that many people diagnosed with cancer are stressed more over the cost of treatment they cannot afford and the threats from hospital debt collectors who served them with summons, more than the stress of the burden of the disease itself! In a country where access to health ceases to be a basic right owing to user fees, many who cannot afford hospital cancer treatment, sniff their death upon diagnosis, as diagnosis becomes a death sentence.

Despite a few options of getting funded from the Social Dimension Fund, money is the password to one accessing modern cancer treatment and lack of it thereof, poses immediate existential challenges which threaten the lives of people diagnosed with cancer in Zimbabwe. Pruitt et al (2015) similarly found dire financial constraints on women diagnosed with cancer of the breast and weak health systems as prominent barriers to cancer diagnosis or cancer treatment in Nigeria. The link between poverty and cancer in Sub-Saharan Africa has been highlighted; where due to limited access to health services and poverty, cancer progresses to an incurable stage in 80% of people by the time of detection and diagnosis (Parkin, Sitas, Chirenje et al, 2008; Chirenje, Rusakaniko, Kirumbi et al, 2001). According to Parkin et al (2008), in Africa the lifetime risk of a woman, dying of cancer is double that of their counterparts in developed countries. In a context where, currently, there is no special fund earmarked for cancer treatment-most people diagnosed with cancer confront an existential threat of financial constraints which may cause their premature and agonizing death.
9.7 Existential Challenges due to Treatment Side Effects and Clinical Guidelines

One of the major contributions of phenomenological analysis of [ill] health is to draw our attention to the subjective experiences of clients receiving treatment and giving a holistic picture of the social impact of a health condition. As part of the clinical guidelines, during the time when someone is receiving radiation therapy, people diagnosed with cancer are not supposed to apply water on the body site targeted in radiation therapy. It became an everyday existential challenge and a source of discomfort for women participants, to discontinue a routine of personal hygiene in the genitalia and to disregard self-presentation in their day-to-day life undertakings.

Most female participants, who received chemotherapy, reported the discomfort and distress that came with loss of hair, which undermined their esteem and womanhood. Traditionally, in most societies including ours, to women, hair is a symbol of beauty and performs various functions. Thus, when a woman loses hair during chemotherapy, it is a physical loss which impacts the inner self, which spoils identity, which disfigures and which leaves a woman ‘exposed’ and ‘stripped off’ for her humiliation, making her susceptible to a ‘legitimation crisis’ to justify the loss. To buttress similar observations, Kathryn, Lisa, Cecilia et al (2013: 5) noted that for women the hair is a symbol of attractiveness, physical health and cultural identity and in the case of women undergoing chemotherapy for breast cancer, two important symbols of her womanhood; attractiveness and healthy identity are affected. Thus, alopecia constituted a huge existential challenge to women, especially what it means to be a woman.

When a woman has her uterus removed, she can no longer conceive- a scenario, which comes with heavy costs in our society, where child-bearing is one of the major ‘cultural duties’ and social expectations for any woman of childbearing age. For women, a breast
and a uterus are vital sexual and reproductive organs whose malfunctioning or removal challenges femininity, sexuality and reproductive capacity (Nesvold et al, 2010).

9.8 The challenge of food

Food is a basic human need for life sustenance. In resource-constrained environments like Zimbabwe, and in a context of high lived poverty and limited food varieties, it is a challenge to exercise free will on choice of meals and diet in accordance with the recommendations of health care practitioners. Diet is one of the widely cited lifestyle risk factors of cancer and a crucial healthy lifestyle factor in reducing the risk of cancer or management of illness (Zhang et al, 2015; Dumalaon et al, 2014). For people who live in poverty and who experience food scarcity, the options on preferences of food are quite limited in the battle for survival. It was a familiar picture as well, at the Radiotherapy Centre, to observe that most people, who came from the rural areas and from outside the capital could only afford a basic soft drink, some bread or a bun. The alternative was bringing their own food. Outpatients do not receive food in all health care centres in Zimbabwe.

9.9 Transport and Accommodation

Novel data capturing techniques extracted deeper insights into the challenge of transport and accommodation, which are usually discussed in the media. From listening to gossip and informal chats in the Waiting Area at the Radiotherapy Centre or from overhearing conversations between clients and medical staff, some participants with cancer missed deadlines for review dates put on the medical records due to lack of bus fare. Some in Harare were forced to walk on foot to attend a radiotherapy session. A twin challenge was lack of [overnight] accommodation to cater for people from outside Harare. From semi-detached observations at the Radiotherapy Centre, it was a familiar picture to see some clients carrying blankets, buckets, toiletry and utensils with them. From the informal chats,
I learnt that some clients would resort to sleeping on open hospital floors at night until they completed 23 days (on average) of radiotherapy. These challenges which are not unique to people diagnosed with cancer pose huge existential challenges to people with cancer in the country.

9.10 Existential Challenges of living with a Permanent Stoma

In this study, I captured a single case of an ostomate, a 32-year-old male whose 27 cm long perforated colon was removed and he was, therefore, now using a permanent stoma. The pronounced life changes brought about by the presence of a permanent stoma makes the case unique and worth singling out for discussion. An ostomate with a permanent stoma ceases to use the toilet the normal way. This scenario on its own, posed a huge existential challenge of living with a foreign body part and a deviance of excreting. For an ostomate, incidences of colostomy diarrhoea can cause the ‘bag’ to leak and get damaged, in the process messing up clothes and producing an unpleasant odour. At the time of the interview, Mr. S.M. had experienced colostomy diarrhoea thrice and bag leakages twice. Another challenge presented at a time of travelling, in which case he had to make sure he had enough bags including for contingencies, in the case of colostomy diarrhoea. For someone who has partially disclosed his condition to selected relatives and friends, it became a challenge when he came to share a bathroom or had to explain his condition to strangers who can give mixed reactions. Sometimes the stoma could release an unusual sound as it releases gases, when he took gas forming foods, onion or much water, causing a lot of discomfort. In addition, it was the existential challenge of ensuring a constant supply of colostomy bags to someone who is unemployed and who currently relies on a supply from a non-governmental organisation. Without the colostomy bags, normal social and physical life would not be possible.
9.11 Compromised Quality of Life due to Long Term Treatment-after effects

The World Health Organisation defines quality of life as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1997: 1). Such a novel definition finds better application in phenomenological analysis, which privileges the novel, subjective narratives of participants. Given the terminal nature of the cancer illness and the aggressive nature of the treatment, people living with cancer characteristically find themselves living a generally poor quality life, exacerbated in our context by a poorly performing economy and escalating treatment costs, quite beyond the reach of many. Mr. C.M. perceived his life after being diagnosed with cancer as being of poor quality.

The side effects of breast cancer treatment are well documented in literature. Gho (2013) highlighted self-reported side effects of breast cancer treatment like pain numbness, restricted arm motion, fatigue itself a major source of morbidity and post-treatment distress. Nesvold et al (2010) cited depression, hot flushes, sleep disorders, nausea and broken/painful ribs and impairments in the upper body, which reduces quality of life. Ms. M.V. diagnosed with cancer of the breast 3 decades ago, shared a gloomy picture of the after effects of treatment, particularly morphine and the tamoxifen that she took for 5 years. She was getting frail day by day and her quality of life was being further compromised by approaching old age, social isolation and loneliness, as she had never had a child. Such daily experiences posed challenges of existence emanating from the after-effects of aggressive cancer treatment. Most governments in Africa have no focus on end-of-life care, despite WHO recommendations and calls for high priority for palliative care in developing countries (Stjernsward, 2002).
9.12 Cultural and Financial Barriers in Deciding on choice of Treatment

From evidence presented in Chapter 8, it was apparent that the decision-making process on choice of treatment was variously influenced. It can be posited that people who were available to meet the financial cost of treatment tended to have a big say on what treatment modality people with cancer came to utilise. Coupled with imposing cultural arrangements and scepticism on hospital treatment, some family members came to prescribe indigenous traditional healing systems, as a treatment modality even though the diagnosis would have been done clinically. The major argument, therefore, is that some people with cancer are faced with a matter of life and death in the case of ‘significant others’ other than themselves making treatment decisions on their behalf. The decisions, however, were informed by the socio economic positions of families and people with cancer, the levels of poverty as well as the levels of knowledge of cancer and education. It follows that some not-so-well-thought-out decisions on treatment came to compromise life or cause the premature death of some people diagnosed with cancer—hence a salient existential challenge.

9.13 Encounter with ‘High Risk’ Health Practitioners and Ineffectual Medicines

Drawing from the experiences of people diagnosed with cancer in my study, the lives and welfare of people with cancer came under threat from what I call ‘high risk’ health practitioners, whether biomedical or traditional. In either case, the practitioners advised their clients not to try alternative medication or treatment indigenous healing systems (*chivanhu*) or hospital treatment. Some biomedical health practitioners tended to give a blanket dismissal and condemnation of the activities of THPs without acknowledging exception where THPs seemed to be competent for instance in treating a wound that does not heal and in symptom relief. In the end, clients miss opportunities of healing or recovery from the best that can come from either system.
9.14 Choosing Between the Medical Imperative and the Imperative of Existence

One woman diagnosed with cancer of the leg in the year 1992, declined double amputation observing that, “...it is better I die while I keep my both legs so that I can fend for my children”. The statement by the woman demonstrated some of the toughest decisions and dilemmas that people with cancer faced with amputation must confront. It is a choice between the medical imperative versus an existential imperative. In most instances, people choose the existential imperative over the medical one because they take into account the bigger picture, the welfare of their ‘significant other and that their lives are connected to other people. The woman in question, her rejection of the medical imperative was informed by an existential imperative. Such an expression only goes to affirm that a human being is human in relation to other people and not in singularity.

9.15 “It is better I disclose my cancer rather than my positive HIV Status”: The Burden of Proof of HIV among People with Cancer

Subjective realities unknown to authorities and to most health care professionals which may seem secondary in illness experiences were brought to the fore from an analysis of lived realities and micro elements of human behaviour. Estimates from clinical studies are that 60% of the cancer illness cases are related to HIV in Zimbabwe (Parkin et al, 2008; Chokunonga et al, 2009). A striking observation from my study was the spirited effort by people diagnosed with cancer to avoid being identified as HIV positive or to be suspected as such. Rather, many comfortably disclosed their cancer illness rather than their HIV status. In a key informant interview, the senior sister with Island Hospice had this to say,

“
It is an irony that HIV/AIDS come to our side in the fight against cancer, for instance you will find that if someone especially the younger people is HIV positive and has cancer, they will talk about their cancer and not about the HIV. It seems much worse to talk about HIV.
Both cancer and HIV can be associated with dramatic weight loss, alopecia among women, diarrhoea, vomiting and loss of appetite- all related to the side effects of chemotherapy. Consequently, the public can readily associate cancer with HIV positivity. Therefore, people with cancer seemed to live with an existential challenge, *a burden of proof*, to dissociate their cancer illness from HIV sero positivity- an act of managing stigma. The enigma of tolerating cancer over HIV can be traced to the moral blameworthiness dimension in the HIV arithmetic where HIV is generally tied to promiscuity and moral debauchery while cancer can be easily presented as a natural disease, which anyone including young children who cannot be thought to be promiscuous can be diagnosed with.

9.16 Gendered Existential Challenges in Care Provision: Female Husbands and Male Wives

Men and women occupy different roles and social positions in different societies, though things are changing in a globalising world. It follows that cancer and its impact can be experienced differently among men and women underlined by the prevailing daily culture. In our society, women are culturally expected to care for their ailing husbands while at the same time they monitor their own illness and care for children- a big existential challenge indeed. Ms. M.V., diagnosed with cancer of the breast in 1993, had to care for her husband who was diagnosed with cancer of the pancreas 12 years later. Nonetheless, there were exceptions in the study. I observed a sizeable number of husbands accompanying their sick wives to the Radiotherapy Centre.

In contradistinction, men had to grapple with loss of breadwinner status due to a terminal illness, which put them out of work and relegated them to the home. Men worried about loss of virility in the case of prostate cancer, a development which presents huge existential challenges to their masculinities. It was evident from the narratives of family carers mostly spouses of men with cancer of the prostate that their husbands were no
longer in a position to provide for the welfare of the family as of old. This stressful eventuality engendered a manhood crisis. Metaphorically, the scenario illuminated a transition to female husbands and male wives— a scenario, which presents as a colossal existential challenge to men and masculinities.

9.17 Conclusion

This chapter sought to make intelligible the existential challenges experienced by people diagnosed with cancer in Zimbabwe today. The multiple sources of data which illuminated shared experiences, made a compelling presentation of what an ordinary citizen diagnosed and living with cancer in Zimbabwe today goes through, following Heidegger’s emphasis on situatedness. A recurring challenge is the lack of finances to afford hospital cancer treatment, which is very expensive, and currently beyond the reach of many. Under the spotlight as well, were hostile environmental factors largely constituted by a failure of the government through the relevant ministry to provide adequate, accessible, affordable cancer treatment infrastructure. In addition, a host of other challenges were located in the complicit behaviour of some health professionals who induced harm and delays due to negligence, medical errors and ‘professional bias’.
10. CHAPTER 10: SUGGESTIONS FOR IMPROVING SERVICE DELIVERY AND REDRESSING THE CHALLENGES FACED BY PEOPLE LIVING WITH CANCER AND CONCLUSIONS

10.0 Introduction

This chapter attends to the question: how can we address the challenges facing people living with cancer in the country, to improve their quality of life? A section on recommendations or implications is treated as a given in the last chapter of a study. Usually, the researcher uses deductions based upon the empirical issues raised in the study and own interpretations to make recommendations—a kind of postscript. I have departed slightly from this convention by adhering to the cardinal principles of phenomenological research—that of emphasizing the essences of the experiences as lived and putting at the centre of analysis, the insider view of issues. Thus, rather than being an addendum, this chapter is constituted as one of the objectives of the study whose data was generated mainly from participants who lived the experience and key informants who drew from their experiences of interacting with people diagnosed with cancer. In line with Heidegger’s, ‘double hermeneutics’ the participants’ submissions are blended with the researcher’s interpretations. The questions were tailor-made to enable the participants to make their submissions around policy issues raised in the background to the study chapter on treatment, prevention, support, care, education and research priorities. In the end, the role of the research was to infer suggested solutions from participants and locate this in literature and policy guidelines. The chapter ends by enunciating the thesis of the study and its major conclusions.

10.1 Knowledge, Information, Cancer Education and Sensitization

One of the most prominent and recurring issues throughout the study was the low knowledge levels and awareness of cancer in the context of basic clinical knowledge or ethno-medical knowledge especially those to do with early cancer symptomatic elements.
It follows that the absence of early detection, conspicuous presentation with advanced cancer disease and high morbidity and mortality cancer rates can be attributed to lack of basic cancer knowledge.

On enhancing the knowledge levels and increasing awareness of cancer among the generality of people in communities, the majority of participants living with cancer called for a massive roll out of educational programmes spearheaded by the government. One woman living with cancer of the breast, Mrs. R.G., commented on rural areas as follows,

“My main worry is women in remote areas who for various reasons fail to get information about breast cancer, where to go if they are diagnosed with the disease...”

The packaging of updated information on available treatment infrastructure in the country and other services critical in cancer treatment is crucial. The availability of information not only saves finances but also facilitates prompt service. The energy and zeal that characterised intensive educational programmes and awareness campaigns on the HIV and AIDS epidemic has not been replicated with regard to the growing numbers of cancer cases and cancer deaths in the country.

10.2 Involvement of Cancer Survivors in Cancer Education and Social Marketing Initiatives

For most of the educational programmes, and social marketing initiatives to be successful in effecting behaviour change and awareness, such initiatives would need to ensure the meaningful involvement of people diagnosed and living with cancer. Asked what they looked forward to from government, based on their experiences so far, in terms of prevention and early detection, Mrs. P.M., a woman with cancer of the thyroid had this to say in a focus group discussion,
“...so I find the government should work hand in glove with cancer sufferers to go out and spread the word of cancer, share experiences of our journey with cancer and be able to conscientize those who are living with cancer and not knowing that it is cancer. Because I find that us talking to them, will actually result in early detection. For instance, at our church, ... I had so many people who wanted to talk to me in private because they could not ask questions in front of other people. Early detection will eradicate this problem”.

Thus, the incorporation of people who have real experience with cancer or that of a close relative is meant to compel most sceptical people into action based on lived experiences. The same strategy brought positive results with HIV and AIDS.

10.3 The Need to Dispel Fear of Hospital-Related Treatment and Miscommunication

From field data, it became apparent that there are a lot of myths, misconceptions and miscommunication surrounding cancer in Zimbabwe, including on treatment options. Education and awareness programmes would need to go to the rural areas, to schools, and to all areas where men and women gather including churches, sporting activities, health care centres and traditional ceremony gatherings. Patterson, Neuhouser, Hedderson et al (2002) and Richardson, Sanders, Palmer et al (2000) note that to increase indigenous people’s willingness to accept modern oncology treatments, would require a different approach, one that appreciates and addresses their concerns and provides more psychosocial and holistic care alongside Western medical treatment. Such an approach would enlist local interpretations of the cancer illnesses expressed in local terminology and cultivation of a referral system between biomedical practitioners and THPs based on mutual trust, respect and evidence-based knowledge (which includes experiential knowledge). Again, the involvement of people with cancer who have walked the treatment journey is germane.
10.4 Cancer Information Education Communication Material and the Politics of Language

Participants living with cancer who are active in advocacy work raised concern on the little Information Education Communication material (IEC) available to the public courtesy of the Cancer Association of Zimbabwe (CAZ). Their worry was that the communication material was restricted to the two dominant languages used in the country- Shona and English. They proposed that basic knowledge on cancer (causes, risk factors, symptoms, cancer treatment and management, available support services et cetera) had to be made available in other local minority languages like Ndebele, Venda and Nyanja among others. People who cannot read or write Shona and/or English are disadvantaged.

The tradition of phenomenology underscores the importance of language, as language is a medium of communication plus an expression of culture (Moran, 2000). Of note, the Senior Sister with Island Hospice noted during an interview that some elderly people from rural areas understood better the nature of cancer and its manifestation when it is related using local terms and illness metaphors. Airihihenbuwa (1995, 2007a), Shahid et al (2009), Patterson et al (2002), Richardson et al (2000) and Kleinman (1988) advocate the viewing of culture as a resource in health intervention of which language is part of. In addition, it was revealed that the little available IEC material has very few distribution points. Just like the massive social marketing exercise that characterised HIV and AIDS, the parent ministry had to be involved in the production and dissemination of IEC material on cancer. Advertisements can be posted and broadcast on various media.

10.5 Responsive Leadership: Meaningful Involvement of People Living with Cancer

Molen (2000: 53) noted that, “the voices of people with cancer must be heard and the views of their experience incorporated in the commissioning of cancer services, service delivery and ongoing monitoring of services”. Participants with cancer advocated
meaningful involvement of people diagnosed and living with cancer in providing sensitive leadership. Most people at the helm of cancer service organisations are perceived as not proactive and sympathetic enough to everyday existential challenges faced by people with cancer. They lack the lived experience. The current lukewarm response from government and the private sector in committing resources to people with cancer is also attributed to the lack of proactive leadership. People diagnosed with cancer in my study suggested a replication of similar initiatives to HIV and AIDS, which saw meaningful involvement of competent HIV positive people in the National AIDS Council. A 46-year-old woman diagnosed with cancer of the breast in 2006 made the following remarks,

“Entrusting leadership in people who only have a theoretical appreciation of cancer, he/she is not well positioned to appreciate excruciating pain experienced by people with cancer. Such an individual may give secondary attention to someone in dire need of finances to go for a chemotherapy session or blood tests. But having someone with experiential knowledge of cancer, any available funds would be directed towards helping those patients in need”.

10.6 The Stewardship Role of Government in Coordinating Cancer Programmes

Currently there is no standalone government body tasked with overseeing interventions, resource mobilisation and cancer programming in the country. Women who participated in the focus group discussion in Harare submitted that no meaningful and tangible benefits could accrue to people with cancer in the current situation, of numerous small splinter cancer service organisations formed around individuals who are not accountable to the government or the public. The participants alleged rampant abuse of funds sourced privately from international donors and from donations by private companies during fundraising initiatives. They bemoaned what they perceived as the exploitation of people diagnosed with cancer whose testimonies are used to animate and give moral justification
during fundraising initiatives but such proceeds have so far not been channelled to assist people diagnosed with cancer in desperate need. Thus, such an umbrella body run by the government through the responsible ministry could then rope in representatives of cancer service organisations to give leadership in streamlined thematic areas in education, palliative care and support services and treatment among other areas.

10.7 Dealing with Funding and Cost of Treatment: Government Options as Suggested by Participants

10.7.1 The Option of a Cancer Levy

The first proposal similar to the one mooted by a former deputy prime minister during the Government of National Unity (2008-2013) who herself is living with cancer of the breast, implored the government to consider putting a cancer levy to fund cancer treatment. This proposal was widely shared in personal and group interviews as well as in informal chats.

Mrs R.G a 46-year-old woman diagnosed with cancer of the breast in 2006 said,

*I appeal to the Government to raise money for cancer patients through such things as a cancer levy. The money can be used to buy machines for radiotherapy and mammogram, chemotherapy drugs, medicinal drugs and vitamin tablets that help boost the immune system.*

In light of the proposal on a cancer levy, it follows that other sections of the population feel that there is already a big tax burden borne by workers, hence the reluctance by the government. I would also argue that the lukewarm response by the government on the proposal is partly informed by ‘unscaary’ statistics of incidence cases when compared to epidemic levels of HIV and AIDS at its peak in 1997, hence the continued viewing of cancer as an individualised condition. However, government intervention should be driven
by principles of health equity to a condition which not only causes agonising pain but which is incurable and fatal. In an environment where there is thin donor support, the government has an obligation to assist its citizens live a better quality of life with cancer.

10.7.2 The Option of Subsidizing Treatment Costs

Participants from the urban areas and the more educated implored the government to provide a subsidy on the cost of drugs. A woman with cancer of the colon said,

*Government should subsidize the cost of drugs because they are very expensive and many are dying because they cannot afford the cost of drugs. In my case, were it not for my brother who chipped in, I could have found it difficult to procure drugs*."

It is noteworthy that women drawn from the middle density suburbs of Harare gave a different proposal to that of participants from rural areas. When asked whether treatment should be made free or should be subsidised, women from the urban areas who participated in a FGD suggested subsidy-affordable services while the majority of participants from rural areas recommended free cancer treatment. The differences in response illustrate the differences in life chances.

10.7.3 The Option of Free Treatment and Preferential Treatment

A senior community sister with Island Hospice, suggested that government considers providing free medication and free treatment to the poor and to those with advanced cancer disease. She noted that if the costs of treatment were waived, then people seeking treatment in hospitals would increase.

Participants from rural areas and those from a very low socio-economic status proposed the total scrapping of all cancer treatment costs with the government making cancer treatment free. One male participant in a FGD noted,
“For people lacking medical cover like me, cancer treatment is expensive and you will die. Moreover, diseases like cancer, the government must just make them free. People should be treated free because many are dying.

Indeed due to the current biting economic environment, that has hit the people in rural areas hardest, many now have limited access to disposable income and optimal health.

10.7.4 The Option of Harmonizing Cancer and HIV Funding

Another prominent proposal mooted by cancer activists and educated participants during the course of fieldwork was the possible harmonisation of HIV and cancer funding. According to the Zimbabwe National Cancer Annual Report of 2005, 60% of cancers diagnosed in the country were HIV related (Chokunonga et al, 2009).

A woman with cancer of the oesophagus noted that,

“Then of course we would like them to talk of subsidy. We understand that the financial situation of the country is not stable but what I am saying is let us put cancer levy together with AIDS levy and let the two go hand in hand you know, because definitely we need a subsidy for cancer treatment-its expensive”.

Thus, the association between cancer and HIV at epidemiological level presents an opportunity for possible harmonisation of cancer and HIV funding. However, the current state of affairs where most funds for HIV and AIDS involve multilateral organisations and the donor community restricts any unilateral decisions on the use of such funds. This just goes to demonstrate how a country is limited in setting and implementing its own health priorities when a considerable part of its health budget is funded from the donor community and outside partners.
10.1.8 Cancer Designated Pharmacy Outlets to Ensure Drug Availability

Due to economic stress, which has not spared the health delivery system, cancer drugs often run out of stock. Women participants from the FGD in Harare noted the need for government to designate specific pharmacy outlets to ensure that there is a consistent supply of cancer drugs. For people under palliative care whose daily life depends on drugs to ease pain, it was an unequivocal call for the government to act. The arrangement makes it easier for people with cancer to access drugs without inconvenience.

10.8 Free Screening Services and Surveillance

The increased coverage of screening services for cancer leads to early detection, better survival rates, reduced cost of treatment and reduced morbidity (Cockburn et al, 2003; Hansen, 2008; Kowalski, Franco, Torlon et al, 1994). The participants noted the need for cancer screening services to be offered free in all the country’s health centres as in the United Kingdom. Currently, screening services for cancers of the breast, cervix and prostate are offered by the Cancer Centre at a subsidised fee. Many screening services in the country are available in the private sector at a cost, which can be prohibitive (MoHCW, 2014). Participants suggested that the health centres dotted around the country should offer free screening just like in the case of free HIV testing. Screening would not only help minimise cases of ‘misdiagnosis’ and delay in presentation. It would also promote active health-seeking behaviour and probably change perceptions as people are offered evidence based information. However, offering free cancer screening services, which is not matched by provision of affordable treatment is akin to sentencing someone to death if there is no follow-up treatment.
10.9 Food Assistance

One of the existential challenges that face people diagnosed and living with cancer as revealed in the study was the lack of adequate food due to loss of livelihoods and sickness. Participants diagnosed with cancer called on the government to consider parcelling food handouts to those in need. One man diagnosed with cancer of the leg said,

“The government should consider giving food assistance. It is a tall order to look for money to buy expensive treatment drugs, at the same time you need to buy food to eat. Life becomes very expensive”.

10.10 Funding Self-Help Projects

Some key informants suggested a more sustainable way to assist people diagnosed with cancer some of whom become impaired and unable to provide for their families. The government could consider sponsoring families in dire need with self-help projects like poultry, peanut butter making and sewing among other projects to improve the quality of life of people adversely affected by the effects of the disease and aggressive cancer treatment. When a breadwinner becomes sick from cancer in Zimbabwe, the welfare of the concerned family is compromised where no safety nets are provided.

10.11 Accommodation Options

In light of the plight of many people who come for treatment from rural areas and from out of the city, some people diagnosed with cancer called on the government to consider providing overnight accommodation to people diagnosed with cancer. A woman diagnosed with cancer of the mouth gave one of the options - to build guesthouses to accommodate such people. She said,

“Government should consider providing guest houses to accommodate those who do not have a place to stay while they receive chemotherapy and radiotherapy treatment. Some
experience stigma and discrimination in homes of relatives, hence if they are accommodated in guest houses, it will help a lot”.

10.12 Travel Warrants
Given the prolonged nature of cancer treatment, government could consider issuing special travel warrants to people diagnosed with cancer who require assistance in meeting transport costs. A 38-year-old man diagnosed with cancer of the leg suggested that the government could issue some people with cancer who are in need, with travel warrants to enable them to travel without paying transport fares. This is in light of the concern that many especially from far rural areas are forced to discontinue treatment due to inability to meet travel costs or they get treatment irregularly leading to treatment ineffectiveness.

10.13 Circumventing the Challenge of Centralised Diagnostic and Treatment Services: Decentralisation
With the major referral treatment centre located in Harare the capital and some treatment infrastructure found in the second largest city of Bulawayo, one of the major existential challenges faced by people diagnosed with cancer in Zimbabwe is to put together all the logistics, which ensure access treatment. Most cancer diagnostic infrastructure is located in Harare and some urban areas. One woman with cancer of the cervix had this to say,

“...Ideally each district hospital should have own radiotherapy and chemotherapy treatment infrastructure to prevent people from travelling long distances to get treatment. Many, who get diagnosed in the two major cities, would not manage to come back for actual treatment due to distance and associated transport costs”.

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A female participant diagnosed with cancer of the liver observed that,

“Decentralisation of treatment is very important, we need it. Then you see what happens, when people come to one place, corrupt activities begin among the radiographers because it is going to be ‘help me jump the queue...’ whereas you know when its decentralised people are working at their normal paces. When somebody has travelled all the way to Harare, where do they stay? Where do they sleep?”

The nearer the treatment centres the shorter the distances to be travelled, the more adherence to treatment, the less the costs of transport, food, accommodation, the better the quality of life and enhanced health outcomes.

10.14 The Need to Procure New Machines

It was apparent that most treatment infrastructure in use today at the major referral Centres is now very old and is no longer efficient and sensitive. It was striking to note from people diagnosed with cancer during the 1990s, that such challenges as machine breakdowns were also evident. Machine breakdowns were a common feature as well experienced during my field study. Women who participated in a focus group discussion in Harare, suggested that the government consider replacing old machines, which are no longer as effective as they should be. One woman with cancer of the cervix alleged that, when she went for radiation treatment, she was ‘burnt as the machines are no longer as sensitive as they should’. A twin challenge is the lack of maintenance of the old machines due to underfunding and lack of trained engineers or artisans. Trained and competent artisans are required to maintain and service the machines before outright breakdown.
10.15 Training needs and Communication and Coordination among Hospital Treatment Teams

It was evident that general practitioners (GPs) and other health professionals, who offer primary health care, were complicit in misdiagnosis and the resultant ‘patient’ delays. The oncologist noted that due to lack of knowledge on cancer symptoms most GPs and nurses hold on to a client for long as they offer piecemeal treatment to symptoms. The urgent need to train all health care professionals in health care centres on reading the symptomatic elements of cancer and the need to refer clients for further examination by GPs was underscored. The study further revealed poor coordination and synchronisation of roles among the treatment teams. The oncologist noted the need for whole teams to meet and jointly decide on best treatment outcomes even before the client commences any treatment.

10.16 The Need for Family Counselling

In light of widespread stigmatisation of radiotherapy and chemotherapy, there is a need to involve family members of a person diagnosed with cancer to familiarise them with treatment procedures, benefits and expected side effects. The jurisdiction of Western medicine, which emphasizes individuality, privacy and confidentiality, illuminate a disconnection with the collective decision-making process characteristic of Shona families, in the context of a major disease like cancer that require major treatment. Thus, when oncology nurses sit down with key family members that can go a long way to dispel fears and misconceptions associated with radiotherapy. In a way, family members would help the individual diagnosed with more information in case of memory lapses as well as holding him or her accountable. When doctors consult in the presence of family caregivers and other family members who can ask for clarifications, cases of miscommunication can be kept at minimum.
10.17 Options in Palliative Care

That palliative care and end-of-life care are not a priority in most developing countries and that in-patient palliative care is a far rarer model in Africa compared to high income countries, has been noted (Schaepe et al, 2011; Stjernsword, 2002). Currently, a few private institutions like the Island Hospice and Bereavement Centre offer palliative care and pain management. Male and female participants diagnosed with cancer and their family caregivers suggested that support from government and non-state actors on palliative care be channelled through the hospice.

It was noted that government needed to prioritise palliative care around home based care models with adequate support to families and community teams. The government could specifically collaborate with hospices in training trainers, particularly public health officers who will in turn educate family caregivers in pain management and care. In addition, in resource-constrained settings like Zimbabwe, a thrust on developing capacities of already existing institutions in palliative care through training will be more sustainable. Such institutions include [extended] families, church caregivers, family caregivers and traditional health caregivers.

10.18 Developing a Referral System for Optimal Health Outcomes: Possible Collaboration between Traditional Health Practitioners and Bio Medical Practitioners.

In several instances as discussed in chapter 8, traditional indigenous healing practices stood as standalone ‘alternative medicine’ and in some other instances, they were ‘complementary’ to hospital treatment. One woman with cancer of the thyroid aptly put it, that,
“You try with various therapies such that right now I do not exactly know what helped me to be on remission”.

The government could seriously consider the role played by traditional health practitioners in cancer treatment, support and care. This is against a background of high costs of treatment, prevalent beliefs and myths around cancer in the country and inadequate centralised cancer treatment. The government can seek to regularise and support THPs who have a proven record of accomplishment of offering effective treatment, who are open and ready to have their medicines tested and who are willing to comply with minimum guidelines on efficacy, quality and no harm. Indeed my study established the presence of such THPs who were willing and ready to serving national interests.

10.18.1 Services offered by Hospitals which THPs can refer their Clients to

THPs pointed out that there are procedures and services that they cannot offer to clients with cancer for instance-blood tests, surgery, blood transfusion, cancer staging, cancer diagnosis (though from experiential knowledge some can ‘diagnose’ cancer), bone tests, liver function tests among other clinical procedures in diagnosis and prognosis. It was evident in my study that all cases attended to by the herbalists had to be confirmed first via biopsy. Thus, a traditional herbalist can attend to a client with cancer and administer a herbal concoction in addition to prayer and counselling while he sends the client to a doctor for scans, blood tests, reviews, prescription for pain stopping drugs or for a surgical operation if the need be.

10.18.2 Bio medical Practitioners in return

Bio medical doctors can refer clients who may need to try treatment from THPs, in cases of hospital treatment failure, in cases of clients with advanced cancer who are receiving palliative care, in cases where THPs seem to be competent like treating cancer of the
wound and in alleviating the side effects of hospital treatment. Biomedical doctors can share knowledge and experiences with THPs, with an objective of giving candid comments to clients who are curious to try traditional medicines but who retain trust in the advice of a medical doctor in all treatment recommendations.

10.18.3 Provision of Basic Infrastructure to THPs by the government

THPs proposed that government could provide space or compartments in central hospitals for them to work alongside Western medical practitioners in a referral system. The other option is the construction of health care centres where registered, screened THPs can operate. Infrastructure provision would include ‘consultation rooms’, ‘admission rooms’ for clients who come from distant areas and provision of material for minimum basic hygiene like rest rooms, sanitary gloves and bandages. In-patient clients can be provided with meals just like what is done in major hospitals and some health care centres. In addition, THPs attending to people with cancer implored the government to provide space for gardens to grow their medicinal plants.

10.19 Leadership in Indigenous Traditional Healing Practices

THPs underscored the need for appropriate, responsive leadership, which has a good appreciation of traditional ethno medical practices rather than being led by students of Western Medicine in the Traditional Medical Practitioners Council. One of the THP’s had this to say,

“The leadership of the Traditional Medical Practitioners Council are ignorant of fundamental traditional indigenous health knowledge and practices. That is where our major challenge lies”.

During the course of my study, the incumbent chairperson of the Traditional Medical Practitioners Council (TMPC) was a pharmacist by training who professed passion for
traditional medicine. The office incumbent also sits on the Medicines Control Authority of Zimbabwe (a statutory body that regulates use of all medicines in the country including overseeing conducting of [new] drug tests). Indeed, there is bound to be conflict of interest where a trained pharmacist under the tutelage of Western medicine, represents the interests of THPs. Stigmatisation of traditional medicine in Zimbabwe traced from the colonial legacy is well-documented (Mandizadza and Chavunduka, 2013; Chavunduka, 1994; Waite, 2000).

**10.20 Removal of Red Tape in Drug Tests**

THPs in a group interview in this study appealed to government to avail funds and a platform for THPs to test their drugs in an open and professional manner. University pharmacists can work hand in glove with THPs in drug development and drug trials. A major sticking point for possible patenting and standardisation of traditional herbal medicines is the difference in epistemology between protagonists of Western medicine and traditional herbal concoctions (Mandizadza and Chavunduka, 2013). Western medicine prescribes singular elements in drugs specifically made to attack a particular disease while traditional medicines are usually made of composites, which may offer medicinal, and health values than just fighting one specific disease. It follows that the Medicines Control Authority of Zimbabwe (MACZ), the statutory body that runs drug trials runs and registers drugs manned mainly by pharmacists, subject all drugs to satisfy benchmarks of clinical medicine. Thus, most medicines from THPs are jettisoned for failure to meet required set standards, which THPs do not subscribe to. THPs proposed the setting up of a similar institution with set benchmarks, which would suit the healing philosophies in traditional medicines.
10.21 Provision of Genetic Cancer Testing Infrastructure

Though research has restricted the share of genetic or inherited factors to the global burden of cancer to between 10% and 15%, (AIWH, 2012; MoHCW, 2014), such a share can be a significant one in a single country. Due to lack of basic knowledge on cancer and the secretive nature in which family health issues are dealt with in our society, there is no active discourse on the matter in both the public and private domain. Genetic counselling on cancer will have cumulative benefits to families and individuals: children will be wary of the need for periodic screening, families will have increased knowledge of cancer and families will be well equipped to provide social support in the event of a cancer diagnosis in the family. The Angelina Jolie effect on cancer was much hyped in the media. This American actress filmmaker considered a double mastectomy because she had family genes of cancer of the breast and she did not want to take chances (Evans, Barwell, Eccles et al, 2014). It is reported that her publicity triggered a high health-related help-seeking behaviour among the young and old in the United Kingdom (Evans et al, 2014).

10.22 Suggestions for Further Research from People Diagnosed with Cancer and other participants

In line with the tradition of phenomenological hermeneutic inquiry, that privileges the voices of participants experiencing the phenomena, people diagnosed with cancer suggested areas, which require on-going research. It is interesting to note that most of the participants would give the following parting messages,

“Keep on researching and learning about cancer our child. Who knows you may find a treatment breakthrough to treat us or your knowledge will assist others who will be diagnosed with the ailment later”.
Such a statement underlies the appreciation by people with cancer of the intrinsic and extrinsic value of cancer research and the strength of their resolve to fight cancer.

A woman diagnosed with cancer of the oesophagus encouraged the government to prioritize epidemiological and social science research into why cancer incidences have risen especially this point in time in the country. The Zimbabwe National Cancer Registry noted the need for further epidemiological inquiry into why cancer of the prostate has registered a sharp increase among males in the last 4 years, overtaking Kaposi Sarcoma. Despite generalised knowledge of cancer risk factors, it may be important to have country specific empirical tests on possible risk factors more applicable to our context, which can then inspire programmatic interventions.

Traditional herbalists implored the government to do some thorough investigations to unravel possible drivers to rising cancer incidences. They especially raised issues of (imported) food that people are consuming, the air we are breathing, the state of drinking water in urban areas, and pollutants in our industries. Men and women diagnosed with cancer mainly encouraged the government to prioritize research into new medicines, which could cure cancer.

Traditional Health Practitioners who participated in the study registered their wish to have some of their herbal concoctions undergo drug trials for adoption or further enhancement. The Cancer Control Strategy for 2014-2018, noted the need to research on indigenous and traditional medicines and remedies on cancer in the country (MoHCW, 2014). However, from knowledge by hindsight, to date, the government has not taken any bold steps to fund research on indigenous healing and traditional medicines and therapies, having already missed on funding such research on HIV and AIDS drugs.
In a context where there are many myths and misconceptions about cancer, one woman with cancer of the cervix had this to say,

“What research has not been able to show so far is what really causes cancer and how those diagnosed with cancer can alter their lifestyles. We need to know why now cancer incidence cases have risen sharply, because many associate cancer with the white race. Such a research thrust can be informing to the black population which of late has rising numbers of cancer diagnosis among them”.

10.23 Research, then what? Who should benefit from Research?

Besides comprehending the specific research agenda submitted by research participants, a phenomenological study envisions the need to have research priorities which are set by governments, universities and research institutions after consultation with people experiencing or who have lived the phenomenon-cancer. Indeed, research about people, on people and for people can go beyond questioning the question to pinpointing deliverables.

In the case of phenomenology and cancer, research can have implications on nursing practice, clinical practice, civic pride in ethno medical cancer knowledge in communities, design and implementation of national educational programmes and other policy thrusts.

With biomedical and clinical studies, the medical jargon used alienates [lay] people from medical findings, which make more relevance in medical journals and scientific communities!

10.24 Further Studies

Below I outline areas for further research; drawn from my key findings, which I perceive, need more attention in any future qualitative health research on cancer in this country.

- Longitudinal studies on the lived experiences of individuals diagnosed with cancer in Zimbabwe will illuminate insights that are more comprehensive. As noted by
Mathieson and Stan (1995) documenting experience over time is critical given that experience and identity are fluid and part of the negotiation of ongoing multiple and intersecting influences.

- Further research in a longitudinal fashion on people diagnosed and living with cancer who utilise traditional healing practices, to establish treatment outcomes and survival rates.

- Research, which draws our attention to the information needs of people diagnosed and living with cancer and their families drawing from existing information sources, is essential. Molen (2000: 48) underscored the need for adequate, appropriate and timely information, which becomes a key resource for many people in managing the experience of cancer (predominantly new to many in Zimbabwe). Research has shown that information decreases anxiety (Harris, 1998); it facilitates adjustment and coping (Harris, 1998; Fallowfield and Jenkins, 1999). Family information needs remain unmet (Harrison et al, 2009; Echlin and Rees, 2002).

- Documenting the lived experiences of children diagnosed with cancer and their families in Zimbabwe will be an area, which requires research attention.

- In light of a significant number of incidences of cancer cases, traced along family history, a study into how families handle inherited factors of cancer and acceptability of genetic testing and counselling is worthwhile.

- More research is needed to establish availability and utilisation of psychosocial support services to people diagnosed with cancer in Zimbabwe. Cancer is a terminal illness, which demands that one mobilises the soul, mind and body and
which involves a reformation of the self (Ohman, Soderberg and Lundman, 2003). Currently research shows that the main focus in light of cancer is often the medical treatment and psycho social aspects are given less priority (Saegrov and Halding, 2004; Ohman et al, 2003).

- A qualitative analysis of the doctor-client relationship in the context of the cancer illness in Zimbabwe is an important area for future research.

- The phenomenon of patient delay among people diagnosed with cancer in Zimbabwe is worth further pursuit in the context of sociology of cancer symptoms interpretations.

10.25 THESIS CONTRIBUTION TO KNOWLEDGE

This Heideggerian inspired, interpretive hermeneutic phenomenological study has been able to contribute robust insights into the lived experience of selected people diagnosed with cancer in Zimbabwe. The predication of this study on the local understanding of cancer at both epistemological and ontological levels defines the unique contribution of this study. On answering the question on what participants with cancer perceive to have caused their cancer, the thesis has been able to illustrate how individuals drew from their life worlds and situated realities. The thesis has been emphatic in elucidating how perceptions on the causal-attribution of cancer by participants embodied composite, multifactoral narratives from various knowledge repertoires. Such a thrust is not highlighted in most studies, where ‘causes’ are aggregated and quantified. Cultural knowledge on [cancer] disease causation mainly from traditional health practitioners illuminated on local cosmology and experiential knowledge, especially on incurable and less understood diseases like cancer. This is missing in most literature.
The thesis revealed novel insights on the diversity of everyday embodied experience of the cancer illness of the situated participants, which is not captured in conventional medical research. The thesis shared compelling empirical evidence from thick descriptions in stories by people living the phenomenon, of what it is like to live with cancer in Zimbabwe. The thesis exploited one of the major tenets of Heideggerian interpretive hermeneutic phenomenology—the salience of context in undergirding meaning and experience. Contextuality allowed for the explication of the impacts of both micro (personality, family relations) and macro elements (economic climate, health systems, cultural systems) in underwriting experience. The situatedness of experience and the constitution of data by participants living the very experience make the empirical evidence new and insightful.

One of the major contributions of this thesis in the process of tracing health-related help-seeking behaviour is attention devoted on inspecting treatment modalities on cancer by traditional health practitioners. The modalities, which espoused holistic healing, allowed the sharing of fringe data, which is deliberately sidelined in most conventional medical research. The thesis pursued key questions on the phenomenon of delayed presentation and pathways to treatment, all of which revealed novel insights underlined by medical pluralism and myths associated with cancer treatment. The study has managed to explore, theorise and elevate everyday lay knowledge on cancer, extant marginalised, rich ethno medical knowledge on cancer in the country and the indissoluble experiential knowledge of people diagnosed with cancer into solid data and evidence, in a fashion, which is intelligible and palatable to clinicians, policy makers and the public.

This sociological study and phenomenological model of studying chronic illness is a means of comprehending better, the social basis of experiencing a disease, the negotiated reality people fashion in response to a disease as well as suggesting the need for a multi
dimensional view of its impact on everyday life. The findings of the study are distinct in that they are constituted in the actual people that have lived the experience and the meaning they assign to the experience. They affirm Husserl's (1962) statement - "we can only know what we experience" and Heidegger’s (1962) Dasein—the mode of being human or the situated meaning of a human in the world’.

10.26 SUMMARY OF MAJOR FINDINGS

The primary aim of the thesis was to describe and analyse local cancer-causing narratives, lived illness experiences and health-related help-seeking behaviours of people diagnosed with cancer in Harare, Zimbabwe.

The foregoing study aim was guided by the following research questions,

1. How do people living with cancer account for their cancer and the general rise in the cancer illness in Zimbabwe?

2. What are the local perceptions, beliefs, cultural interpretations on causes of the cancer illness in Zimbabwe?

3. What is the lived experience of people living with cancer in Zimbabwe?

4. What are the trajectories followed by people living with cancer in their quest to become well, to manage the pain and the debilitating impacts of the illness in Zimbabwe?

5. How can we characterise the help-seeking behaviour of people living with cancer in Zimbabwe?

6. What existential challenges do people diagnosed with cancer in Zimbabwe experience?

7. How can we address the challenges facing people living with cancer in the country, to improve their quality of life?
Chapter 1 essentially provides the rationale of the study as enunciated in the introduction, where existing gaps on empirical studies on cancer are highlighted. The chapter notes increasing trends on new cancer incidences, morbidity and mortality rates at a global level, in Sub Saharan Africa and in Zimbabwe. The chapter gives a detailed background of the study, highlighting the institutional services and support on cancer [not] available in the country. The bigger picture is a weak response on the part of the government. The chapter outlines the problem statement, study objectives, research questions and the significance of the thesis. The central argument points to the paucity of sociological and qualitative analysis on cancer in the country. Such analysis has potential of giving a comprehensive understanding of cancer by extracting novel fringe data. The chapter ends with an outline of basic biomedical knowledge on cancer for fore understanding of common medical jargon on cancer and treatment regimens by the researcher and his readers.

In Chapter 2, related literature on the overarching research questions is reviewed and debated. It is apparent that dominant literature on phenomenological studies on cancer is mainly from Western Europe, Western Australia, America and Asia. Of note, most assumptions informing the methodologies and evidence resemble and buttress biomedical knowledge. There is hardly a single study on cancer in Zimbabwe, informed by phenomenological analysis. Literature on lived experiences debates the notion of [cancer] stigma and the central argument is to concur with Kleinman and Hall-Clifford (2009) that understanding the unique social and cultural processes that create stigma in the lived worlds of the stigmatized should be the first focus of our efforts at combating and studying stigma. Literature on health-related help-seeking behaviour does not have a single phenomenological study on the Zimbabwean experience. In the end, this chapter familiarise us with the kind of data essential for comparative analysis and broadening our insights on the phenomenon under study.
Chapter 3 gives major highlights of the theoretical frameworks of the study grounded in the tradition of phenomenology and specifically Heidegger’s interpretive phenomenology. The central argument is that the phenomenological model of studying chronic illness is a means of comprehending better, the social basis of experiencing a disease, the negotiated reality people fashion in response to a disease as well as suggesting the need for a multi dimensional view of its impact on everyday life.

Chapter 4 highlights the methodological orientation of the study, which again is rooted in the traditions of phenomenology and qualitative analysis. The chapter outlines how I carried out the study. A consistent argument is that qualitative analysis engendered in interpretive phenomenological analysis provides competent tools to extract intimate, nuanced, marginalised data rooted in the lived experiences of people living with a cancer diagnosis. I believe this thesis has managed to make intelligible these realities to fellow researchers interested in the area, to health care professionals and to authorities. The chapter ends by highlighting challenges faced in the research process, which are critical for readers to appreciate the environment in which the researcher was operating from including shedding light on the politics of doing a doctoral study.

The presentation of 10 detailed stories of participants diagnosed with cancer in chapter 5, gives an open glare on the heterogeneity and density of experiences studied. The stories give unfettered access to representative experiences across gender, age, socio economic positions, family arrangements and personality character traits. A seminal observation is that the narrative of people diagnosed with cancer is learned. It is a cosmopolitan one, informed by own life world, experiential knowledge, time lapse since diagnosis and knowledge coming from health care professionals, the public and other people diagnosed with cancer. Thus, there is nothing like a pristine narrative.
Chapter 6 presents and discusses evidence on reported indigenous [local] knowledge and perceptions, beliefs and knowledge on the causes of an individual’s cancer as well as accounting for the sudden rise in new cancer incidences in the country. Though thematic analysis allows for the bunching of similar narratives into themes on singular causal factors, individual accounts embodied multifactoral causes of cancer, a departure from conventional health research, which streamlines the factors thereby distorting reality. Though the narratives on causes of cancer are comparable with evidence from other research settings like Western Europe, evidence from this study reflects the lifeworlds of the participants, informed, in part by traditional popular beliefs or myths, experiential knowledge and the prevailing sociocultural and economic environment. Of note, most female participants diagnosed with cancer on the reproductive organs tended to invoke biology and culture in causal attribution. Interestingly, metaphysical causes like witchcraft were hardly cited as causes by participants and if they were cited, they were ancillary in a multicausal narrative. It is striking also to note that the perceptions and beliefs on causes of cancer differed between ‘experts’ and people diagnosed with cancer. The former emphasized more on life style factors while in line with the findings of Lykins, Graue, Brechting et al (2008) people diagnosed with cancer did not want to share any responsibility of their life styles in their cancer diagnosis, probably to preserve self-esteem.

Chapter 7 highlights the major experiences of living with cancer in Zimbabwe. The major theme results that emerged include: strong reactions upon a cancer diagnosis by women; indifference in the narratives of men on early reactions; prolonged initial symptoms; pronounced pain experiences among those with advanced disease; the harsh side effects of radiotherapy and chemotherapy treatment; gendered experiences; cancer as a life-changing illness; the salience of spirituality among people with cancer; pronounced stigma underlined in various contexts; biographical disruption; and ‘liminality as a cancer illness.
category. A central argument is that these experiences were shaped by the different demographic and cancer variables and the prevailing socio-cultural and economic political climate in the country.

Chapter 8 addresses one of the key areas in the sociology/anthropology of health and illness: help-related health-seeking behaviour. The chapter establishes that the majority of participants with cancer presented with initial symptoms at various institutions of primary care dotted around the country. Symptom-interpretation had a far-reaching impact on time lapse upon initial symptoms and presentation to a doctor as well as in informing health-seeking behaviour. Symptom interpretation was informed by a world of familiars for the person, previous personal health history and cultural interpretations. The chapter reveals that the majority of people with cancer present late and that they practise medical pluralism. Women seek help and support more than men do. The major contribution of the chapter is keen attention shown on indigenous healing practices and activities of traditional health practitioners in the context of cancer. The chapter reveals evidence, which points to the rich ethnology of cancer and philosophies behind the treatment modalities employed-all, which point to holistic care.

Chapter 9 is meant to amplify and make intelligible to all concerned stakeholders, the dominant challenges experienced by people living and diagnosed with cancer in Zimbabwe today. It would seem, together with chapter 10; the researcher adopts the role of an advocate in submitting suggestions to address some of the major challenges faced by people with cancer. These two chapters, in essence shed light on what it is like for an ordinary Zimbabwean today to live with a cancer diagnosis. In line with the cardinal principles of Heidegger’s phenomenology, a double hermeneutics is played out where the interpretations and voices of the participants are blended with that of the researcher.
10.27 CONCLUSIONS OF THE STUDY

This study sought to elicit, describe and analyse narratives about the causes of cancer, lived illness experiences and health-related help-seeking behaviours of people diagnosed with cancer in Harare, Zimbabwe. I believe the study has provided a rich insight into the lived experiences of people living with cancer in Zimbabwe. This is the first in-depth study in Zimbabwe on the lived experiences of people diagnosed with cancer, selected from across a range of demographic and cancer variables and understood from a phenomenological and sociological point of view. The key findings on cancer-causal narratives point to multiple attributions rooted in the socio-cultural milieu of participants and showing traces of new knowledge on cancer acquired since diagnosis, some of which was comparable with findings from similar studies elsewhere. However, some were at variance with extant scientific evidence. The results on lived experiences indicated the diversity of individual and shared experiences of people living with cancer. The major categories of the experiences included pronounced pain for those with advanced disease, body disfigurement among female participants due to treatment side effects, ‘disrupted biographies’, existential challenges emanating from lack of adequate financial resources and pronounced stigma experiences for some.

The results from exploring the pathways to treatment by people diagnosed with cancer established significant medical pluralism, where people with cancer enlisted the services of biomedicine concurrently or parallel with traditional health practitioners and other complementary therapies. The study established that the decision-making processes on choice of treatment were mediated by such factors like the dread of radiotherapy, the influence of the extended family and the neighbourhood, availability of finances, family history of cancer and associated treatment, marital status, level of knowledge on basic biomedical information on cancer and the belief systems. The phenomenon of delayed
presentation was theorized in light of field data and treatment experiences from both hospital care and traditional indigenous healing systems and indicated both positive and negative elements. The management and coping mechanisms of people diagnosed with cancer portrayed the agentic behaviour of human beings and the tenacity of the human spirit in the face of adversity. Salient existential challenges faced by people diagnosed with cancer illuminated the situatedness of participants as well as the institutional, economic, social and political determinants on health. Taken as a whole, in addition to the prime function of knowledge contribution, this knowledge can assist in the framing of educational resources and also inform oncology nursing in the management of clients with cancer in personally meaningful ways, which can enhance health behaviours, satisfaction, adherence, and quality of life.
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APPENDICES

Appendix 1 Permission letter from the Medical Research Council of Zimbabwe

Ref: MRCZ/A/1834

19 May, 2014

Mr. Enoch J.R. Mandizadza
University of Zimbabwe
P.O. MP 167
Mount Pleasant
Harare

RE: Indigenous Knowledge and Social Experiences on Cancer in Harare. A Case Study of Harare

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has reviewed and approved your application to conduct the above titled study. This is based on the following documents (among others) that were submitted to the MRCZ for review:

a) Research Protocol
b) Informed Consent Form People living with Cancer (English and Shona)
c) Informed Consent Form for all Key Informants (English)
d) Informed Consent Form Community Experts (English and Shona)
e) Informed Consent Form for Focus Group Discussions (English and Shona)

- APPROVAL NUMBER: MRCZ/A/1834
- TYPE OF REVIEW: FULL BOARD
- EFFECTIVE APPROVAL DATE: 19 May, 2014
- EXPIRATION DATE: 18 May, 2015

After this date, this project may only continue upon renewal. For purposes of renewal, a progress-report on a standard form obtainable from the MRCZ Website should be submitted three months before the expiration date for continuing review.

- SERIOUS ADVERSE EVENT REPORTING: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Website.
- MODIFICATIONS: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Website is required before implementing any changes in the Protocol (including changes in the consent documents).
- TERMINATION OF STUDY: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Website.
- QUESTIONS: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw

- Other

Please be reminded to sign in copies of your research results for our records as well as for Health Research Database.
You’re also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully,

[Signature]

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

[Stamp]
Appendix 2 Letter from the Ministry Of Health and Child Welfare

20 January 2014

Enoch J R Mandizadza
University of Zimbabwe

RE: LETTER OF APPLICATION FOR CLEARANCE TO UNDERTAKE A DPHIL FIELD RESEARCH IN HARARE AND MAZOWE DISTRICTS

Communication on the request to conduct the above study is acknowledged.

The Ministry of Health and Child Welfare is in support of the above mentioned study, as the study is qualitative in nature and has been prompted by the rising cancer mortality and morbidity rates in the country.

We will appreciate feedback from your study findings.

Brigadier General (Dr) G Gwinji
Secretary for Health and Child Welfare
### Appendix 3 List of Key Informants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Designation/Nature of Work</th>
<th>Data Contribution to this Study</th>
</tr>
</thead>
</table>
| Sekuru N.C         | 56  | Male   | Registered Faith Healer; Uses Prayer and Herbs Full time attending mainly to clients with cancer. Well known in community and referrals beyond, since 2008 | -Insights into traditional/ herbal and faith treatment modalities of cancer  
-Experiences with clients                                                                 |
| Sekuru Muc         | 59  | Male   | Registered Traditional Healer: Specialises on cancer of the wound. 5 years of experience | Insights into traditional and herbal treatment modalities of cancer                               |
| Registrar          | Not provided | Male   | Registrar, Zimbabwe National Cancer Registry since 1989 | Insights and commentary on National Cancer Statistics                                                |
| Oncologist         | Not provided | Female | Qualified Oncologist: Radiotherapy Centre :Parirenyatwa Group of Hospitals since 2010 | -Insights into oncology  
-biomedical interpretations  
-experiences with clients                                                                                   |
| Sekuru Pasi        | 76  | Male   | Former well-known traditional healer for 30 years                                | Deeper insights on ethno medical science and cultural interpretation of the cancer illness in the country |
| Mr L.M             | 33  | Male   | Knowledge Manager at Cancer Association of Zimbabwe since 2012                   | Insights on services provided to clients by the oldest cancer service organisation and experiences with clients as well as levels their of cancer knowledge and education |
| Mrs Nd             | 66  | Female | Senior Community sister/ Coordinator with Island Hospice/ Heads home care team. Has been with the hospice since 1992 | Insights on provision of institutionalised palliative care to people diagnosed with cancer in Zimbabwe |
| Mai Bee            | 45  | Female | Local Herbalist in Mazowe Rural/Knowledge passed from a relative. Has been attending to clients for the past 4 years | Insights into non-hospital cancer therapies in a rural area                                           |
| Sekuru MB          | 64  | Male   | Local Herbalist/ Knowledge passed from Parents/ Well known in his community and beyond for attending to clients with cancer for 25 years | Insights into non-hospital therapies in a rural area and testimonies of attending with clients       |
| Sekuru M.T         | 71  | Male   | Village Elder/ Knowledge of traditional health Issues                            | Insights into localised cultural assignment of the cancer illness                                    |
| Sister-in Charge   | Not Provided | Female | Sister-in-charge: Parirenyatwa Radiotherapy Centre                               | Insights into oncology nursing, Experiences with clients of cancer and information on treatment costs |

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Appendix 4 Life Histories Interview Guide

1) Can you relate to me the story of your early life to the present?

2) Can you relate to me your employment history/work life?

3) Describe your family health history.

4) Describe any family history of cancer.

5) Can you describe your personal health history?

6) Can you describe to me the story of your life with cancer since the day you were diagnosed to date? In your response can you highlight the following issues:-

   • How did you react to the news of your cancer diagnosis?
   • Whom did you disclose to the results of your diagnosis and why?
   • How did family members receive the news of your diagnosis?
   • Can you outline the practical steps you took to get treatment?
   • Can you relate the pain experiences that you went through daily.
   • What have been your major experiences in seeking treatment?

7) How has your life changed since your cancer diagnosis?

   • Relations with spouse and family
   • Bodily changes
   • Perception on life

8) What daily practical steps do you take to manage the cancer illness
Appendix 5 Semi-structured interview guide (Personal Interviews)

First Study objective: Causal-attribution narratives

1) Personally, what do you attribute to have caused your cancer?
2) How do people in your community explain the causes of cancer?
3) How do you account for the current rise of new cancer incidences in the country?

Second Objective: Lived Illness Experiences of People Diagnosed with Cancer

1) In what ways has the cancer illness changed your daily life?
2) Can you relate to me any daily pain experiences you go through?
3) Can you describe your experiences with various treatment regimens?
4) In what ways has cancer changed your social relations?
5) Can you relate to me any experiences of stigma and discrimination that you went through due to your cancer illness?
6) What stigma experiences do people living with cancer that you associated with report?
7) How do you sum up a life with cancer?

Third Objective: Pathways to seeking treatment and management of the illness

1) Can you take me through the whole journey in seeking treatment of cancer and associated symptoms before and after a cancer diagnosis right up to today?
2) Can you describe the decision making process in seeking treatment/healing with your cancer along the way? Who made what decision and why?
3) What influenced your choice of treatment?
4) Can you describe the kind of social support you have received from family members/friends/organisations/support groups?
5) Personally, how do you manage the negative impacts of your cancer illness?

Fourth Objective: Existential challenges

(These were mainly extracted from narratives of people diagnosed with cancer)

1) What are the main challenges that you experienced throughout your journey with cancer?
2) What are the main challenges faced by people diagnosed and living with cancer in Zimbabwe?
Fifth Objective: Recommendations and Suggestions on redressing challenges

1) What are your demands to the government in light of the cancer illness based on your experiences so far?

2) What has been the undoing of government so far?

3) What are your suggestions on what needs to be done on treatment, care, research, support and prevention

4) Any demands on organizations involved with people living with cancer?
Appendix 6 Focus Group Discussion Guide

- Cancer causing narratives
- Ethnomedical knowledge on cancer
- Salient cancer risk factors in Zimbabwe
- Pain Experiences
- Stigma Experiences
- Any unique gendered experiences of the cancer illness
- Implications of the cancer illness/treatment side effects on masculinities or femininities
- Experiences with health service providers
- Health related help seeking behaviour
- Experiences with hospital treatment
- Experiences with Traditional Indigenous healing practices
- Non-hospital treatment utilised
- Any cultural arrangements that mediates illness management
- Elements in the management of the cancer illness
- Challenges faced and suggested solutions
### Appendix 7 Demographic Data of Participants with cancer

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
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<tbody>
<tr>
<td>Male</td>
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<tr>
<td>31-40</td>
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<tr>
<td>41-50</td>
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<tr>
<td>51-60</td>
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<td>60+</td>
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<tr>
<td>Pentecostal</td>
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<td>African Traditional Religion</td>
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<tr>
<td>Secondary</td>
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<tr>
<td>Tertiary</td>
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<tr>
<td>Status</td>
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<td>Percentage</td>
</tr>
<tr>
<td>-------------</td>
<td>--------</td>
<td>------------</td>
</tr>
<tr>
<td>Widow</td>
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<td>Divorced</td>
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<td>Number of Children</td>
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<tr>
<td>One</td>
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<tr>
<td>Two</td>
<td>3</td>
<td>10.0%</td>
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<tr>
<td>Three</td>
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<tr>
<td>Four</td>
<td>4</td>
<td>13.4%</td>
</tr>
<tr>
<td>Five</td>
<td>11</td>
<td>36.7%</td>
</tr>
<tr>
<td>Six</td>
<td>4</td>
<td>13.4%</td>
</tr>
<tr>
<td>Seven</td>
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Geophysical location

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Urban Residence

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<td>Medium Density</td>
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<tr>
<td>High Density</td>
<td>14</td>
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<tr>
<td>Total</td>
<td>18</td>
<td>100.0%</td>
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Home Ownership

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<th>Count</th>
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<tr>
<td>Owned</td>
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<td>46.7%</td>
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<tr>
<td>Parent/relative owned</td>
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<tr>
<td>Temporary residence</td>
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<tr>
<td>Rented</td>
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<td>Total</td>
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<td>100.0%</td>
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</table>
### Main Source of Income

<table>
<thead>
<tr>
<th>Source</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support from children and siblings</td>
<td>10</td>
<td>33.3%</td>
</tr>
<tr>
<td>Pension</td>
<td>3</td>
<td>10.0%</td>
</tr>
<tr>
<td>Salary</td>
<td>8</td>
<td>26.7%</td>
</tr>
<tr>
<td>Home project</td>
<td>7</td>
<td>23.3%</td>
</tr>
<tr>
<td>Cancer organization</td>
<td>3</td>
<td>10.0%</td>
</tr>
<tr>
<td>Spouse</td>
<td>1</td>
<td>3.3%</td>
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<tr>
<td>Well wishers</td>
<td>4</td>
<td>13.3%</td>
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</tbody>
</table>

### Employment History

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
<th>Percentage</th>
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<tr>
<td>Unemployed</td>
<td>13</td>
<td>43.4%</td>
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<tr>
<td>Employed</td>
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<td>23.3%</td>
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<tr>
<td>Pensioned</td>
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<tr>
<td>Self-employed</td>
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**Total** 30 100.0%

### Living arrangement

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<thead>
<tr>
<th>Arrangement</th>
<th>Count</th>
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<tr>
<td>Living with children</td>
<td>5</td>
<td>16.7%</td>
</tr>
<tr>
<td>Living with siblings</td>
<td>5</td>
<td>16.7%</td>
</tr>
<tr>
<td>Living with children and siblings</td>
<td>8</td>
<td>26.6%</td>
</tr>
<tr>
<td>Living with spouse and children</td>
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<td>40.0%</td>
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</table>

**Total** 30 100.0%
## Appendix 8 Cancer Illness Variables of Participants

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<tr>
<th>Cancer site</th>
<th>Frequency</th>
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<td>Colon</td>
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<tr>
<td>Cervical</td>
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<tr>
<td>Liver</td>
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<td>3.3%</td>
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<tr>
<td>Breast</td>
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<td>20.0%</td>
</tr>
<tr>
<td>Mouth</td>
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<td>3.3%</td>
</tr>
<tr>
<td>Vulva</td>
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<td>6.7%</td>
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<tr>
<td>Oesophagus</td>
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<td>10.0%</td>
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<tr>
<td>Prostate</td>
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<td>10.0%</td>
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<td>Leg</td>
<td>3</td>
<td>10.0%</td>
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<tr>
<td>Thyroid</td>
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<td>3.3%</td>
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<tr>
<td>Rectum</td>
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<td>3.3%</td>
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<tr>
<td><strong>Total</strong></td>
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### Mode of Diagnosis

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<tr>
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<th>Frequency</th>
<th>Percentage (%)</th>
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<tbody>
<tr>
<td>Biopsy</td>
<td>29</td>
<td>96.7%</td>
</tr>
<tr>
<td>Magnetic Imaging Resonance</td>
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<td>3.3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
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### Stage of Cancer

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<th>Percentage (%)</th>
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<td>Stage 2A</td>
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<tr>
<td>Stage 2B</td>
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<td>6.7%</td>
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<tr>
<td>Stage 3</td>
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<tr>
<td>Stage 4</td>
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<td>16.7%</td>
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<tr>
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<tr>
<td><strong>Total</strong></td>
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### Treatment being received at the time of the interview

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<tr>
<th>Treatment</th>
<th>Frequency</th>
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<td>Clinic Review and Palliative Care</td>
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### Palliative Care

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<th>Participants</th>
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<td>Hospital</td>
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<tr>
<td>Non Hospital</td>
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### Hospital treatment received since diagnosis

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<th>Participants</th>
<th>Percentage</th>
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<tr>
<td>Radiotherapy</td>
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<tr>
<td>Chemotherapy</td>
<td>1</td>
<td>3.3%</td>
</tr>
<tr>
<td>Surgery</td>
<td>6</td>
<td>20.0%</td>
</tr>
<tr>
<td>Chemotherapy and Radiotherapy</td>
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</tr>
<tr>
<td>Surgery and Chemotherapy</td>
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<td>26.7%</td>
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<td>Preliminary treatment</td>
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<tr>
<td>Surgery, chemotherapy, Radiotherapy</td>
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### Non-hospital treatment utilised since diagnosis

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<tr>
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### Source of recruitment

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<th>Percentage</th>
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<td>Radiotherapy Centre</td>
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<td>26.7%</td>
</tr>
<tr>
<td>Hospice Centre</td>
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</tr>
<tr>
<td>Traditional Health Practitioners</td>
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<td>23.3%</td>
</tr>
<tr>
<td>Cancer Service Organisation</td>
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### Date of diagnosis (range)

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<td>2006 – 2010</td>
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<td>16.7%</td>
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<td>2000 - 2005</td>
<td>2</td>
<td>6.7%</td>
</tr>
<tr>
<td>Late 1990s</td>
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<tr>
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