TOWARDS INTEGRATED CARE OF THE BREAST CANCER PATIENT: PERSPECTIVES ON THE CHALLENGES AND OPPORTUNITIES OF MEDICAL PLURALISM IN A DISPARATE SOCIETY

By
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ABSTRACT

"Medical Pluralism" refers to the co-existence of many different medical systems, practices and products within a healthcare landscape. Whilst in most countries, mainstream biomedical treatment protocols dominate, many practices exist which are not routinely incorporated into these treatment protocols. For the ease of academic discourse, this large array of practices and products are often referred to collectively as "Traditional, Complementary, and Alternative Medicine" or "TCAM".

Patients with cancer, and specifically women with breast cancer, are some of the highest utilisers of TCAM as they battle the disease and mainstream treatment side-effects. Concurrent use alongside conventional oncology treatments however can hold risks, yet many patients do not disclose TCAM use to oncologists, and many oncologists do not engage in TCAM discussions with patients. "Integrative Oncology" incorporates a variety of evidence-based practices from across the pluralistic landscape, neither rejecting mainstream treatments nor accepting alternatives uncritically, and could potentially offer clarity to patients and oncologists in navigating medical pluralism.

Whilst many studies have investigated patient TCAM use elsewhere in the world, there is a dearth of data on the choices and experiences of cancer patients and oncologists navigating the local pluralistic landscape. This study sought to describe aspects of current practice and lived experience of eThekwini breast cancer patients and their oncologists with respect to TCAM use. In doing so, it also sought to throw light on the incorporation of holistic or integrative practices by way of ascertaining the status of formalised Integrative Oncology in eThekwini, as well as outlining some of the challenges and opportunities for its growth in the local setting.

The study utilised a mixed-methods sequential explanatory design which consisted of patient and oncologist surveys, followed by patient and oncologist interviews. Participants (316 patients and 18 oncologists) were recruited from government (GOV) and private (PVT) facilities in eThekwini by snowball and convenience sampling.

Patients reported incorporating a range of lifestyle modifications and interventions as a way to gain control, combat side-effects and support the body in healing. These included dietary approaches, supplements, cannabis, exercise, meditation, yoga, psychological counselling, support groups, relaxation techniques, and prayer. Apart from spiritual support practices, frequencies of inclusion were consistently and significantly lower in the government cohort. Thirteen percent of government patients and 53% of private patients also consulted with TCAM practitioners. This included massage therapists, African traditional healers, chiropractors, homeopaths, aromatherapists, and acupuncturists. Most patients are incorporating additional practices in a self-directed fashion with varying levels of disclosure and reports of very limited to no patient-practitioner discussions on TCAM. Many patients expressed the need for more information and guidance.

Oncologists were divided as to the role of various TCAM inclusions. In terms of lifestyle modifications, the majority (79%) supported the role of nutrition in oncogenesis and healing, and 58% reported having a nutritionist associated with the practice. Fifty-three percent believed supplements are an important consideration in cancer management, with 79% discouraging supplement use during active mainstream treatments. All oncologists supported the vital role of exercise and 95% report raising this with their patients. Regarding TCAM practitioners, oncologists described their knowledge as “very little” or “none” for all the fields included in the survey and remain divided on the role that these practitioners can play in oncology. Oncologist reservations were rooted in previous negative experiences where patients had incorporated TCAM practices (mainly African traditional medicine); in proponents of questionable practices with unfounded claims of cure; and in a perceived lack of evidence for TCAM inclusions.

Formalised Integrative Oncology is currently not evident in oncology care in eThekwini. There are, however, oncologists who strive towards a holistic model of patient care and are open to other evidence-based inclusions and collaborations. With the disparate nature of medical provision in South Africa, the government sector holds more challenges for both oncologists and patients. As such, the private sector is more suited to the growth of Integrative Oncology. Medical pluralism brings many challenges and opportunities. Empowering patients through accessible evidence-based health literacy remains a priority for them to navigate the health landscape of South Africa safely and effectively, avoiding risk whilst optimising quality of life and clinical outcomes across the cancer continuum.

PREFACE AND DECLARATION OF PLAGIARISM

The investigations described in this thesis were carried out within the Faculty of Health Sciences, Durban University of Technology under the supervision of Professor Ashley Hilton Adrian Ross and co-supervision of Professor Champaklal Chhaganlal Jinabhai.

This thesis, unless specifically indicated in the text, is the candidates own work and has not been submitted, in part or in whole, to any other tertiary institution. Where use has been made of the work of others, it is duly acknowledged in the text.

I, Jennifer Frances Ducray, declare that:

1. The research reported in this thesis, except where otherwise indicated, is my original research.
2. This thesis has not been submitted for any degree or examination at any other university.
3. This thesis does not contain other persons' data, pictures, graphs, or other information, unless specifically acknowledged as being sourced from other persons.
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    a) Their words have been re-written, but the general information attributed to them has been referenced.
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5. This thesis does not contain text, graphics or tables copied and pasted from the Internet, unless specifically acknowledged, and the source being detailed in the thesis and the references sections.

Signed: ___ _______________ Date: 28 July 2024
Name: Jennifer Frances Ducray

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

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DEDICATION

I dedicate this work to:

My husband and children: My participation in a wonderfully happy marriage and rich family life through 30 years of beautiful companionship, faith, growth, blessings, and delights, will always be my greatest achievement. Your relationships with me and with each other will forever be my dearest treasure, and the cherished titles of affection you give me, those of which I am most proud.

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God: And finally, I dedicate this to He who brought me into being, through whose great love and goodness I am sustained, inspired and strengthened, and to whom, through his own merciful design, I will one day return.

LIST OF TERMINOLOGY AND ABBREVIATIONS

Medical Pluralism: the co-existence or availability of many different healthcare options that people can use when seeking health and wellbeing. A term that draws attention to the presence of a diversity of practises within a health landscape.

Mainstream Biomedicine: A healthcare system based on a biomedical understanding of disease and healing. Also referred to as “conventional” or “Western” medicine.

Alternative medical practices: Practises that are being used in place of mainstream biomedicine.

Complementary medical practises: Additional health-seeking practices being utilised alongside/in conjunction with mainstream biomedical treatments.

Traditional medicine: Also referred to as “indigenous” medicine. Refers to long-established healing practises indigenous to different cultures, used in the maintenance of health as well as diagnosis and treatment of illness. Common examples in include African traditional medicine which originated amongst African tribes, Chinese medicine which originated in China, and ayurveda which originated in India.

TCAM: An acronym which stands for Traditional, complementary, and alternative medicine. This acronym is used in academic discourse to represent a wide array of health-seeking practices and products.

Holistic medicine: a healing approach that acknowledges the multi-dimensional nature of wellness and seeks to address all aspects of a person including mind, body and spirit to support the body’s capacity to heal. Holistic practises seek to empower patients to become active in their own healing, especially with respect to lifestyle changes such as diet, exercise, and stress reduction.

Integrative Oncology: An approach to oncology that uses an evidence-informed combination of conventional cancer therapy with complementary interventions. It does not reject conventional medicine nor accept alternative treatments uncritically. Utilizing lifestyle modifications, natural products, mind and body practices, it seeks to address the whole person living with and beyond cancer.

1. INTRODUCTION

1.1 Background and Field of Exploration

“Medical pluralism” refers to the co-existence of many different treatment options and approaches that people can utilise when seeking healing (Khalikova 2021). Whilst biomedicine is the dominant medical tradition in many countries, there are numerous products, practitioners and therapies that lie outside of those routinely practiced within mainstream biomedicine. For the convenience of academic discourse, these numerous options are often referred to as “traditional”, “complementary” and “alternative” medical practices (TCAM) (Lee *et al.* 2022). TCAM offerings can be classified into different categories including alternative medical systems (e.g., homeopathy, ayurveda, naturopathy, Chinese medicine, African traditional medicine); biologically based practices (dietary approaches, exercise approaches, vitamins, minerals, herbs and botanicals); manipulation practices (chiropractic, massage, reflexology); mind-body interventions (meditation, relaxation techniques); energy therapies (acupuncture, reiki); and spiritual and psychological support practices (counselling, support groups, spiritual activities) (Wanchai, Armer and Stewart 2010; Cramer *et al.* 2013; Pinzon-Perez and Perez 2016). It is of interest to note that some TCAM offerings such as energy healing, are founded on philosophies incongruent with the biomedical model of understanding the human body, whilst others rest on biomedical principles (such as diet and exercise) yet may not be routinely incorporated into biomedical treatment protocols. Medical pluralism can be seen to offer a wide variety of options for those battling illness. However, the complexity of a pluralistic medical landscape holds not only potential benefits, but also possible risks, and requires careful decision-making processes that many patients and clinicians are not equipped to navigate (Khalikova 2021).

A 2022 systematic review reported that an average of 45% of the general worldwide population incorporate TCAM as part of their health seeking behaviour (Chowdhuri, Kunda and Meyur 2022). Patients with cancer, and specifically women with breast cancer, are reportedly some of the highest utilisers of the varied healing options within a pluralistic landscape, with some researchers reporting usage as high as 90%. This is attributed to these patients seeking ways to battle this devastating disease, as well as the numerous physical and emotional side-effects of conventional oncology treatments (Perlman *et al.* 2013; Kleine Wortmann *et al.* 2016). A 2021 systematic review reported 25-80% of cancer patients incorporating TCAM concurrently with mainstream treatments (Alsharif 2021), and explorations focussing on low, or lower-middle income countries, reported 55% TCAM usage by cancer patients (Hill *et al.* 2019).

Cancer is the second leading cause of death worldwide, accounting for one in every six deaths (World Health Organization 2019). With cancer diagnoses increasing, a 47% rise in the global cancer burden is expected by the year 2040 (Ghufran and Duddukuri 2023). Whilst cancer patients are some of the highest utilisers of TCAM, concurrent use of alternative therapies alongside conventional oncology treatments may risk adverse interactions (Alsanad, Howard and Williamson 2016; Sweet *et al.* 2016). Yet as much as 60% of patients who incorporated TCAM chose not to disclose their additional practices to their oncologist (Lo-Fo-Wong *et al.* 2012). Reasons for this included that patients were never asked, sensed limited interest, feared opposition, or did not realise that disclosure was important (Alsharif 2021). These patients essentially navigate medical pluralism alone, where the numerous options, and often conflicting opinions of the pluralistic landscape, bring additional stress to patients trying to discern the best interventions to incorporate in battling their cancer (Currin-McCulloch *et al.* 2021).

As many cancer patients choose to incorporate TCAM, patient-practitioner conversations about additional inclusions are vital to educate patients with respect to potential benefits as well as dangers. Researchers have urged oncologists to familiarise themselves with the evidence base to properly engage with patients on the topic and to empower patients to participate in their own healing journey (Wanchai *et al.* 2017; Alsharif 2021). However, within the vast complexity of medical pluralism, there is a lack of clarity for patients and their oncologists. This clarity is necessary for them to be able to harness the potential for healing to be found in different traditions and practices, whilst avoiding potential pitfalls inherent in pluralism (Currin-McCulloch *et al.* 2021). To make matters worse, the relationship between mainstream biomedicine and many elements of TCAM practice remains fractious. Many TCAM approaches rest on different philosophical belief systems, with resulting differences in the root cause of disease and what brings about healing (Gale 2014; Uibu and Koppel 2021). Collaboration across this divide is generally absent as practitioners from different traditions work in silos, harbour distrust and emphasise professional boundaries (Uibu and Koppel 2021).

The formalised field of Integrative Oncology holds the potential for offering clarity to patients and oncologists navigating the complexity of medical pluralism. Integrative Oncology incorporates practices from across the pluralistic landscape, neither rejecting conventional therapies nor accepting alternative therapies uncritically, but rather embracing the principle of evidence-based medical practice (EBM) and formulating integrated recommendations that rest on good scientific evidence (Abrams and Weil 2014). Integrative Oncology seeks to offer the cancer patient safe and effective holistic care, addressing aspects such as stress management, nutrition and exercise, vitamin deficiencies and sleep disturbances. In addition to alleviating symptoms associated with cancer and treatment side effects, research into complementary therapies seeks to increase survival and address pathological mechanisms underpinning certain cancers (Mao *et al.* 2022b; O'Brien *et al.* 2022). Integrative practice aims to be patient-centred, honouring the role of the doctor-patient relationship while empowering the patient to become an active participant in their own healing journey (Abrams and Weil 2014). Proponents of Integrative Oncology continue to gather evidence of therapies that improve quality of life and outcome of patients, providing guidelines for patients and oncologists in helpful complementary therapies, as well as options for battling mainstream side-effects such as pain and fatigue (Lyman *et al.* 2018; Balneaves *et al.* 2021; Berretta *et al.* 2022; O'Brien *et al.* 2022).

Numerous studies have been conducted globally on the health-seeking behaviour of cancer patients within pluralistic landscapes (Naja *et al.* 2015; Greenlee *et al.* 2016; Kleine Wortmann *et al.* 2016; Noraini, Soon and Azlina 2016; Wanchai, Armer and Stewart 2016; Hill *et al.* 2019; Wode *et al.* 2019; Hammersen *et al.* 2020; Alsharif 2021). These studies explore patient choices as well as factors affecting those choices. Researchers also delve into sources of information used by patients when making decisions on TCAM inclusions and reported deficits in patient information needs. Also of importance, are the figures of patient disclosure of TCAM inclusion reported by these studies.

Whilst there is a growing body of literature on patterns of TCAM use by patients elsewhere in the world, there is currently a dearth of data on the choices and experiences of patients and clinicians navigating the pluralistic landscape of South Africa. This research set out to begin addressing this scarcity of knowledge. South Africa has a fairly unique medical landscape due to its checkered history, which adds to the complexity facing patients and practitioners. As a multicultural society it has many healing traditions rooted in various cultures. Whilst its colonial history resulted in a dominance of biomedicine, there are many other traditions including African, Indian (ayurveda) and Chinese traditional medicine; homeopathy; chiropractic; naturopathy; and phytotherapy amongst others. Thus, the South African medical landscape can be described as richly pluralistic (Digby 2008; Allied Health Professions Council of South

Africa 2018). In addition, the political impact of Apartheid left a legacy of disparity in access to health care, with portions of the population receiving excellent medical care and the majority of citizens relying on a constrained government medical service. Not only is there disparity in health provision, but there is disparity in those socio-economic enablers that underpin health literacy and personal agency that contribute to health seeking behaviour (Coovadia *et al.* 2009). These disparities likely affect patient and oncologist choice and lived experience, as well as critically impact the potential for the growth of Integrative Oncology in the local setting. Accordingly, any exploration of patient navigation of medical pluralism in the local setting needs to incorporate some interpretation through the lens of this disparity.

1.2 Research Question, Focus Area, Aim and Objectives, and Hypothesis

1.2.1 The research question

The research question at the heart of this study is: “What is the current status of Integrative Oncology in the local setting”? In exploring this question, sub-questions include “What practices are patients and oncologists currently including alongside mainstream treatments”? and “What is the lived experience (both positive and negative) of patients and oncologists navigating the local pluralistic medical landscape”.

1.2.2 The focus area

Breast cancer was selected as the focus area in which to explore this practice and lived experience of patients and their oncologists. Breast cancer is the most diagnosed cancer worldwide (Arnold *et al.* 2022), and the leading cause of female cancer-related deaths (DeSantis *et al.* 2015). In South Africa it has the highest incidence of all female cancers diagnosed annually (National Cancer Registry 2014). The mainstream treatments for breast cancer include surgery, radiation therapy, chemotherapy, and endocrine therapy, all of which result in side-effects and compromised quality of life, which continue beyond active treatments (Edge and Buccimazza 2019; Waks and Winer 2019). In selecting this focus area, cognizance was given to the findings of previous research that placed breast cancer patients amongst some of the highest utilisers of multiple healing options to combat these side effects and seek healing (Perlman *et al.* 2013). Whilst exploring aspects of patient and oncologist practice and lived experience, this research sought to gain insight into the status of formal Integrative Oncology in the local setting.

1.2.3 Aim and objectives

This study therefore set out with the following aim:
To investigate perspectives on the challenges and opportunities for pluralistic integrative management of the breast cancer patient in eThekwini, within the context of the disparate nature of the South Africa society.

In pursuit of this aim, the following objectives were outlined:

- To describe some of the current practices amongst eThekwini breast cancer patients in the use of TCAM alongside allopathic treatments, as well to explore the factors influencing these practices.
- To describe some of the current practices amongst eThekwini oncologists in the use of TCAM alongside allopathic breast cancer treatments, as well as to explore oncologist attitudes towards the role (if any) of TCAM.
- To seek a deeper understanding of the lived experience of cancer patients and oncologists in navigating medical pluralism in the local setting.
- To identify the various factors enabling and constraining the development of Integrative Oncology in the local setting.

1.2.4 Hypothesis

At the outset of this research, the hypothesis was that Integrative Oncology would not be very prevalent in the local setting; that there would be a disparity between government and private patients in terms of the use of additional supporting practices alongside mainstream treatment protocols; that whilst many different inclusions would be utilised, these would be more holistic practices such as nutrition and psychological support as opposed to practices such as acupuncture and homeopathy; and that there would be a wide mix of opinion amongst patients and oncologists as to the potential role of Integrative Oncology in patient management.

1.3 Basic Methodology

A mixed-methods sequential explanatory design was selected as most the appropriate to address the study objectives. Data was collected via patient and oncologist surveys, followed by patient and oncologist interviews. By using this design, the quantitative phase provided data on aspects of current practice on the use of TCAM by both patients and oncologists. The quantitative data then formed the foundation from which qualitative questions were formulated to explore the lived experience of patients and oncologists at a deeper level through a narrative lens. This was done using through personal interviews. The four data sets emanating from these two phases were then be used for the purposes of triangulation.

The sample population was sourced from biomedical clinics across eThekwini. To explore the effects of disparity on health seeking behaviour patterns, patients and oncologists from both the government sector and private sector were included. Patients who opted to use exclusively alternative treatments, whilst refusing mainstream treatments were excluded.

As one of the first of such studies in South Africa, this research provides novel insights into the navigation of medical pluralism and the utilization of TCAM by the eThekwini oncology community and lays a foundation for future research into the opportunities offered by our pluralistic medical landscape to improve patient outcomes.

1.4 Outline of Chapters

Chapter 1: Introduction
Chapter 2: Literature Review

Chapter 3: Methodology

Chapter 4: Patient quantitative results
Chapter 5: Oncologist quantitative results
Survey results

Chapter 6: Patient qualitative results
Chapter 7: Oncologist qualitative results
Interview results

Chapter 8: Discussion (synthesis and contextualising of chapters 4 to 7)
Chapter 9: Conclusions

Chapter 10: Bibliography
Chapter 11: Appendices

2. LITERATURE REVIEW

This literature review will define medical pluralism, clarify terminology utilised in academic discourse on medical pluralism, and present opportunities and challenges a pluralistic medical landscape brings for both practitioners and patients. After outlining factors affecting patient health-seeking behaviour within a pluralistic landscape, it will consider the bioethical responsibilities of the practitioner caring for these patients. The review will then explore the dynamics at the interface of mainstream biomedical practice and TCAM. It will define holistic and integrative practice and present a brief overview of the different levels of legitimation and incorporation of complementary practices into mainstream medical practice. In doing this, it will highlight the role of evidence-based medicine (EBM) in the legitimation of TCAM and the development of formal integrative practice.

The review will then turn its attention to breast cancer as the specific clinical field of interest in this study, starting with its incidence both worldwide and in South Africa. The main biological hallmarks of cancer will be defined, and the role played by genetics and epigenetics will be presented before outlining the mainstream biomedical therapies employed in the treatment of breast cancer.

The review will then describe the field of TCAM, summarising some of the common therapies utilised by oncology patients worldwide and examining them in the light of research evidence. It will explore aspects of TCAM use amongst cancer patients including prevalence, reasons for use, patient sources of information, and patient disclosure. Integrative Oncology will be presented as a field seeking to combine the best of both TCAM and mainstream biomedical treatments, supporting patients and oncologists in navigating the pluralistic medical landscape through rigorous evidence and clinical guidelines.

The review will end by contextualising the current research geographically and socially, highlighting the pluralism of the local medical landscape as well as the multicultural and historically disparate nature of the population.

2.1 Medical Pluralism

2.1.1 Defining medical pluralism

The suffering caused by disease and the accompanying quest for healing are as old as humankind itself, and many medical systems and practices have evolved within various cultures through the centuries, either independently or side by side (Ackerknecht 2016; Khalikova 2021). The term “medical pluralism” refers to the co-existence or availability of many different healthcare options when seeking health and wellbeing (Khalikova 2021). Distinct from “medical monism”, in which a single medical system defines a society’s healthcare, “medical pluralism” draws attention to the presence of a diversity of practises within a health landscape (Gale 2014; Khalikova 2021).

Whilst the biomedical model of disease and healing has become the most widely accepted model in many countries, it is only one of several approaches to health in a complex and multi-cultural world (Gale 2014; Lichtenstein, Berger and Cheng 2017). According to the World Health Organization, medical pluralism occurs in almost every country in the world (World Health Organization 2013), and one only need look at how people approach illness, often utilising a mix of home remedies, formal biomedical approaches and religious healing, to become aware of the presence of medical pluralism in most societies (Khalikova 2021). Medical pluralism has been the focus of abundant research activity and philosophical debate across fields such as medicine, anthropology, and sociology, because it impacts vital matters including health seeking behaviour patterns, regulation of practice, medical funding, and design of culturally sensitive healthcare systems (Gale 2014).

Medical landscapes are constantly shifting, as medical thought and practice are shaped by numerous internal and external factors (Gale 2014; Khalikova 2021). Factors that shape medical landscapes include health ideologies; constant growth in medical knowledge; and increased patient health literacy (Khalikova 2021). With the advent of technology, many patients have increased access to information which changes personal expectations and demands (Alsharif and Mazanec 2019; Zhou and Fan 2019). In addition, there are political-economic factors including globalization and population migration; commercial medical industry; matters of economic viability and sustainability; and government policy and regulation (Khalikova 2021). Within the pluralistic medical landscape, there is not a single system of medicine that has proved itself capable of addressing all the healthcare needs of modern society (Pan, Yang and Zhou 2016).

Patients have multifaceted needs and continue to search for the best approaches and alternatives to wellness (Khalikova 2021).

Use of complementary or alternative therapies by the general population has increased worldwide in the last two decades, ranging between 9.8% and 76% (Harris *et al.* 2012). A 2020 systematic review summarised the main reasons for use and non-use of complementary and alternative medicine. Reasons for use included positive attitudes towards these therapies (perceived benefits and safety; accessibility and affordability; an internal locus of control); dissatisfaction with experiences of conventional medicine; influences by friends and family; recommendation by practitioners; and cultural tradition. Reasons for non-use included negative attitudes towards these therapies (concerns about benefits and safety; dissatisfaction with experiences of complementary or alternative therapies; affordability and convenience); satisfaction with conventional medicine; and lack of information and knowledge about other therapies (Tangkiatkumjai, Boardman and Walker 2020b).

2.1.2 Terminology matters

There are several different terms used when describing the numerous and varied practices that lie outside the Western biomedical model of care within a pluralistic landscape, including “alternative”, “complementary” and “traditional” (World Health Organization 2013; Mullins-Owens 2016; Ng et al. 2016; James et al. 2018; Scarton et al. 2019). According the World Health Organization (WHO) “complementary medicine” or “alternative medicine” “refer to a broad set of health care practices that are not part of of that country’s own tradition or conventional medicine and are not fully integrated into the dominant health-care system” (World Health Organization 2013). The term “alternative” is usually used to refer to practices utilised in place of mainstream biomedicine, whereas “complementary” is usually used to describe practices utilised in conjunction with mainstream biomedicine (National Center for Complementary and Integrative Health 2019c). “Traditional medicine” also sometimes called “indigenous” or “folk” medicine, generally refers to long-established healing practises which have originated in a geographically specific area (Gale 2014). The WHO defines “traditional medicine” as “the sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness” (World Health Organization 2013).

For the purposes of academic discourse, these terms are often collectively abbreviated into the acronyms “CAM” (for complementary and alternative medicine), T&CM (traditional, and complementary medicine), or “TCAM” (for traditional, complementary and alternative medicine) (World Health Organization 2013; Mullins-Owens 2016; Ng et al. 2016; James et al. 2018; Scarton et al. 2019). The conflation of different terms into acronyms can lead to confusion amongst those who are exploring health care options and cause grey areas in academic writings. In many situations, it is therefore better to utilise them separately so as to provide clarity as to whether the health approach in question is being utilised alongside, or in place of conventional methods of therapy (Deng and Cassileth 2014). Nevertheless, these acronyms remain in use and play a useful role in academic discussions (Gale 2014; Pinzon-Perez and Perez 2016). There are also instances where their separation is not that simple. Some “alternative” choices (for example replacing conventional treatments for nausea, pain, sleeplessness etc.), can be used as “complementary” therapies in an integrative approach (Abrams and Weil 2014). It is worth nothing that many practices, like the use of nutritional approaches and exercise as holistic support, that are classified as “complementary” that *do* in fact draw on the principles and science of the biomedical model. . Accordingly, not all therapies and practices classified as TCAM are necessarily based in philosophies and theories that are incompatible with those underpinning biomedicine (Abrams and Weil 2014) .

One cannot discuss the concept of medical pluralism without simultaneously introducing issues of power, legitimation and social constructs that naturally develop over time within any society. Even a cursory exploration of the terminology that is utilised reveals an international dominance of the biomedical model amongst those writing about the medical landscape. Western medicine is described as “conventional” and “mainstream”, whilst health practices that lie outside the biomedical model are described in relation to it, using terms such as “unconventional” or “alternative” (Ng *et al.* 2016). Thus, practices stemming from other theoretical frameworks/models are defined relative to biomedicine in terms of what they are *not*, rather than in terms of what they *are* (Gale 2014; Ng *et al.* 2016). This terminology resulted because the field of medical anthropology has its roots in the Western world and study of non-Western medical traditions and their encounters with biomedicine (Khalikova 2021). This notwithstanding, such terminology remains the norm in established academic conversations and will be utilised for the purposes of this thesis, particularly given that the sample population in this research were all on mainstream biomedical treatment programs.

2.1.3 Opportunities and challenges of a pluralistic medical landscape

A diverse and ever-changing pluralistic landscape brings with it both opportunities as well as challenges for the patients, practitioners and state (Chernichovsky 2002; Khalikova 2021). The clear advantage of a pluralistic environment is that patients have more healthcare options and access to a wider selection of services addressing various aspects of health (Khalikova 2021). A diverse healthcare system also fosters innovation and competition which in turn can increase the quality of healthcare provision (Federal Trade Commission 2023).

Whilst the presence of different approaches, (often underpinned by different theories and ideologies), provides a variety of options for the consumer, it naturally increases the complexity of health navigation and decision-making on the part of the patients and caregivers when seeking solutions to illness (Khalikova 2021). Practitioners from different approaches generally operate in silos, often lacking knowledge and trust of the other (Uibu and Koppel 2021). This leaves patients to inform themselves in order to make their own assessments and choices (Wiese and Oster 2010b). This decision making occurs under physical and emotional distress, patients can find decision-making stressful and may need guidance navigating medical pluralism safely and to best advantage (Balneaves *et al.* 2007; Jones *et al.* 2019). Related to patient navigation of the pluralistic landscape are the issues of late presentation and defaulting on mainstream treatments. Patients may turn to alternatives for serious health conditions and not seek biomedical treatments timeously, a matter of particular concern in cancer (Mujar et al. 2017; Burman 2019). Delay or refusal of conventional cancer treatment can negatively impact survival (Johnson *et al.* 2018).

Ensuring quality control amongst all the health professionals and for all practices and products is a challenge in any pluralistic medical landscape, requiring systems and processes to create and enforce the necessary standards (Care, Steel and Wardle 2022; Young and Smith 2022). There are also issues of cost and accessibility for many individuals with lower-income consumers having limited access, thus increasing disparities in care (Riley 2012).

Use of some TCAM practices and products concurrently with mainstream treatments also brings risk of adverse interactions (Alsanad, Howard and Williamson 2016; Sweet *et al.* 2016). Patients do not always divulge their use of additional medical systems and practices to their primary practitioners, making their management more complex and fraught with challenges and risks (Lo-Fo-Wong *et al.* 2012).

Thus, whilst medical pluralism brings with it advantages for patient and clinician, it also brings dangers and challenges that need to be navigated.

2.1.4 Patient health-seeking behaviour in a pluralistic landscape

There are numerous factors which influence health-seeking behaviour of individuals within a pluralistic health landscape, making these decisions complex and dynamic. Many studies have sought to identify important contributing factors and develop conceptual models (Chowdhuri, Kunda and Meyur 2022). The many (and often interrelated) factors at play include socio-demographic aspects (race; age; gender; religion; education; finances; cultural milieu) as well as patient internal processes and preferences (cognitive ability; understanding and perception of treatments; dissatisfaction with current choices or past experiences; anxiety; philosophical congruence; and holistic orientation). Additional factors impacting decision making are social influence; peer pressure; perceived or real disease burden and treatment availability (Chowdhuri and Kundu 2020).

The most widely accepted model of healthcare decision-making is Andersen and Davidson’s Behavioural Model of Healthcare Utilization which recognises the role of both individual, as well as contextual determinants in health-seeking choices. In both these arenas, there are *predisposing factors,* and *needs* which, together with *enabling factors*, will result in the observed patient health-seeking practices (Andersen 1995; Andersen and Davidson 2001). Individual predisposing factors might include demographics (such as age and gender); social factors (such as education, ethnicity, and social network) and mental factors (such as attitudes, beliefs, values, and knowledge). Individual need is referencing the patient’s perceived and/or clinically evaluated personal disease burden. Individual enabling factors include financial agency (personal income and medical aid); the availability of personal support; and practical matters such as transportation. Andersen and Davidson divide the contextual determinants in the same way into *predisposing factors*, *need* and *enabling factors*, but with reference to the societal level. Contextual predisposing factors include the demographics, collective values, and cultural norms of the society in which the individual lives. Contextual need references the greater needs of the society and contextual enabling factors are societal considerations such as hospital density, provider mix, health education and health policy (Andersen 1995; Babitsch, Gohl and von Lengerke 2012). A summary of some of the main *individual* and *contextual* factors of this model is presented in table 2.1.4.1 below. The various elements of this model are naturally interrelated, affecting each other. There is interplay between the individual and their environment/ context in which they are living. In addition, the personal health choices and utilization of health services feed back into the system, impacting processes at both the individual and contextual levels (Andersen 1995; Chowdhuri and Kundu 2020).

Table 2.1.4.1: Individual and contextual determinants affecting health seeking choices (Adapted from Andersen and Davidson 1995, and Chowdhuri and Kundu 2020).

	Predisposing Factors	Need	Enabling Factors
Individual	**Demographics**: Age, gender. **Social factors:** Education, occupation, ethnicity, social relationships. **Mental factors:** Attitudes, beliefs, values, knowledge, and cognitive understanding.	**Perceived need:** how people view and experience their own illness. **Evaluated need:** Professional assessments and objective clinical measures.	**Financial:** Income, med aid. **Support:** Personal needs for support. **Practical issues:** transportation, travel time, clinic waiting time.
Contextual	**Sociodemographic:** Demographic and social composition of communities. **Community norms:** Collective values, cultural norms. **Politics:** Political perspectives.	**Needs of wider community:** Population health needs and epidemiological indicators.	**Community resources:** Economy, resources available to the wider community, provider mix, physician & hospital density, **Literacy:** Health education, outreach programs **Governance:** Quality management, governance, and health policies.

Whilst this model has been, and continues to be, extensively used, there is flexibility and large variations in exactly how variables are categorised within the model (Babitsch, Gohl and von Lengerke 2012).

2.1.5 Medical pluralism and the bioethical responsibilities of medical practise

Arguably some of the most important and contentious issues in relation to TCAM concern medical ethics (Smith 2016). There are strong arguments against the practice, promotion, and tolerance of TCAM based on several factors. These factors include the potential risk of patients failing to seek effective evidence-based healthcare; the possibility of harm resulting from dangerous preparations and procedures; and the potential for wastage of resources on ineffective therapies (Smith 2016). There is also the perception that promotion of TCAM promulgates non-scientific theories and exploits poorly informed and vulnerable patients (Smith 2016). Counterarguments of include the opinion that a plausible biomedical basis is not the only plausible theoretical underpinning of worth and that openness to TCAM maximises patient-centred care by consideration of aspects such as autonomy (Smith 2016). These arguments are rooted in the ethical responsibilities of the medical field and clinicians in particular.

Medical ethics is the study of moral values applied to medical practise, and can be traced back to the introduction of the Hippocratic Oath around 500 B.C.E. (*Internet Encyclopedia of Philosophy* 2018). A cardinal text in Biomedical ethics was written by Beauchamp and Childress in which the authors identified and outlined four main principles of medical practise, each holding ethical obligations for the clinician (Beauchamp and Childress 2013). These four principles have subsequently had tremendous influence on clinical practise guidelines and are amongst twelve outlined by the Health Professions Council of South Africa (HPCSA) in their guidelines for good practise of health professionals (HPCSA 2021). The four main principles outlined by Beauchamp and Childress, together with their inherent clinical obligations are as follows:

1. *Respect for patient autonomy.* In upholding this principle, clinicians are obliged to respect the patient as an individual with the right to make their own informed decisions consistent with their personal beliefs, values and preferences (Beauchamp and Childress 2013; HPCSA 2021). Related to this, HPCSA incorporates the principle of Tolerance which states that “clinicians need to respect the different beliefs of patients which “may arise from deeply held personal, religious or cultural convictions” (HPCSA 2021).
2. *Nonmaleficence*: Clinicians have an obligation to identify potential harm to patients and minimise or avoid this harm (Beauchamp and Childress 2013; HPCSA 2021).
3. *Beneficence:* Clinicians have an obligation to always seek the patient’s good and act in their best interests, even if this conflicts with their own personal best interests (Beauchamp and Childress 2013; HPCSA 2021).
4. *Justice*: Clinicians have the obligation to work towards the promotion of fair distribution of medical services to different patient populations (Beauchamp and Childress 2013; HPCSA 2021).

In daily clinical practise, ethical choices are not always clear cut. There are occasions when the core values may clash, placing competing demands on healthcare practitioners (HPCSA 2021). This is the case with the dilemmas posed to clinicians by the interface of TCAM and biomedicine, requiring practitioners to respect autonomy and beneficence whilst still ensuring non-maleficence (Tilbert and Miller 2007).

It is clear that failing to acknowledge the existence of medical pluralism and the potential it holds for harm or healing, and failing to address medical pluralism with their patients, is a failure to deliver an ethical service. Tilbert and Miller (2007) set about examining some of the complexities of the ethical challenges posed by medical pluralism, and constructed a three point approach to applying the principles of biomedical ethics in the light of medical pluralism (Tilbert and Miller 2007). The three points are: Inquiry; Acknowledgement and Accommodation. This approach begins with Inquiry, asking patients about their TCAM use. The authors emphasised that by expressing genuine interest, they are more likely to get accurate information from their patients. Connected to this first point is the need to explore the evidence for treatments normally lying outside their scope of practice. The second point involves acknowledgement of the cultural and personal meaning associated with the diverse health beliefs and practices of patients, which may require recognising the legitimate role for patients played by these nonbiomedical approaches, even if unable to endorse them. The third point is to consider possible accommodation of the additional practices where evidence has demonstrated a satisfactory risk-benefit ratio. The authors felt that by recognising medical pluralism and using this three-point approach, clinicians can enhance patient care in a manner consistent with bioethical principles (Tilbert and Miller 2007). A similar viewpoint was expressed by Pinzon-Perez who stated that ensuring personal understanding of TCAM therapies, and assisting patients to safely navigate and integrate these where possible, does not necessarily mean unconditional endorsing of practices on the part of the clinician, but rather a recognition of bioethical responsibilities (Pinzon-Perez and Perez 2016).

2.1.6 The mainstream-TCAM interface

The history of the relationship between mainstream health care and TCAM is an interesting and generally fractious one. For many reasons, a pluralistic health landscape, incorporating healing traditions from different theoretical frameworks, will inevitably lead to elements of antagonism, hostility and exclusion (Wiese and Oster 2010b). The sociology of the interplay between TCAM and mainstream biomedicine in a pluralistic environment is a large field of study in itself (Gale 2014). TCAM approaches are often underpinned by different beliefs and philosophical systems which result in incompatible understandings of what causes disease and how healing is brought about. Both TCAM and biomedical mainstream practitioners place strong emphasis on the boundaries between the two (Gale 2014; Uibu and Koppel 2021).

The two disciplines have reservations, disrespect, and antagonism between different schools of thought. Those who are against TCAM criticise it for “lacking biological plausibility”, describing it using words such as “quackery”, “pseudoscience”, “superstition”, “witchcraft”, “propaganda” and “fraud” (Uibu and Koppel 2021; Wikipedia 2023). TCAM is considered deficient in that it is largely based on testimonials vs randomised control studies (RCT), promulgated by TCAM practitioners, and lacks adequate monitoring and quality controls necessary to ensure safety (Wikipedia 2023). On the other hand, TCAM practitioners distrust and undermine mainstream biomedicine, describing it as “hegemony”, “narrow”, “limited”, and “corrupted by big pharma” (Uibu and Koppel 2021). They believe that mainstream biomedicine lacks adequate attention to holism, and view the requirement for randomised controlled trials as oppression by a dominant ideology (Uibu and Koppel 2021).

In 2007, Broom and Tovey described a movement away from a binary view of “mainstream” vs “alternate” medical care. They portrayed this binary view as being replaced in some part by a “grudging acceptance” and increased collaboration with “integration” of different medical traditions. (Broom and Tovey 2007; Wiese and Oster 2010a, 2010b). In 2010, Wiese et al. presented a review paper in which they outlined three ways that they believed TCAM has been, and is being, included into mainstream medical practise (Wiese and Oster 2010b). Firstly, they used the term “pluralization” to describe a situation in which the mainstream and TCAM practices retain their own distinctiveness and operate separately, leaving the consumer to inform themselves and select the approach that most suits them. Secondly, they use the term “incorporation” to describe a situation that involved the selective inclusion of aspects of TCAM alongside biomedical treatments. This could be through mainstream practitioners learning aspects of TCAM practices, or with TCAM practitioners working alongside mainstream practitioners allowing for some incorporation of TCAM practices. In the latter situation however, mainstream practitioners act as gatekeepers to the TCAM practices. Lastly, Wiese et.al. use the term “integration” to describe a situation in which practitioners who hold different views of health and healing work together with respect and collaboration which actually leads to mutual transformation (Wiese and Oster 2010b). This movement towards collaboration and integration reveals a growth in the concerted efforts by practitioners of different persuasions to work collaboratively with each other in order to offer the best care for their patients (Gale 2014). This is summarised in figure 2.1.6.1 below.

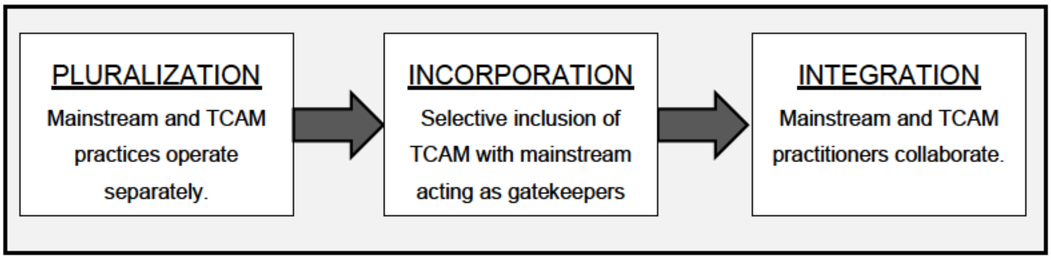
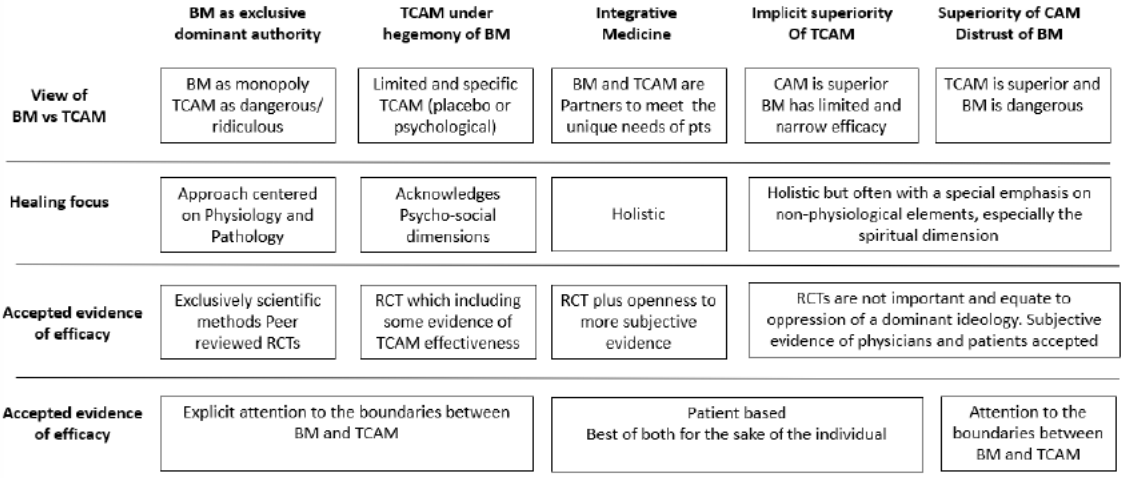


Figure 2.1.6.1: Summary of Wiese et al. outline of TCAM inclusion into mainstream medicine.

A similar but more detailed mapping of the views and the relationship between Western Biomedicine (BM) and TCAM was constructed by Uibu and Koppel (Uibu and Koppel 2021). In their study, based on the rhetoric used by practitioners in Estonia, these authors present a tabulated description of practitioner views, health definitions and accepted evidence of efficacy from both sides. The table juxtaposes the polar approaches and opinions of exclusive Western Biomedicine vs TCAM fields. It also includes approaches that represent the middle ground, with varying degrees of harmony and collaboration (Wiese and Oster 2010b). Figure 2.1.6.2 below is an adaptation of this table. At the two extremes of this table are the divergent views of the Biomedical (BM) and TCAM professionals. In the centre, the model presents the three further positions of varying inclusion of both, with the central position held by a completely integrative approach which aims to incorporate the best of both worlds and provide holistic patient-centred care (Uibu and Koppel 2021).



	BM as exclusive dominant authority	TCAM under hegemony of BM	Integrative Medicine	Implicit superiority Of TCAM	Superiority of CAM Distrust of BM
View of BM vs TCAM	BM as monopoly TCAM as dangerous/ ridiculous	Limited and specific TCAM (placebo or psychological)	BM and TCAM are Partners to meet the unique needs of pts	CAM is superior BM has limited and narrow efficacy	TCAM is superior and BM is dangerous
Healing focus	Approach centered on Physiology and Pathology	Acknowledges Psycho-social dimensions	Holistic	Holistic but often with a special emphasis on non-physiological elements, especially the spiritual dimension	
Accepted evidence of efficacy	Exclusively scientific methods Peer reviewed RCTs	RCT which including some evidence of TCAM effectiveness	RCT plus openness to more subjective evidence	RCTs are not important and equate to oppression of a dominant ideology. Subjective evidence of physicians and patients accepted	
Accepted evidence of efficacy	Explicit attention to the boundaries between BM and TCAM		Patient based Best of both for the sake of the individual		Attention to the boundaries between BM and TCAM

Figure 2.1.6.2: Uibu and Koppel's presentation of the positioning and interplay between Biomedicine and TCAM within a pluralistic landscape.

Integrative medicine, as a formal field of endeavour, seeks to utilise both biomedical approaches as well as evidence-based TCAM approaches to treat the whole person (Cleveland Clinic 2022c). Integrative Medical practice has developed rapidly as a field of research and practice over the last two decades (Pan, Yang and Zhou 2016).

Proponents of integrative practice hold that it is a framework by which practitioners can provide holistic patient-centred care, bridge health care gaps, address cultural needs of patients, and reduce the risk by relying on evidence-based inclusions (Mao *et al.* 2022b).

2.2 Breast Cancer

2.2.1 Incidence and mortality

Cancer is the second leading cause of death in the world, with the World Health Organization (WHO) reporting it as accounting for one in every six deaths globally (World Health Organization 2019). Approximately ten million new cancer cases are reported every year with an expected 47% rise in the global cancer burden by 2040 (Ghufran and Duddukuri 2023). Breast cancer is now the most diagnosed cancer worldwide accounting for 1 in 8 cancer diagnoses (Arnold *et al.* 2022). It is also the leading cause of female cancer-related deaths worldwide (DeSantis *et al.* 2015). In 2020, over 2.3 million new cases were diagnosed, and 685 000 deaths occurred worldwide due to breast cancer, but by 2040, these figures are expected to increase to over 3 million new cases and 1 million deaths every year as a result of population growth and aging (Arnold *et al.* 2022).

The most recent South African National Cancer Registry (NCR) report released in 2014, indicated that, at 21.78%, breast cancer has the highest incidence of all female cancers diagnosed annually in South Africa (National Cancer Registry 2014). The National Cancer Registry reports also indicate that the number of newly diagnosed cases per year in South Africa is increasing, with 5280 diagnosed in 2000 and 8230 diagnosed in 2014 (Herbst 2018). A recent paper predicted that South African cancer rates are set to double by 2030 (Finestone and Wishnia 2022). De Santis et al. (2015) suggested that increasing incidence and mortality rates observed in low- and middle-income countries could be due to adoption of a Western lifestyle, with alterations in reproductive patterns, diet and physical activity (DeSantis *et al.* 2015). Whilst there are many possible explanations for the increased number of new diagnoses, the fact remains that this presents challenges to the patients and health care providers of the country. This is a burden that is likely to increase as the possibility of an epidemiological transition shifts the disease patterns of the country from infectious diseases such as HIV to chronic diseases including cancer (Omran 2005).

2.2.2 The genetic and epigenetic basis of cancer

2.2.2.1 The genome, transcription, and translation

The genetic code, composed of approximately 20 000 to 25 000 genes, takes the form of helical strands of deoxyribonucleic acid (DNA), found packaged in chromosomes within the nucleus of each cell (Nenclares and Harrington 2019). The genes within DNA code for various proteins, and through these proteins, genes have the capacity to alter cellular activities such as secretion, growth and survival (Nenclares and Harrington 2019). Protein production takes place through the processes of transcription (copying of the relevant section of DNA code) and translation (the synthesis of proteins by assembling the amino acid chains), together known as gene expression (Medline Plus 2021b). The control of protein production occurs through the switching on or switching off of the genes, a process known as gene regulation, which, whilst it can occur at any level of gene expression, commonly occurs at the level of transcription (Medline Plus 2021b).

2.2.2.2 The epigenome

There are a multitude of chemical compounds that can affect gene expression, effectively telling the genome what to do via impacting transcription, translation and post-translation modifications (Moosavi and Ardekani 2016; National Human Genome Research Institute 2023). These chemical compounds are found attached to, or around the DNA, affecting gene activity without changing the DNA sequence itself (Lustberg and Ramaswamy 2011; International Human Epigenome Consortium 2019; Medline Plus 2021b). When these compounds attach to the genome and modify gene expression, they are said to have "marked" the genome (National Human Genome Research Institute 2023). The main types of epigenetic marks are DNA methylation (where methyl groups attach to a gene to silence it); histone modification (compounds that control DNA wrapping, affecting transcription); and non-coding RNA (which attaches to coding RNA to control translation) (Moosavi and Ardekani 2016; Centers for disease control and prevention 2022). Within a given cell, all the modifications which are present and involved in regulating gene expression are referred to collectively as the epigenome (Medline Plus 2021a), and the study of these epigenomic compounds and mechanisms involved in modifying gene expression is known as epigenetics (Medline Plus 2021a). The epigenome varies between different cells, tissues and individuals, and epigenetic marks can be passed from cell to cell during mitosis, and from one generation to the next (National Human Genome Research Institute 2019). Thus, an individual's epigenetic profile is developed from when they are in utero, and continues to change with age, affected by lifestyle and environmental factors. In addition, unlike genetic mutations, epigenetic changes are reversible (Centers for disease control and prevention 2022).

2.2.2.3 Epigenetics and disease

Errors in the epigenetic markers and processes lead to abnormal gene activity or inactivity (Medline Plus 2021a). Because of this, aberrant epigenetic changes have been implicated in human disease processes including inflammatory processes, diabetes and cancer (International Human Epigenome Consortium 2019). Therefore, epigenetics is as important as genetics when trying to understand disease, and when developing ways to prevent, diagnose, treat and possibly reverse disease (International Human Epigenome Consortium 2019; Medline Plus 2021b).

2.2.2.4 Genome, epigenome, and cancer

It has long been known that cancer is a genetic disease which results from congenital or acquired alterations in the genes themselves, or in gene regulation and expression (Goldberg, Parker and Gevers 1991). The aberrations relate to proto-oncogenes and tumour suppressor genes (TSGs) (Nenclares and Harrington 2019). As the name implies, congenital/inherited gene mutations are passed on from parent to child and present in the very first cell, giving the individual a predisposition to that cancer. Hereditary breast cancer is the result of mutations on the gene locations *BRCA1*; *BRCA2*; *ATM* gene; *PTEN*; and *p53* (Bennett, Gattas and Tean Teh 1999; Murray and Davies 2013). By contrast, acquired gene mutations are not inherited from the parent, but develop at some point during a person's life as a result of random errors or environmental exposures. Such mutations are also known as sporadic or somatic mutations (American Cancer Society 2022). Around 10% of cancers are inherited and 90% are acquired (National Cancer Institute 2022a).

Proto-oncogenes, responsible for cell proliferation, survival and invasion, are normally carefully regulated, but when upregulated through mutation or amplification, cellular growth and proliferation go unchecked and cell survival is enhanced (Nenclares and Harrington 2019). Tumour suppressor genes on the other hand, are responsible for inhibiting cell proliferation and survival, frequently through affecting cell cycle progression and apoptosis, but when inactivated through genetic or epigenetic alterations, will fail to do so (Nenclares and Harrington 2019).

There is strong evidence demonstrating that alterations in DNA methylation; histone modification; non-coding RNA expression; and post-transcriptional epigenetic regulators play a pivotal role, not only in cancer development, but also in disease progression, response to therapy and clinical outcome (Rosenquist, Esteller and Plass 2018). Aberrant DNA methylation is the most studied epigenetic factors in relation to cancer (Rosenquist, Esteller and Plass 2018). Methylation levels are known to play an important role in cell division, DNA repair, differentiation, apoptosis, angiogenesis, metastasis, growth factor response, and detoxification (Moosavi and Ardekani 2016). Specifically, there is increasing evidence that epigenetic mechanisms play a key role in breast cancer. Drugs, aimed at reversing epigenetic defects, have been developed to target breast cancer cells (Lustberg and Ramaswamy 2011; Basse and Arock 2015; Pasculli, Barbano and Parrella 2018).

2.2.3 The molecular subtypes of breast cancer

In 2000, Perou et al. published a seminal work in which they utilised DNA microarrays to explore what they referred to as the “distinctive molecular portraits” of 65 surgical specimens of breast cancer, concluding that unique molecular subtypes could explain diversity in breast cancer, biological activity, and responsiveness to treatments (Perou *et al.* 2000). Over the following decade, intensive study led to the classification of breast cancer into five intrinsic subtypes called Luminal A, Luminal B, HER2-enriched, Claudin-low and Basal-like (also known as triple negative) (Prat and Perou 2011). These subtypes demonstrate different tumour biology and respond differently to various treatments, therefore consideration of tumour subtype is critical when making clinical decisions (Edge and Buccimazza 2019).

In the case of breast cancer cells, the elements of tumour cell biology that (amongst others) are of most relevance, are cellular sensitivity to oestrogen, progesterone and/or human epithelial growth factor 2, as well as cellular levels of the proliferation protein Ki-67 (Edge and Buccimazza 2019). Increased cell sensitivity to oestrogen, progesterone and/or human epithelial growth factor results in increased cellular growth and proliferation, as does increased cellular levels of Ki-67(Inwald *et al.* 2013; Edge and Buccimazza 2019). In the case of hormonal growth stimulation, oestrogen receptors (ER) and progesterone receptors (PR) are stimulated by attachment of the corresponding hormone, and the HER2 receptors are stimulated by the attachment of HER2/ERBB2 protein (Human epithelial growth factor 2). This receptor binding results in the activation of intracellular signalling cascades which allow for increased cellular growth and division, and therefore the fuelling of tumour growth (Key 1995). Utilising immunohistochemistry, breast biopsies are tested for oestrogen, progesterone and HER2 (ERBB2) receptor positivity, as well as nuclear expression of Ki-67, in order to classify the specific tumour molecular subtype for each patient and to make the most suitable clinical decisions (American Cancer Society 2019c; Edge and Buccimazza 2019).

A tumour is classified as oestrogen receptor positive (ER^+) or oestrogen receptor negative (ER^-); progesterone receptor positive (PR^+), or progesterone receptor negative (PR^-); and HER2 receptor positive ($HER2^+$) or HER2 receptor negative ($HER2^-$) (American cancer society 2019a). Ki-67 is expressed as a percentage of tumour cells showing a strong positive response for Ki-67, with a lower percentage (below 15%) being associated with increased survival (Inwald *et al.* 2013). On the basis of the presence or absence of these molecular markers, tumours are then categorised into one of the following: Luminal A (ER/PR^+; $HER2^-$; Ki-67<14%); Luminal B HER2 negative (ER/PR^+; $HER2^-$; Ki-67>14%); Luminal B HER2 positive (ER/PR^+; $HER2^+$; Ki-67<14%); HER2 non luminal (ER/PR^-; $HER2^+$); Basal like/triple negative (ER/PR^-; $HER2^-$) (Edge and Buccimazza 2019). Together with other clinical factors such as stage of the cancer, these subtypes are a major determinant of prognosis and therapeutic options (Waks and Winer 2019).

2.3 The Biomedical Treatments for Breast Cancer

The treatment for Breast cancer will depend on many factors such as tumour biology, the stage of the cancer and patient factors. It will generally include a combination of local and systemic therapy (Edge and Buccimazza 2019; Waks and Winer 2019). Local therapies target the specific tumour area and include surgery and radiotherapy, whereas systemic therapies circulate systemically and include chemotherapy, endocrine therapy, targeted therapy and immunotherapy(American Cancer Society 2019c; Edge and Buccimazza 2019).

2.3.1 Surgery

Surgery is used to remove as much of the cancer as possible, as well as to determine whether the cancer has spread to the local lymph nodes (generally through a sentinel lymph node biopsy or SLNB), thus allowing for accurate staging of the disease. Breast conserving surgery (BCS), also known as lumpectomy or partial mastectomy, aims to remove the tumour and some surrounding normal tissue whilst conserving the breast. BCS is now the treatment of choice for early stage breast cancer and for select cases of locally advanced cancer where there is no skin involvement (American Cancer Society 2019c; Edge and Buccimazza 2019). In a Mastectomy, the whole breast is removed, and in a bi-lateral mastectomy, both breasts are removed. The type of mastectomy and the extent of surrounding tissue that is removed will depend on the clinical scenario (American Cancer Society 2019c; Edge and Buccimazza 2019). Short-term complications that might occur with surgery include, bleeding and infection, whilst long-term complications include shoulder problems, numbness and lymphoedema (Edge and Buccimazza 2019).

2.3.2 Radiation therapy

In radiation therapy, ionising radiation is used to treat the cancer by causing damage to the DNA, leading to cell death (American Cancer Society 2019b; Edge and Buccimazza 2019). Using CT scan guidance, the beams are directed towards the tumour from many different angles, so that convergence will result in the sites of concern receiving the highest dose, whilst keeping the dose delivered to surrounding normal tissues to a minimum (Edge and Buccimazza 2019). Cancer cells are less efficient at repairing DNA than normal cells, so dividing the therapy into numerous small doses (factions) allows normal tissues time for DNA repair between factions (Edge and Buccimazza 2019). The short-term effects of radiotherapy include inflammatory changes in the overlying skin as well as varying levels of fatigue. Long term effects could include decreased cardiac or pulmonary function (although rare), fracture and pain of the bones in the chest wall, lymphedema, scar tissue and shoulder stiffness (American Cancer Society 2019c, 2019b; Edge and Buccimazza 2019; National Cancer Institute 2019).

2.3.3 Systemic therapy

2.3.3.1 Chemotherapy

Systemic therapy (including chemotherapy, endocrine therapy, targeted therapy and immunotherapy), are therapies that are administered to the whole body as opposed to a localised area (Edge and Buccimazza 2019). Most chemotherapy drugs interfere with the reproduction of cells by disrupting DNA, RNA and interfering with various mechanisms of cell division, and specifically targeting rapidly growing cells (Edge and Buccimazza 2019). Because the therapy does not distinguish healthy cells from cancer cells, it is associated with many side effects as the healthy cells become damaged, especially hair follicles, lining of the digestive tract, the reproductive system and hemopoietic cells of the bone marrow (American Cancer Society 2020a). These side effects may include severe diarrhoea or constipation; nausea and vomiting; hair loss and nail changes; inflammation of mucous membranes, especially the mouth and intestinal lining; fatigue; lack of mental clarity; painful joints; neuropathy; infertility and low blood counts leading to anaemia and infections. In addition, many patients need assistance with psychosocial problems (Edge and Buccimazza 2019; Leach 2019; Waks and Winer 2019; American Cancer Society 2020a).

2.3.3.2 Targeted therapy

As part of the growing field of precision medicine, targeted therapies are designed to target specific cancer cells or specific tumorigenic elements of biochemical pathways, thus minimising the impact on healthy cells (National Cancer Institute 2019). Targeted therapy drugs include angiogenesis inhibitors, monoclonal antibodies, proteosome inhibitors and signal transduction inhibitors (National Cancer Institute 2019; American Cancer Society 2020c). The targeted therapy most widely used in breast cancer is a Trastuzumab (Herceptin), a monoclonal antibody drug used in HER 2 positive breast cancer which blocks the receptors for HER 2, preventing the stimulation of these receptors by this growth protein (Edge and Buccimazza 2019).

2.3.3.3 Endocrine therapy

Systemic endocrine therapy is utilised in hormone-positive cancers, and the aim of endocrine therapy is to stop the tumorigenic stimulation by the reproductive hormones. This can be achieved either by stopping oestrogen production at the source (whether ovarian or non-ovarian tissues), and/or by blocking or degrading the oestrogen receptors (Edge and Buccimazza 2019; American Cancer Society 2020b). Before menopause, the ovaries are the source of most oestrogens, but oestrogens are also released from other tissues including the adrenal glands and adipose tissue (including breasts) (Cleveland Clinic 2022b). Other extra-gonadal sites that produce oestrogen include the osteoblasts and chondrocytes of bone, the vascular endothelium and aortic smooth muscle cells, and numerous sites in the brain, where it is believed the hormone has a paracrine or intracrine action. These sites continue production even after menopause (Simpson 2003). Thus, oestrogen plays numerous vital roles in the body besides reproductive functions. In reviewing the sources, metabolism, receptor distribution, and signalling pathways for oestrogen, Cui *et al.* concluded that they “believe that oestrogens are no longer just sex hormones, but important therapeutic targets for preventing diseases as disparate as osteoporosis, heart disease, and neurodegeneration” (Cui, Shen and Li 2013).

Stopping production of oestrogen by the ovaries in premenopausal women is achieved through the use of a LHRH agonist (luteinising hormone releasing hormone agonist) (Edge and Buccimazza 2019). The hypothalamic luteinising hormone releasing hormone (LHRH) would normally stimulate the anterior pituitary to release luteinising hormone, a tropic hormone, which in turn stimulates the production and release of oestrogen from the ovaries (National Library of Medicine 2022). When a LHRH agonist blocks the anterior pituitary receptor sites for LHRH, luteinising hormone secretion does not occur, and therefore ovarian oestrogen production does not occur. The most commonly used LHRH agonist is Zoladex (Goserilin) (Edge and Buccimazza 2019). In postmenopausal women the approach is to utilise aromatase inhibitors (AI’s), such as Anastrozole or Letrozole, to supress oestrogen production from non-ovarian sources (Edge and Buccimazza 2019). There are also drugs that block oestrogen receptors on all tissues, thus preventing stimulation by oestrogens. These are referred to as selective endocrine receptor modulators (SERMs), and Tamoxifen is the SERM commonly used in breast cancer therapy (Edge and Buccimazza 2019). Given the broad actions of oestrogen, endocrine therapy has many possible side-effects: Tamoxifen side effects include hot flushes, weight gain, vaginal discharge or dryness, increased risk of blood clots, thickening of the endometrium and decreased libido (Edge and Buccimazza 2019; American Cancer Society 2020b). Aromatase inhibitors cause muscle and joint pain, weight gain, hot flushes, vaginal dryness and osteoporosis (Edge and Buccimazza 2019; Waks and Winer 2019). Ideally, future modulators of oestrogen production and its receptors, will be refined to the point of targeting cancerous tissues and tumorigenesis whilst sparing the many other vital sites and roles of this hormone.

2.3.3.4 Immunotherapy

Immunotherapy utilises drugs aimed at modulating or enhancing the patient’s own defence system, and is used in metastatic breast cancer (National Cancer Institute 2019).

All the systemic and local treatments described above, are based on the Western biomedical model of physiology, pathophysiology, and pharmacology. They have been well researched and have proven track records of increasing survival rates and even potentially bringing about cures. However, they are not without negative side effects which can interfere with treatment compliance and with patient quality of life (Neugut *et al.* 2016; Lambert *et al.* 2018; Leach 2019; Waks and Winer 2019).

In addition to these mainstream biomedical treatments, there are other practices which are being utilised by patients in their search for health and healing. Some of these are rooted in the biomedical model, such as nutritional approaches and exercise. Others are from traditions underpinned by different philosophies and world views. These additional support practices are explored below.

2.4 Traditional, Complementary and Alternative Health Practices

2.4.1 An overview of TCAM categories

TCAM houses a wide variety of diverse traditions, practises, modalities and products, and there are various ways in which they can be categorised or classified (Pinzon-Perez and Perez 2016). The classification outline set out below, is adapted from those presented in Pinzon-Perez (2016), Cramer (2013) and Wanchai (2010):

(1) Alternative medical systems: Several medical systems, usually with their own bodies of theory and practise have evolved over many years, generally developing within specific cultures. For example, eastern medical systems include Chinese medicine and Indian ayurvedic medicine, whereas alternative western medical systems include homeopathy and naturopathy (WebMD 2019). African traditional healers, who have developed a long-standing and widely used system of cultural healing practices in South Africa, will be included in this category for the purposes of this thesis.

(2) Biologically based practices, which includes the use of herbs, botanicals, vitamins, food supplements, minerals, probiotics, as well as exercise and dietary approaches. (Some of the alternative medical systems listed above would utilise biologically based practises as part of their approach to health and healing, and as aromatherapy utilises aromatic oils derived from plants, it could also be considered to be part of this category).

(3) Manipulative and body-based practices. This includes techniques utilising body manipulation such as chiropractic and osteopathy, as well as different forms of massage, including reflexology.

(4) Mind-body interventions, for example meditation, yoga, muscle relaxation techniques, tai-chi, hypnotherapy, guided imagery, and biofeedback.

(5) Energy therapies such as acupuncture or Reiki.

(6) Spiritual and psychological/emotional support practices (psychotherapy, prayer, religious rituals, art/dance/music therapy, support groups).
(Wanchai, Armer and Stewart 2010; Cramer *et al.* 2013; Pinzon-Perez and Perez 2016).

As each of the many different specialities and approaches that fall into the arena of TCAM form a field of research in their own right, this literature review cannot do them justice. However, it will now look at some of these practices, the theoretical understanding that underpins them, and the uses they have in the cancer arena, starting with lifestyle and self-help practices and then looking at some prevalent fields of TCAM practitioners.

2.4.2 An overview of some prevalent lifestyle and self-help practices

This section will outline some of the lifestyle and self-help practices used by cancer patients and/or recommended by practitioners. These factors include diet and exercise, as well as supporting the psychological and spiritual dimensions of the patient. One of the reasons that lifestyle approaches are gaining interest and importance is due to the impact that some can have on the epigenome, and therefore DNA expression (Bernstein, Meissner and Lander 2007; Ross *et al.* 2008; Tiffon 2018; International Human Epigenome Consortium 2019; National Human Genome Research Institute 2019; Medline Plus 2021b).

2.4.2.1 Dietary approaches

Nutrition has long been considered as playing a central role in a comprehensive approach to managing all stages of the cancer continuum (Abrams and Weil 2014). Nutritional assessment and intervention are routinely utilised when addressing anorexia, cachexia, gastro-intestinal cancers, and specialised feeding (such as enteral feeding), but are also increasingly becoming a means of improving quality of life and survival for all cancer patients (Abrams and Weil 2014). Ongoing advances in nutritional epidemiology, nutrition-related clinical trials, and scientific insights, have resulted in increased recognition of the important role nutrition plays in cancer management, and provided the basis for the nutritional guidelines of bodies such as the American Cancer Society (Abrams and Weil 2014; Rock *et al.* 2022).

“Dietary pattern studies” are studies looking at broad eating patterns. These studies utilise data gathered through food surveys to compare healthier patterns of eating (generally higher intake of fruit and vegetables) to unhealthy ones (generally high in meats; processed foods and refined grains) in relation to cancer risk and survival (Hou *et al.* 2019; Xiao *et al.* 2019; Rock *et al.* 2022). Meta-analysis of dietary pattern studies has shown a statistically significant lower risk of breast cancer associated with healthy dietary patterns (Dandamudi *et al.* 2018; Hou *et al.* 2019; Xiao *et al.* 2019). In addition, healthy dietary patterns can affect outcome, with breast cancer patients who adhere to healthy versus unhealthy eating habits having reduced breast cancer mortality as well as overall mortality (Vrieling *et al.* 2013). Patients who adhere to healthy dietary patterns are also less likely to develop food aversions in response to adjuvant chemotherapy, thus better tolerating treatment (Reitz *et al.* 2022).

The most rigorous analysis and interrogation of evidence related to the role of diet and physical exercise in cancer is performed by the Continuous Update Project (CUP), coordinated by the World Cancer Research Fund International (WCRF) and the American Institute for Cancer Research (AICR) (World Cancer Research Fund International 2023). CUP conducts ongoing systematic literature reviews and collates data to be judged by an expert panel according to predefined criteria, with the express purpose of assessing likely causality of observed associations (World Cancer Research Fund International 2023). The criteria for judging data include the amount and quality of data, the size and consistency of effect, the presence of a graded relationship, biological plausibility, and risk of bias. Recommendations are then made on evidence of causality that is judged by the panel as strong ("convincingly" or "probably" causal (Wiseman 2019). Table 2.4.2 below outlines some of the nutritional factors determined by CUP as being underpinned by strong evidence for causality/increasing the risk of cancer.

Table 2.4.2: Nutritional factors supported by strong evidence as increasing risk of cancer.

Factor	Systemic impact	Cancer Hallmarks affected
Greater body fatness	Hyperinsulinemia Increased oestradiol Inflammation	Reduced apoptosis Increase proliferation Genome instability
Greater intake of red and processed meat	Elevated exposure to nitrites	Reduced apoptosis Increase proliferation Genome instability
Greater intake of dairy foods	Higher IGF-1	Reduced apoptosis Increased proliferation
Lower vegetable and fruit intake	Folate deficiency Low fibre intake Low levels of vit A, C E	Genome instability Reduced apoptosis Increased proliferation Increased inflammation
Greater alcohol intake	Elevated acetaldehyde Increased oestradiol Inflammation Folate deficiency	Genome instability Reduced apoptosis, increased proliferation

These main factors of concern included greater body fatness, greater intake of red and processed meat, greater intake of dairy foods, lower vegetable and fruit intake, and greater alcohol intake, which affected the systemic environment and increased risk via the cancer hallmarks of reduced apoptosis, increased proliferation, increased inflammation and genome instability (Wiseman 2019). There has been consistency in recommendations for over a decade, supporting the robustness of findings. Systematic reviews looking at adherence to these recommendations have found such adherence is linked to lower incidence, and post-diagnosis to improved outcome and lower mortality rates (Wiseman 2019). Adherence to healthy eating patterns has been significantly associated with downregulation of metastatic genes in primary breast cancer. Conversely*,* following an unhealthy diet with high levels of meat, processed meat, hydrogenated fat, fast food, refined cereals, sweets, and soft drinks was associated with the overexpression of a gene controlling aspects of metastatic behaviour (Foroutan-Ghaznavi *et al.* 2022).

A major consideration when addressing diet and nutrition of breast cancer patients is adiposity and obesity. There is strong evidence that obesity it linked to a worse prognosis for breast cancer patients (Abrams and Weil 2014; Wiseman 2019; Rock *et al.* 2022). A 2022 systematic literature review and meta-analysis demonstrated that a higher post-diagnosis BMI (body mass index) is associated with increased all-cause mortality, breast cancer-specific mortality and second primary breast cancer (Chan *et al.* 2022). Limited randomised trials suggest that weight loss in obese patients might ameliorate a poor outcome, but there is inadequate evidence to conclude this with certainty. Supervised weight loss remains prudent for obese patients, as it is plausible that this can improve survival (Abrams and Weil 2014; Hou *et al.* 2019; Wiseman 2019; Chan *et al.* 2022).

Nutritional counselling can also help ameliorate hyperinsulinemia and insulin resistance (IR), which are critical considerations recognised as playing a pivotal role in cancer by promoting tumorigenesis, both increasing the risk of cancer and contributing to a poor prognosis (Chefari *et al.* 2021). Whilst there is no single factor that explains the link between IR and cancer, there are many possible mechanisms that could contribute, including epigenetic modifications, inflammation, receptor signalling, and gut microbiota as potentially playing a role (Chefari *et al.* 2021).

Linked to hyperinsulinemia and insulin resistance are patterns of glucose loading in the blood and the debate surrounding sugar consumption. Reprogramming of cellular metabolism and the use of glycolysis as the main pathway for energy is one of the hallmarks of cancer (Hanahan and Weinberg 2011). How carbohydrate intake, glycaemic index and glycaemic load influence cancer remains unclear, with meta-analyses largely reporting no association (Song 2020). Whilst this appears to indicate that carbohydrate intake does not majorly influence cancer development, the possibility that specific groups of carbohydrates or carbohydrate-containing foods carry increased risk cannot be ruled out (Song 2020). Sugar has been receiving increased attention as a possible culprit. Whilst many epidemiological studies have indicated a null association between total sugar intake and cancer risk (Song 2020), more recent data has reported that total sugar intake is associated with increased overall cancer risk, and specifically increasing the risk for breast cancer. This study found significant associations with cancer risk for added sugars, sucrose, sugars in dairy products, milk-based desserts, and sugary drinks (Debras *et al.* 2020). These findings of positive associations of total and added sugar with breast cancer are in contrast to previous findings. This could possibly be due to the rigor of Debras *et al*. in adjusting for confounding variables in their research approach (Song 2020). The more recent data of quality research suggest that sugar intake could be a modifiable risk factor , particularly for breast cancer and important in oncology nutritional considerations (Song 2020).

Another consideration for some breast cancer patients is addressing the risk of cardiovascular disease post treatments. Whilst advances in cancer care have increased breast cancer survival rates, the biomedical treatments leave many patients with an increased risk of cardio-vascular disease (Kim *et al.* 2023). For patients on aromatase inhibitors, the risk of cardiovascular disease is equal to the risk of cancer recurrence. Thus nutritional counselling needs to address overall mortality risks and not just cancer-specific risks (Abrams and Weil 2014; Kim *et al.* 2023).

Some diets promoted for cancer patients in the media employ dramatic dietary alterations and exclusions including low carb and ketogenic diets, severe caloric restriction diets and intermittent fasting (Abrams and Weil 2014). Caloric restriction has demonstrated powerful anticarcinogenic actions in animal studies including decreased production of growth factors, inflammatory cytokines, anabolic hormones and DNA damage caused by oxidative stress (Clifton *et al.* 2021). However, some results are controversial, suggesting that intermittent fasting has some detrimental effects in certain conditions. Given the current lack of high-quality clinical trials, knowledge of effects and safety for cancer patients remains unclear. Therefore patients on active treatments are not advised to utilise intermittent fasting (Clifton *et al.* 2021). Similarly, there is currently increasing interest in the potential of a ketogenic diet to improve cancer outcomes via epigenetic modifications (Bandera-Merchan *et al.* 2020). A 2021 systematic review declared the current evidence to be lacking, referencing mixed results, low quality investigations, high risk of bias, and no conclusive evidence for anti-tumour effects or impact on overall survival (Romer, Dorfler and Huebner 2021) Such interventions are unsuitable for many cancer patients and would need to be supervised by an experienced physician (Abrams and Weil 2014).

Based on the evidence for the role of nutrition in many aspects of cancer from risk to survival, practitioners seeking to offer holistic care support the need for nutritional counselling to be offered to every patient (Abrams and Weil 2014; Rock *et al.* 2022). Patients are exposed to a lot of “nutri-babble” promoting nutritional interventions which lack a thorough scientific basis. There are even claims of the ability to cure cancer without other treatments (Segado-Fernandez *et al.* 2023). Thus, there is a need to provide all cancer patients with verified guidance in nutritional approaches (Segado-Fernandez *et al.* 2023). It is also important to consider the trajectory of survivors, providing support to patients once declared disease-free, as well as to address the disparities, empowering all patients with the guidance they need to reduce risk of recurrence and increase survival (Rock *et al.* 2022).

2.4.2.2 Use of Supplements

It is widely accepted that obtaining nutrients from a healthy diet if possible is best, as whole foods contain many compounds needed for optimal health (Abrams and Weil 2014). The National Comprehensive Cancer Network (NCCN) and the American Society for Clinical Oncology (ASCO) caution against the overuse and misuse of dietary supplements during treatments (Rock *et al.* 2022). That being said, supplements can be vital in addressing nutritional deficiencies in cancer patients (Abrams and Weil 2014).

Research has found that supplements are widely used by cancer patients, with vitamins and minerals; herbal remedies; and antioxidants being particularly popular (Krejbich and Birringer 2022). Whilst patient reasons for consuming supplements are varied, they are often taken whilst undergoing active adjuvant treatments, and decisions are made independently without medical advice, and their use raises concerns regarding diminished effectiveness of conventional therapies (Krejbich and Birringer 2022).

Multivitamin: Whilst reports on multivitamin use have been mixed, a large prospective study in 2013 demonstrated a consistent association between multivitamin and mineral

(MVM) use and lower breast cancer mortality in post-menopausal women, supporting the use of MVM by these patients (Wassertheil-Smoller *et al.* 2013). As many commercial multivitamins may contain some vitamins and minerals that are inappropriate for some cancer patients (such as iron, copper, magnesium and folic acid, there is need for caution (Abrams and Weil 2014).

Folic Acid: Folic acid, or vitamin B9 is involved in methylation and nucleotide synthesis in rapidly growing cells (Wien *et al.* 2012; Mount Sinai 2023). Population studies have shown that people with adequate folate in their diet have lower rates of certain cancers, including breast cancer. Low dietary intake of folate combined with high alcohol intake is of particular concern with respect to breast cancer (Pieroth *et al.* 2018; Mount Sinai 2023). This could be due to the fact that in folic acid deficiency, methylation and repair of DNA are hampered, resulting in DNA instability and increased risk of cancer (Wien *et al.* 2012). However, supplementation carries risks, possibly promoting progression of preneoplastic and undiagnosed neoplastic lesions (Wien *et al.* 2012; Abrams and Weil 2014). A meta-analysis of 10 randomised control trials demonstrated borderline significant increase in the incidence of cancer in the folic acid group compared to controls (Wien *et al.* 2012). Supplementation can also raise the serum levels of some chemotherapeutic agents to dangerous levels (Mount Sinai 2023). Therefore, folic acid supplementation should be omitted in formulations for most cancer patients (Abrams and Weil 2014).

Vitamin C: Vitamin C, a powerful antioxidant and epigenetic regulator, has long been known to show anti-cancer properties, and has emerged in recent years as a potential anti-cancer therapy, eliciting mixed responses and contradictory arguments (Fritz *et al.* 2014; Mussa *et al.* 2022). There is no evidence that it is effective as a stand-alone anti-cancer therapy, but high-dose vitamin C therapy has shown great promise as an enhancer of immunotherapy and improvements in quality of life (Fritz *et al.* 2014). As it is widely available, has minimal toxicity and low cost, it is an attractive option as a safe and effective adjuvant therapy (Mussa *et al.* 2022). However, adequate high quality evidence is still lacking further explorations are needed to determine optimal delivery, and to understand the mechanisms of action (Mussa *et al.* 2022). One of the concerns is due to its being an antioxidant. Antioxidant use during chemotherapy or radiotherapy has also been associated with worsened breast cancer prognosis, significantly increasing risk of overall mortality and recurrence, thus highlighting the need to avoid antioxidants whilst on these active treatments (Jung *et al.* 2019).

Vitamin D: Vitamin D has also been a focus of interest regarding its potential role in cancer. Vitamin D is a precursor which undergoes a two-step metabolism to produce the biologically active metabolite calcitriol, which binds to vitamin D receptors (VDR) thereby regulating the expression of a variety of genes via epigenetic mechanisms (Fetahu, Hobaus and Kallay 2014; Jeon and Shin 2018). Studies have demonstrated an inverse correlation between vitamin D levels and increased risk of cancer including breast cancer (Jeon and Shin 2018; Hossain *et al.* 2019). Meta-analyses have demonstrated the same inverse correlations between high total vitamin D receptor (VDR) expression in the cytoplasm and nucleus, and overall survival of breast cancer patients (Xu *et al.* 2020). Preclinical studies have suggested that vitamin D enhances chemotherapy-induced cell death, a finding supported by research demonstrating the association between low serum vitamin D levels and failure to obtain pathologic complete response (absence of disease) with adjuvant chemotherapy (Chiba *et al.* 2018). Researchers have proposed several potential anti-cancer roles of vitamin D including anti-inflammation; antioxidant defence; DNA damage repair; cell proliferation; and apoptosis (Jeon and Shin 2018). Interestingly, a study of 2510 women with invasive breast cancer found that breast cancer survival was inferior in women with low levels of vitamin D but also in women with high vitamin D levels, a finding that supports caution against excess supplementation in the absence of deficiency (Kanstrup *et al.* 2020). Besides deficiency however, growing data also suggest dysregulation of vitamin D metabolism and functioning, which creates a resistance to the antitumorigenic effects of vitamin D. Given the complexity of interplay between vitamin D, VDR and epigenetics, there is still much to understand regarding the role of vitamin D and VDR in breast cancer (Jeon and Shin 2018; Huss *et al.* 2022).

Omega-3: Omega-3 and omega-6 fatty acids are a group of essential polyunsaturated fatty acids that are important in cell membrane structure and signalling. Omega-6 tends to be pro-inflammatory, and omega-3 anti-inflammatory (Fabian, Kimler and Hursting 2015). There has been interest in the use of omega-3 supplementation as a way to decrease cancer risk via anti-inflammatory mechanisms and alteration of plasma membrane growth factor signalling (Fabian, Kimler and Hursting 2015). However, epidemiologic evidence is inconsistent (Abrams and Weil 2014). A recent meta-analysis of studies exploring omega 3 supplementation, have demonstrated that when used as a co-adjuvant to mainstream anti-cancer therapies, it shows remarkable results compared to the anti-cancer therapies alone, contributing to increased tumour growth and weight, and increasing survival rate. The best results are obtained when omega 3 supplementation starts early and is maintained for a long time (Theinel *et al.* 2023).

Probiotics*:* Studies exploring the role of the microbiome in cancer have identified a possible link between the presence of specific microbial elements (in the breast and gut) and breast cancer, even to the point of associating particular microbial “signatures” with the various breast cancer subtypes. Whilst it remains unclear whether it is an alteration in microbiome that leads to breast cancer or the reverse, probiotics are currently being investigated as a possible tool in oncology. They hold promise as potential biomarkers for prognosis and diagnosis, but also as targeted prevention and treatment (Chadha *et al.* 2021). *In vitro* studies have shown that probiotics can induce apoptosis of tumour cells and inhibit proliferation. Animal models have reported probiotics inhibiting tumour growth, reducing tumour size, and affecting immunomodulatory, anti-angiogenesis and anti-metastatic activities (Ranjbar *et al.* 2019).

2.4.2.3 Herbs and Botanicals

Herbal or botanical products are some of the leading inclusions by cancer patients, with an average of 22% of patients (around one in five) reporting use of these products following their cancer diagnosis, many of whom continue such use during active treatments (Asiimwe *et al.* 2021). Together with Asia, Africa also has the highest prevalence of the use of herbal medicines. This is partly due to the cultural beliefs and practices (traditional healing systems) together with low levels of regulation (Asiimwe *et al.* 2021). Several natural bioactive compounds show demonstrated the potential to reverse epigenetic changes, reactivating and upregulating tumour-suppressor genes. Included in these are lycopene, indole-3 carbinol (I3C), folic acid, and sulforaphane. However, whilst these show promise of being therapeutic epigenetic agents, much work is needed to fully explore their clinical potential (Aggarwal *et al.* 2015).

Sulforaphane *Sulforaphane is a natural plant compound derived from cruciferous vegetables, such as broccoli and Brussels sprouts.* and Indole-3 carbinol *Indole-3-carbinol comes from a substance called glucobrassicin, which is also found in cruciferous vegetables such as broccoli, cauliflower, and kale.* have shown particular promise in both in-vitro and animal studies as epigenetic modifiers in breast cancer (Aggarwal *et al.* 2015). Resveratrol *is a chemical mostly found in red grapes and products made from these grapes.* has also shown much promise, with anti-cancer properties confirmed by both *in vitro* and *in vivo* studies. It demonstrates the ability to inhibit carcinogenesis, as well as having anti-inflammatory, cardioprotective, neuroprotective and phyto-estrogenic and powerful antioxidant properties. Clinical trials have not yet been conducted and challenges remain regarding bioavailability and potential adverse effects (Salehi *et al.* 2018).

Amongst the botanicals is a group of compounds known as adaptogens. Adaptogens were first recognised for their potential to assist the body in resisting the damaging physiological effects of stress and anxiety whilst promoting overall wellbeing. However, adaptogens are gaining attention for their potential to act as chemo-preventive agents alone or in combination with other chemotherapy drugs (Sulaiman and Lakshmanan 2022). Adaptogens have different constituents/bioactive compounds and therefore different and complex mechanisms of action both systemically and on tumour cells (Sulaiman and Lakshmanan 2022). One of the better known adaptogens is *astragalus membranaceus* which has demonstrated immune system activation of macrophages; inhibition of proliferation and upregulation of apoptosis of breast cancer cells *in vitro* and in animal models (Sheik *et al.* 2021).

There are many risks involved for cancer patients who consume biologically active TCAM products (Smith *et al.* 2014). This can be through direct adverse effects related to the TCAM product such as allergic reactions, gastrointestinal upset, and hepatotoxicity. There is risk linked to the lack of quality controls in the manufacturing of many of these products, with considerable variation in constituents, bioavailability, and pharmacological activity of active ingredients. In addition, there is the risk of potential interactions between mainstream therapies and TCAM, increasing toxicity or compromising therapeutic actions of the mainstream treatments (Smith *et al.* 2014; Fasinu and Rapp 2019).

<u>Cannabis:</u> *Cannabis* is a group of herbaceous plants, long used by humans for its healing and psychotropic properties (Crocq 2020). In recent years, medicinal cannabis has increasingly become a topic of debate within the oncology arena (Bodine and Kemp 2022). The human cannabinoid receptors CB1 and CB2 were characterised in 1991 and 1993 respectively (Zou and Kumar 2018). CB1 is primarily expressed in the central nervous system whereas CB2 is expressed in the immune system (Zou and Kumar 2018). The endocannabinoid (eCB) system is a group of endogenously produced lipid-based agonists that bind to these cannabinoid receptors. CB1 receptor agonists affect the release of neurotransmitters from synapses and CB2 receptor agonists affect regulation of the immune system and inflammation (Abu-Amna *et al.* 2021).

When phytocannabinoids (cannabinoids from the cannabis plant) are consumed, they interact as agonists with these same cannabinoid receptors to produce numerous psychotropic and therapeutic effects (Abu-Amna *et al.* 2021). Over 150 different cannabinoids have been isolated which show diverse physiological effects (Bodine and Kemp 2022). The most notable are delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD). Both THC and CBD are psychoactive, but CBD does not cause the “high” associated with THC (Crocq 2020; Breastcancer.org 2023b). Different varieties of cannabis plants, and the formulations derived from them, will contain different proportions of these active compounds. There are many ways to consume natural or synthetic cannabinoids including orally (oils, capsules, edibles and teas, mucosal sprays) by smoke inhalation, suppositories and injection (Abu-Amna *et al.* 2021), with bio-availability, peak concentrations and effects all depending on the formulation and administration (Abu-Amna *et al.* 2021).

Cannabis use has been found to alleviate cancer-related sleep problems; fatigue; anxiety and depression; nausea and vomiting; anorexia; and pain, thus improving quality of life and decreasing opioid use (Abu-Amna *et al.* 2021). As it can be used to manage numerous symptoms, it has the potential to decrease polypharmacy in cancer patients whilst increasing compliance with mainstream treatments (Maida and Daeninck 2016). Though some cannabis studies included randomised control studies and large numbers of patients, many cannabis studies rely on self-reporting and a control cohort is missing in many cases (Abu-Amna *et al.* 2021). In addition to the above palliative indications, cannabinoids have also received attention for their potential as anti-neoplastic agents via modulation of cell proliferation and apoptosis, as well as angiogenesis, with some promising in vitro results (Turgeman and Bar-Sela 2019). In Vitro studies have recently shown that cannabidiol in combination with the aromatase inhibitor exemestane potentiated apoptosis whilst also abolishing oestrogen-like effects and preventing its oncogenic role on the androgen receptor (Almeida *et al.* 2023). But whilst adequate evidence exists for the use of cannabis for palliation of symptoms, more research needs to be done into its antitumor potential (Turgeman and Bar-Sela 2019).

Unfortunately there are numerous unfounded claims of cures to be found on the internet, which are simply extrapolating the results of pre-clinical in vitro studies without factual evidence of in vivo work (Maida and Daeninck 2016). There are reports of unpleasant side-effects (Bodine and Kemp 2022) and well-founded concerns about the potential for cannabis to interact with other drugs the patient is taking. These interactions can cause alterations in the concentrations of either drug; additive effects or diminished efficacy;

changes in clearance and increasing risk of toxicity (Antoniou and Bodkin 2020). Thus, cannabinoids could possibly interfere with the effectiveness of cancer therapy. Of particular concern is a decrease in effectiveness of immunotherapy (Bodine and Kemp 2022). Another challenge is the increasing need for control of the formulation and sale of cannabinoids, establishing and enforcing the prescriptive controls needed for the purpose of protecting the consumer (Al-Hamdani *et al.* 2021). Healthcare teams would also need to be better informed and keep up with recent developments so that they can correctly inform and guide patients in their decision making (Bodine and Kemp 2022).

2.4.2.4 Exercise

Research has established that physical activity plays an important role in many aspects of cancer management including prevention, mitigation of treatment side-effects, rehabilitation and increased survival (Abrams and Weil 2014; Torregrosa *et al.* 2022). In terms of preventing cancer, physical activity has potential to reduce cancer risk via a variety of mechanisms: These include immunomodulatory effects (enhancing both innate and acquired immunity and promoting tumour surveillance); decreasing oxidative stress and enhancing DNA repair; reduction in levels of circulating oestrogen; reducing inflammation and insulin resistance all of which have been linked to cancer (Abrams and Weil 2014; Kelly 2016; American Institute for Cancer Research 2018; Wiseman 2019; Groeneveld 2021). Also linked to physical activity is its vital role in maintaining an ideal body weight. This is considered to be very important in protecting against cancer, as obesity has the potential to affect a wide range of cellular and molecular processes which in turn can promote cancer development and progression (American Institute for Cancer Research 2018). Moore et al did a study of 1.44 million adults exploring the association between leisure-time physical activity and risk of 26 types of cancer found that higher levels of activity were associated with lower risks of many types of cancer including breast cancer (Moore *et al.* 2016). Another large cohort study (1,476,335 participants) looking at physical activity trajectories concluded that long-term persistent high frequency physical activity should be widely promoted as part of daily routine to reduce the risk for all cancer development in women (Tran *et al.* 2023).

The same array of mechanisms operating in cancer prevention, will naturally still be important post diagnosis (Torregrosa *et al.* 2022). Post diagnosis, exercise has been associated with a better quality of life, less depression and anxiety, and fewer adverse events of adjuvant therapy in breast cancer patients (Vehmanen *et al.* 2022). Besides enhancing quality of life, adhering to a program of physical activity was found to enhance the functional status of the patient, working against the cycle of deterioration, cachexia and fatigue associated with cancer and increasing their ability to cope with the disease- or treatment- related side effects (Abrams and Weil 2014; Shaw, Atkinson and Jones 2020; Rocha-Rodrigues 2021). In particular, aerobic and/or resistance training has the capacity to maintain muscle and skeletal health, both compromised in breast cancer patients (Ballinger, Thompson and Guise 2022). Participants in qualitative explorations have declared that they considered exercise essential in their ability to continue working through active treatment (Shaw, Atkinson and Jones 2020).

A meta-analysis of published research on exploring the role of physical activity on cancer outcomes of over 12 000 patients concluded that post-diagnosis physical activity reduced breast cancer deaths by 34%, all-cause mortality by 41% and disease recurrence by 24% (Ibrahim and Al-Homaidh 2011). Similar findings were presented in a meta-analysis by Spei *et al* 2019, who found that high levels of physical activity after breast cancer diagnosis were associated with lower all-cause and breast cancer mortality (Spei *et al.* 2019). Studies are being done to determine practical matters related to exercise such as mediators of physical activities in survivors (Kindred, Pinto and Dunsiger 2020); feasibility of home-based programs for patients on chemotherapy (Sturgeon *et al.* 2022); and exercise prescription tailoring for treatment-related impairments in breast cancer patients (Wagoner, Capozzi and Culos-Reed 2022).

These and many other studies into the role of physical exercise in cancer management have shown it to be associated with numerous beneficial effects, even being declared by some as the “best supportive care” for cancer patients (Torregrosa *et al.* 2022). Therefore, promoting physical activity of cancer patients is of immense importance, and the role of the medical oncology environment in this is crucial. Smith-Turchyn *et al*. found that those patients who received education regarding the importance of physical activity from their medical oncologist were more likely to be “sufficiently active”, but that these discussions often don’t take place and that few patients of the patients surveyed were actually sufficiently active (Smith-Turchyn *et al.* 2022). A separate study exploring oncologist attitudes and recommendations regarding the role of physical activity in oncology management, found that although a large percentage (83.7%) of oncologists surveyed believed in the benefits of exercise and 87.2 recommended it to their patients, that many felt ill-equipped to correctly educate and advise on specifics (Delialioglu, Mandiroglu and Goskel 2022). So, although physical activity brings multiple benefits at all stages of cancer management, this vital arena seems to be under-emphasised in many care programs.

2.4.2.5 Yoga

Diagnosis with cancer is a highly stressful event for numerous reasons (Cancer.Net 2023). Chronic stress promotes cancer development and needs to be managed to optimise the body in seeking healing (Dai *et al.* 2020). Mind-body practices are therapies that combine mental focus, controlled breathing, and body movements, with the aim of supporting both mind and body, bringing about relaxation; assisting with control of pain, stress, anxiety and depression; and improving overall health (National Cancer Institute 2023a). Mind-body practices include yoga and tai chi amongst others (National Cancer Institute 2023a). Yoga is an ancient form of exercise for body and mind, developed about 5000 years ago in India (National Cancer Institute 2023a). There are different styles of Yoga including Hatha; Iyengar; and Astanga, some of which are more strenuous and others gentler with more focus on breathing and meditation (mbgmovement 2022; National Cancer Institute 2023a).

Breast cancer patents have reported numerous benefits in physical, mental and social arenas (Van Puymbroeck *et al.* 2013). Yoga has been shown to decrease depression, anxiety and stress (Shohani *et al.* 2018). A randomised control trial exploring it's use in breast cancer patients undergoing active treatment showed a significant decrease in anxiety; depression; treatment-related symptoms; severity of symptoms; and toxicity, along with increased quality of life (Rao *et al.* 2017). It has also been shown to significantly improve physical function in patients with chemotherapy-induced peripheral neuropathy, including flexibility; balance; and coping with daily activities (Galantino *et al.* 2019). It significantly increased degree of shoulder movement and increased quality of life in patients with radical mastectomy (Koontalau, Ngowsiri and Sangsaikeaw 2019).

2.4.2.6 Tai Chi

Tai Chi uses a combination of postures and gentle flowing movements, whilst practicing deep breathing and mental focus to assist with improving quality of life, mood and pain (National Center for Complementary and Integrative Health 2019d; BreastCancer.org 2023c). Tai Chi originated as a martial art in 12th-century China but has developed into a popular form of exercise for mental and physical health. Research incorporating Tai Chi for breast cancer patients has shown that it can help to increase strength, flexibility, balance, cardiovascular function whilst improving feelings of well-being (BreastCancer.org 2023c). As a gentler form of exercise, it may offer a more feasible option for many cancer survivors when compared to other forms of exercise (Yang *et al.* 2021). A recent randomised clinical trial reported a statistically significant difference in quality of life for breast cancer patients utilising a meditation intervention whilst on chemotherapy (Mofid *et al.* 2023). However, there is an ongoing need for more research. Researchers are calling for larger and methodologically sound trials with longer follow-up periods and appropriate comparison groups in order to come to more definitive conclusions on the role of Tai Chi in managing cancer related symptoms and quality of life, including its use during pre-treatment and end of life stages (Wayne *et al.* 2018; Zeng, Xie and Cheng 2019; Yang *et al.* 2021).

2.4.2.7 Relaxation techniques

Relaxation has many physiological benefits for the body, including lowering blood pressure; reducing stress hormones; controlling blood sugar; improving sleep quality; reducing pain; and improving digestion (Toussaint *et al.* 2021; Mayo Clinic 2022b). There are different kinds of relaxation techniques generally incorporating slow deep breathing. In progressive muscle relaxation (PMR) the individual will hold tension in specific muscles and then release it, starting at the toes and progressively working upwards through the body (National Cancer Institute 2020; Mayo Clinic 2022b). Progressive muscle relaxation has shown statistically significant differences in promoting physiological and psychological relaxation compared to controls (Toussaint *et al.* 2021).

A randomised controlled trial demonstrated a significant improvement in sleep quality and anorexia in cancer patients using a relaxation technique (Harorani *et al.* 2020). A 2001 review and meta-analysis demonstrated consistently positive results, with clinically significant reductions in pain, nausea, anxiety and depression, whilst reducing blood pressure and pulse rate in cancer patients. This despite a wide array of cancer types, stages and treatment protocols utilised in the studies reviewed in this meta-analysis, urging the authors to propose implementation of relaxation training into the clinical routine of cancer patients (Luebbert, Dahme and Hasenbring 2001). However, whilst a 2021 systematic review and meta-analysis showed PMR to be effective for reducing stress and anxiety, and improving quality of life in cancer patients, it reported no significant improvement in chemotherapy-related side effects (Sinha *et al.* 2021). As relaxation techniques are easily taught and can be used in many clinical scenarios from pre-diagnostic and pre-surgical anxiety as well as holding potential for alleviation of treatments side-effects, it is a viable option for inclusion in patient empowerment.

2.4.2.8 Meditation

Meditation is a practice that involve a quietening and clearing of the mind. It can be used alone or in combination with Yoga and Tai Chi or relaxation techniques (Cancer Research UK 2022e). There are many different forms of meditation, including focussed meditation, mindfulness, and visualization (see below) (Cancer Research UK 2022e). Studies have revealed that meditation can reduce proinflammatory cytokines; improve T-cell function; and stimulate natural killer cell activity in cancer patients (Mehta *et al.* 2019). It has also been shown to reduce anxiety, stress and depression; help with sleeping difficulties and/or fatigue; pain and nausea; improve cachexia; and improve cognitive impairment resulting from biomedical oncology treatments (Biegler, Chaoul and Cohen 2009; Christensen and Marck 2017; Mehta *et al.* 2019; Cancer Research UK 2022e).

2.4.2.9 Visualization

Visualization is a method of meditation where one forms and focuses on positive mental images (Toussaint *et al.* 2021; Mayo Clinic 2022b). These images can assist patients to relax, reducing stress and anxiety (Toussaint *et al.* 2021). Mental imagery is designed to take individuals to a different place mentally, such as the beach, shifting attention to the sights, sounds, smells and details of that place (Mayo Clinic 2022b). Visualization can also be done through guided descriptions, a technique referred to as Guided Imagery (Toussaint *et al.* 2021). Besides relief from anxiety, visualization is also used to assist patients in dealing with relief from symptoms and to practice positive thinking on healing processes (National Cancer Institute 2020; Toussaint *et al.* 2021). Cancer patients have reported a high degree of satisfaction with relaxation and Guided imagery has shown linear decreases in electrodermal activity and self-reported relaxation scores, supporting its potential to help patients cope with stress (Toussaint *et al.* 2021). It has also been shown to significantly reduce anxiety and cortisol levels in patients immediately pre-operatively (dos Santos Felix *et al.* 2018).

2.4.2.10 Creative therapy (writing/art/dance/music)

The idea that creative expression can make a contribution to healing is not a recent concept and has in fact been accepted by many cultures for centuries (Stuckey and Nobel 2010). A variety of creative pursuits can assist patients in processing the trauma associated with a cancer diagnosis and its treatments, providing for self-expression, decreasing depression and promoting a sense of well-being and emotional healing.

Commonly used creative activities include art, creative writing, and music (Stuckey and Nobel 2010; Stanford Center for Integrative Medicine 2023).

Art therapy holds the potential of being a relatively simple yet effective therapeutic intervention to help relieve the distress of cancer patients. It helps patients explore and express difficult thoughts and emotions, thus offering a form of emotional support (Cancer Research UK 2022a). Cancer patients use art therapy to help control anxiety and depression; take their mind of side-effects; and adjust to a changing body image, and can take many forms including drawing, painting, sculpture and crafts (Chan and Michaels 2021; Cancer Research UK 2022a). Many studies have explored the use of art therapy by cancer patients, and initial evidence suggests that it holds potential to benefit cancer patients by improving quality of life, and psychological outcome, as well as impacting fatigue and subjective sense of wellbeing (Fu *et al.* 2020; Chan and Michaels 2021). However, a 2020 review concluded that the quality of research made definitive conclusions difficult and that more research was needed (Fu *et al.* 2020). Since then, some studies have shown art therapy as significantly improving anxiety and hope (as measured by validated tools) in gynaecologic patients undergoing chemotherapy (Bell *et al.* 2022), to decrease anxiety pre- and post-surgically (Liu *et al.* 2022b), as well as improving scores for depression; emotional distress; and pain (Elimimian *et al.* 2020). Art therapy may (but not necessarily) follow a set program to walk patients through specific aspects on their personal journey of healing (Luzzatto P and Gabriel 2011).

Exploring creative writing as an intervention, positive feedback from patients participating in a formal creative writing program confirmed that it supported their need for holistic healing (Justice *et al.* 2017). A small study exploring the quantitative efficacy of creative writing workshops in improving mental health of cancer patients, demonstrated a positive impact on mood relative to standard care patients (Zhu *et al.* 2020). This was followed by a larger randomised clinical trial in which measures for distress, anxiety, depression and anger were all significantly lower in patients participating in creative writing workshops compared to standard care controls (Nesterova *et al.* 2022).

Use of music as an intervention for oncology patients is low-cost, easily accessible and safe (Kiernan, Stark and Vallerand 2018). It has been explored as a way to relieve anxiety and improve quality of life. A systematic review looking at the role of music in mitigating chemotherapy-induced nausea and vomiting found that sample sizes were small and that few studies controlled for the emetogenicity of the specific chemotherapy being administered, calling for substantive additional enquiries to generate more clinically relevant data (Kiernan, Stark and Vallerand 2018). A similar call was made by authors in another 2018 systematic review, where it was found that, whilst music was a promising tool for reducing anxiety and pain whilst improving mood, methodological limitations in studies continues to prevent firm conclusions (Bro *et al.* 2018). A 2019 systematic review and meta-analysis evaluating the effect of music intervention on cancer pain concluded that it is an effective way of reducing pain (Yangoz and Ozer 2019); another in 2020 that it can improve their quality of life, whilst decreasing scores for anxiety, depression, and pain (Li *et al.* 2020); and another in 2022 that is a beneficial tool in reducing anxiety and improving quality of life in patients receiving chemotherapy (Nguyen *et al.* 2022). All three reviews called for more research and higher quality trials.

Whilst different forms of creative expression show promise in their capacity to positively impact patient psychological and physiological health, there remains the need for more randomised controlled trials, including groups with diverse cultural and socio-economic backgrounds and incorporating long-term follow-up (Stuckey and Nobel 2010).

2.4.2.11 Spiritual practices

Research has shown that many patients with serious diseases rely on spirituality as a means of coping (Leao *et al.* 2021; National Cancer Institute 2022b). There is a significant positive correlation between spiritual wellbeing and quality of life in cancer patients, and a significant negative relationship with hopelessness and anxious preoccupation (Whitford, Olver and Peterson 2008; Goyarrola *et al.* 2023). In patients for whom religion and spirituality have a stable high or increasing importance, psychological resilience was stronger, weakening the link between cancer and psychological distress (Upenieks 2022). In addition, multiple regression analyses have demonstrated that it plays a more important role in quality of life than physical and social wellbeing (Whitford, Olver and Peterson 2008). Many cancer survivors view cancer as an opportunity for emotional and spiritual growth, a time to reconnect with spirituality, and find meaning and strength (Gifford *et al.* 2019; Leao *et al.* 2021). In women with breast cancer, spirituality has been shown to help with adjusting to the disease and it's personal impact, as well as coping with the side-effects of adjuvant endocrine therapy (Toledo, Ochoa and Farias 2021).

Nurses caring for people with advanced cancer recognise that spirituality inevitably permeates all aspects of their work and that they are in fact working in a spiritual context. This calls for spiritual care of the patients and the staff, and collaboration with religious ministers, social workers and psychologists (Carroll 2001). Although addressing spiritual concerns is generally considered to be an end-of-life issue, grappling with spiritual matters can be a challenge at any point in the cancer journey, impacting quality of life (National Cancer Institute 2022b).

Many studies have emphasised the need for a spiritual assessment as part of history taking, asking the patient about their cultural and spiritual beliefs, needs, and concerns. The use of a semi-structured inquiry into these aspects is generally well received by patients and associated with positive perceptions of care (Leao *et al.* 2021; Abbasi *et al.* 2022; Khosravani and Nejat 2022; National Cancer Institute 2022b). In failing to assess spiritual wellbeing of patients, clinicians can miscalculate the true cancer burden of their patients (Whitford, Olver and Peterson 2008). Developing a structure for ongoing care of the spiritual dimension of patients; establishing open communication; and supporting spiritual rituals of patients are all dimensions of supportive spiritual care (Abbasi *et al.* 2022).

Addressing of spiritual needs naturally requires sensitivity and flexibility. Whilst many patients expect and appreciate enquiries into their spiritual wellbeing, some patients do not feel comfortable sharing personal spiritual views, needs and experiences (Dalcali and Kaya 2022). In addition, spiritual needs are not uniform, but related to individual characteristics and psychosocial aspects (Du *et al.* 2022). Thus, spirituality is complex and personal, with different religions, different beliefs and attitudes to spirituality, varying spiritual needs, and different practices used to address those spiritual needs (Gifford *et al.* 2019; Hamilton and Fluker 2021; Khosravani and Nejat 2022). Being cognizant of and sensitive to the spiritual needs of cancer patients remains a critical aspect of holistic care (Khosravani and Nejat 2022).

2.4.2.12 Psychological support (counsellor/support groups)

A cancer diagnosis and subsequent journey can have a large impact on mental health, resulting in clinically significant symptoms of distress, anxiety, post -traumatic stress and depression (Niedzwiedz *et al.* 2019; Fortin *et al.* 2021; Lee *et al.* 2021). Depression affects about 25% of cancer patients, significantly exceeding the 5% of the normal population, yet only 5% of those suffering depression consult a mental health professional (National Cancer Institute 2023b). A 2022 publication reported 40% of breast cancer chemotherapy patients demonstrated depressive symptoms (Nakamura *et al.* 2022), and another reported 33% of breast cancer patients receiving hormone therapy suffered from depression (Zhao, Liu and Gao 2022). There are many factors that contribute to depression in cancer patients including psychosocial, biological and iatrogenic causes (Smith 2015). Loss (or anticipated loss); pain; metabolic abnormalities; sleep disruptions; endocrine abnormalities; and medication side effects. In addition, disruption in life plans; changes in body-image and self-esteem; fear of death and financial concerns can all contribute to depression (Niedzwiedz *et al.* 2019; National Cancer Institute 2023b). Evidence suggests that biological processes, especially via inflammatory mediators linked to cancer and its treatments can contribute to depression (Smith 2015).

For breast cancer patients, treatments have numerous devastating side effects: Surgical scarring, deformity, and weight gain; compromised mental function; ongoing fatigue and decreased physical stamina to name a few. All of these factors impact self-image and self-esteem (Bolte 2020). Medically induced menopause also leads to premature aging, vaginal dryness, hot flushes, and mood changes, all impacting sexual identity and sexual function, and due to these detrimental effects, altered sexuality is one of the most cited quality of life issues for these women (Bolte 2020). The psychological distress that the partners of these women experience can be equally challenging (Bolte 2020). Breast cancer patients are also grieving the loss of what was. Grief counselling can help them deal with that loss and redefine the future (Bolte 2020).

A review and meta-analysis of 76 studies showed that a diagnosis of depression and/or higher levels of depressive symptoms in cancer patients predicted elevated mortality, a link that persisted after controlling for confounding medical variables (Pinquart and Duberstein 2010). Therefore, besides the need to enhance quality of life and diminish suffering in cancer patients, psychological support and psychotherapy interventions may hold the potential to increase survival (Pinquart and Duberstein 2010). A subsequent review and meta-analysis demonstrated that depression and anxiety were related to poorer cancer survival and higher cancer-specific mortality, suggesting that depression and anxiety ay have an etiologic role and prognostic impact on cancer (Wang *et al.* 2020). This could be due to immune modulation (Smith 2015). Therefore, there is a need for ongoing evaluation for depression and anxiety in patients and their caregivers throughout the cancer journey, with a focus on recognising or assessing the levels of depression present in order to determine the appropriate level of intervention (National Cancer Institute 2023b). Group psychotherapy can also be done and has proved effective in reducing distress of breast cancer patients (Rosendahl *et al.* 2022)

Peer support groups are numerous and available to most patients, although (Cansa Association of South Africa 2023). These peer-led support groups gather cancer sufferers, survivors and their families to provide mutual emotional support as well as informational support (Jablotschkin *et al.* 2021). However, there are limitations and challenges: A randomised control trial conducted in 2012 found that group support significantly reduced anxiety but had no effect on depression (Bjorneklett *et al.* 2012). There are also divergent information needs, difficulty in coming face to face with the suffering of others, sometimes distressing group dynamics, and problems with leadership and sustainability (Bjorneklett *et al.* 2012). Support groups are not suitable for everyone and generally only a small percentage of patients participate in these groups, with the greatest determinant being recommendation by family and friends, geographical accessibility, and perceived benefits(Sherman *et al.* 2008).

There is a lack of high-quality studies investigating the mental health needs and psycho-oncology interventions for cancer patients following treatments and in long-term survivors. With an increasing number of people living with and beyond cancer, research into this population is urgently needed (Niedzwiedz *et al.* 2019).

2.4.3 An overview of some prevalent TCAM practitioner fields

2.4.3.1 Acupuncture

Acupuncture involves inserting very thin needles through the skin of the patient at specific points on their body to support restoration of health and wellbeing (Mayo Clinic 2022a). It is underpinned by the theory of chi (also qi or ki), a life force that flows through the human body along specific pathways known as meridians (Longhurst 2010). Acupuncture is aimed at re-balancing and opening flow of energy along these meridians (Mayo Clinic 2022a). Many biomedical practitioners believe that acupuncture stimulates nerves, muscles and connective tissue, sending signals to the brain and/or boosting endogenous pain-killers that account for any clinical changes (Longhurst 2010; Mayo Clinic 2022a). A 2013 systematic review reported benefits of acupuncture in cancer-related fatigue; pain; hot flushes and anxiety amongst others. These researchers commented on the paucity of rigorous trials (Towler, Molassiotis and Brearly 2013). A 2018 systematic review of randomized controlled trials reported no significant differences between acupuncture and controls in relieving side effects in breast cancer patients, and stating that larger studies were needed to explore its benefits (Pan *et al.* 2018). Whilst there is evidence that suggests that acupuncture can be helpful in the management of common side effects of breast cancer therapies, there are barriers that patients experience in using the therapy. These include knowledge about the acupuncture, concern about covering the cost and difficulty finding qualified acupuncturists (Bao *et al.* 2018).

2.4.3.2 African Traditional Medicine

The 2008 draft policy on African Traditional Medicine describes it as “A body of knowledge that has been developed and accumulated over tens of thousands of years, which is associated with the examination, diagnosis, therapy, treatment, prevention of, or promotion and rehabilitation of the physical, mental, spiritual or social well-being of humans and animals (South African Government Gazette 2008a). There are two main kinds of indigenous healers in South Africa called Isangomas and Inyangas (South African History Online 2019). An ancestral calling in the form of a sudden unexplained illness, visions, or voices, precedes an extended training which occurs through adopting a specific lifestyle, undergoing specific rituals and learning through apprenticeship to an experienced practitioner (Zuma *et al.* 2016; South African History Online 2019). Isangomas (often women) are diviners, using spiritual communication with ancestors (often in an altered state of consciousness) to diagnose, advise and prescribe. “Inyanga”, literally translated as “man of the trees”, make medicines from herbs, roots and bark to use for healing (Cumes 2013; South African History Online 2019). The knowledge systems underpinning these traditions have been gained by experience and not scientific methods and is passed on orally (Cumes 2013). This notwithstanding, African Traditional Medicine is said to be one of the oldest and most diverse medical systems, and is used by 4 out of 5 Black South Africans (Digby 2008; Mothibe and Sibanda 2019).

An estimated 72% of the Black South African population make use of African traditional Healers (Sobiecki 2014). Many Black Africans will consult traditional healers before a conventional health provider, and withhold this information from mainstream providers (Mothibe and Sibanda 2019). The South African Traditional Health Practitioners Act of 2007 solidified the legal status of African traditional healers. This pivotal Act was promulgated to protect the members of the public who use these services, and had three main aims: To establish an Interim Traditional Health Practitioners Council (ITHPCSA); to provide a regulatory framework to ensure the quality, safety, and efficacy of traditional health care services; and to manage training, registration, and conduct of practitioners (South African Government Gazette 2008b). A draft policy for African Traditional Medicine was compiled in 2008 (South African Government Gazette 2008a) and nomination for the interim council was called for in early 2022 (South African

Government Notices 2022). The 2021/2022 Annual Health Report however reflects that, whilst stakeholder consultations have been conducted, implementation of the guidelines for traditional medicines had not yet commenced (South African Department of Health 2022). As of early 2023, the interim council had also not yet been established. Thus, there is as yet no control over production of traditional medications or the training, registration and conduct of traditional healers (People's Assembly 2023).

Reports indicate that anywhere between 7% and 48% of African cancer patients will utilise African traditional medicine either alone or together with mainstream treatments (Xego, 2021). There is currently a dearth of information on the role played by African traditional Healers in treatment of oncology patients, whether purporting to fight the cancer itself or to alleviate side effects of mainstream treatments. As is the case with all herbal medicines, there is the potential for toxicity and drug interactions (Xego, 2021).

2.4.3.3 Aromatherapy

Aromatherapy is the practice of using essential aromatic oils extracted from plants which, when inhaled, stimulate olfactory pathways and thereby the brain, especially the emotional centres of the amygdala, thus helping to alleviate anxiety, depression, and insomnia amongst others (John Hopkins Medicine 2023). A 2019 systematic review found that aromatherapy was effective against a variety of physical and psychological complications of cancer but called for more studies to determine best protocols and dosages (Farahani *et al.* 2019b). A 2022 meta-analysis of studies using aromatherapy for anxiety and depression in cancer patients demonstrated that aromatherapy was effective in alleviating these symptoms. However, the authors also concluded that current research was not yet adequate enough to support clinical implementation, calling for higher quality studies (Liu *et al.* 2022a).

2.4.3.4 Ayurveda

Ayurveda is an ancient system of Indian traditional medicine (National Center for Complementary and Integrative Health 2019a). It is based on the theory that each person has a combination of three energies referred to as vata, pitta and kapha, which can become unbalanced leading to disease (The Ayurvedic Institute 2022). Ayurvedic treatment is tailored to the individual and uses a holistic approach combining detoxification, diet, exercise, lifestyle and ayurvedic medicines (derived from plants but also from animal, metal and mineral) (National Center for Complementary and Integrative Health 2019a).

There are concerns regarding potential toxicity due to some of the substances in ayurvedic medications, especially those that contain metals, and particularly in combination with mainstream chemotherapy agents (Meiman, Thiboldeaux and Anderson 2015; National Center for Complementary and Integrative Health 2019a). Detoxification approaches sometimes include enemas, laxatives, emetics and bloodletting, all of which can be harmful (Cancer Research UK 2022b).

Some work is also being done in administering ayurveda via nanotechnology. In 2020, Koobchandani et al. reported “excellent efficacy” of an adjuvant nano-ayurvedic drug administered together with chemotherapeutic agents in human breast cancer patients, with the cohort of patients receiving the drug (n=3) demonstrating zero disease progression compared to control (n=3) where one patient had disease progression. On the strength of these results the authors recommended nano-ayurvedic treatment as a potentially valuable adjuvant therapy. However, the very small sample size detracts from the strength of the conclusions in this instance (Khoobchandani et al. 2020). There is currently no scientific evidence to prove that ayurveda can be used to treat cancer (Cancer Research UK 2022b).

2.4.3.5 BodyTalk

BodyTalk addresses treatment holistically, taking into account emotional, physical and environmental aspects of the past and present to find the underlying causes for dis-ease and supporting the body’s own inherent ability to heal itself (BodyTalk Health 2023). It is based on the belief in an inextricable link between the psyche and the physical body with a constant flow of communication through energy circuits/channels within the body, thus falling into the category of mind-body medicine (BodyTalk South Africa 2023). All of one’s experiences, memories, emotions, beliefs, expectations, ancestral and environmental triggers can have a profound effect on the physical body (BodyTalk South Africa 2023). Communication circuits become “compromised” and need to be re-established (BodyTalk Health 2023).

Relying on the belief that the body has inherent knowledge of itself, BodyTalk practitioners use” neuromuscular biofeedback to “obtain yes/no answers” from the body in response to “questions” regarding compromised circuits within the body, then using tapping techniques, activates restoration of these circuits, synchronising and balancing the body to support inherent healing activities (BodyTalk Health 2023). BodyTalk has been shown to be effective in the management of pain (Stuve *et al.* 2014), but the general opinion of medical science is that there is “no credible evidence to suggest that BodyTalk treatments have any meaningful therapeutic effects” and also that there’s “no credible published evidence to substantiate the concepts of BodyTalk or any of its claims” (Science-Based Medicine 2012).

2.4.3.6 Chinese Medicine

Traditional Chinese medicine (TCM) is an ancient medical system that uses a combination of Chinese herbal products, acupuncture and Tai Chi to seek healing (National Center for Complementary and Integrative Health 2019d). Different Chinese herbal medicines use a variety of mechanisms to support oncotherapy, including regulating immunity; inducing differentiation; anti-angiogenesis; anti-metastasis; increasing efficacy and decreasing toxicity of biomedical treatments. A large body of clinical research has been done on the use of Chinese medicine together with mainstream biomedical oncology treatments and both the clinical observations and biomolecular research have confirmed the therapeutic efficacy of TCM use in cancer (Tang et al. 2020). However, studies have shown some Chinese herbal products to be contaminated with undeclared plant and/or animal material including drugs (such as warfarin and anti-inflammatories), heavy metals (such as arsenic, lead and cadmium) and pesticides, thus calling into question the safety of their use and the need for caution (National Center for Complementary and Integrative Health 2019d).

2.4.3.7 Chiropractic

Chiropractic is a profession that specialises in the diagnosis, treatment and prevention of mechanical musculoskeletal disorders, declaring that musculoskeletal dysfunction can also impact the functioning of the nervous system and health in general (Chiropractic association of South Africa 2022). Whilst chiropractic techniques are largely aimed at helping with musculoskeletal issues, the balancing of body function is also believed to assist the body in healing itself (National Center for Complementary and Integrative Health 2019b; Breastcancer.org 2022). The techniques used by chiropractors include joint adjustments, soft tissue therapy, exercises and stretches, joint bracing, and dry needling (Cleveland Clinic 2022a). In addition they utilise heat, ice, ultrasound and electrical stimulation (Breastcancer.org 2022). Neuromuscular conditions are common side-effects in breast cancer patients following surgery and radiation (Ballinger, Thompson and Guise 2022). These include frozen shoulder; rotator cuff pathologies; fibrosis; brachial nerve damage; myofascial dysfunction; restricted range of motion and pain (Physiopedia 2013). Chiropractic treatment Studies have shown that chiropractic treatment can help relieve headaches, joint pain and back pain in breast cancer patients (Breastcancer.org 2022). Patients with osteoporosis should not undergo chiropractic treatment as there is an increased risk of bone breakages during manipulation (Breastcancer.org 2022). Any cancer affecting the bone or marrow is also a contraindication (Cancer Research UK 2022c).

In a Delphi study surveying 13 experienced chiropractors concerning their opinions on the role of chiropractic care in cancer management, the following insights were obtained: Firstly, the practitioners believed that chiropractic treatment can assist with pain relief, better quality sleep, improving the functioning of the immune system improvement, and better energy levels and sense of wellbeing. However, several concerns were raised by the same chiropractic practitioners. They felt that there was lack of evidence to support the safety of chiropractic treatment in cancer patients; they reported poor reporting and communication with the medical teams of the patients; they experienced a lack of specific guidelines in treating cancer patients; and they feared the patient having the misconception that chiropractic can cure cancer as opposed to just assisting with the musculoskeletal side effects of the treatments, emphasising the strong need to make this distinction clear for patients (Laoudikou and McMarthy 2020). Thus, even those working in the field see need for improved communication and protocols for the use of chiropractic in cancer management.

2.4.3.8 Homeopathy

Homeopathy is a natural form of medicine utilised by more than 200 million people across the world (British Homeopathic Association 2023). The principles and practices of homeopathy which have been utilised for over 200 years, were discovered and documented by a German Doctor, Samuel Hahnemann. Looking for a way to treat patients with less side effects than the allopathic treatments of his day, Hahnemann experimented on himself and a group of friends, with fascinating results that formed the theoretical basis of homeopathy practised today (Society of Homeopaths 2019; Aphale and Sharma 2022). Seeking to trigger the body's own healing mechanisms, homeopathy is based on the "law of similars" in which "like treats like", a principle dating back to Hippocrates (460-377BC) (Pinzon-Perez and Perez 2016; Society of Homeopaths 2019; Aphale and Sharma 2022). Homeopathic theory claims that primary actions of remedies lead to secondary and opposite reactions, which thus harness the curative response of the body to the specific ailment being treated (Aphale and Sharma 2022). This concept of therapeutic similarity is not foreign to mainstream biomedicine, seen in the use of digitalis for heart conditions; colchicine for gout or Ritalin for hyperactivity (Aphale and Sharma 2022).

There are over 2000 different homeopathic remedies, extracted from a wide array of substances, including vegetable, animal, metal and mineral sources (Life Force Homeopathy 2023). Interestingly, there are also many similarities between ingredients used in biomedical preparations and homeopathic preparations (Aphale and Sharma 2022). Unlike allopathic medications however, homeopathy utilises the law of minimum dose in which the lower the dose of the homeopathic agent, the greater the effectiveness (Henry Spink Foundation 2023). For this reason, homeopathy utilises highly diluted substances as a way to increase effectiveness whilst decreasing toxicity (Pinzon-Perez and Perez 2016). Homeopathic drugs are prepared by a process known as "Potentization" in which the crude extracts undergo successive dilutions with ethanol or distilled water, and shaken at high velocity to disperse the extract (a process known as succussion), with increasing dilutions representing increasing potencies of the formulation (Joubert *et al.* 2021; Life Force Homeopathy 2023). These high levels of dilution beyond Avogadro's number are incongruous with current scientific understanding of molecular limits, and have been an underlying reason for considerable censure of homeopathy, with critics often ascribing beneficial outcomes to placebo effects only (Pandolfi 2010; Antonelli and Donelli 2018; Henry Spink Foundation 2023). In the light of this conflict, much research is being done in an attempt to provide credible hypotheses on the mechanism of action of homeopathic preparations, entering the subatomic field of the quantum physics and the emerging field of nanomedicine (Vithoulkas and Berghian-Grosan 2020; Aphale and Sharma 2022). Many *in vitro* studies using cell lines, as well as *in vivo* animal studies have demonstrated biological activity of highly diluted homeopathic remedies which could account for clinical effects (Waisse 2017; Joubert *et al.* 2021).

When exploring the use of homeopathy in oncology, consideration is given to its potential in alleviation of side effects, as well as its potential to act at the cellular level on cancer cells, and also for palliation in end-stage disease (Ankushe 2020; Bagal and Agale 2020; Kaur 2022). Research exploring the use of homeopathy in combination with conventional medicine in oncology care has shown a reduction in conventional medications use for palliation of side effects, and improved quality of life in those patients using homeopathy (Medioni *et al.* 2023). The biological activity demonstrated included inhibition of cancer cell proliferation; promotion of apoptosis of cancer cells by upregulation of apoptotic proteins; and modulation of inflammatory pathways whilst sparing normal cells (Waisse 2017; Joubert *et al.* 2021). Some studies have demonstrated the capacity of homeopathic remedies to upregulate and downregulate genes, thus impacting carcinogenesis (Joubert *et al.* 2021).

Reviews often indicate paucity of high quality evidence, citing deficient methodologies as problematic (Unlu, Kirca and Ozdogan 2017). Proponents of homeopathy do themselves recognise the need for increased quality research with larger sample sizes and quality clinical trials (Patel 2021). Clinical trials are however challenging in homeopathy due to the use of individualised therapy. Very importantly, and notably bringing a complexity to the study of the field, homeopathy claims that that the same disease can have subtle differences in different individuals, therefore requiring different triggers for healing. It is thus very possible that two individuals will get different remedies for the same condition (Henry Spink Foundation 2023). Individuality is one of the most important parameters in case taking, and precision prescribing of the correct individualised medicine of homoeopathy is necessary for success (Ankushe 2020). The mass rollout of randomised clinical trials is counterintuitive to this key principle of homeopathic practice (Husain, Goswami and Vishnoi 2022), but work to increase the evidence base continues.

2.4.3.9 Iridology

Iridology is a diagnostic field that uses the characteristics of the iris to determine the state of systemic health in a patient (Scholarly Community Encyclopedia 2022). Proponents claim to be able to give insights into present as well as underlying inherited disease patterns, allowing preventative interventions before clinical manifestations of disease processes (Iridology Institute of Southern Africa 2023). According to iridologists, pathological changes in body tissues result in noticeable changes in the appearance of the iris such as pigmentation and unusual stromal architecture (Scholarly Community Encyclopedia 2022). Iridologists will use illuminating and magnifying equipment to examine the iris according to a set of “Iris charts” that correlates zones of the iris with various parts of the body (Scholarly Community Encyclopedia 2022). The practice of Iridology is formally traced back to around 1665 with evidence of the first iris charts and descriptions of iridological principles (Scholarly Community Encyclopedia 2022). Iridologists will recommend dietary and lifestyle advice and give herbal remedies (Irish School of Herban Medicine 2020). Iridology is not supported by rigorous scientific evidence, and much evidence in fact disputes it's claims (Ernst 1999; Scholarly Community Encyclopedia 2022). In the absence of adequate evidence, the potential exists for misdiagnosis, leading to treating of conditions that do not exist or giving a false sense of security when existing conditions go undetected, leading to improper or delayed treatment (Scholarly Community Encyclopedia 2022).

2.4.3.10 Massage therapy

Massage therapists apply varying amounts of pressure to the body, focussing on muscles, soft tissues or acupuncture points as a way to alleviate stress, anxiety, and bring about an increased sense of well-being (Cancer Research UK 2022d). Massage therapy use by oncology patients was endorsed by the American Society of Clinical Oncology (along with other integrative therapies), as having sound clinical basis and being worthy of incorporation into Integrative Oncology (Lyman *et al.* 2018). Massage therapists may need to be careful when a patient is undergoing active treatment, have fragile bones or co-morbidities like cardiac problems. In addition, specialised lymphatic massage needs to be done by a suitably qualified person in cases of patients with lymphedema (Penny and Sturgeon 2021; Cancer Research UK 2022d). A 2014 systematic review and meta-analysis found significant reductions in anger and fatigue but no significant reductions in depression, pain, anxiety, and lymphedema (Pan *et al.* 2014). A 2021 systematic review of 1624 articles concluded that body-based practices like massage appear to be effective in managing symptoms such as cancer-related pain and fatigue but that most studies held a high risk of bias. The authors called for more robust methodologies in future studies (Calcagni, Gana and Quintard 2019).

2.4.3.11 Naturopathy

Naturopathy is a holistic system of healing using a multi-pronged approach to treat the whole person. It seeks to harness the healing power of nature through the use of lifestyle changes (including exercise, rest, stress reduction); dietary recommendations; herbal remedies and counselling (South African Naturopathy Association 2018; Department of Health Australia 2021). Naturopaths seek to address the root cause of disease, irrespective of source (South African Naturopathy Association 2018). Naturopathy is recommended as a complementary system to be used alongside other therapies (Department of Health Australia 2021). It can be used to support and educate patients at the time of diagnosis, to alleviate side effects during active treatments, and assist with recovery once treatments are completed (Natural Medicine Journal 2018). A recent study comparing two groups of women, both receiving mainstream treatment for breast cancer whilst one of the groups also received complementary naturopathic treatment. The authors reported a troubling outcome with patients receiving the complementary naturopathic treatment having worse disease-free survival rates than those who received conventional treatment only, a result needing further exploration to explain why this might be the case (Standish *et al.* 2021). As a therapy that uses herbal products, naturopathy will hold the risks of potential interactions with mainstream therapeutic agents (Fasinu and Rapp 2019).

2.4.3.12 Reflexology

Reflexology, is a therapy that uses pressure on feet (or hands or ears) to effect a range of health benefits both emotional and physical (Healthline 2018). It is based on the belief that different areas on surface of the feet correlate with different organs and body parts and that placing pressure on a particular area of the foot can have a beneficial effect on the corresponding organ (WebMD 2021). Besides easing specific health issues, reflexologists also claim to reduce stress and anxiety, and improve general well-being (Healthline 2018). Reflexology has been shown to be effective in relief of side effects such as pain and nausea in oncology patients, whilst improving quality of life (Gholamzadeh *et al.* 2018; Anderson and Downey 2021). However, a strong body of scientific evidence is still lacking. A systematic review and meta-analysis exploring its use in improving the mental health of cancer patients concluded that whilst there is a moderate body evidence supporting benefits of reflexology, an “unequivocal recommendation cannot be made due to conflicting and mixed evidence” and that more robust research is needed in this field (Tian *et al.* 2023).

2.4.3.13 Reiki

The word reiki comes from the Japanese words “rei” which means universal and “ki” which means life energy and refers to the energy that flows through all living things (Cleveland Clinic 2021; Medical News Today 2021; International Association of Reiki Professionals 2023). This non-invasive form of energy healing was developed by Mikao Usui in Japan around 1900, and is now used all over the world, including as a complementary therapy in hospitals and hospices (Cleveland Clinic 2021; International Association of Reiki Professionals 2023). Reiki practitioners believe that a person’s ki should be strong and free-flowing, and that when it is not, symptoms of physical or emotional imbalance result (International Association of Reiki Professionals 2023).

Reiki treatments last between 45-90 minutes with the practitioner placing their hands on or just above the body in at 12-15 specific energy locations. This is recommended for promoting relaxation, reducing stress and anxiety; relieving pain and tension and supporting natural healing (Cleveland Clinic 2021; International Association of Reiki

Professionals 2023). As Reiki uses gentle touch without pressure or manipulation, it is safe for all patients (Cleveland Clinic 2021). Anecdotal evidence from palliative care nurses describes the positive impact of reiki for the patients as well as the palliative care teams, with patients reporting relief from pain, nausea and anxiety whilst allowing a shift from “survival mode” to a sense of peace and calm (Pischke 2018; Metzger *et al.* 2022). Anecdotal patient responses include comments such as “I haven’t felt this peaceful since my diagnosis”; “you don’t know how much Reiki means to me”, with some requesting the treatment be done as often as twice a day (Pischke 2018; Metzger *et al.* 2022). There are several clinical studies which support the efficacy of Reiki in promoting relaxation whilst alleviating pain, stress, depression and anxiety (Lipinski and Van de Velde 2020). However, high quality research into the effectiveness of Reiki is lacking, with much evidence being anecdotal, many studies using small sample sizes and lacking a control group (Medical News Today 2021). Nurses using reiki in the oncology arena still find the benefits to patients on the ground outweigh the need for more scientific evidence, inspiring them to continue its use and promotion in oncology care (Pischke 2018).

2.4.4 TCAM use

2.4.4.1 Prevalence of TCAM use

A 2022 systematic review of 20 surveys from across the world reported that 44.48% of the general population will use a plurality of health-seeking offerings, including both mainstream medicine and TCAM options (Chowdhuri, Kunda and Meyur 2022). Another systematic review of 40 studies from 14 countries reported a range of 24%-71.3% (Lee *et al.* 2022). Some studies suggest that cancer patients could be more likely than the general population to incorporate TCAM as they seek additional tools for battling their illness, relief from cancer symptoms or treatment side effects (Kleine Wortmann *et al.* 2016; Alsharif 2021). A 2017 systematic review exploring use of TCAM by breast cancer patients reported an increase in use following diagnosis (Roumeliotis, Dostaler and Boyd 2017).

Western countries report utilization figures of TCAM by cancer patients as high as 90% (Kleine Wortmann *et al.* 2016). Women are more likely than men to utilise TCAM (Kleine Wortmann *et al.* 2016), and breast cancer patients are more likely to incorporate TCAM than other cancer patients (Perlman *et al.* 2013). A 2021 systematic review reported between 25% and 80% of cancer patients using complementary and alternative practices concurrently with their mainstream treatments (Alsharif 2021). Focussing on low, and lower-middle income countries specifically, 55% of the cancer patients reported using TCAM or seeking a TCAM provider with 27% utilising these together with active treatments (Hill *et al.* 2019). Sub-Saharan Africa (not including South Africa) was reported in this study as having 50% median TCAM use by cancer patients, and 42% using concurrently with active treatments (Hill *et al.* 2019). Some studies however, have demonstrated a higher frequency of TCAM use during active treatment (Kleine Wortmann *et al.* 2016).

2.4.4.2 What cancer patients are using

Reports of cancer patient TCAM use include special dietary approaches; vitamins and minerals; herbs or herbal products; vitamin C infusions; homeopathy; naturopathy; acupuncture; yoga; relaxation techniques; and spiritual approaches amongst others (Saghatchian *et al.* 2014; Naja *et al.* 2015; Kleine Wortmann *et al.* 2016; Hammersen *et al.* 2020). 2021 systematic review reported that the most common inclusion was supplements such as herbal products; minerals and vitamins; as well as the use of traditional medicine; relaxation techniques; spiritual practices; and reflexology (Alsharif 2021).

Using latent class analysis, Strizich *et al* identified four distinct classes of complementary medicine users among women with breast cancer, characterised by varying degrees of use. Users characterised as “Low dose supplement users” who utilised only common nutritional supplements constituted 40% of their sample; “vitamin/mineral supplement users” utilised an abundance of supplements in addition to other practices constituted 39% of their sample; “mind-body medicine users” who utilised supplements, mind-body techniques and massage constituted 12%; and “multi-modality high-dose users” who were highly likely to use all types of CAM constituted 9% of their sample (Strizich *et al.* 2015).

The TCAM therapies being utilised by cancer patients in sub-Saharan Africa as reported by Hill *et al*. are varied. The alternative medical systems utilised include traditional African medicine, Chinese medicine, acupuncture, reflexology, homeopathy, chiropractic and ayurveda. Modalities include nutritional approaches, dietary supplements, herbal medicines, mind-body techniques, massage, relaxation techniques, meditation, visualization, and support groups (Hill *et al.* 2019). In addition, spiritual approaches were numerous and diverse, with a greater prominence than many other world regions. Examples of these include prayer, divinations, spiritual healing ceremonies and rituals amongst others (Hill *et al.* 2019).

2.4.4.3 Reasons cancer patients utilise TCAM

There are many reasons why cancer patients seek out complementary and alternative therapies. In a systematic review, Alsharif aptly summarises the use of TCAM by patients as “an attempt to investigate all possibilities, a manifestation of a coping style, or an illustration of unmet desires in the cancer management continuum” (Alsharif 2021). Patients want to improve their quality of life by controlling cancer-related symptoms and treatment side effects. They also want to increase immunity and the ability of their body to fight cancer in order to improve survival (Jones *et al.* 2019; Alsharif 2021; Farahani *et al.* 2023). In addition to reducing physical complications or side effects, patients also seek out TCAM to reduce anxiety and stress associated with the disease, and enhancing emotional wellbeing (Alsharif 2021; Dehghan *et al.* 2023). Kleine-Wortmann reported that cancer patients cited their “most important goal” in using TCAM, was to strengthen their immune system (Kleine Wortmann *et al.* 2016). Patients believe that TCAM can help healing and recovery, and they are simply trying to do everything they can to help themselves (Alsharif 2021). A 12-year survey of a free clinician-led telephonic consultation service (5269 callers) found that 55% of callers sought ways to personally improve healing and recovery, asking “what else can I do?”, possibly reflecting both the need of the patients to explore options as well as to be empowered to participate in their own healing journey (Horneber *et al.* 2018).

Qualitative studies of patients incorporating TCAM have shown that these patients appreciated being able to utilise treatment options with lower perceived toxicity than conventional drugs. They also appreciated the way integrative physicians give of their time to truly listen, demonstrate caring and treat them as individuals, which they had felt a lack of from conventional doctors. In addition, being empowered to participate and collaborate in their own healing through improved self-care skills was also highly valued (Koithan *et al.* 2007).

2.4.4.4 Factors affecting TCAM use

Increased use of TCAM has been associated with younger and middle age, female gender, higher education (increasing percentage of patients with increasing level of education), higher income, and previous use (Strizich *et al.* 2015; Reid *et al.* 2016; Chowdhuri and Kundu 2020). A 2022 systematic review (including six national surveys) reported that the major drivers of a patient incorporating TCAM were access and cognitive factors; followed by social factors, philosophical congruence and post-decision dissonance (Chowdhuri, Kunda and Meyur 2022).

Health literacy has been directly and significantly linked to the use of TCAM, with patients use linked to their capacity to read and make informed decisions based on health information. However, a higher level of education does not mean that patients struggle to understand the terminology and concepts of health information, and make appropriate decisions (Jones *et al.* 2019; Dehghan *et al.* 2023). Whilst a higher level of education is associated with increased TCAM use, patients with a lower education may pose an even bigger challenge in terms of medication management due to a lack of understanding, posing a high risk for misinformation and drug interactions (Jones *et al.* 2019).

For some patients, the TCAM approaches they use have long been a part of their religious and/or cultural beliefs and previous usage has been shown to be a significant driver (Chowdhuri and Kundu 2020; Alsharif 2021; Dehghan *et al.* 2023). Differences in cultural beliefs have been found to have more of an impact on health-seeking behaviour than level of education (Jones *et al.* 2019). For example, Chinese patients tend to use herbal medicines, African Americans often use spiritual healing practices, and Caucasians turn to a variety of approaches including diet, physical approaches, acupuncture and massage (Jones *et al.* 2019). Gall *et al.* found that indigenous populations perceive TCAM as more than just a treatment, but rather as an intrinsic to their belief system (Gall *et al.* 2018). Pedersen et al found that breast cancer patients who reported a high degree of faith were more frequent users of CAM and more inclined to believe in the beneficial influence of such CAM on their cancer (Pedersen *et al.* 2013). Another factor that affects the dynamics of decision making for a patient is their perception of where the locus of control lies regarding the disease (course, treatment, and other related factors). An individual may believe that they do not have any agency, that the disease is fate and all agency lies outside themselves such as the doctors (Chowdhuri, Kunda and Meyur 2022).

TCAM use can also be affected by the cancer journey and treatment situation. Mannle 2021 challenged the notion of static practices and explored the possibility of use being affected by therapies. They found an increased use of TCAM following radiation therapy (Mannle *et al.* 2021). Increased use of TCAM by cancer patients is also significantly associated with patients receiving adjuvant chemotherapy (Strizich *et al.* 2015). Improved biomedical treatments have increased survival rates, and the number of patients living in remission is growing. This brings with it its own set of challenges for the survivors, as many suffer long after being declared disease-free, finding themselves in a state of health "liminality". Many of these survivors turn to TCAM to fulfil unmet needs during the aftermath of cancer, to forge a path forwards and build a lifestyle to support ongoing healing and future health (Hansen, Rosvold Berntsen and Salamonsen 2019).

2.4.4.5 Sources of information

Decision making is stressful all along the cancer continuum (Reyna *et al.* 2015). When faced with a diagnosis, patients often want to learn, not only about the mainstream treatments, but also about possible TCAM supporting practices (Horneber *et al.* 2018). The patient needs to navigate challenges and choices, all whilst feeling unwell. The numerous options and (often conflicting) opinions of a pluralistic environment can potentially add to these stresses, as patients try to discern what is best for their healing and wellbeing (Currin-McCulloch *et al.* 2021).

A 2021 systematic review stated that the most common source of TCAM information for cancer patients is the internet and social media, followed by family and friends, with some patients getting information from physicians (Alsharif 2021). Whilst social media is an accessible and useful tool, research has shown that acts as a vehicle for the spread of misleading and false information regarding TCAM (Ng, Verhoeff and Steen 2023). Cultural factors appear to play a role in preferred sources of information. For example a review found that Asians and Pacific Islanders preferring gathering information from other people (doctors, fellow patients, and social groups), Caucasian patients preferring information from reputable sources (medical journals and research institutions), and Japanese patients preferring media sources (television, CAM providers) (Jones *et al.* 2019).

There is increasing use of the internet by cancer patients as they seek answers to their questions (Zhang *et al.* 2017). A 2015 study set out to explore posts on the discussion board of Breastcancer.org, a highly active and popular online breast cancer community (Breastcancer.org 2023a). The researchers downloaded all posts from the alternative medicine forum, a total of 25013 posts and 396 threads. Many of the debates were started by newly diagnosed patients and/or patients suffering side effects of conventional treatments, who were seeking information on effectiveness, scientific validity and helpfulness of TCAM (Zhang *et al.* 2017).

Media has the potential to influence the decision-making of patients, with many patients getting their TCAM information from media (Jones *et al.* 2019). However, TCAM is often portrayed as completely safe and promoted via unverified anecdotes and misleading information (Jones *et al.* 2019; Ng, Verhoeff and Steen 2023). Many patients are also satisfied to rely on word-of-mouth recommendations without the need for robust supporting evidence. These patients are at increased risk of misinformation, with logic and reason giving way to false hope, resulting in vulnerable individuals making inappropriate decisions and adopting practices that are not in their best interests (Jones *et al.* 2019). Thus, whilst social media platforms provide useful tools to share information, beliefs and experiences of TCAM use, it has been shown to spread a large amount of misleading and false information, placing patients at risk (Ng, Verhoeff and Steen 2023).

2.4.5 Patient-oncologist communications and TCAM disclosure

Although there are risks involved with using certain TCAM practices alongside mainstream treatments, many investigators indicate low levels of communication between patients and oncologists regarding use of TCAM. Research has shown that between 23% and 60% of cancer patients using TCAM do not discuss this use with their oncologist (Lo-Fo-Wong *et al.* 2012). Some of the reasons for non-disclosure concerned the oncologist: possible opposition to patient inclusion of TCAM; fear of a bad reaction from their practitioner; a perception on the part of the patient that the practitioner had low levels of knowledge in TCAM; or sensed a lack of responsiveness/disinterest. Other factors were a belief that it was not necessary to discuss additional incorporations with their practitioner; or simply not being asked about additional practices they might be including (Lo-Fo-Wong *et al.* 2012; Alsharif 2021).

Shelly *et al.* in their article entitled “They don’t ask me so I don’t tell them” found that most patients using TCAM expect the clinician to initiate a TCAM discussion if it is going to happen at all, yet low levels of communication about TCAM is misinterpreted by oncologists as a sign of low use amongst their patients (Shelley *et al.* 2009). Patient willingness to disclose their TCAM practices was strongly influenced by the attitude of the oncologist towards TCAM discussions. When there was perceived clinician receptivity to discussing TCAM, or when the clinician actually initiates the TCAM discussion themselves, patients were more willing to disclose what they were incorporating, and increased patient disclosure was correlated to a participatory decision-making style (Shelley *et al.* 2009). Whist clinicians may not feel they have all the necessary TCAM knowledge, perceived clinician expertise in TCAM was considered less important by patients than clinician willingness to discuss it (Shelley *et al.* 2009). These researchers stressed the importance of the oncologist initiating TCAM discussions whilst displaying non-judgemental interest and candour about the limits in their personal knowledge. This would be with a view to eliciting the patient perspective, respecting patient values, raising issues of safety, and involving patients in decision making (Shelley *et al.* 2009).

Horneber *et al.* studied data of 5269 callers to a cancer support line and concluded that TCAM consultations cannot be separated from consultations about conventional care and should be provided from the beginning of the cancer journey. They stated that these discussions can address unmet needs of patients along the cancer continuum, providing the opportunity for clinicians to engage in open and supportive dialogue about helpful evidence-based TCAM practices (Horneber *et al.* 2018). Frenkel *et al*. summarised important patient needs that can be met through clinicians engaging in TCAM discussions. Patients are facing increasing availability of TCAM and needing to ascertain its usefulness, and TCAM discussions can give patients additional avenues to explore in addressing unmet physical and emotional needs. These authors also emphasised the need for non-judgemental open discussions about TCAM as well as the patients' need to be empowered to participate in their own healing journey and self-care (Frenkel, Ben-Arye and Cohen 2010). These authors listed the benefits of oncologists engaging in open TCAM discussions including addressing patient stress and uncertainty, adding to the quality of care, enabling informed decision-making, enhancing the physician-patient relationship, enhancing patient satisfaction, and reducing patient engagement with misleading information (Frenkel, Ben-Arye and Cohen 2010).

Given that many cancer patients will incorporate TCAM, it is imperative that oncologists raise the discussions of additional practices with their patients and educate them on the usefulness or risks of inclusion (Alsharif 2021). Researchers are urging mainstream oncology practitioners to seek out the latest information regarding TCAM in order to be empowered to engage in conversations with their patients (Wanchai *et al.* 2017). Efforts are being made to provide oncologists with clear guidelines and information in order to be able to discuss realistic expectations and potential benefits and risks of TCAM with their patients (Frenkel *et al.* 2013; Rossi *et al.* 2021; Berretta *et al.* 2022; O'Brien *et al.* 2022; Society for Integrative Oncology 2023).

2.5 Holistic and Integrative Oncology

2.5.1 Defining holistic and integrative medical practice

Holistic medicine is defined by the American Holistic Health Association as “ the art and science of healing that addresses the whole person- body, mind, and spirit” (American Holistic Health Association 2020). Medical Subject Heading® defines it as an approach that rests on “the perspective that humans function as complete, integrated units rather than as aggregates of separate parts” (National Library of Medicine MeSH 2009a). Thus, this approach to prevention and management of disease acknowledges the multi-dimensional aspects of wellness (Western Connecticut State University 2022), and seeks to provide a team of caregivers who address different aspects of holistic patient health (St Catherine University 2022). Patient education and participation in their personal healing process is a core value of holistic health, especially with respect to lifestyle changes that optimise and support the body’s own innate capacity for healing (American Holistic Health Association 2020).

The national library of medicine defines *integrative medicine* as “the discipline concerned with using the combination of conventional allopathic medicine and alternative medicine to address the biological, psychological, social, and spiritual aspects of health and illness” (National Library of Medicine MeSH 2009b). This definition highlights care of the whole person (holistic health) whilst emphasising the embracing and integration of healing approaches from different traditions. It is possible to conceive of integration of complementary therapies (such as acupuncture or meditation) without addressing holistic care, or vice versa. However, it could be argued that the ideal might be an openness to merging safe and proven modalities from different traditions (integrative medicine) whilst ensuring care of the whole individual (holistic care).

Distinguishing between the terms “holistic” and “integrative” can be difficult. Holistic medical practice can, and often does, embrace healing approaches from different traditions, and thus the two terms are often conflated (American Holistic Health Association 2020). For the purposes of this thesis however, the term “holistic” care will be used to refer to the addressing of all aspects of wellbeing (including lifestyle elements such as diet; exercise; relaxation; psychological; and spiritual); whilst the term “integrative” care will be used to specifically refer to the merging of approaches from different traditions (conventional allopathic; and complementary).

2.5.2 Integrative oncology

2.5.2.1 Introduction to Integrative Oncology

In their book titled “Integrative Oncology”, Abrams and Weil define it as “the rational, evidence-based combination of conventional therapy with complementary interventions into an individualised therapeutic regimen that addresses the whole person living with and beyond cancer: body, mind and spirit” (Abrams and Weil 2014). This definition emphasises the use of interventions from different traditions whilst specifying that such inclusion needs to be informed by good scientific evidence, “neither rejecting conventional medicine nor accepting alternative treatments uncritically” (Abrams and Weil 2014). In recognising the different aspects of the patient that need care, it also speaks to the ideals of holistic medicine, believing that an individual’s mental/emotional, and spiritual well-being are also of importance in healing (Abrams and Weil 2014).

Another comprehensive definition of Integrative Oncology was developed in 2017 by Witt *et.al*. using literary analysis as well as an interdisciplinary survey and consensus procedure. The final definition that emerged out of these processes was “Integrative Oncology is a patient-centred, evidence-informed field of cancer care that utilises mind and body practices, natural products, and/or lifestyle modifications from different traditions alongside conventional cancer treatments. Integrative Oncology aims to optimize health, quality of life, and clinical outcomes across the cancer care continuum and to empower people to prevent cancer and become active participants before, during, and beyond cancer treatment”. This definition includes the aim of optimization of clinical outcomes as well as quality of life. It also speaks to the full cancer care continuum before, during and beyond treatments, and highlights the need to empower patients to become active participants in their own health and healing (Witt *et al.* 2017).

In addition to integration of evidence-based complementary practices and use of the holistic approach, Abrams and Weil set out several other principles that underpin, and are therefore emphasised in Integrative Oncology, including the role of the patient and the critical role of the therapeutic relationship (Abrams and Weil 2014).

- Belief in the natural healing power of the organism: Integrative practice assumes that the human body has an innate capacity to heal, self-repair and adapt, and that a primary goal of treatments should be to support and augment that capacity.
- Stressing the importance of lifestyle: Integrative practice believes that all aspects of lifestyle will impact health and disease by interacting with genes. Factors include diet, physical activity, rest and sleep patterns, stress effects,

work, relationships etc. Lifestyle medicine therefore is an important component of the holistic Integrative Medicine approach.

- Honouring the critical role of the Doctor-Patient relationship: Down the centuries, many practitioners have attributed a very important role to the Doctor-Patient relationship. Integrative medicine recognises the devaluing of this role in many pressurised contemporary medical settings and seeks to reclaim the fullness of healing practice rooted in a strong therapeutic relationship between doctor and patient.

For these reasons that Weil also describes the field of integrative medicine as having the potential to restore some of the core values of medicine that have become eroded in an era of profit-driven health care (Abrams and Weil 2014).

Integrative Oncology specifically seeks to unite conventional oncology and TCAM within a cohesive evidence-based framework (Mao *et al.* 2022b). Integrative Oncology research and resulting guidelines, aim to reduce the risk associated with independent decision making by patients within the pluralistic landscape. Instead, patients are practitioners can rely on safe, effective and evidence-informed guidelines (Mao *et al.* 2022b).

2.5.2.2 International guidelines for Integrative Oncology

In 2017, the Society for Integrative Oncology set out guidelines for the use of integrative therapies during and after breast cancer treatment (Greenlee *et al.* 2017). These guidelines were for the management of symptoms and adverse effects of the cancer and mainstream treatments such as pain, anxiety and stress, mood disorders, chemotherapy induced nausea and vomiting, chemotherapy-induced peripheral neuropathy, fatigue, quality of life, and lymphedema. The recommendations were based on randomized controlled trials (RCT's) published from 1990-2015 (Greenlee *et al.* 2017). The key recommendations based on the RCT's included the use of music therapy, yoga and meditation for anxiety/stress reduction; relaxation techniques, meditation, yoga, massage, and music therapy for depression/mood disorders; and acupressure/acupuncture for reducing chemotherapy-induced nausea and vomiting and sleep disturbance (Greenlee *et al.* 2017). These guidelines were interrogated by the American Society of Clinical Oncologists in 2018 and endorsed as "clear, thorough, and based on the most relevant scientific evidence" (Lyman *et al.* 2018).

In addition, the Society for Integrative Oncology also published guidelines for exercise, diet and weight management during cancer treatments based on 52 systematic reviews and 23 randomised control trials (Ligibel *et al.* 2022). These guidelines emphasised the multifaceted advantages of exercise for cancer patients and recommended aerobic and resistance exercise for all patients on active treatments with curative intent. However, it highlighted the need for more research regarding dietary interventions as well as exercise for patients with advanced disease (Ligibel *et al.* 2022).

Similarly, guidelines for management of pain in cancer were published in 2022 based on randomised controlled studies from 1990-2021. These recommend acupuncture for aromatase inhibitor-related joint pain; acupuncture, acupressure or reflexology for general cancer pain and musculoskeletal pain; hypnosis for procedural pain; and massage for palliative care (Mao *et al.* 2022a).

Planning and implementing of integrative therapies into the clinical setting is a challenging task, requiring both exploration and ongoing fine-tuning (Weeks *et al.* 2014). The needs, concerns and expectations of stakeholders, including patients and healthcare providers, must be considered whilst also taking into account matters of feasibility, efficacy, safety and cost (Ben-Arye *et al.* 2012b; Weeks *et al.* 2014). Actioning the formulated plans requires a co-ordinated team approach with well-trained providers who hold the necessary credentials and understand the benefits and risks of integrative therapies (Greenlee *et al.* 2017). In addition, bi-directional communication between the conventional and complementary practitioners is essential (Frenkel *et al.* 2010; Ben-Arye *et al.* 2012b). The evolution of Integrative Oncology in different countries is influenced and shaped by many social and cultural factors. As stated by Toledano *et al.* “Successful provision of Integrative Oncology services requires matching the clinical need with available expertise and resources within the available financial infrastructure to achieve the best local, regional, or national solution. In reality, several models may provide this” (Toledano *et al.* 2021).

Given the complexity of factors involved, Integrative Oncology programs take on different designs and approaches to suit stakeholders (Brazier, Cooke and Moravan 2008; Ben-Arye *et al.* 2012a; Dobos *et al.* 2012; Lin *et al.* 2016; Lopez *et al.* 2017; Rossi *et al.* 2021). Essentially, comprehensive Integrative Oncology programs seek to empower patients with lifestyle information and/or interventions that can positively impact outcome and survival. They also seek to address quality of life issues along the cancer continuum including into survival or palliative care (Brazier, Cooke and Moravan 2008; Ben-Arye *et al.* 2012a; Dobos *et al.* 2012; Lin *et al.* 2016; Lopez *et al.* 2017; Rossi *et al.* 2021).

Patients report a sense of increased hope through active engagement in their own journey with quality information and resources supporting empowered decision-making and personal change, as well as improved quality of life (Brazier, Cooke and Moravan 2008; Lin *et al.* 2016; Ben-Arye *et al.* 2018).

Much work remains to be done in the complex arena of Integrative Oncology. Currently, much of the research involves trials of single treatment options in order to validate their inclusion, yet the very nature of Integrative Oncology is the utilization of holistic strategies that focus on the whole patient (Dobos *et al.* 2012). Whilst randomised controlled trials are the scientific gold standard, they are insufficient as a tool in answering questions about the effectiveness of whole system strategies (Dobos *et al.* 2012).

2.6 The South African Context

2.6.1 The population of South Africa and eThekwini

The 2019 mid-year population estimates released by Statistics South Africa (Stats SA), listed the total population of the country at 58.78 million. Just over half of this (51.2%), or approximately 30 million, are female (Republic of South Africa 2019a). Primarily a Black majority nation, South Africa's history has resulted in a multicultural population and the National Development plan recognises this multiculturalism as "the defining element of our identity" and describes South Africa as "a community of multiple, overlapping identities, cosmopolitan in our nationhood" (National Planning Commission 2011). Black Africans form 80.7% of this population, with 8.8 % being coloured, 2.6% Indian or Asian and 7.9% being white (Republic of South Africa 2019a).

Around nineteen percent (19.2 %) or 11.3 million of the total South African population live in the province of KwaZulu-Natal (Republic of South Africa 2019a). When comparing racial proportions of the province to those of the country as a whole, KwaZulu-Natal has a larger percentage of Africans (87.6%) and Indians (7%) and a smaller percentage of coloureds (1.4%) and whites (4%) (KwaZulu-Natal Provincial government 2018).

Figure 2.6.1.1: Map of South Africa showing the province of KwaZulu-Natal (Google Maps 2019b).

The province of KwaZulu-Natal is divided up into 11 districts, one of which is the eThekwini municipal district, located on the East coast of KwaZulu-Natal and spanning an area of 2297km^2 (Republic of South Africa 2019b; South Africa Gateway 2019). Approximately 34% of the population of KZN reside in the municipal area of eThekwini (Republic of South Africa 2019b). The city of eThekwini, also known as the city of Durban, is the largest city in the province and the third largest city in the country, and like the rest of South Africa, it consists of a culturally diverse society and faces numerous social, economic and governance challenges (eThekwini Municipality 2019; Republic of South Africa 2019b).

This research project incorporated patients and oncologists from the greater eThekwini area, spanning from Amanzimtoti in the South to Umhlanga in the North, and Hillcrest and Hilton in the West.

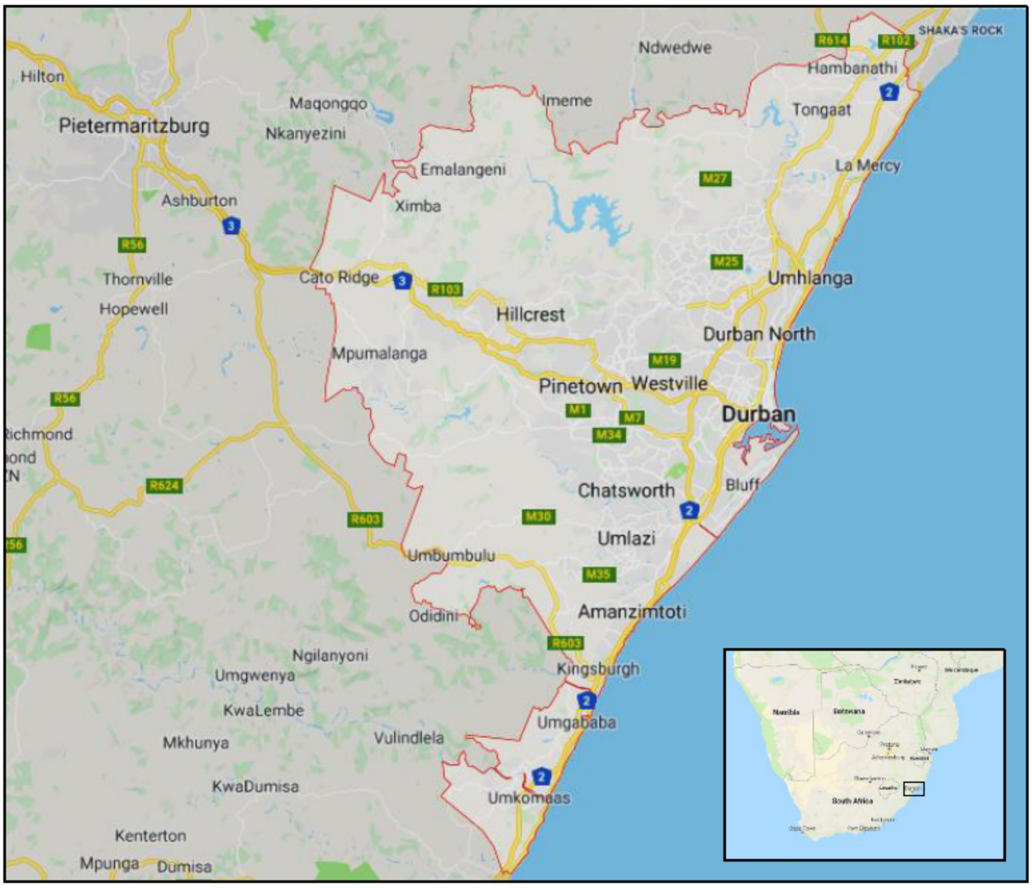


Figure 2.6.1.2: Map showing the boundaries of the eThekwini municipal district (Google Maps 2019).

2.6.2 The medical landscape of South Africa

2.6.2.1 Medical Pluralism in South Africa

The colonial history of South Africa resulted in a dominance of biomedical practice in both public and private health provision, but the landscape remains pluralistic with a diversity of health offerings including African and Indian traditional medicine as well as numerous other TCAM practices (Digby 2008; Allied Health Professions Council of South Africa 2018; Burman 2019). In the interests of decolonization, the department of health has set about formalizing indigenous and alternative health practices in the constitution and governance. The Allied Health Professions Act (Act 63 of 1982), recognises and provides for the regulation of alternative health practitioners such as chiropractors, homeopaths, naturopaths, osteopaths, phyto-therapists, ayurvedic doctors, acupuncturists, and reflexologists (South African Government 1982). A similar Act promulgated in 2007 legally recognises and regulates African Traditional Healers (South African Government Gazette 2008b). Whilst the need to increase collaboration between biomedical and traditional health systems is recognised, “cohabitation rather than true integration remains the norm” (Burman 2019).

2.6.2.2 Health disparities

The history of South Africa has been characterised by racial discrimination, which began in colonial times and has dominated many aspects of the country until recent decades (Coovadia *et al.* 2009; Benatar 2013; Columbia University Irving Medical Center 2023). The policy of Apartheid resulted in social separation, political exclusion, and economic marginalization, impacting social structure, and access to resources including health care. This history had a pronounced effect on both societal health patterns, as well as health policy and services (Coovadia *et al.* 2009). Although legal discrimination ended in 1994, it left an aftermath that remains today, with the country still dealing with the resulting inequalities (Buisman and Garcia-Gomez 2015; Gordon, Booysen and Mbonigaba 2020). This has been compounded in recent decades by persistent violence, as well as poor stewardship and deficient implementation of health policies (Digby 2008; Coovadia *et al.* 2009; Columbia University Irving Medical Center 2023). South Africa has also been faced with the largest HIV/AIDS epidemic in the world, which became the main focus of health systems and uses a disproportionate amount of public health funding (Columbia University Irving Medical Center 2023).

The South African constitution guarantees every citizen access to health services with public health services available at no cost (South African Government 2024). Each province has a Department of Health responsible for health delivery and health promotion (Department of Health 2024). Primary care clinics staffed by nurses provide community health services; district hospitals provide for testing and minor procedures; and provide more advanced technologies for serious conditions, most of which is funded by a National Revenue Fund These government facilities cater to approximately 82% of the population (Columbia University Irving Medical Center 2023; South African Human Rights Commission 2024).

There are, however, many issues with the public/government sector of health delivery as outlined by the report on the Presidential health summit (Presidential Health Summit 2019). There are issues related to human resources such as inadequate training of staff, poor retention of well-trained professionals, top-heavy management structures, and weak governance. There are ongoing problems related to procurement and supply chains, with slow tender awarding, inaccurate budgets, and deviation from supply agreements. Maintenance of health facilities is poor and audits lacking. Quality and safety of many health services is also a problem needing to be addressed, as is the health literacy needed to empower people to take charge of their own health. Poor management of funds is compounded by corruption and wastage at both national and provincial levels, as well as high levels of unacceptably high levels of medico-legal litigation. Dysfunctional systems and processes (including the digital management of health information) add to the challenges as do a lack of monitoring and evaluation and compliance checks (Digby 2008; Presidential Health Summit 2019).

By contrast, the private healthcare sector provides health services to 18% of the local population, but accounts for the largest share of health expenditures via personal out-of-pocket payments and medical schemes (Columbia University Irving Medical Center 2023). About 70% of the doctors in the country work in the private sector, with only 30% working in the government sector (Mayosi and Benatar 2014), and only 17% of the population have medical aid (South African Human Rights Commission 2024).

2.6.2.3 The Oncology crisis in KwaZulu-Natal (KZN)

The future of oncology is a challenging field of health services for many developing countries including South Africa. There have been repeated calls to action regarding a possible oncology crisis in Southern Africa (Farmer *et al.* 2010). Over the last decade, cancer has become a public health crisis in the low- and middle-income countries of Southern Africa, due to limited and deteriorating oncology infrastructure, a scarcity of the necessary trained personnel, limited availability of drugs and rising costs of cancer care. In addition, many patients present with advanced disease, requiring more intervention (Kingham *et al.* 2013). Within the provincial hospitals of South Africa, these challenges have been an ongoing problem, resulting in unacceptable waiting times from screening to treatment, and centres that are “unable to provide holistic care for the majority of patients”, and increasing the gulf of inequitable access to critical health services (Department of Health 2017).

In 2016, a human rights complaint was lodged by a member of the Democratic Alliance concerning the oncology crisis in KZN. This complaint raised the issues of a lack of functional health technology for screening, diagnosis and treatment, as well as staff shortages (South African Human Rights Commission 2017). The report on the investigations that followed confirmed many aspects to the crisis: Inadequate equipment installation and maintenance. An oncology backlog, with patients waiting an average of five months before they can see an oncologist, and a further 8-9 months before accessing radiotherapy, impacting outcome and sometimes resulting in a patient progressing from a treatable to a palliative stage (South African Human Rights Commission 2017). Staffing at Inkosi Albert Luthuli Central Hospital, the main hospital servicing cancer patients, was found to be under pressure with significant shortage of oncologists, a problem exacerbated by oncologists leaving public hospitals due to frustrations in the public setting and better remuneration in the private sector (South African Human Rights Commission 2017). Overall, the conditions of the oncology services in KZN were found to have violated the rights of cancer patients (South African Human Rights Commission 2017).

2.6.2.4 Integrative Oncology in the South African context

There is not data on the extent to which true Integrative Oncology exists in South Africa. A cursory perusal of internet sites claiming to offer Integrative Oncology suggests a different utilization of the term. These sites include those who are offering a wide array of TCAM modalities for the patient without any consultation with the patient's mainstream provider; as well as mainstream biomedical providers who include a complementary therapy such as psychotherapy (Cancer Care 2023; House of Holistic Health 2023; SA 2023). There is limited evidence of some independent providers claiming to work alongside the oncologists to provide alternative therapies, nutritional and supplement guidance as well as lifestyle and emotional support (Oncology Integrated 2023; Syringa Health 2023). There was however no evidence of single centres offering fully integrated care. When specifying the province of KwaZulu-Natal (or eThekwini), the search results do not display any local oncology centres offering integrative care.

2.7 Summary of Chapter 2

Chapter 2 reviewed the concepts, terminology and literature associated with the thesis. It began by introducing the concept of medical pluralism and defined the terminology associated with academic discourse on medical pluralism. It then outlined some of the challenges and opportunities that medical pluralism brings for patients and practitioners, and spoke to health-seeking behaviour, as well as bioethical considerations for clinicians. Considerations of medical pluralism were rounded off with a brief exploration of the dynamics of the mainstream-TCAM interface.

The chapter then went on to review the theory of breast cancer, its incidence and genetics, before outlining the mainstream therapies and their side-effects. Following this, the chapter examined the varied traditional, complementary and alternative medical practices used by cancer patients the world over. These practices were examined in terms of current evidence in support of, or cautioning against, their use in cancer patients. Prevalence of use, reasons for use and information sources were examined as well as considering the matter of patient disclosure.

Holistic and integrative approaches to oncology were then defined, highlighting their foundational principles. The international Integrative Oncology guidelines were also presented. Finally, the geographical, social and medical context of the thesis were presented to give the reader insight into the social and political issues at play, and to facilitate an informed and nuanced interpretation of findings.

3. RESEARCH METHODOLOGY

This chapter will outline and substantiate various aspects of the research methodology. Starting with the choice of research design, it will go on to describe the paradigm; research setting; research samples; tools used; and analyses done on data collected. In addition, it will describe ethical considerations and address matters of validity and reliability.

3.1 Research Design, Paradigm, and Theoretical Framework

3.1.1 The main types of research designs

A research design is the strategy selected by a researcher for answering their specific research question/s. It forms the blueprint that guides the whole research process, including the choice of research setting, specific approach to sampling, data collection and analysis methods (Kalaian 2008). There are many different types of research designs, each with its specific strengths, limitations, and philosophical underpinnings.

Quantitative research seeks to quantify findings numerically. Generally underpinned by a positivist philosophy, quantitative research gathers a range of numerical data. This can be intrinsically numerical such as age or coded by allocating numbers to specific responses such as race. The variables in this data can then be analysed using statistics to describe basic patterns (frequencies, averages and percentages) or explore more complex mathematical relationships and comparisons between variables (Coghlan and Brydon-Miller 2014). The advantage of a quantitative approach is precision and the ability to analyse data with sophisticated mathematical techniques. It is limited in its ability to truly explore personal lived experience and describe the cultural the social construction of the variables being investigated (Smith and Zajda 2018).

Qualitative research on the other hand seeks in-depth understanding and rich descriptions of phenomenon such as personal lived experience and meaning. It investigates these through a variety of methods such as personal narratives, focus groups, or use of texts and images. Findings are generally presented as thematic written analyses, bringing a depth of insight into the issues at play. Qualitative research is suited to studying attitudes and behaviours, with the main benefit being the depth of understanding and insight in can bring. It is limited in the transferability of its findings and the potential for “anecdotalism” (Smith and Zajda 2018).

Mixed methods research collects and analyses both quantitative and qualitative data to answer specific research questions, integrating these two forms and data and the insights they provide (Creswell and Plano Clark 2018). Emerging out of the paradigm wars between quantitative and qualitative approaches, mixed methods has become a widely used mode of enquiry, opening up many different design choices involving a range of concurrent and sequential strategies (Terrell 2012). The core assumption of mixed methods research is that the combination of both qualitative and quantitative approaches can provide a more complete understanding of the particular research question than either one of them alone (Creswell and Plano Clark 2018).

3.1.2 Research design used in this study

The current study was a cross-sectional study which utilised the explanatory sequential mixed methods design as it was considered well suited to the varied nature of the objectives. Given the fact that there is a dearth of data on the use of traditional and complementary medicine by cancer patients and oncologists in KwaZulu-Natal, there was the need to first gain insights into current practise before delving deeper to explore attitudes, motivations and personal lived experiences. This lent itself naturally to a research design of multiple phases and approaches. The project therefore incorporated the initial quantitative phase which utilised patient and oncologist surveys, followed by the qualitative phase which explored at a deeper level through semi-structured interviews.

The aims of the researcher in selecting explanatory sequential mixed methods are as follows:

- To provide the possibility of triangulation from the different data sets where possible, with a view to mutual corroboration, thus supporting the validity of findings.
- Offsetting the gaps that might arise in one method with explorations utilising a different method.
- Elaboration, enhancement and clarification of quantitative findings where necessary with qualitative findings.
- To allow for an emergent approach to refining of qualitative aims based on the quantitative findings.
- To ensure that the best method is being utilised to answer each of the specific research questions being posed. This quantitative method could provide initial

insights, uncover patterns and relationships between variables. The qualitative methods could be used to delve deeper, exploring experiences and opinions of individuals on the ground, form their own perspective and in their own words (Bryman 2006; Creswell and Plano Clark 2018; Busetto, Wick and Gumbinger 2020).

3.1.3 Research paradigm: Pragmatism

All research is underpinned by a set of philosophical assumptions. Researchers bring a set of personal beliefs to the inquiry that will inform and guide their explorations (Creswell and Clark 2017). These assumptions concern the researcher's beliefs regarding ontology (the nature of reality) and epistemology (concerning knowledge and the relationship between the researcher and the would-be-known) (Killam 2013). These philosophical assumptions can also be described as a "worldview" or "paradigm" (Creswell and Clark 2017).

Over the years, several paradigms have become associated with mixed methods research, but Pragmatism has been embraced by numerous researchers as the optimal paradigm for mixed methods (Tashakkori and Teddlie 2003). In Pragmatism, the focus is on answering the research question/s and it is oriented towards "what works" in order to best do that. It therefore uses pluralistic approaches and philosophies to understand and engage with real-world issues (Creswell and Clark 2017)

Tashakkori and Teddlie (2003) proposed a set of factors that make Pragmatism highly appropriate as a paradigm for mixed methods. These factors are:

- Pragmatism holds that the research question/s should be of primary importance and focus, above method or philosophical worldview.
- It allows both quantitative and qualitative research methods to be used in a single study.
- It allows for the abandoning of the forced-choice dichotomy between post positivism and constructivism, with incorporation of both should it be suitable.
- It allows a practical and applied philosophy to guide methodological choices (what works?).
- It allows for the abandoning of metaphysical concepts such as the nature of truth and reality (Tashakkori and Teddlie 2003).

The current research is seeking to gain insights into real world matters of the health-seeking choices and lived realities of breast cancer patients and oncologists.

Participants are from differing backgrounds, disparate medical arenas and all are navigating a pluralistic medical landscape. So many elements of the research are inherently pluralistic, including setting, participants, and personal lived realities. The study needed to embrace different methodological choices as well as utilise inductive and deductive approaches to gain the insights it sought. For all these reasons, Pragmatism was the best choice of paradigm.

3.1.4 Theoretical framework for qualitative enquiry: Narrative theory with elements of phenomenology

3.1.2.1 Narrative research

As the name implies, narrative research seeks to explore the lived experiences of individuals via the use of their personal narratives. Thus, it generally involves in-depth interviews of participants on the topic of interest. It is used by researchers from a wide variety of disciplines and research approaches (*Encyclopedia of Research Design* 2012; Renjith *et al.* 2021). Narrative research is underpinned by a postmodern epistemology in that it respects the multiple truths within human science research, giving credence to context and subjective truths from multiple perspectives (Moen 2006; *Encyclopedia of Research Design* 2012).

Paul Ricoeur wrote a seminal work in which he argued that humans experience the events and circumstances of our lives narratively and that our personal narratives bring meaning and order to personal experiences (Ricoeur 1984). Storytelling is a natural way of both recounting experiences and making order of the complexity of experience (Moen 2006). Jerome Bruner has been a strong advocate of what he termed the “narrative modes of knowing” in which the narrated particulars of individual lived experience are more important than pre-conceived constructs and lenses when seeking understanding of that lived experience (*Encyclopedia of Research Design* 2012; Goldin 2019). Whilst narrative theory uses personal stories, those stories carry significance and provide valuable insights into the field of exploration (Renjith *et al.* 2021).

Narrative theory has emerged as a powerful framework within qualitative research, particularly in the medical field, for its ability to delve deep into the multifaceted dimensions of illness and healthcare practices, as well as the subjective experiences of patients and healthcare providers (Overcash 2003; Renjith *et al.* 2021). By prioritizing the voices and stories of individuals, this approach not only enriches our understanding of health-related phenomena but also informs compassionate and patient-centered care practices. As medical research continues to evolve, narrative theory stands as a valuable tool for uncovering the complexities of human health and promoting holistic approaches to healthcare delivery (Overcash 2003).

3.1.2.2 Phenomenology

Whilst the approach to qualitative data collection used in this study is in keeping with the theory of narrative research, the exploration also has many aspects of phenomenological research. Phenomenology is a philosophy of experience, a lens developed by German philosopher Edmund Husserl, and further expanded by Martin Heidegger (Stanford Encyclopedia of Philosophy 2023). In phenomenology, individuals who have had similar experiences of one kind or another are the “units” of analysis, with personal interviews generally forming the main source of data (Renjith *et al.* 2021). The aim in phenomenological research is to understand the participant’s experience of the phenomenon, and identify key elements related to that experience. The phenomenological approach can further be divided into descriptive phenomenology (in which the researcher seeks to describe the lived experience of the phenomenon in a structured and textured manner) and interpretive phenomenology (in which the researcher moves beyond the description to uncover possible meanings behind the descriptions of lived experience) (Renjith *et al.* 2021). The phenomenon being explored in this study is the cancer journey, from the point of view of both the patient and the oncologist.

3.2 The Setting and Research Populations

3.2.1 The choice of populations

Two populations were utilised for the study, namely a patient population and an oncologist population. It was necessary to include both these populations in order to provide perspective. Holistic and Integrated care is about striving for an approach that best serves the patient, so we need to know what patients are currently doing, as well as what their vision of the ideal support environment might look like for someone on a cancer journey. Ultimately though, the providers, and the most powerful players in service provision, are the oncologists. They determine how to approach care and what avenues they might be willing to explore for their patients. They can share what their vision is and give insight into the challenges and opportunities they believe are inherent in medical pluralism.

3.2.2 The choice of research setting

As described in the literature review, the setting for the research was the municipal district of eThekwini in Kwa-Zulu Natal. With a dearth of data on the practices of South African oncologists and cancer patients in the use of TCAM, any setting would provide useful insights in determining the current landscape and informing planning going forwards. However, the researcher is based in eThekwini for work and study, and this therefore formed the logical choice. The population of eThekwini reflects the multicultural nature of the country and includes a large government treatment facility as well as numerous smaller private treatment facilities, offering views into different socio-economic patient backgrounds and differing patient experiences.

3.2.3 Inclusion criteria

Patient inclusion criteria:

- Breast cancer patients who have received any aspects of their mainstream treatment from a clinic within the eThekwini municipal district of KwaZulu-Natal within the years of 2016 to 2020.
- Females over the age of 18.

Oncologist inclusion criteria

- Practicing at an oncology clinic within the eThekwini municipal district at the time of the study.

3.2.4 Sample size calculation

3.2.4.1 Calculating patient sample size

In order to calculate the required sample size, cancer statistics were obtained from the National Cancer registry (NCR), which is the formal cancer surveillance agency for South Africa. The NCR provides breast cancer statistics by sex and race for the whole of South Africa (Registry 2023). Regional statistics (for the eThekwini district or for KZN) is unfortunately not available in the reports (due to large numbers of statistical entries excluding accurate regional data), so it was decided to utilise population ratios to estimate figures for breast cancer incidence in eThekwini. Because inclusion criteria spanned a five-year period (2015-2019), a five-year incidence figure of 45 000 for the whole country was utilised as the starting point. Incidence within eThekwini for this same period was then estimated based on the population ratios for SA to eThekwini. The total number of breast cancer diagnoses in eThekwini for the time period 2010-2019 was estimated at approximately 2800 cases. Utilising the Raosoft sample size calculator, with a 5% margin of error and a 95% confidence interval, the recommended sample size was calculated to be 340 participants. At 90% confidence interval a sample size was calculated at 248.

3.2.4.2 Calculating oncologist sample size

Using data from the oncology consortium, together with internet searches, a list of 27 oncologists practicing in eThekwini was compiled. Using the Raosoft sample size calculator, with a 5% margin of error and a 95% confidence interval, the recommended sample size was calculated to be 26 participants.

3.2.4.3 Sample size for qualitative phase

There has been much debate about the sample size required for qualitative investigations. The general guide is that investigations should continue until the researcher is no longer hearing new information, and no new themes are emerging from the data, an occurrence referred to as “data saturation” (Lincoln and Guba 1985; Ellis 2020). However, it is also important that the data acquired is scrutinised in a detailed manner that allows for rich descriptions. If there are too many sample units, detailed insights and descriptions could be compromised. The epistemological and practical considerations contribute to deciding on what would be a suitable sample size (Robinson 2014). Sandelowski 1995 emphasised the fact that the qualitative researcher needs to guard against the sample size being too small or too large for the specific kind of qualitative design being utilised and the specific consideration of the presence or lack of homogeneity in the target population (Sandelowski 1995; Ellis 2020). Moser and Korstjens (2018) proposed that explorations into a specific lived experience require less than 10 interviews (Moser and Korstjens 2018). The current study incorporated 16 x 1.5hr interviews.

3.2.5 Sampling approach and recruitment process

Due to several constraining factors, probability (stratified random) sampling could not be utilised. These constraining factors included the Protection of Personal Information Act (POPIA) which prevented access to patient records for the purposes of planning a stratified approach. Therefore, non-probability sampling was utilised, including both convenience as well as snowball sampling.

For the purposes of including patients and oncologists from the *government sector*, the main large eThekwini cancer treatment facility based at Inkosi Albert Luthuli Central Hospital was approached for gatekeeper permission. For the purposes of including patients and oncologists from the *private sector*, 15 private clinics across eThekwini were approached for gatekeeper permission. This included oncology centres from Durban, Amanzimtoti, Umhlanga, Hillcrest and Hilton.

In addition, other organizations that could provide potential avenues of recruiting were also approached for gatekeeper permission. These included the cancer association of South Africa (CANSA); Reach for Recovery (RFR) and Conrad Barnard Prosthetics. Once gatekeeper letters were obtained from the clinics and organizations mentioned above, a variety of recruitment strategies were utilised in order to invite participation of patients and oncologists. For both populations, informed consent and surveys completion could be done as a hard copy or on a digital platform.

At the government centre, the breast cancer clinic is held on a specific day of the week and all patients arrive early, waiting for long periods in a large room for their appointments. This allowed the researcher (and isiZulu research assistant in the case of isiZulu speakers) to invite voluntary patient participation and perform researcher-assisted completion of the consent and survey forms where necessary. By contrast, at the private centres, breast cancer appointments are random, and patients arrive at the time of their appointment, making it difficult for researchers to be present for recruitment. Therefore, in these clinics, posters and fliers informed patients about the research and gave details for finding out more regarding the research and participation. This could be done by contacting the researcher, or by accessing the digital information, consent and survey through a QR code on the flier/poster. In the case of CANSA, recruitment was done through support groups (via in-person attendance as well as invitations posted on CANSA WhatsApp groups) as well as the CANSA website (research promotion page). In the case of Reach for Recovery, recruitment was also done by attending group sessions and sharing invitations in WhatsApp groups. Conrad Barnard Prosthetics also sent out invitations via their WhatsApp community. Later, as COVID-19 restrictions put a stop to researcher access to all clinics, data collection was limited to the digital groups and snowballing.

Oncologists: Using data from the oncology consortium, together with internet searches, 27 oncologists were identified. All 27 oncologists were invited to participate in the oncologist survey. This was initially done by dropping off hard copies of the research materials and covering letter at practices, together with personally addressed surveys for each oncologist. This was done twice to increase participation. In addition, a link to a digital version was circulated via email to all the oncologists through the administration of the different practises, as well as several personal associations within the oncology practitioners' community.

3.2.6 Final study sample

Quantitative data collection commenced in 2019. Once COVID lockdown occurred in 2020, it brought about severe restrictions in access to clinics, patients and oncologists. Ethical permission had to be obtained to complete data collection via digital outreach and survey completion, all of which had to be put into place and which therefore had a large impact on timelines. Patient data collection resulted in 316 participants, consisting of 224 government patients and 92 private patients. Seventy-five of these were acquired from digital completions and the remainder from hard copy surveys. Of the oncologist population targeted, eight declined to participate and 19 responses were obtained. Several repeat calls for participation were made through various channels but did not lead to any further volunteers from either population. Qualitative data collection was conducted throughout 2022 and completed early in 2023.

3.2.7 Limitations in the sampling approach and resulting study population

The sampling approach and the resulting study population have inherent limitations. Non-probability sampling approaches such as convenience and snowball sampling limit the claims that can be made about what the results are actually revealing. Statements about the sample cannot necessarily be extrapolated to the larger target population. Another factor related to sampling is the dual nature of the sources (government and private). This was intentional in order to explore the inherent disparities which are of great relevance in the South African context. However, when combining groups, overall frequencies would be affected. Statistics applied would naturally correct for the discrepancies in patient numbers between the two data sources. Another limiting factor is the small sample size of the oncologist population. In addition, the racial profile of the population is not consistent with the racial distribution of cancer diagnoses in SA. In spite of the limitations outlined above, the research offers valuable insights into some of the current attitudes and practices of both patients and oncologists, and as such forms a valuable exploratory study into TCAM use within the South Africa oncology arena.

3.3 Quantitative Phase

3.3.1 Research tools

Two separate surveys were used for quantitative data collection, one for patients and one for oncologists (see appendices). Development of the questionnaires was guided by literature and suggestions of authors in the field (Quandt *et al.* 2009; Lo Re, Schmidt and Guthlin 2012; Abrams and Weil 2014), with the additional inclusion of questions of interest and relevance to the local context and research study objectives. Variables were mainly nominal/categorical with some ordinal variables such as age and years since diagnosis. A focus group interrogated the questionnaires with a view to adapting and refining questions where necessary. Members for this session consisted of individuals with expertise in the field, staff with research expertise, isiZulu research staff as well as some patients and practitioners. In addition, pilot studies were done for both questionnaires to allow for validation by the statistician.

The patient questionnaire consisted of a total of eighty questions addressing different aspects of demographic, clinical and health seeking behaviour. For the TCAM tables, only the relevant sections for each patient were completed.

Table 3.3.1.1: Outline of patient survey questions.

Category	Number of questions
Demographic information	9
Clinical information	5
Basic health seeking behaviour before and after diagnosis	6
Reporting of TCAM visits and self-help practices	2 tables of 16
Exploring dietary alterations and inclusions	5
Reasons for use and non-use	2
Patient-oncologist communications on TCAM	4
Patient role in healing process	1 table of 9
Patient views on Integrative Oncology	1 table of 8

The oncologist questionnaire consisted of a total of eighty questions incorporating demographic information; information on qualification and clinical practice; opinions of and referral to TCAM practitioners; opinions on the role of nutrition, exercise, supplements, mind and spiritual factors; role of the patient in the healing process, patient-oncologist communications; TCAM training and opinion of Integrative Oncology. Open-ended questions were incorporated to assist in planning the qualitative explorations.

Table 3.3.1.2: Outline of oncologist survey questions.

Category	Number of questions
Demographic data	6
Factors related to training and practise	5
Knowledge, opinion and referral to TCAM practitioners	1 table of 9
Role of Nutrition and supplements in oncology	5 plus 1 table of 10
Role of exercise	1 table of 7
Role of mind and spirit	2 plus 1 table of 7
Patient role in the healing process	1 table of 6
Patient-oncologist communications on TCAM	2 plus 1 table of 6
TCAM and cancer outcomes	Table of 4
TCAM training	5
Views on Integrative Oncology	3

3.3.2 Quantitative phase data analysis

Data was entered into SPSS version 27 and cleaned. The following statistical calculations were done on the data:

- Simple frequency runs were done together with calculation of percentages for these frequencies within each cohort.
- Pearson’s chi-square tests (or Fisher’s exact test if conditions for chi-square are not met) were used to explore the relationships between demographic and clinical variables and the use (or non-use) of various supporting practices.
- McNemar’s test was used to explore changes in health-seeking behaviour occurring with a cancer diagnosis.
- Odds ratios were also used to compare likelihood of use (or non-use) of specific support practices between categories of demographic and clinical variables.
- Binomial tests or Chi-square goodness of fit was used to determine if a significant proportion of respondents selected a particular option from an array of possible options.
- Wilcoxon signed ranks test was used to check for significant agreement/disagreement with statements in Likert scales.

3.3.3 Validity and reliability of the quantitative phase

Validity is the extent to which research measurements (and therefore conclusions) are well-founded and accurate, measuring what they claim to measure and addressing all vital aspects of a particular construct (Heale and Twycross 2015). Ensuring validity in quantitative research requires that the researcher follows well established research procedures. In the case of research that uses a tool such as a questionnaire, it is important that measures are put in place to ensure validity of the tool.

Reliability deals with quality of measurement, and essentially refers to “repeatability” or “consistency” of the measures (Heale and Twycross 2015). The following measures were adopted to ensure validity and reliability:

- Use of well-established research methods.
- Survey tool was based on existing tools and literature. It was interrogated by a focus group of experts for clarity, validity and comprehensiveness (only minor changes suggested). It was also checked for internal consistency by a statistician using Cronbach’s alpha.
- A statistician was consulted to ensure adequate sample sizes.
- A strong audit trail was maintained.

3.4 Qualitative Phase

3.4.1 Qualitative sampling approach and sample size

In the interests of getting multiple stakeholder opinions in the qualitative phase, breast cancer patients and oncologists from both the private and public sectors were invited to participate. The last page of the quantitative surveys, for both the patient and oncologist populations, was an invitation to volunteer to participate in the qualitative phase should they be interested. Ninety-one patients and nine oncologists expressed a willingness to participate in an interview. These volunteers formed the source cohort for the qualitative explorations.

Purposive sampling was utilised in those instances where people had been vocal during the quantitative recruitment and expressed a desire to say more, or where quantitative data suggested cases of varying views that were worth exploring further. This was with a view to obtaining rich data. As part of the reflexive process during the qualitative phase, checks were done to ensure that data was being gathered from patients and oncologists within the private as well as the public sector, and that different races were incorporated. The final sample size was determined by saturation, which was 16 patients and 5 oncologists.

3.4.2 Preparation for the qualitative phase

Both the primary researcher as well as the isiZulu research assistant (responsible for isiZulu patient interviews) utilised qualitative research resources to educate themselves in best practise for conducting semi-structured interviews in a healthcare setting. This was achieved through reading and discussion (Rabionet 2011; Dammak 2015; Brinkmann and Kvale 2018; DeJonckheere and Vaughn 2019; Solarino and Aguinis 2021). The areas covered included basic interview techniques such the utilization of main questions, follow-up questions and probes; the importance of the interviewer-interviewee relationship; ethical considerations (purpose; consequences; consent; confidentiality); interviewing patients; interviewing elite informants; the critical role of reflexivity and upholding integrity throughout qualitative explorations. In addition to striving for best practise, this in-depth discussion was held in order to ensure common approaches, to agree on the core aims and finalise the best format for the interview.

The main domains of enquiry were determined by the primary researcher, based on areas from the quantitative phase that emerged as needed further exploration. The interview guides for both the patient and oncologist populations are presented in the appendices.

3.4.3 The interview process

Interviews were scheduled with each participant, arranging a suitable time and place to ensure focus and privacy. Due to the risks associated with the COVID pandemic, most interviews were conducted telephonically (patients) or electronically via Teams/Zoom (oncologists). Special ethical approval was obtained to conduct the interviews in this manner. Where preferred, arrangements were made for face-to-face interviews with appropriate COVID-19 precautions. Participants were provided with the formal information sheet as well as a verbal explanation of the research. They were made aware of the reasons for the research being conducted, and the potential outcomes of the PhD qualification, publications and conference presentations. They were assured on matters of confidentiality, there being no right or wrong answers to the questions, the thematic nature of reporting findings and the anonymous manner in which findings are supported with quotations. They were also made aware of the intention to record and transcribe the interview and the manner in which this data would be stored. Once recording began, verbal consent for participation as well as recording of the interview was obtained from the participants and then semi-structured interviews were conducted utilising the interview guide. Excluding initial establishing of rapport and research explanations, interviews took between 1 and 1.5 hours each. The audio recordings that were made, were stored in a password-protected folder only accessible to the researcher.

3.4.4 Reflexivity

Personal interviewer reflexivity was included as a vital part of the process after every few interviews. This reflexivity took the form of some written personal reflections and discussions on the process with the main supervisor. Rigour was further sought through meetings of the researcher and research assistant. During these times the interviewers reflected on personal experiences and discussed elements of good practise, striving to improve interview technique and refining approach where necessary. Ethical considerations were also reiterated, including respect for the integrity of knowledge creation, mitigating the influence of any pre-conceptions and bias, and the importance of confidentiality.

The reflexivity of the process was of great importance to the researcher for many reasons. Firstly, as a relatively new researcher growing in the skills of qualitative research with a strong commitment to authentic knowledge creation; secondly as a researcher with PhD aims and objectives that needed to be fulfilled by the process; thirdly as the guardian of the stories shared by the generosity of the participants; and lastly as a double mastectomy breast cancer survivor navigating and controlling the unexpected personal reactions that resulted when revisiting the breast cancer arena in such an immersive way.

It quickly became apparent that patients needed to tell their personal stories as opposed to simply answering a set of questions. As a result of reflexivity, it was determined to allow a relatively free flow of patient narrative. Participants needed to tell their stories, and within that the interviewer needed to ensure the specific domains of enquiry were addressed. Therefore, the interviewer allowed more narrative on the part of the patient and used follow-up probing questions to fill in domain gaps or gain any additional clarity needed.

3.4.5 Data analysis

3.4.5.1 Transcription and translation of recordings

All English transcription was done by the main researcher/PhD candidate. This was both in the interests of confidentiality on the part if the participants and their practitioners, as well as to strengthen the qualitative skills of the researcher and provide more opportunities for immersion in and familiarity with the material. For the isiZulu candidates, the isiZulu research assistant transcribed the interviews in isiZulu after being briefed in the requirements for the transcription process. These transcripts were then translated into English.

Standard (non-verbatim) transcription was utilised for all the interviews with the following being incorporated/utilised: “P” was used to denote a patient participant, “O” an oncologist participant, and “R” denoted the researcher (Whilst qualitative research traditionally uses the term “Participant” for all those consenting to take part in the research, there was the need in this investigation to differentiate between the patient participants and the oncologists participants, hence the use of these terms). False starts were removed from sentences as well as minor researcher comments that interspersed the patient commentary such as “yes”; “OK”, “I understand” “interesting”, “can you tell me more” etc. Square brackets were utilised to show replacement of words. For example, personal names were replaced by role of person or place being referred to such as [oncologist] or [homeopath]; any swear words utilised by participants were replaced by suitable adjectives; missing information was included to make sense of incomplete sentences; and on occasion quotations of conversations were transposed into the third person for the sake of flow. Some grammatical corrections and light editing were done without altering the intended meaning of the events or experiences being related.

The completed transcripts were sent to patient and oncologist participants for member-checking wherever possible in order to enhance rigour and validity. Any deletions, additions or alterations requested by the participants were incorporated into the transcripts.

3.4.5.2 Thematic analysis

Transcripts were imported into NVivo (2020) for thematic analysis. The six-phase approach to thematic analysis, as developed by Braun and Clarke (2006), was then used (Braun and Clarke 2006).

1. Familiarisation with the data. This included personal transcribing, reading, and re-reading the transcripts, whilst noting down some initial ideas for coding.
2. Generating initial codes. This was partially deductive (based on the main domains of enquiry) and partially inductive (emerging out of the reading of the transcripts.
3. Codes collated into potential themes and sub-themes.
4. Themes and sub-themes reviewed against the entire data set, ensuring that critical issues in the data were reflected.
5. Ongoing refinement and defining of themes during analysis of data. In addition to the initial coding tree, when new themes or sub-themes emerged during this process, these were incorporated, and earlier transcripts revisited to check for material that supported these new emergent codes. All coding was done by the researcher, with ongoing reflections and discussions with the supervisor to allow for reflexivity.
6. Producing the report. Extracts of the transcripts were collated and presented under the thematic headings together with commentary.

3.4.6 Trustworthiness of the qualitative phase

Trustworthiness of a study refers to the degree of confidence in the methods, data and data interpretation approaches used. It essentially deals with the rigor of protocols and procedures applied by researchers to ensure quality research worthy of readers consideration (Polit and Beck 2014; Connelly 2016). In 1985, Lincoln and Guba outlined four criteria for qualitative researchers. These included credibility; dependability; confirmability; and transferability (Lincoln and Guba 1985). At a later date the same authors added authenticity (Guba and Lincoln 1994).

3.4.6.1 Credibility

Credibility is a confidence in the truth of the study and its findings (Polit and Beck 2014). It rests on the utilization of well-established qualitative procedures. For the current study, the strategies used to ensure credibility included the following:

- A thorough and lengthy engagement with each participant and recording of the interviews.
- Meticulous transcription and participant checking of transcripts.
- Iterative engagement with the data, together with reflection and reflexivity on the part of the researcher, and supervisor checking of analysis,
- Inclusion of varied points of view and deviant cases, as well as exploring alternate explanations, whilst still seeking data saturation.

3.4.6.2 Dependability

Dependability is the equivalent of reliability in quantitative research. It refers to the stability of data over time (Polit and Beck 2014). As the study was exploring lived experience in the dynamic environment of oncology, it is possible that a future researcher may come up with different results. However, every effort was made to maintain evidence of due process to ensure dependability of the current explorations. Peer debriefing with the supervisor was also done regularly.

3.4.6.3 Confirmability

Confirmability is the degree to which findings are consistent and could be repeated (Polit and Beck 2014). Once again, this was supported through due process, reflexivity, supervisor debriefing, and member checking. Only two researchers collected the data: the principal researcher and one research assistant for the isiZulu participants (who was trained in order to avoid introduction of researcher error).

3.4.6.4 Transferability

Transferability is the extent to which the research findings could be helpful to people in different settings. Qualitative research by nature is documenting participant stories that may not be everybody's story (Connelly 2016). However, by providing clear insights into the context, research setting, and the participants being studied, the researcher strove to strengthen relevance and usefulness for other researchers, oncology patients and oncologists, thus increasing the value of the findings and laying the foundations for similar investigations in different settings.

3.4.6.5 Authenticity

Authenticity is the extent to which researchers realistically and accurately reflect participant realities/experiences, and account for a range of different realities (Polit and Beck 2014). The researcher sought to create a respectful yet relaxed and open rapport with the participants. Participants were reassured that there are no preconceived expectations or correct/incorrect answers. Together with striving for good listening skills, this assisted freedom of expression of the participants. Authenticity was strengthened by allowing as much free narrative as possible during data collection and authenticating the transcripts through participant checking. Rich detailed descriptions and verbatim participant quotes incorporated into thematic reporting added authenticity to the research.

In addition to the measures described above, the Consolidated criteria for reporting qualitative research (COREQ) checklist was utilised throughout the process from planning to completion in order to bring as much rigour to the process as possible.

3.5 Ethical Considerations and Compliance

All aspects of the research were passed through the DUT institutional research ethics committee (IREC) and granted full ethical approval (IREC043/18). When COVID-19 resulted in constraints that required a move to digital methods of qualitative data collection, this was also approved by IREC, and permission was granted to obtain verbal informed consent as part of the interview process. Participants were fully informed as to the purpose, nature and intended output of the research. Participants were given time before and after data gathering to ask any questions or raise any concerns. In addition, every participant was given contact details of the researcher and DUT research office should they need to make contact or any reason after participation. Voluntary participation, informed consent, option to withdraw and confidentiality were carefully considered and upheld at every stage of the research process.

Confidentiality was maintained by a variety of strategies. For the quantitative phase, voluntary consent included names and participant numbers, but only participant numbers were included on the completed questionnaires, which were filed separately in secure storage. For the qualitative stage, digital recordings were saved in password protected files, and all transcription only done by the researcher and (in the case of isiZulu interviews), the isiZulu research assistant. Research numbers replaced names in the transcriptions and confidentiality was also upheld in reporting by using these numbers when quoting exemplars. Digital and hard copies of research to be destroyed after five years.

3.6 Summary of Chapter 3

This chapter presented the choice of research design as well as the paradigm underpinning the research, offering reasons that substantiated the choices made. It described the details of the chosen methodology of both the quantitative and qualitative phases of the research, including sampling, tools, and data analysis. The chapter also addressed matters of validity and reliability of the quantitative phase, the trustworthiness of the qualitative phase, and matters of ethical compliance.

4. PATIENT QUANTITATIVE RESULTS

In this chapter, demographic and clinical data of the patient sample will be presented, followed by data on their reported health-seeking practices. Due to the disparities in patient access to health care in South Africa, results will incorporate separate frequencies for patients from the government sector (GOV) and the private sector (PVT) as well as the total sample (TOT). In addition, due to the multicultural nature of the South African population, some data will be explored by racial groups with a view to discovering whether there are different patterns of use associated with different race groups. The chapter will go on to explore other possible associations between demographic and clinical data, and the use (or non-use) of various complementary practices. It will end by presenting data of patient responses to questions probing aspects of lived experience with respect to additional supporting practices.

4.1 Sociodemographic and Clinical Profiles of Patient Sample

4.1.1 Sociodemographic profile of patient sample

A total of 316 breast cancer patients fulfilled the inclusion criteria and consented to participate in the study. The greater proportion of these (70.89%; n = 224) were patients attending the oncology clinic at Inkosi Albert Luthuli Central Hospital, which is the main government-funded cancer clinic in eThekwini. The remaining patients (29.11%; n = 92) were attending private oncology clinics across eThekwini. Of the 316 participants, 162 were Black; 9 were Coloured (mixed race); 72 were Indian; and 73 were White. The socio-demographic profile of the patient sample is presented in table 4.1.1 below. There is a spread of ages from women in their 20’s to women in their 80’s, with the largest frequencies falling between the ages of 40 and 69. Different religions are represented with the largest number of patients (n=258) identifying as Christian. As expected, the socio-economic divide is evident between the different cohorts (government vs private). Treatment centre was found to be significantly related to race (Black vs others); education (school vs degree); employment (unemployed vs employed); and income (<5000 vs >5000), amongst others ($p<.001$). Thus, treatment centre also represents a suitable summary variable and a measure of disparate socio-economic profiles.

Table 4.1.1: Socio-demographic profile of patient sample (frequencies with percentages of each cohort: government; private and total sample)

GOV = government hospital PVT = Private oncology clinic TOT = Totals	**GOV** *n* (%)	**PVT** *n* (%)	**TOT** *n* (%)
Patient cohort numbers	224	92	316
Age			
20-29	5 (2.2)	0 (0)	5 (1.6)
30-39	24 (10.7)	4 (4.3)	28 (8.9)
40-49	60 (26.8)	21 (22.8)	81 (25.6)
50-59	65 (29.0)	31 (33.7)	96 (30.4)
60-69	50 (22.3)	18 (19.6)	68 (21.5)
70-79	19 (8.5)	14 (15.2)	33 (10.4)
80-89	1 (0.4)	4 (4.4)	5 (1.6)
Patient total	224	92	316
Religion			
Atheist and Agnostic	0 (0)	8 (8.70)	8 (2.5)
Christian	197 (88.0)	61 (66.3)	258 (81.7)
Hindu	20 (8.9)	13 (14.1)	33 (10.44)
Muslim	7 (3.1)	6 (6.5)	13 (4.1)
Patient total	224	92	316
Race			
Black	155 (69.2)	7 (7.6)	162 (51.3)
Coloured	4 (1.8)	5 (5.4)	9 (2.8)
Indian	46 (20.5)	26 (28.3)	72 (22.8)
White	19 (8.5)	54 (58.7)	73 (23.1)
Patient total	224	92	316
Highest level of education			
No formal schooling	14 (6.3)	0 (0)	14 (4.4)
Primary school	55 (24.6)	0 (0)	55 (17.4)
Secondary school	124 (55.4)	19 (20.7)	143 (45.3)
Apprenticeship/trade certificate	6 (2.7)	4 (4.3)	10 (3.2)
University undergraduate/diploma	23 (10.3)	48 (52.2)	71 (22.5)
University postgraduate	2 (0.9)	21 (22.8)	23 (7.3)
Patient total	224	92	316
Marital status			
Single	75 (33.5)	9 (9.8)	84 (26.5)
Permanent relationship/marriage	110 (49.1)	64 (69.6)	174 (55.1)
Divorced	9 (4.0)	10 (10.9)	19 (6)
Widowed	30 (13.4)	9 (9.8)	40 (12.6)
Patient total	224	92	316
Employment status			
Unemployed	66 (29.5)	9 (9.8)	75 (23.7)
Housewife/home maker	16 (7.1)	4 (4.3)	20 (6.3)
Self-employed	12 (5.4)	16 (17.4)	28 (8.9)
Employed	41 (18.3)	35 (38.0)	76 (24.1)
On Pension	89 (39.7)	28 (30.4)	117 (37.0)
Patient total	224	92	316
Combined monthly income			
R1- R1 500-00	47 (21.0)	1 (1.1)	48 (15.2)
R1 501-R5 000	143 (63.8)	5 (5.4)	148 (46.8)
R5 001-R10 000	16 (7.1)	13 (14.1)	29 (9.2)
R10 001- R20 000	16 (7.1)	9 (9.8)	25 (7.9)
R20 001- R40 000	2 (0.9)	37 (40.2)	39 (12.3)
More than R40 000	0	27 (29.3)	27 (8.5)
Patient total	224	92	316
World view			
Scientific/practical	21 (9.4)	16 (17.4)	37 (11.7)
Spiritual	29 (12.9)	15 (16.3)	44 (13.9)
Mix of both	174 (77.6)	61 (66.3)	235 (74.4)
Patient total	224	92	316

4.1.2 Clinical profile of patient sample

Aspects related to the clinical profile of the breast cancer patient sample are shown in table 4.1.2, including years since diagnosis; spread; and mainstream treatments received. Also included in Table 4.1.2 are frequencies of health-seeking choices (mainstream; TCAM; or mix of both) that patients reported having *before* being diagnosed with cancer, indicating 82% of government patients and 59% of private patients having chosen mainstream biomedical treatments exclusively before diagnosis.

Table 4.1.2: Clinical profile of the patient sample (frequencies with percentages of each cohort: government; private and total sample)

GOV = government hospital PVT = Private oncology clinic TOT = Total of both cohorts	**GOV** *n* (%)	**PVT** *n* (%)	**TOT** *n* (%)
Patient cohort numbers	224 (71)	92 (29)	316 (100)
Years since diagnosis			
Less than a year	27 (12.05)	6 (6.52)	33 (10.44)
1 Year	107 (47.77)	13 (14.13)	120 (37.98)
2 years	42 (18.75)	24 (26.09)	66 (20.89)
3 years	19 (8.48)	13 (14.13)	32 (10.13)
4 years	7 (3.13)	11 (11.96)	18 (5.69)
5 years	6 (2.68)	9 (9.78)	15 (4.75)
5-9 years	8 (3.57)	6 (6.52)	14 (4.43)
10-19 years	5 (2.23)	8 (8.70)	13 (4.11)
20+ years	3 (1.34)	2 (2.17)	5 (1.58)
Had remission followed by relapse.			
No	211 (94.20)	70 (76.09)	281 (88.92)
Yes	13 (5.80)	22 (23.91)	35 (11.08)
Spread			
I do not know	29 (12.9)	2 (2.2)	31 (9.8)
Only in my breast	81 (36.2)	57 (62.0)	138 (43.67)
Found in my lymph nodes	74 (33.0)	30 (32.6)	104 (32.91)
Found in other organs	40 (17.9)	3 (3.3)	43 (13.61)
Mainstream Treatments received.			
Lumpectomy	57 (25.4)	25 (27.17)	82 (25.95)
Mastectomy	80 (35.7)	48 (52.17)	128 (40.51)
Double mastectomy	4 (1.80)	19 (20.65)	23 (7.28)
Radiation therapy	71 (31.70)	62 (67.39)	133 (42.09)
Chemotherapy	183 (81.70)	53 (57.60)	236 (74.68)
Hormone-suppressing injections (e.g. Zoladex®)	8 (3.57)	21 (22.82)	29 (9.18)
Hormone-blocking tablets	91 (40.63)	56 (60.87)	147 (46.52)
Health seeking choices before diagnosis			
Mainstream	184 (82.1)	54 (58.7)	238 (75.3)
TCAM	4 (1.8)	2 (2.2)	6 (1.9)
A combination of both	36 (16.1)	36 (39.1)	72 (22.8)
Delaying mainstream to try TCAM.			
Yes	11 (4.9)	2 (2.2)	13 (4.1)
No	213 (95)	90 (98)	303 (96)

4.2 Current Health-Seeking Behaviour

This section will present reported use of supporting therapies or approaches by the patient sample during their cancer journeys. We cannot assume that all additional therapy use was directly related to the patients' cancer. However, in seeking health and wellbeing, patients were nonetheless using these additional approaches whilst on mainstream oncology treatment. These figures therefore still provide valuable insights into cancer patients' health-seeking behaviour.

The section will begin by presenting data on the use of lifestyle factors and self-help practices by patients. This will include dietary approaches and supplementation; exercise and mind-body practices; as well as emotional and spiritual support practices (4.2.1). It will then go on to present reported use of visits to TCAM practitioners (4.2.2). In the interests of providing the necessary insight into usage percentages within government and private cohorts, all data will first be presented as simple frequencies with percentages showing proportions of the cohorts (government; private and total sample) using the approach. Thereafter, findings of Chi Square and McNemar's tests used to explore relationships between use of supporting practices and treatment centre (government / private), or race will be presented. All data is a cross-sectional snapshot, providing insights into the practices by patients within the sample population at the time of the survey. The study does not claim to represent the choices of the broader breast cancer population, or to account for the complexities of the numerous factors that might be associated with such use.

4.2.1 The use of lifestyle factors to support healing and wellbeing

4.2.1.1 Frequencies of lifestyle and self-help practices

The reported use of lifestyle and self-help practices by the patient sample are outlined in table 4.2.1.1 (reported as frequencies of use for government cohort, private cohort, and total sample together with percentages of each cohort using each approach). It is worth noting that about half of the patient sample (52.85%) are utilising dietary approaches and one third (30.06%) are utilising supplements. Reflected separately due to its rising significance in oncology circles, is the use of cannabis oil, self-reported at 13.61 % in this sample (excluding 2 government patients who reported drinking cannabis tea). Use of exercise was 31%. Use of psychological support systems was low at 8.86% whilst use of personal prayer was high at 85.44%.

Table 4.2.1.1: Reported frequencies of lifestyle and self-help practices of patients. Percentages are column percentages, indicating the proportion of that cohort (government, private or total) using the approach.

GOV = government hospital (224 participants) PVT = Private oncology clinic (92 participants) TOT = Totals (316 participants)	**GOV** *n* (%)	**PVT** *n* (%)	**TOT** *n* (%)
Diet and supplementation			
Dietary approaches	105 (46.88)	62 (67.39)	167 (52.85)
Use of supplements	46 (20.54)	49 (53.26)	95 (30.06)
Cannabis oil	17 (7.59)	26 (28.26)	43 (13.61)
Exercise and mind-body practices			
Exercise intervention	37 (16.52)	62 (67.39)	99 (31.33)
Yoga	2 (0.89)	19 (20.65)	21 (6.65)
Tai Chi	1 (0.5)	1 (1.09)	2 (0.63)
Relaxation Techniques	-	16 (17.39)	16 (5.06)
Meditation	1 (0.5)	29 (31.52)	30 (9.49)
Visualization	-	8 (8.70)	8 (2.53)
Emotional and spiritual support			
Spiritual healing ceremony/rite	16 (7.14)	6 (6.52)	22 (6.96)
Spiritual prophet	8 (3.57)	1 (1.09)	9 (3.09)
Prayer	205 (91.52)	65 (70.65)	270 (85.44)
Psychological counselling	8 (3.57)	20 (21.74)	28 (8.86)
Support Group	9 (4.02)	29 (31.52)	38 (12.02)
Music or art therapy	4 (1.79)	13 (14.13)	17 (5.38)

4.2.1.2 Relationship between treatment centre and incorporation/non-incorporation

Pearson’s chi-square (or Fisher’s exact test, where necessary) were then used to explore the relationship between treatment centre (government or private) and the incorporation or non-incorporation of specific lifestyle and self-help practices. Results are presented in table 4.2.1.2 below. For many practices, a significant proportion of the patients who *did not* incorporate them were from the government sector whereas a significant proportion of the patients who *did* include them were from the private sector. These results are best understood in the light of the disparate socio-economic factors associated with these two cohorts.

Practices with a significant proportion of non-inclusion by patients at the government facility included dietary approaches; use of supplements; exercise; meditation; and support groups. This same cohort of patients accounted for a significant proportion of those patients who included prayer approaches. Practices with a significant proportion of inclusion by patients at a private facility included dietary approaches; use of supplements; use of cannabis; exercise; yoga; relaxation techniques; meditation; visualization; counselling; support groups; and art or music therapy.

Table 4.2.1.2: Chi square results for inclusion (YES) and non-inclusion (NO) of self-help practices related to treatment centre (government vs private). Expressed as frequencies and row percentages. Categories in which a significant number of patients fall are in bold.

Self-help practices	Use after diagnosis	Frequency (Row %)		Chi square	*df*	p-value
		GOV	PVT			
Dietary approaches	NO	**119(79.9)**	30 (20.1)	11.016	1	**<.001**
	YES	105(62.9)	**62(37.1)**			
Use of supplements	NO	**178(80.5)**	43(19.5)	33.218	1	**<.001**
	YES	46(48.4)	**49(51.6)**			
Cannabis oil	NO	207(75.8)	66(24.2)	23.705	1	**<.001**
	YES	17(39.5)	**26(60.5)**			
Exercise	NO	**187(86.2)**	30(13.8)	78.453	1	**<.000**
	YES	37(37.4)	**62(62.6)**			
Yoga	NO	222(75.3)	73(24.7)	41.042	1	**<.001**
	YES	2(9.5)	**19(90.5)**			
Tai Chi	NO	223(71.0)	91(29.0)	.425	1	1.000
	YES	1(50.0)	1(50.1)			
Relaxation techniques	NO	224(74.7)	76(25.3)	Fisher's	1	**<.001**
	YES	0(0)	**16(100)**			
Meditation	NO	**223(78.0)**	63(22.0)	73.294	1	**<.001**
	YES	1(3.3)	**29(96.7)**			
Visualization	NO	224(72.7)	84(27.3)	Fisher's	1	**<.001**
	YES	0(0)	**8(100)**			
Spiritual prophet	NO	216(70.4)	91(29.6)	1.455	1	.293
	YES	8(88.9)	1(11.1)			
Spiritual healing rite	NO	209(70.8)	86(29.2)	.003	1	1.000
	YES	15(71.4)	6(28.6)			
Prayer	NO	19(41.3)	**27(58.7)**	22.828	1	**<.001**
	YES	205(75.9)	65(24.1)			
Psychological counselling	NO	216(75)	72(25)	26.655	1	**<.001**
	YES	8(28.6)	**20(71.4)**			
Support group	NO	**215(77,3)**	63(22.7)	46.632	1	**<.001**
	YES	9(23.7)	**29(76.3)**			
Music/art therapy	NO	220(73.3)	80(26.7)	Fisher's	1	**<.001**
	YES	4(25)	**12(75)**			

4.2.1.3 Additional insights into the use of dietary approaches

As diet and supplements are some of the most widely utilised lifestyle approaches in health and healing, the investigation into these aspects by the current sample was expanded. Table 4.2.1.3 below shows the number of patients who reported utilizing specific dietary adjustments and supplement inclusions which give insight into the approach of patients when seeking to support healing through diet and supplementation. Some of the practices adopted included “greatly reduced” intake of sugar (44.3%); red meat (26.9%) and processed foods (27.53%) whilst greatly increasing vegetables (35.76), reflecting a desire to generally make healthier choices regarding diet. The most utilised supplements were multivitamins (24.37%) and vitamin D (11.39%), but there was also use of omegas (9.81%); antioxidant tablets (8.54%); antioxidant teas (9.17%); and 9 patients who had used high-dose vitamin therapy.

Table 4.2.1.3 Dietary adjustments and supplement use expressed as frequencies for each cohort (government; private and total sample). Column percentages are proportions of each cohort using the practice.

GOV = government hospital (224 participants) PVT = Private oncology clinic (92 participants) TOT = Totals (316 participants)	**GOV** *n* (%)	**PVT** *n* (%)	**TOT** *n* (%)
Dietary adjustments made			
Juicing	19 (8.48)	33 (35.87)	52 (16.46)
Greatly reduced sugar intake	82 (36.6)	58 (63.04)	140 (44.30)
Greatly reduced red meat	51 (22.77)	34 (36.96)	85 (26.90)
Greatly reduced carbs	22 (9.82)	39 (42.39)	61 (19.30)
Greatly reduced dairy	12 (5.36)	20 (21.74)	32 (10.13)
Increased fruit & vegetables	53 (23.66)	60 (65.22)	113 (35.76)
Choose organic foods	8 (3.57)	34 (36.96)	42 (13.29)
Greatly reduced processed	36 (16.07)	51 (55.43)	87 (27.53)
Greatly reduced alcohol	6 (2.68)	38 (41.30)	44 (13.92)
Supplements utilised			
Multivitamin	40 (17.86)	37 (40.22)	77 (24.37)
High dose vitamin therapy	2 (0.89)	7 (7.61)	9 (2.85)
Antioxidant	6 (2.68)	21 (22.83)	27 (8.54)
Omegas	1 (0.45)	30 (32.61)	31 (9.81)
Green tea/Essiac tea	7 (3.12)	22 (23.91)	29 (9.17)
Folic acid/Folate	5 (2.23)	7 (7.61)	12 (3.80)
Alkalinising powder/bicarb	5 (2.23)	14 (15.22)	19 (6.01)
Additional Vitamin D	4 (1.79)	32 (34.78)	36 (11.39)
IC3(Indole-3-Carbinol)	2 (0.89)	5 (5.43)	7 (2.22)

In addition to those patients who had utilised dietary adjustments, there were others who indicated that they had wanted to alter their diet but were constrained by financial factors (n= 19; 6%). Only 7.27% (n=23) stated that they did not believe there was a link between diet and cancer. Of the patients attending the government facility, only 1% (n = 3) had consulted a dietician to get guidance on how to eat to assist health and healing in cancer, whereas 27% (n = 25) of the patients attending the private practices had done so. Also of interest is the figures of patients receiving genetic testing for food allergies/intolerances as part of an approach to health after diagnosis. Out of the patients attending the government facility, 1% (n = 3) had these tests done whereas 15% (n = 14) private patients had utilised this dietary investigation.

4.2.2 Patient visits to TCAM practitioners

4.2.2.1 Frequencies of TCAM practitioner visits (government, private and total sample)

Patient reporting on visits to different types of TCAM practitioners is outlined as frequencies in table 4.2.2.1. When presented for each different kind of practitioner, the figures are relatively low, but using binary scores for use or non-use of a TCAM practitioner (1 or 0), it is seen that 30 (13.4%) government patients and 49 (53.3%) private patients reported visiting at least one TCAM practitioner. African traditional healers were the highest frequency of TCAM consultations reported by government sector patients, whilst massage; chiropractor and homeopath were the highest in the private sector. A wider variety of practitioners was consulted by private patients. It is important to keep in mind that disclosure of use is problematic in patients using complementary therapies, especially for practitioners such as African traditional healers (with disclosure reported in this study at zero percent. See 4.2.6). This was also potentially confounded by researcher-assisted completion which was necessary for many patients at the government facility. Therefore, the figures below represent what is reported and use could potentially be higher.

Table 4.2.2.1: Frequencies of patients reporting use of different TCAM practitioners. Reported as frequencies for each cohort (government, private and total sample). Percentages show proportion of that cohort using the practitioner.

GOV = government hospital (224 participants) PVT = Private oncology clinic (92 participants) TOT = Totals (316 participants)	**GOV** *n* (%)	**PVT** *n* (%)	**TOT** *n* (%)
TCAM practitioner use			
Acupuncture	1 (0.5)	6 (6.52)	7 (2.22)
Aromatherapy	-	9 (9.78)	9 (2.85)
Ayurveda	1 (0.5)	2 (2.17)	3 (0.95)
BodyTalk	-	7 (7.61)	7 (2.22)
Chinese Medicine	3 (1.34)	1 (1.09)	4 (1.27)
Chiropractic	2 (0.89)	17 (18.48)	19 (6.01)
Homeopathy	1 (0.5)	15 (16.3)	16 (5.06)
African traditional	21 (9.38)	-	21 (6.65)
Iridology	-	1 (1.09)	1 (0.32)
Kinesiology	-	2 (2.17)	2 (0.63)
Massage therapy	-	27 (29.35)	27 (8.54)
Naturopathy	-	6 (6.52)	6 (1.90)
Physiotherapy	2 (0.89)	1 (1.09)	3 (0.95)
Reflexology	-	6 (6.52)	6 (1.90)
Reiki	1 (0.5)	4 (4.35)	5 (1.60)
Binary scores 1 or 0 for use/non-use of at least 1	30 (13.4)	49 (53.3)	79 (25)

4.2.2.2 Relationship between treatment centre and use of at least one TCAM practitioner

The relationship between treatment centre (government or private) and binary data (0/1) for consulting with a TCAM practitioner was explored using a Pearson's chi-square test. Results showed that a significant proportion (86.6%) of patients from the government facility did *not* consult any TCAM practitioners, while a significant proportion (53.3%) of patients from the private facilities *did* consult at least one TCAM practitioner (χ^2 (1) = 42.404, p <.001).

4.2.2.3 Relationship between treatment centre and use of specific TCAM specialities

Pearson's chi-square (or Fisher's exact test, where necessary) were used to explore the relationship between use of specific TCAM practitioners and treatment centre (government or private). These percentages are presented in table 4.2.2.3 below. There is a significant association between government patients and the use of traditional healers. There are also significant associations between private patients and the use of several different TCAM practitioners including acupuncture; aromatherapy; chiropractic; homeopathy; massage and naturopathy.

Table 4.2.2.3: Chi-square results for TCAM practitioner vs treatment centre. Significant associations are highlighted in bold.

TCAM practitioner	Use after diagnosis	Row %		Chi square	*df*	p-value
		GOV	PVT			
Acupuncture	NO	72.2%	27.8%	#	1	**.003**
	YES	14.3%	**85.7%**			
Aromatherapy	NO	73.0%	27.0%	#	1	**<.001**
	YES	0%	**100%**			
Ayurveda	NO	71.2%	28.8%	#	1	.204
	YES	33.3%	66.7%			
BodyTalk	NO	72.5%	27.5%	#	1	**<.001**
	YES	0%	**100%**			
Chinese	NO	70.8%	29.2%	#	1	1.000
	YES	75.0%	25.0%			
Chiropractic	NO	74.7%	25.3%	35.688	1	**<.001**
	YES	10.5%	**89.5%**			
Homeopathy	NO	74.3%	25.7%	#	1	**<.001**
	YES	6.3%	**93.8%**			
African traditional	NO	68.8%	31.2%	9.239	1	**.002**
	YES	**100%**	0%			

Table 4.2.2.3 continued: Chi-square results for TCAM practitioner vs treatment centre. Significant associations are highlighted in bold.

TCAM practitioner	Use after diagnosis	Row %	Chi square	*df*	p-value	TCAM practitioner
Iridology	NO	71.1%	28.9%	#	1	.291
	YES	0%	100%			
Kinesiology	NO	71.3%	28.7%	#	1	.084
	YES	0%	100%			
Massage	NO	**77.5%**	22.5%	71.881	1	**<.001**
	YES	0%	**100%**			
Naturopathy	NO	72.3%	27.7%	#	1	.001
	YES	0%	**100%**			
Reflexology	NO	72.3%	27.7%	#	1	.001
	YES	0%	**100%**			
Reiki	NO	71.7%	28.3%	#	1	**.027**
	YES	20%	**80%**			
Physio	NO	70.9%	29.1%	#	1	1
	YES	66.7%	33.3%			

 # Fisher's exact test

4.2.2.4 Pre-diagnosis health-seeking behaviour and use of TCAM practitioner post diagnosis

Results of a Fisher's exact test also showed a significant relationship between a patient using TCAM as part of their health seeking behaviour before diagnosis (clinical profile data) and binary data for TCAM practitioner consultation after diagnosis (Fisher's = 39.198, p<.001). A significant proportion of those who chose only mainstream treatments before diagnosis, did not visit a TCAM practitioner after diagnosis; while a significant proportion of those who chose TCAM modalities or a mixture of TCAM and mainstream before diagnosis, included TCAM practitioner consultation/s after diagnosis.

4.2.2.5 Changes in TCAM practitioner visits before and after diagnosis

Using data for patient consultations with specific TCAM practitioners before and after diagnosis, McNemar's test was applied to determine if there were any significant changes in TCAM practitioner consultations from before to after diagnosis. Results showed a significant increase (95% level) in the proportion of patients using traditional healers/inangas (p = .031) and massage therapists (p = .008); and a marginally significant increase (90% level) in the proportion of patients using chiropractors (p = .063), homeopaths (p = .063) and naturopaths (p = .063).

4.2.2.6 Frequencies of reported use of specific TCAM practitioners by race

Frequencies of TCAM practitioner use by the different race groups are presented in table 4.2.2.6 below. The majority of the patients reporting use of the various TCAM practitioners were from the White participants whilst the lowest reporting of TCAM practitioner use was seen in the Black cohort. African traditional healers were the most utilised TCAM practitioners amongst Black participants and massage therapy the most utilised by the non-Black patient participants.

Table 4.2.2.6: Frequencies of patients reporting use of different types of TCAM practitioners by race. Percentages are the proportion of that specific race group using the therapy.

Participants by race group: Black = 162; Coloured = 9; Indian = 72; White = 73	Black *n* (%)	Coloured *n* (%)	Indian *n* (%)	White *n* (%)
TCAM practitioners				
Acupuncture	-	1 (11.11)	1 (1.39)	5 (6.89)
Aromatherapy	-	1 (11.11)	5 (6.94)	3 (4.11)
Ayurveda	-	-	3 (4.17)	-
BodyTalk	-	-	2 (2.78)	5 (6.89)
Chinese Medicine	3 (1.85)	-	-	1 (1.37)
Chiropractor	-	2 (22.22)	4 (5.56)	13 (17.81)
Homeopath	1 (0.62)	-	3 (4.17)	12 (16.44)
African traditional	21 (12.96)	-	-	-
Iridologist	-	-	-	1 (1.37)
Kinesiology	-	-	-	2 (2.74)
Massage therapy	1 (0.62)	3 (33.33)	10 (13.89)	13 (17.81)
Naturopath	-	-	1 (1.39)	5 (6.89)
Physiotherapy	-	-	-	3 (4.11)
Reflexology	-	-	3 (4.17)	3 (4.11)
Reiki healer	-	-	2 (2.78)	3 (4.11)
Other (Quantum med and live blood analysis)	-	-	-	3 (4.11)

4.2.2.7 Significant relationships between race and the use of specific TCAM practitioners

Results of Fisher's exact test (no table included) showed that there is a significant relationship between race and the use of certain TCAM practitioners. A significant proportion of Black patients consulted traditional healers (Fisher's 23.099, p < .001); a significant proportion of Indian patients used ayurveda (Fisher's = 10.258, p = .040); and a significant proportion of White patients used homeopathy (Fisher's 23.607, p <.001). In addition, a significant proportion of Coloured and White patients visited an acupuncturist (Fisher's = 15.322, p = .003); a significant proportion of Coloured and Indian patients visited an aromatherapist (Fisher's = 15.451, p = .003); a significant proportion of White patients utilised BodyTalk (Fisher's = 12.606, p = .014); and a significant proportion of Coloured and White patients used a chiropractor (Fisher's = 34.076, p<.001).

4.2.3 Examining merged TCAM categories

This section was included to examine frequencies and significant differences using merged categories, where similar practices were grouped into a single category. For this exercise, various lifestyle and self-help practices were merged as follows: dietary approaches and supplement use; different forms of exercise; different forms of relaxation activities; psychologist and support group; and different forms of spiritual activities. For visits to TCAM practitioners, those doing external treatments were merged separately from those administering remedies to be taken internally. African traditional healers were however kept separate due to patterns seen in the initial exploratory statistics. Binary scores were utilised with a score of 1 being for use of one or more practices in the merged category (irrespective of how many), and a score of 0 being for non-use.

4.2.3.1 Frequencies of binary scores for merged categories

Frequencies of binary scores for the merged categories are laid out for the two main cohorts (government and private) in table 4.2.3.1.1 and 4.2.3.1.2 below, together with p-values and odds ratios (OR) from Pearson's Chi-square tests. Table 4.2.3.1.1 shows comparisons for lifestyle and self-help practices, whilst table 4.2.3.1.2 shows comparisons for TCAM practitioner consultations. All merged categories show significantly different usage between the government and private cohorts.

Table 4.2.3.1.1: Frequencies of patients utilising support practices (merged categories). Percentages indicate proportion of patients from that cohort using that merged category.

Self-help practice	**GOV n(%)** [3]	**PVT n(%)** [3]	**p-value** [1]	**OR [95% CI]** [2]
Diet and supplements	127 (56.7)	70 (76.1)	.001	2.430 [1.41; 4.20]
Cannabis	17 (7.6)	26 (28.3)	<.001	4.797 [2.45; 9.39]
Exercise approaches	38 (17.0)	65 (70.7)	<.001	11.784 [6.67; 20.80]
Relaxation techniques	5 (2.2)	42 (45.7)	<.001	36.792 [13.85; 97.72]
Spiritual support	207 (92.4)	65 (70.7)	<.001	.198 [.10; .39]
Psychological support	16 (7.1)	41 (44.6)	<.001	10.451 [5.44; 20.10]

[1] Pearson's chi-square test.

[2] Odds ratio reflects the odds of a PVT patient using a self-help practice when compared to a GOV patient.

[3] Values reflect numbers who do the self-help practice and % within GOV/PVT.

African traditional healer and spiritual approaches were the only categories that had odds ratios below 1 (private patients less likely than government patients to use these approaches). The odds ratios for all other approaches showed that patients in the private facilities were more likely to use them: 2.5 times more likely to use diet and supplements; almost 5 times more likely use cannabis; 12 times more likely to incorporate exercise; 37 times more likely to use relaxation techniques; and 10 times more likely to use psychological support. With respect to consultations with TCAM practitioners, private patients are 40 times more likely to consult TCAM practitioners who use external treatments and 7 times more likely to consult TCAM practitioners who prescribe medication for ingestion (excluding African traditional healers).

Table 4.2.3.1.2: Frequencies of patients utilising TCAM consultations (merged categories). Percentages indicate proportion of patients from that cohort using that merged category.

TCAM practitioner		**GOV n(%)** [3]	**PVT n(%)** [3]	**p-value** [1]	**OR [95% CI]** [2]
All TCAM practitioner consults		30 (13.4)	49 (53.3)	<.001	7.369 (4.20; 12.92]
Separated to sub-groups	African Traditional Healer	21 (9.4)	0 (0)	.002	-
	Involving External treatment	5 (2.2)	44 (47.8)	<.001	40.150 [15.13; 106.58]
	Involving Ingested medication	6 (2.7)	15 (16.3)	<.001	7.078 [2.65; 18.89]

[1] Pearson's chi-square test

[2] Odds ratio reflects the odds of a PVT patient using a TCAM practitioner when compared to a GOV patient.

[3] Values reflect numbers who consult a TCAM practitioner and % within GOV/PVT

4.2.3.2 Significant relationships between treatment centre and merged TCAM categories

Pearson's chi-square tests were done to explore possible significance between use or non-use of these merged categories and treatment centre (government or private). These are presented in table 4.2.3.2 below. It is striking to note the significant relationships (indicated in bold) between *use* and *private centres*; whilst also noting the significant relationships between *non-use* and the *government centre*. Use is significantly related to the private centres for all categories except spiritual activities; whilst non-use is significantly related to the government centre for all except 2 of the merged categories (cannabis use and spiritual support activities).

Table 4.2.3.2: Chi square results comparing relationship between treatment centre (government or private) and use of merged categories. Significant associations in bold.

Support activities by patient	Use after diagnosis	Row %		Chi square	*df*	p-value
		GOV	PVT			
TCAM practitioner	NO	**86.6%**	13.4%	Pearson's 55.284	1	**<.001**
	YES	46.7%	**53.3%**			
Diet and/or supplements	NO	**81.5%**	18.5%	Pearson's 10.445	1	**.001**
	YES	64.5%	**35.5%**			
Cannabis	NO	75.8%	24.2%	Pearson's 23.705	1	**<.001**
	YES	39.5%	**60.5%**			
Exercise approaches	NO	**87.3%**	12.7%	Pearson's 85.558	1	**<.001**
	YES	36.9%	**63.1%**			
Psychological support	NO	**80.3%**	19.7%	Pearson's 61.775	1	**<.001**
	YES	28.1%	**71.9%**			
Relaxation /stress reduction activities	NO	**81.4%**	18.6%	Pearson's 97.108	1	**<.001**
	YES	10.6%	**89.4%**			
Spiritual support activities	NO	38.6%	**61.4%**	Pearson's 25.761	1	**<.001**
	YES	76.1%	23.9%			

4.2.4 Cumulative totals for individual patients

In addition to the analysis presented in the tables above, cumulative totals of use were also calculated for each patient, in which they were allocated one point *for every supporting practice reported*. Supporting practices included in this score were TCAM practitioner visits (each different one given a score of 1); use of dietary approaches; use of supplements; use of cannabis oil or smoking cannabis; massage therapy; yoga; tai chi; other exercise activities; relaxation techniques; art therapy; psychologist consultations; support groups; healing rite; other spiritual support. The scores ranged between zero and fourteen for individual patients. Frequencies of the various scores from zero to 14 are presented in Figure 4.2.4 below.

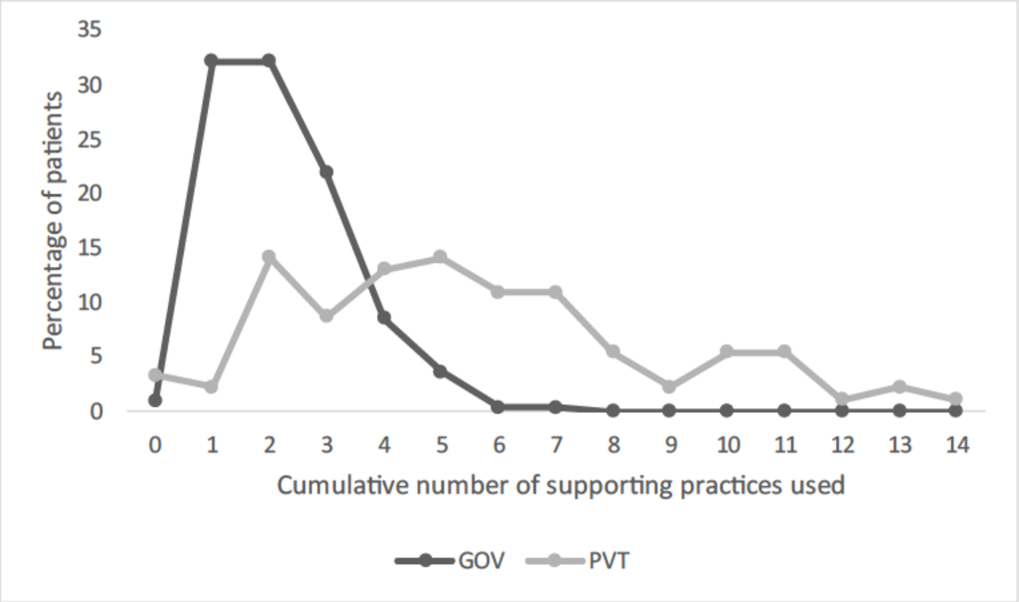


Figure 4.2.4: Cumulative totals of the use of supporting practices. Shown as percentage of patients using that number of practices in each cohort (government and private).

This graph shows that, for the government sector patients, supporting practices are restricted to between 1 and 4 different practices for most patients. Other data suggest that for most of these participants, these practices are likely to be spiritual activities and dietary approaches with some patients utilising cannabis, supplements and/or visiting alternate practitioners. By comparison, many private sector patients are using a larger number of supporting practices, with some participants reporting using as many as 10-14 supporting practices.

4.2.5 Sources of information utilised by patients in deciding to utilise and selecting complementary practices

When reporting use of complementary practices, patients were asked for the source/s they used to get their information. This was done by presenting them with a list of 13 possible reasons and asking them to select all the sources they utilised. 172 participants answered this question (104 government sector patients and 68 private sector patients) and results are presented in figure 4.2.5 below. All results are expressed as a proportion of those answering the question in each cohort. Percentages above brackets reflect the proportion of all question respondents (n=172) utilising that source of information in decision making. The most highly cited sources of information are family (reported by 42% of those who answered this question); friends (40%); childhood use (35%); Internet (24%); fellow patients (21%); and oncologists (19%). It is of interest to note that friends and family were cited as sources of information on supporting practices by double the number of patients who cited oncologists. For government patients, fellow patients at 21% were cited twice as often as oncologists at 10%.

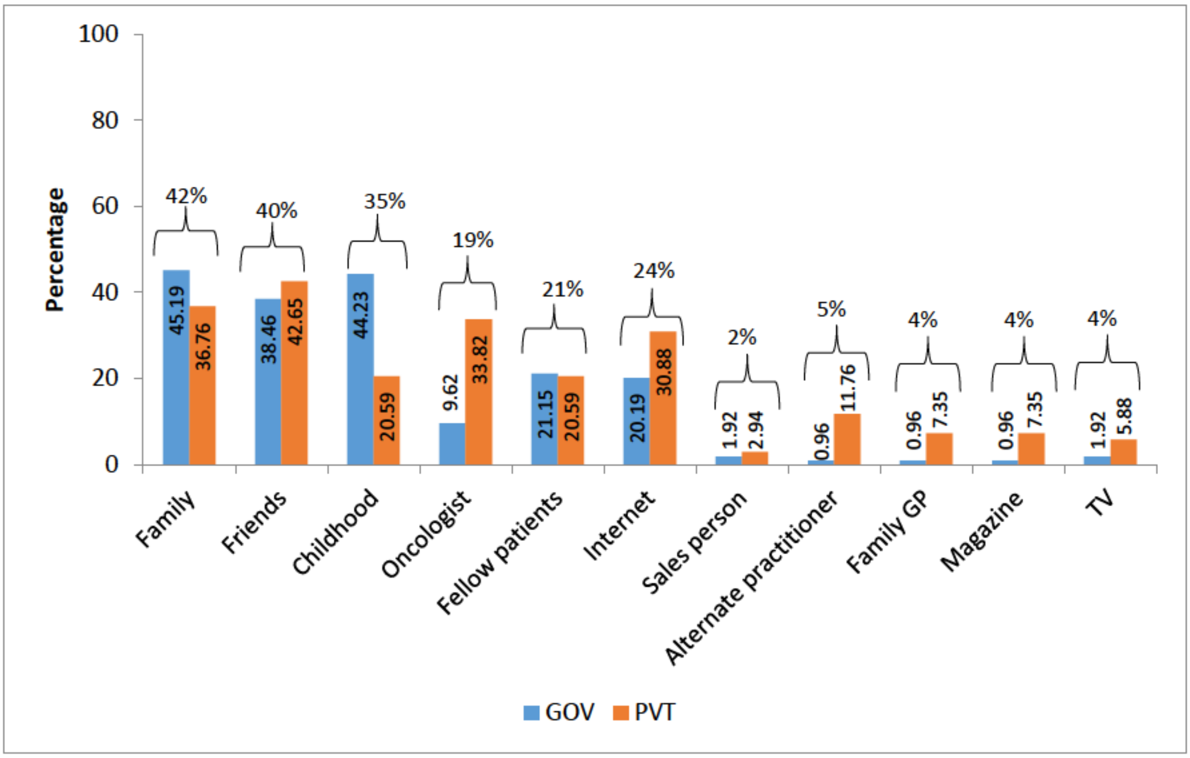


Figure 4.2.5: Patient sources of information on supporting practices. Numbers are percentages of the patients citing that source in each cohort (government; private and total).

4.2.6 Patient disclosure of the use of additional health seeking practices and reasons for non-disclosure

A vital part of patient management concerns patient-practitioner communications, and information sharing on the part of both. It is helpful, and often critical, for a practitioner to be aware of any additional health-seeking choices of the patient, especially when it comes to disclosure of practices that might impact their treatment program in any way. The possibility exists that patients are incorporating practices that they find extremely helpful, but their experience is not being discussed in the oncology environment. Alternatively, it could be that they are engaging in potentially harmful practices. For this reason, we explored patient disclosure for all supporting practices.

4.2.6.1 Frequencies of non-disclosure

Within the government cohort, 222 of 224 patients used at least one supporting practice, and within the private cohort 89 of 92 patients used at least one supporting practice (n=311 in total). Of these 311 patients, 270 failed to disclose at least one practice. These numbers were made up of 207 from the government facility (93% of the government patients using a supporting practice) and 63 from the private facilities (71% of the private patients using a supporting practice). However, this needs to be unpacked more, to see if there are specific practices which are or aren’t disclosed. When a patient reported using a specific practice, we had asked them to indicate whether they had informed their oncologist of its use or not. This information is outlined for each practice in table 4.2.6.1 below, together with percentages.

In addition, the superscripts 1, 2 and 3 have been used to indicate the relative clinical importance of patient disclosure of each supporting practice. Whist disclosure of an additional practice such as personal prayer or visualization is of interest in forming deeper insights into a patient, it is not of biomedical clinical importance. These practices were allocated a superscript of 1. Supporting practices were allocated a superscript of 2 if they are of more clinical interest yet innocuous and therefore unlikely to cause complications or impact mainstream treatments. Non-disclosure in these instances is unlikely to negatively impact clinical management. However, if a supporting practice includes use of internal medicines or herbs, there is the potential for drug interactions and negative effects on mainstream treatment programs. Such use could decrease effectiveness of mainstream therapies, or even be dangerous and therefore contra-indicated. Therefore, disclosure of such use is clinically vital. These were allocated a superscript of 3. This includes chiropractic due to its being contraindicated in patients with bone metastases and osteoporosis. Although categories 2 and 3 are indicating higher clinical significance, insight into what patients are using and finding helpful in category 1 is also useful for caregivers in the oncology arena.

The superscripts need to be considered when interpreting percentages of disclosure (and therefore non-disclosure) in the table below. The main practice of concern for non-disclosure is visits to African traditional healers with a 0% disclosure reported by those who utilised these additional practitioners.

Table 4.2.6.1: Percentage of patients using additional health-seeking practices who disclosed this use to their oncologists.

	Number of sample who used it (n)	Users who disclosed use to oncologists. *n* (%)
TCAM practitioners		
Acupuncture^2	7	4 (57.14)^2
African traditional^3	21	0 (0.00)^3
Aromatherapy^2	9	4 (44.45)^2
Ayurveda^3	3	2 (66.67)^3
BodyTalk^2	7	4 (57.14)^2
Chinese Medicine^3	4	1 (25.00)^3
Chiropractor^3	19	7 (36.84)^3
Homeopath^2	16	11 (68.75)^2
Iridologist^3	1	0 (0.00)^3
Kinesiology^2	2	1 (50.00)^2
Massage therapy^2	27	16 (59.25)^2
Naturopath^3	6	2 (33.33)^3
Physiotherapy^2	3	3 (100.00)^2
Reflexology^2	6	2 (33.33)^2
Reiki healer^1	5	1 (20.00)^1
Other (Quantum med and live blood analysis)^3	3	1 (33.33)^3
Lifestyle factors and self-help prac		
Dietary changes^2	167	89 (53.29)^2
Use of supplements^3	95	51 (53.68)^3
Cannabis oil^3	46	20 (43.48)^3
Exercise intervention^2	99	66 (66.67)^2
Yoga^1	21	16 (76.19)^1
Tai Chi^1	2	1 (50.00)^1
Relaxation Techniques^1	16	6 (37.50)^1
Meditation^1	30	15 (50.00)^1
Visualization^1	8	3 (37.50)^1
Emotional and spiritual support		
Spiritual healing ceremony/rite^1	22	2 (9.09)^1
Spiritual prophet^1	9	1 (1.11)^1
Prayer^1	270	61 (22.59)^1
Psychological counselling^2	28	20 (71.43)^2
Support Group^1	38	21 (55.26)^1
Music or art therapy^1	17	5 (29.41)^1

Superscript 1 = Personal, and of interest to patient profile but no risk in non-disclosure.
Superscript 2 = Of Increased clinical interest but low risk of adverse effects.
Superscript 3 = Disclosure is of vital clinical importance due to potential risks of adverse effects.

4.2.6.2 Reasons for non-disclosure

Those patients who utilised TCAM practices but reported non-disclosure of this use to their oncologists, were asked to answer a question related to why this was the case. This was done by indicating the reasons they identified with from a list of four possible reasons. 135 participants answered this question (88 government patients and 47 private patients). Their responses are presented in figure 4.2.6.2 below, together with percentages (proportion of each cohort who identified with each reason). Percentages above the brackets reflect proportion of all question respondents (n=135) identifying with that statement.

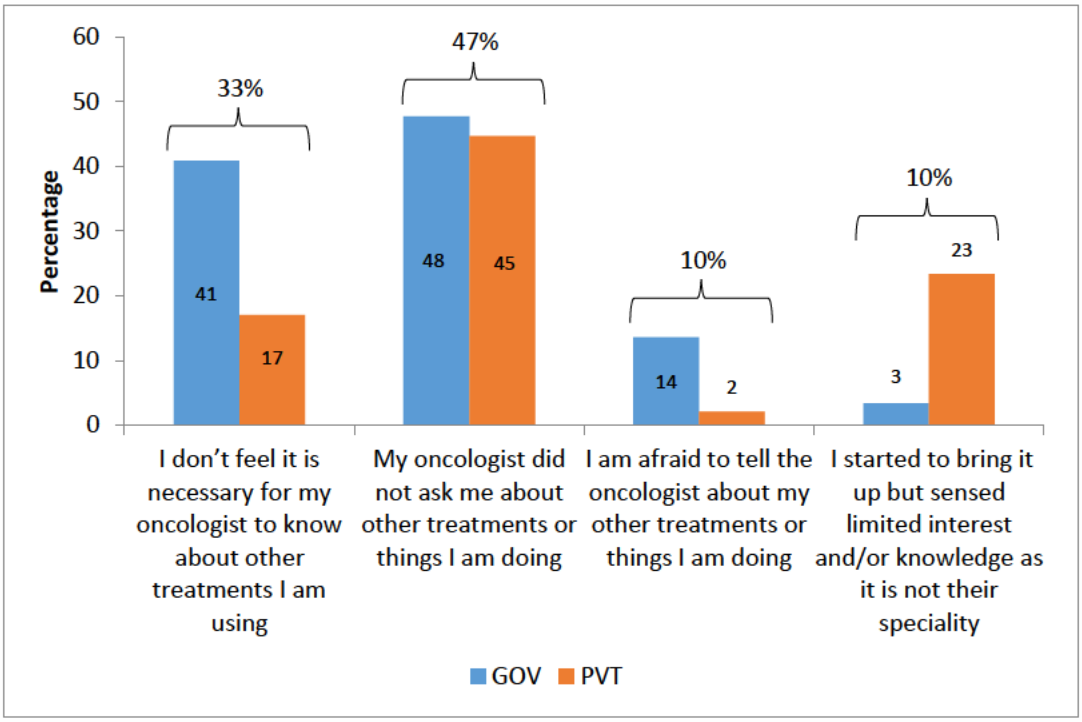


Figure 4.2.6.2: Reported reasons for non-disclosure of the use of supporting practices expressed as percentage of patients from each cohort within the respondents (government, private and total) who identified with that statement as a reason they did not disclose TCAM use.

The most cited reason given by those answering this question was that they were not asked (48% of all government cohort respondents and 45 % of private cohort respondents). This was followed in the government respondents by the feeling that the oncologist did not need to know everything they were doing (41%) and fear of disclosing (14%). In the respondents from the private cohort, 23% reported limited interest on the part of the oncologist and 17% that they did not believe it necessary to tell their oncologist everything. Using Pearson's chi square, results showed that significantly more government patients than private selected "not necessary" (p<.001); "I was not asked" (p<.001); "I was afraid to tell them" (p<.001).

4.2.6.3 Who initiates TCAM discussions?

The patients who reported having a conversation with their oncologist about supporting practices were asked who brought up the topic first. This question was unfortunately only answered by 69 participants (26 from the government facility and 43 from the private facility). However, it still provides interesting insights, and the results are reported in table 4.2.6.3 below. Percentages are expressed as a proportion of those patients who answered the question. In over 80% of cases discussions were initiated by the patient.

The highest proportion of TCAM discussions were initiated by patients (82.61%), whether at the government or private facilities.

Table 4.2.6.3: Responses to the question of who first brought up TCAM discussions during consultations (percentages expressed as proportion of the patients who answered this question).

	GOV n = 26	**PVT** n = 43	**TOT** n = 69
Patient brought up the discussion	21 (80.76%)	36 (83.72%)	57 (82.61%)
Oncologist brought up the discussion	5 (19.23%)	7 (16.28%)	12 (17.39%)

4.3 Additional Factors Affecting Patient Health-Seeking Behaviour

The results above elucidate the significant relationships between the use or non-use of specific supporting practices, and factors such as treatment centre and race. We will now explore other possible factors affecting patient health seeking behaviour, starting with the effect of the cancer diagnosis itself.

4.3.1 The effect of a cancer diagnosis on health-seeking thoughts

A cancer diagnosis is very distressing and could immediately start affecting a patient's thoughts regarding how to seek healing. Patients were asked what their "first thoughts" were (concerning health-seeking options) immediately after being diagnosed with cancer. They could choose one of three options: mainstream; TCAM; or a mix of both. The reported frequencies of these 3 different health-seeking choices were then compared to the frequencies for the health-seeking behaviour before diagnosis (see table 4.3.1.1). Comparison of these frequencies allowed an initial exploration into whether receiving a cancer diagnosis might affect a patient's view on what health-seeking options they wanted to use.

Table 4.3.1.1: Frequencies of various health-seeking choices before and thoughts immediately after cancer diagnosis for government cohort, private cohort and total sample (frequencies with column percentages).

GOV = government hospital PVT = Private oncology clinic TOT = Total of both cohorts	**GOV** *n* (%)	**PVT** *n* (%)	**TOT** *n* (%)
Patient column totals	224	92	316
Health seeking choices before diag.			
Mainstream	184 (82.1)	54 (58.7)	238 (75.3)
TCAM	4 (1.8)	2 (2.2)	6 (1.9)
A combination of both	36 (16.1)	36 (39.1)	72 (22.8)
Health seeking thoughts after diag.			
Wanted mainstream tx	177 (79 .0)	70 (76.1)	247 (78.2)
Wanted to try TCAM	16 (7.1)	2 (2.2)	18 (5.7)
Wanted to combine	29 (12.9)	16 (17.4)	45 (14.2)
Nothing. I was too scared.	2 (0.9)	4 (4.3)	6 (1.9)

The frequencies from the above table reflect an initial shift in the thinking of some patients after their cancer diagnosis, thus revealing how receiving such news affected the health seeing behaviour from the very beginning of the cancer journey in these patients. In the cohort from the government facility, the percentage of patients considering exclusively mainstream treatments decreased slightly after diagnosis, whilst in the cohort from the private facilities, the opposite was observed (Note: These frequencies reflecting health-seeking choices need to be viewed with the knowledge that the whole sample in fact ultimately received mainstream treatments. Therefore, whilst these figures are reporting patient *initial thoughts* post diagnosis regarding what treatment options they would prefer, they do not necessarily reflect their ultimate choice, which for every participant included mainstream treatments).

Table 4.3.1.2 below seeks to elucidate this more by exploring the specific shifts in health-seeking thoughts that occurred immediately following diagnosis. For each pre-diagnosis category, one can see the post diagnosis frequencies. It is interesting to note that, of those patients who pre-diagnosis utilised exclusively mainstream therapies, postdiagnosis figures indicate that several wanted to use TCAM only (5%) or a combination of TCAM and mainstream (7%). Likewise, for those who pre-diagnosis only used TCAM or a combination, several wanted to use exclusively biomedical treatments post-diagnosis.

Table 4.3.1.2: Shifting in health seeking preferences before and after cancer diagnosis.

Health seeking choices *before* diagnosis	Health-seeking preference *immediately after diagnosis*			
	Mainstream n (%)	TCAM n (%)	Combination n (%)	Nothing n (%)
MAINSTREAM (n =238) Shifted to	205 (86)	12 (5)	17 (7)	4 (2)
TCAM (n = 6) Shifted to	2 (33)	1 (17)	3 (50)	-
COMBINATION (n = 72) Shifted to	40 (56)	5 (7)	25 (35)	2 (3)

The health-seeking preferences before cancer diagnosis and health-seeking thoughts immediately after diagnosis were also explored by race. The figures are presented in table 4.3.1.3 below. It is interesting to note in the Black population, that the number of patients wanting to use TCAM alone increased from 2 to 14, and 2 patients initially chose to do nothing due to fear. There is also a notable drop in the number of White patients who before diagnosis had used a combination of mainstream and TCAM, yet immediately after diagnosis, shifted their preference to mainstream only. Pearson's chi-square did not reveal any significant differences across race groups in choices before or after diagnosis.

Table 4.3.1.3: Frequencies of patient health-seeking preferences before and immediately after diagnosis by race (Percentages show proportion of that race choosing each option)

Participants by race group: Black = 162; Coloured = 9; Indian = 72; White = 73	Black *n* (%)	Coloured *n* (%)	Indian *n* (%)	White *n* (%)
Health seeking preference before diagnosis				
Mainstream	126 (77.8)	5 (55.6)	57 (79.2)	50 (68.5)
TCAM	2 (1.2)	1 (11.1)	2 (2.8)	1 (1.4)
Combination	34 (21.0)	3 (33.3)	13 (18.0)	22 (30.1)
Patient total	162	9	72	73
Health seeking thoughts after diagnosis				
Wanted mainstream	126 (77.8)	6 (66.7)	54 (75.0)	61 (83.6)
Wanted to try TCAM	14 (8.6)	1 (11.1)	2 (2.8)	1 (1.4)
Wanted to combine	20 (12.3)	2 (22.2)	13 (18.0)	10 (13.7)
Nothing. Too scared.	2 (1.2)	--	3 (4.2)	1 (1.4)
Patient total	162	9	72	73

To explore the relationship between a patient's approach to treatments before cancer diagnosis and their *first thoughts* regarding treatment after diagnosis, binomial data was created for post-diagnosis choices (Mainstream only or TCAM inclusion). Results from Fisher's exact test in table 4.3.1.4 below. A significant proportion of those who chose mainstream treatments before diagnosis, chose mainstream treatment as a first thought after diagnosis; while a significant proportion of those who chose TCAM or a combination of mainstream and TCAM before diagnosis, had inclusion of TCAM approaches in their first thoughts after diagnosis.

Table 4.3.1.4: Results of Fisher's exact test showing relationship between patient health seeking choice before diagnosis and their initial thoughts after diagnosis. Significant proportions are in bold.

Choice before diagnosis	**Thoughts after diagnosis** Frequency (%)		Fishers	p-value
	Mainstream only	TCAM inclusion		
Mainstream	**205 (86.1)**	33 (13.9)	33.909	<.001
TCAM	2 (33.3)	**4 (66.7)**		
A combination	40 (55.6)	**32 (44.4)**		

Using data for patient inclusion of specific lifestyle and self-help practices before and after diagnosis, McNemar's test was applied to determine if there was a significant *change* in the patients' use of these practices from before to after diagnosis. Table 4.3.1.5 below presents the changes in usage. All the significant changes involved patients adopting practices after diagnosis that they had not used before diagnosis.

Table 4.3.1.5: McNemar's results showing changes in the proportion of patients using specific lifestyle and self-help practices from before to after diagnosis. Use is expressed as frequencies with significant 95% and marginally significant 90% p values. (N=316).

Lifestyle and self-help practices	**Use since diag.**	**Use before diag.**		p-value
		NO	YES	
Dietary approaches	NO	148	1	**p<.001**
	YES	**86**	81	
Supplement use	NO	221	0	**p<.001**
	YES	**42**	53	
Cannabis use	NO	273	0	**p<.001**
	YES	**35**	8	
Exercise	NO	217	0	**p<.001**
	YES	**16**	83	
Yoga	NO	295	0	**p=.063**
	YES	**5**	16	
Relaxation techniques	NO	300	0	**p=.016**
	YES	**7**	9	
Meditation	NO	286	0	**p=.004**
	YES	**9**	21	
Prayer	NO	46	0	**p=.063**
	YES	**5**	265	
Counselling	NO	288	0	**p<.001**
	YES	**12**	16	
Support group	NO	278	0	**p<.001**
	YES	**32**	6	
Creative pursuits such as music/art	NO	300	0	**p=.063**
	YES	**5**	11	

4.3.2 Reported reasons for use and non-use of additional practices.

4.3.2.1 Exploring reasons for use of additional practices

As part of the survey, those patients who utilised complementary practices were asked to identify their main reason/reasons for doing so from a list of 11 possible reasons. One hundred and sixty participants (106 government and 54 private) responded to this question and the results are displayed in figure 4.3.2.1 below. Percentages are calculated out of those who responded and are the proportion of each cohort who identified with each reason. Percentages above brackets reflect the proportion of all question respondents (n=160) identifying with that statement.

The reason with the highest proportion of selection by respondents in both groups and overall was “trying to do everything I could” (GOV:76%; PVT:52%; All:68%). The next highest proportion cited in the government cohort was “it is part of my culture” (41%). Both cohorts had around 40% citing “emotional distress” (GOV:37%; PVT:46%; All:40%). Other notable factors in the private respondents included increased immunity (50%); relief from side-effects (41%); and detoxing (39%). In addition to the reasons in the figure below, two patients stated their reason for use as “to contain the cancer whilst waiting for government treatment”. Another was seeking “a possible cure” and another said that “due to my age I decided to reject surgery and chemotherapy”.

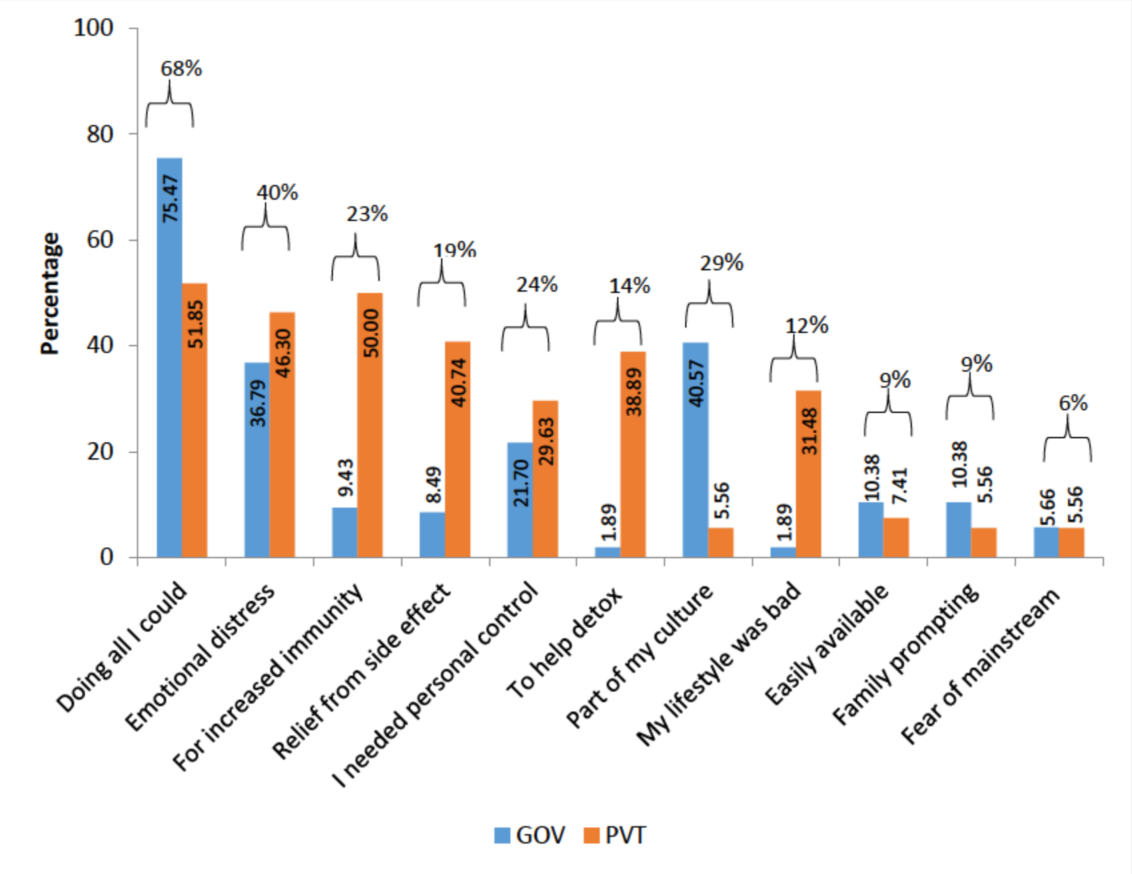


Figure 4.3.2.1: Percentages of respondents identifying with possible reasons for utilisation of additional supporting practices, expressed as percentage of patients from each cohort (government, private and total question respondents) who identified with that reason.

4.3.2.2 Exploring reasons for non-use of additional practices

Those patients who did *not* utilise complementary practices were asked to identify their main reason/reasons for not doing so from a list of 6 possible reasons. One hundred and thirty-one participants responded to this question and the numbers of those who identified with each of the choices are displayed in figure 4.3.2.2 below together with percentages (proportion of the 131 respondents who identified with each reason).

Of interest here is the high percentage of respondents in both cohorts who only included what they were told to include (GOV:98.5%; PVT:77.4%). Most of the government respondents, and almost half of the private respondents in this question also stated that they "simply never considered any additional practices" (GOV: 92.9; PVT:48.3). The government cohort also had many patients (private cohort less so) citing fear of potential interactions; lack of affordability; possible decreasing of the effectiveness of mainstream treatments; and request by the oncologist not to include extra modalities.

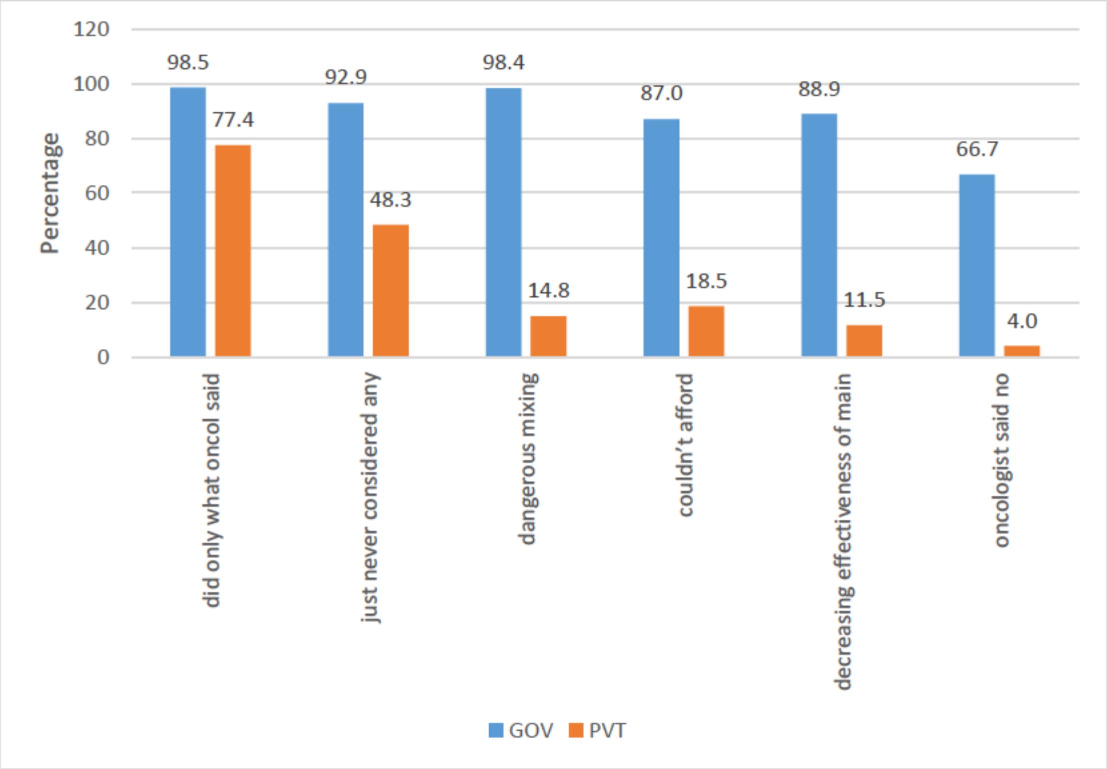


Figure 4.3.2.2: Percentages of respondents identifying with possible reasons for non-utilisation of additional supporting practices, expressed as percentage of patients from each cohort (government, private and total question respondents) who identified with that reason.

4.3.3 Exploring associations between demographic and clinical factors and use of health-seeking categories

4.3.3.1 Cross tabulations of TCAM use with demographic and clinical factors

For this section, the binary scores for use (or non-use) of specific categories of support practices were once again utilised. Cross tabulations were done between these and select demographic and clinical variables. Frequencies from these cross tabulations are presented in table 4.3.3.1.1 and 4.3.3.1.2 below together with p values of Chi Square tests utilised to explore the strength of the association. Significant p values (<0.05) are indicated in bold. Significant associations were seen with race, education level and income level, as well as treatment centre. In addition, the extent of spread of the cancer was significantly linked to several of the practices. Unless indicated, all significant associations are for categories where a significant number of patients *did* use the support therapy. When a significant number of the patients *did not* use the support therapy, this will be indicated using a hashtag superscript (#).

For the TCAM practitioners presented in table 4.3.3.1.2, results are first presented for all TCAM practitioners together; followed by splitting up the practitioners into African traditional; TCAM practitioners who use external modalities (acupuncture, aromatherapy, BodyTalk, chiropractor, kinesiology, massage, reflexology, reiki, physio); and TCAM practitioners who prescribe medications for internal use (ayurveda, Chinese herbal, homeopath, iridologist, naturopath).

Table 4.3.3.1.1: Cross tabulations and Chi-squared results for Various support practices (merged) vs demographic and clinical variables (Table continues overleaf).

Demographic and Clinical factors		Additional factors utilised by patients seeking healing and wellbeing during their cancer journey					
		Diet and supplements	Cannabis	Exercise activities	Relaxation techniques	Spiritual support	Psych support
Variables	n	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Age							
20-39	33	20 (60.61)	4 (12.12)	3 (9.09)	3 (9.09)	28 (84.85)	7 (21.21)
40-49	81	**63 (77.78)**	**16 (19.8)**	25 (30.86)	12 (14.8)	69 (85.19)	17 (20.99)
50-59	96	61 (63.54)	**17 (17.71)**	36 (37.50)	17 (17.71)	83 (86.46)	15 (15.63)
60-69	68	36 (52.94)	6 (8.82)	22 (32.35)	11 (16.2)	59 (86.76)	10 (14.71)
70+	38	17 (44.74)	2 (5.26)	16 (42.11)	4 (10.53)	33 (86.84)	8 (21.05)
Chi Square	P	**.003**	**.045**	.061	.701	.997	.768
Religion							
Atheist	8	6 (75.0)	2 (16.67)	**6 (75.0)**	**4 (50.00)**	**1 (12.5)#**	**4 (50.0)**
Christian	258	156 (60.47)	32 (12.4)	74 (28.68)	29 (11.2)	231 (89.53)	44 (17.05)
Hindu	33	24 (72.73)	6 (18.2)	**16 (48.48)**	11 (33.30)	28 (84.85)	4 (12.12)
Muslim	13	9 (69.23)	3 (23.08)	5 (38.46)	1 (7.69)	12 (92.31)	**4 (30.77)**
Chi Square	P	.474	.264	**.006**	**<.001**	**<.001**	.048
Race							
Black	162	**89 (54.94) #**	5 (3.10)	21 (12.96)	3 (1.85)	**156 (96.30)**	7 (4.32)
Coloured	9	7 (77.8)	**4 (44.4)**	4 (44.4)	1 (11.1)	5 (55.6)	**3 (33.3)**
Indian	72	50 (69.44)	12(16.7)	**31 (43.06)**	14 (19.4)	64 (88.89)	12 (16.67)
White	73	51 (69.9)	**22 (30.1)**	**47 (64.4)**	**29 (39.7)**	47 (64.4)	**35 (47.9)**
Chi Square	P	**.046**	**<.001**	**<.001**	**<.001**	**<.001**	**<.001**
Education							
None/primary	69	27 (39.13)	3 (4.3)	11 (15.94)	1 (1.45)	**68 (98.55)**	1 (1.45)
Second/trade	153	97 (63.40)	19 (12.4)	38 (24.84)	8 (5.2)	135 (88.24)	21 (13.73)
University	94	**73 (77.66)**	**21 (22.34)**	**54 (57.45)**	**38 (40.4)**	69 (73.40)	**35 (37.23)**
Chi Square	P	**<.001**	**.003**	**<.001**	**<.001**	**<.001**	**<.001**
Treatment Centre							
Government	224	127 (56.70)	17 (7.6)	38 (16.96)	5 (2.2)	207 (92.41)	16 (7.14)
Private	92	**70 (76.09)**	**26 (28.26)**	**65 (70.65)**	**42 (45.7)**	**65 (70.65) #**	**41 (44.57)**
Chi Square	P	**.001**	**<.001**	**.000**	**<.001**	**<.001**	**<.001**

Significance indicated in bold, with # indicating significant for non-use.

Table 4.3.3.1.1 continued: Cross tabulations and Chi-squared results for Various support practices (merged) vs demographic and clinical variables..

Demographic and Clinical factors		Additional factors utilised by patients seeking healing and wellbeing during their cancer journey					
		Diet and supplements	Cannabis	Exercise activities	Relaxation techniques	Spiritual support	Psych support
Variables	n	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Income (R1000)							
1-1.5	48	24 (50.00)	3 (6.25)	11 (22.92)	1 (2.08)	45 (93.75)	3 (6.25)
1.5to 5	148	83 (56.08)	9 (6.08)	25 (16.89)	2 (1.35)	139 (93.92)	8 (5.41)
5 to 10	29	21 (72.41)	**7 (24.14)**	10 (34.48)	**8 (27.6)**	27 (93.10)	**8 (27.59)**
10 to 20	25	**20 (80.00)**	**7 (28.00)**	**14 (56.00)**	3 (12.00)	20 (80.00)	**7 (28.00)**
20 to 40	39	26 (66.67)	**11 (28.21)**	**24 (61.54)**	**19 (48.72)**	**24 (61.54) #**	**21 (53.85)**
More than 40	27	**23 (85.19)**	**9 (33.33)**	**19 (70.37)**	**14 (51.85)**	**17 (62.96) #**	**10 (37.04)**
Chi Square	P	**.006**	**<.001**	**<.001**	**<.001**	**<.001**	**<.001**
Years since diag.							
≤ 6 months	33	15 (45.45)	4 (12.12)	8 (24.24)	1 (3.0)	31 (93.94)	4 (12.12)
1 yr.	120	72 (60)	11 (9.17)	27 (22.5)	14 (11.7)	107 (89.2)	11 (9.17)
2 yrs.	66	39 (59.09)	8 (12.12)	24 (36.4)	**14 (21.21)**	56 (84.4)	13 (19.7)
3-5 yrs.	65	49 (75.38)	11 (16.92)	**27 (41.5)**	**15 (23.1)**	54 (83.1)	**22 (33.85)**
6-10 yrs.	16	10 (62.5)	3 (18.75)	**10 (62.5)**	1 (6.3)	12 (75.00)	3 (18.75)
10+yrs	16	12 (75)	6 (37.5)	7 (43.75)	2 (12.5)	12 (75.50)	4 (25.00)
Chi Square	P	.065	.066	**.004**	**.044**	.215	**.002**
Spread							
Unknown	31	**12 (38.71) #**	1(3.2)	4 (12.90)	0 (0.00)	29 (93.55)	1 (3.23)
Breast	138	90 (65.22)	12 (8.7)	50 (36.23)	**28 (20.3)**	117 (84.78)	23 (16.67)
Lymph nodes	104	71 (68.27)	**21 (20.2)**	**41 (39.42)**	17 (16.3)	87 (83.65)	**28 (26.92)**
Organs	43	24 (55.81)	**9 (20.93)**	8 (18.60)	2 (4.65)	39 (90.70)	5 (11.63)
Chi Square	P	**.017**	**.009**	**.006**	**.006**	.405	**.009**
Treatments							
Lumpec /rad	12	5 (41.67)	0 (0)	2 (16.67)	1 (8.3)	12 (100)	0 (0)
Mastc	12	6 (50)	3 (25)	6 (50)	4 (33.3)	10 (83.3)	3 (25.0)
Plus horm blck	56	35 (62.5)	9 (16.1)	23 (41.1)	11 (19.6)	48 (85.7)	12 (21.4)
Plus chemo	236	151 (64)	31 (13.1)	72 (30.5)	31 (13.1)	202 (85.6)	42 (17.8)
Chi Square	P	.340	.289	.144	.144	.647	.288

Significance indicated in bold, with # indicating significant for non-use.

Table 4.3.3.1.2: TCAM practitioner consultations (merged) vs demographic and clinical variables.

Demographic and Clinical factors		TCAM practitioner consults utilised by patients during their cancer journey			
		All TCAM consults	African traditional	Involving ingested meds	External modalities only
Variables	n	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Age					
20-39	33	6 (18.18)	2 (6.1)	2 (6.2)	1 (3.0)
40-49	81	19 (23.46)	5 (6.2)	4 (4.9)	13 (16.0)
50-59	96	25 (26.04)	4 (4.2)	9 (9.4)	17 (17.7)
60-69	68	15 (22.06)	6 (8.8)	2 (2.9)	9 (13.2)
70+	38	13 (34.21)	4 (10.5)	4 (10.5)	9 (23.7)
Chi Square	P	.555	.602*	,399*	.165
Religion					
Atheist	8	**5 (62.50)**	0 (0)	1 (12.5)	3 (37.5)
Christian	258	59 (22.9)	21 (8.1)	16 (6.2)	34 (13.2)
Hindu	33	11 (33.33)	0 (0)	1 (3.0)	7 (21.2)
Muslim	13	2 (15.38)	0 (0)	2 (15.4)	3 (23.1)
Chi Square	P	**.019**	.300*	.260*	.090*
Race					
Black	162	26 (16.0)	**21 (13.0)**	5 (3.1)	3 (1.9)
Coloured	9	**4 (44.4)**	0 (0)	0 (0)	**3 (33.3)**
Indian	72	16 (22.22)	0 (0)	4 (5.6)	13 (18.1)
White	73	**33 (45.2)**	0 (0)	**12 (16.4)**	**30 (41.1)**
Chi Square	P	**<.001**	**<.001***	**.004***	**<.001**
Education					
None/primary	69	12 (17.39)	**11 (15.9)**	2 (2.9)	2 (2,9)
Second/trade	153	24 (15.7)	10 (6.5)	8 (5.2)	14 (9.2)
University	94	**43 (45.74)**	0 (0)	11 (11.7)	**33 (35.1)**
Chi Square	P	**<.001**	**<.001***	.064*	**<.001**
Treatment Centre					
Government	224	30 (13.40)	**21 (9.4)**	6 (2.7)	5 (2.2)
Private	92	**49 (53.26)**	0 (0)	**15 (16.3)**	**44 (47.8)**
Chi Square	P	**<.001**	**.002**	**<.001**	**<.001**
Income (R1000)					
1-1.5	48	3 (6.25)	2 (4.2)	1 (2.1)	1 (2.1)
1.5 to 5	148	26 (17.6)	**18 (12.2)**	6 (4.1)	5 (3.4)
5 to 10	29	6 (20.69)	0 (0)	1 (3.4)	1 (3.4)
10 to 20	25	7 (28.00)	0 (0)	1 (4.0)	5 (20.0)
20 to 40	39	***21 (53.85)***	1 (2.6)	3 (7.7)	**19 (48.7)**
More than 40	27	***16 (59.26)***	0 (0)	**9 (33.3)**	**18 (66.7)**
Chi Square	P	**<.001**	**.015***	**<.001***	**<.001***
Years since diag.					
≤ 6 months	33	3 (9.09)	2 (6.1)	1 (3.0)	0 (0)
1 yr.	120	24 (20.0)	10 (8.3)	2 (1.7)	8 (6.7)
2 yrs.	66	***21 (31.8)***	5 (7.6)	6 (9.1)	**15 (22.7)**
3-5 yrs.	65	***22 (33.8*****)**	4 (6.2)	**9 (13.8)**	**16 (24.6)**
6-10 yrs.	16	3 (18.8)	0 (0)	1 (6.3)	3 (18.8)
10+yrs	16	6 (37.5)	0 (0)	2 (12.5)	7 (43.8)
Chi Square	P	**.034**	.910*	**.012***	**<.001**
Spread					
Unknown	31	10 (32.26)	**8 (25.8)**	0 (0)	1 (3.2)
Breast	138	41 (29.7)	6 (4.3)	13 (9.4)	**29(21.0)**
Lymph nodes	104	18 (17.31)	3 (2.9)	5 (4.8)	17 (16.3)
Organs	43	10 (23.26)	4 (9.3)	3 (7.0)	2 (4.7)
Chi Square	P	.119	**.001***	.233*	**.014**
Treatments					
Lumpec /rad	12	2 (16.67)	1 (8.3)	0 (0)	2 (16.7)
Mastc	12	***5 (41.67)***	0 (0)	3 (25.0)	**5 (41.7)**
Plus horm blck	56	***21 (37.5)***	5 (8.9)	5 (8.9)	**13 (23.2)**
Plus chemo	236	51 (21.6)	15 (6.4)	13 (5.5)	29 (12.3)
Chi Square	P	**.037***	.675*	.064*	**0.014***

*Significance indicated in bold, with # indicating significant for non-use. *= Fisher's exact*

4.3.3.2 Unadjusted Odds Ratios for categories of demographic and clinical variables

Further to the above explorations of associations, unadjusted odds ratios (OR) were done for demographic and clinical variable categories in relation to the merged TCAM categories. The resulting odds ratios are presented in tables 4.3.3.2 below. These only include those which are significant (0.05) and marginally significant (0.1). Odds ratios above 1 indicate that participants in that category are more likely (than the other categories) to utilise the supporting practice, and odds ratios below 1 (#), indicate that participants in that category are less likely (than the other categories) to use it. As these are unadjusted OR's, there could be confounding aspects (for example race could be an explanation for some results linked to religion).

The divide between the government cohort and private cohort was once again evident as well as socio-demographic variables linked to those centres.

- Government less likely (and private centre more likely) to utilise the various supporting practices.
- Odds Ratios repeatedly reveal a low level of education ("no, or only primary education") as less likely to use, and tertiary education level as more likely to use supporting practices.
- Similarly, lower income brackets are less likely and higher income brackets increasingly likely to use supporting practices.
- With the exclusion of prayer, Blacks are less likely and other races more likely to use many of the supporting practices.
- Increasing years since diagnosis showed increased likelihood for use of some practices, as did stage (spread).

These results confirm the use of treatment centre (government vs private) as a potentially helpful summary variable in use of supporting practices by patients.

Table 4.3.3.2: Significant unadjusted odds ratios for demographic and clinical variable categories

Supporting practice used	**Significant independent variable categories**	**Odds Ratio**	**Likelihood**	**95% Confidence Interval**
Use of diet and supplements	Age 40-49	2.638	2.6 X more	[1.471; 4.731]
	Age 70+	0.441#	2.3 X less	[0.222; 0.874]
	Black	0.519#	1.9 X less	[0.327; 0.825]
	No or primary education	0.291#	3.4 X less	[0.167; 0.506]
	University education	2.747	2.7 X more	[1.580; 4.776]
	Income R1 501-R5 000	0.605#	1.7 X less	[0.382; 0.957]
	Income > R40 000	3.800	3.8 X more	[1.281; 11.276]
	Government centre	0.411#	2.4 X less	[0.238; 0.711]
	Private centre	2.430	2.4 X more	[1.406; 4.200]
	<6 months since diagnosis	0.462#	2.2 X less	[0.224; 0.957]
	3 – 5 years since diagnosis	2.131	2.1 X more	[1.149; 3.953]
	Spread unknown	0.341#	2.9 X less	[0.159; 0.732]
Use of Cannabis	Age 60-69	0.335#	3 X more	[0.115; 0.973]
	Black	0.097#	10.3 X less	[0.037; 0.255]
	Coloured	5.497	5.5 X more	[1.415; 21.355]
	White	4.560	4.6 X more	[2.331; 8.920]
	No or primary education	0.235#	4.3 X less	[0.070; 0.785]
	Tertiary education	2.615	2.6 X more	[1.358; 5.036]
	Income R1 501-R5 000	0.150#	6.7 X less	[0.061; 0.366]
	Income R10 001-R20 000	2.755	2.7 X more	[1.076;7.053]
	Income R20 001-R40 000	3.008	3 X more	[1.367; 6.619]
	Income > R40 000	3.750	3.8 X more	[1.561; 9.009]
	Government centre	0.208#	4.8 X less	[0.107; 0.408]
	Private centre	4.797	4.8 X more	[2.452; 9.385]
	>10 years since diagnosis	4.265	4.3 X more	[1.464; 12.422]
	Spread only in breast	0.452#	2.2 X less	[0.223; 0.916]
	Spread to lymph nodes	2.185	2.2 X more	[1.139; 4.191]
Use of exercise approaches	Age 20-39	0.256#	3.9 X less	[0.088; 0.750]
	Atheist	6.526	6.5 X more	[1.294; 32.918]
	Hindu	2.120	2.1 X more	[1.024; 4.391]
	Christian	0.402#	2.5 X less	[0.225; 0.719]
	Black	0.131#	7.6 X less	[0.075; 0.228]
	Indian	1.806	1.8 X more	[1.051; 3.104]
	White	6.036	6 X more	[3.433; 10.615]
	No or primary education	0.320#	3.1 X less	[0.160; 0.640]
	Secondary education	0.498#	2 X less	[0.308; 0.807]
	Tertiary education	4.766	4.8 X more	[2.841; 7.997]
	Income R1 501-R5 000	0.235#	4.3 X less	[0.139; 0.397]
	Income R10 001- R20 000	2.889	2.9 X more	[1.262; 6.612]
	Income R20 001-R40 000	4.010	4 X more	[2.000; 8.042]
	Income > R40 000	5.796	5.7 X more	[2.442; 13.755]
	Government centre	0.085#	11.8 X less	[0.048; 0.150]
	Private centre	11.784	11.8 X more	[6.674; 20.804]
	1 year since diagnosis	0.458#	2.2 X less	[0.274; 0.768]
	6-10 years since diagnosis	3.710	3.7 X more	[1.310; 10.509]
	Spread unknown	0.278#	3.6 X less	[0.095; 0.818]
	Spread to organs	0.428#	2.3 X less	[0.191; 0.960]

less likely

Table 4.3.3.2 continued: Unadjusted Odds Ratios for demographic and clinical variable categories.

Use of relaxation techniques	Atheist	6.163	6.2 X more	[1.485; 25.570]
	Hindu	3.431	3.4 X more	[1.536; 7.664]
	Christian	0.281#	3.6 X less	[0.143; 0.554]
	Black	0.047#	21.3 X less	[0.014; 0.156]
	White	8.239	8.2 X more	[4.212; 16.117]
	No or primary education	0.064#	15.6 X less	[0.009; 0.475]
	Secondary education	0.175#	5,7 X less	[0.079; 0.389]
	Tertiary education	16.060	16 X more	[7.333; 35.171]
	Income R1- R1500	0.103#	9.7 X less	[0.014; 0.763]
	Income R1 501- R5 000	0.037#	27 X less	[0.009; 0.157]
	Income R5 001- R10 000	2.422	2.4 X more	[1.003; 5.849]
	Income R20 001- R40 000	8.448	8.5 X more	[4.033; 17.698]
	Income > R40 000	8.354	8.4 X more	[3.616; 19.302]
	Government centre	0.027#	37 X less	[0.010; 0.072]
	Private centre	36.792	37 X more	[13.853; 97.717]
	3-5 years since	2.053	2 X more	[1.034; 4.077]
Use of spiritual support	Atheist	0.020#	50 X less	[0.002; 0.163]
	Christian	3.547	3.6 X more	[1.776; 7.085]
	Black	8.517	8.5 X more	[3.484; 20.822]
	Coloured	0.187#	5.3 X less	[0.048; 0.727]
	White	0.145#	6.9 X less	[0.073; 0.285]
	No or primary education	14.333	14 X more	[1.937; 106.072]
	Tertiary education	0.258#	3.9 X less	[0.134; 0.498]
	Income R1 501-R5 000	4.064	4 X more	[1.882; 8.779]
	Income R20 000- R40 000	0.187#	5.3 X less	[0.088; 0.397]
	Income > R40 000	0.227#	4.4 X less	[0.096; 0.535]
	Government centre	5.058	5.1 X more	[2.594; 9.862]
	Private centre	0.198#	5.1 X less	[0.101; 0.386]
Use of Psychological support	Atheist	4.811	4.8 X more	[1.166; 19.848]
	Black	0.094#	10.6 X less	[0.041; 0.215]
	White	9.252	9.3 X more	[4.905; 17.454]
	No or primary education	0.050#	20 X less	[0.007; 0.369]
	Tertiary education	5.393	5.4 X more	[2.938; 9.897]
	Income R1-R1 500	0.264#	3.8 X less	[0.079; 0.883]
	Income R5 001- R10 000	0.139#	7.2 X less	[0.063; 0.305]
	Income R20 000- R40 000	7.810	7.8 X more	[3.800; 16.052]
	Income > R40 000	3.029	3 X more	[1.306; 7.025]
	Government centre	0.096#	10.4 X less	[0.050; 0.184]
	Private centre	10.451	10.4 X more	[5.435; 20.097]
	1 years since diagnosis	0.329#	3.0 X less	[0.163; 0.664]
	3-5 years since diagnosis	3.157	3.1 X more	[1.689; 5.903]
	Spread to lymph nodes	2.325	2.3 X more	[1.296; 4.169]
Use of a TCAM practitioner	Tertiary education	4.356	4.4 X more	[2.538; 7.478]
	Income R1-R1 500	0.168#	6 X less	[0.051; 0.558]
	Income R1 501-R5 000	0.462#	2.2 X less	[0.271; 0.789]
	Income R20 001- R40 000	4.405	4.4 X more	[2.203; 8.808]
	Income > R40 000	5.218	5.2 X more	[2.305; 11.810]
	Government centre	0.136#	7.4 X less	[0.077; 0.238]
	Private centre	7.369	7.4 X more	[4.202; 12.924]
	< 6 months since	0.272#	3.7 X less	[0.081; 0.918]
	Had hormone therapy	2.090	2.1 X more	[1.130; 3.864]
	Had chemotherapy	0.512#	2 X less	[0.294; 0.891]

4.3.4 Pre-diagnosis use vs post-diagnosis use

Previous use was explored as a possible factor influencing use of supporting practices after diagnosis. All patients reporting the use of additional supporting therapies were asked to indicate whether they had used this same approach when seeking health and wellbeing *before* their diagnosis. Percentages of previous use for supporting therapies are presented in table 4.3.4.1 below. Usage figures all increased, but many patients had used the same approach before diagnosis.

Table 4.3.4.1 Percentages of TCAM users who have used the same therapy pre-diagnosis.

	Number of the sample who used it. *n*	% of TCAM users who had used it previously. n (%)
TCAM practitioners		
Acupuncture	7	5 (71.43)
African Traditional	21	15 (71.43)
Aromatherapy	9	8 (88.89)
Ayurveda	3	2 (66.67)
BodyTalk	7	3 (42.86)
Chinese Medicine	4	1 (25.00)
Chiropractor	19	14 (73.68)
Homeopath	16	11 (68.75)
Kinesiology	2	1 (50)
Massage therapy	27	19 (70.37)
Naturopath	6	1 (16.67)
Physiotherapy	3	3 (100)
Reflexology	6	5 (83.33)
Reiki healer	5	2 (40)
Lifestyle factors and self-help practices		
Dietary changes	167	81 (48.50)
Use of supplements	95	53 (55.79)
Cannabis	46	8 (17.39)
Exercise intervention	99	83 (83.84)
Yoga	21	16 (76.19)
Tai Chi	2	1 (50)
Relaxation Techniques	16	9 (56.25)
Meditation	30	21 (70)
Visualization	8	4 (50)
Emotional and spiritual support		
Spiritual healing ceremony/rite	22	18 (81.82)
Spiritual prophet	9	88.89 (8)
Prayer	270	265 (98.15)
Psychological counselling	28	16 (57.14)
Support Group	38	6 (15.79)
Music or art therapy	17	11 (64.71)

Binomial tests were done to see if there was a significant link between use of a therapy before diagnosis and use of that same therapy after diagnosis. Those that are significant for use (or non-use) before diagnosis are presented in table 4.3.4.2 below.

Table 4.3.4.2: Binomial test results for significant relationship between pre- and post-diagnosis use of TCAM therapies.

Therapy	Used before (%)		n	p-value
	YES	NO		
Aromatherapy	**89%**	11%	9	.039
Chiropractic	**74%**	26%	19	.064
Inyanga	**71%**	29%	21	.078
Cannabis	17%	**83%**	46	<001
Exercise	**83%**	16%	99	<.001
Yoga	**76%**	24%	21	<.001
Meditation	**70%**	30%	30	.043
Prophet	**89%**	11%	9	.039
Healing ceremony	**81%**	19%	21	.007
Prayer	**98%**	2%	270	<.001
Support group	16%	**84%**	38	<.001

4.4 Patient Experiences of Pluralistic Landscape

4.4.1 Reported stress in decision making

The many options offered by a pluralistic medical landscape can be a source of added stress in decision making. As seen in 4.2.5 above, patients are exposed to information and well-intentioned guidance from many sources including the internet, sales staff, friends, family, and fellow patients to name a few. Table 4.4.1.1 below outlines the numbers of patients who reporting stress when navigating medical choices after their diagnosis.

Table 4.4.1.1 Numbers of patients reporting stress in navigating medical choices after diagnosis.

Stress experienced in navigating a pluralistic medical landscape	**GOV** n (%)	**PVT** n (%)	**TOT** n (%)
Pressure from others to use TCAM instead of	42 (18.75)	15 (16.3)	57 (18.04)
Pressure from others to use TCAM in addition to	74 (33.04)	28 (30.43)	102 (32.28)
Deciding between mainstream and TCAM	32 (14.29)	20 (21.74)	52 (16.46)
Deciding which mainstream treatments to use	19 (8.48)	27 (29.35)	46 (14.56)
Deciding which TCAM treatments to use	26 (11.6)	15 (16.3)	41 (12.97)

Around 18 % of patients experience pressure from others to reject mainstream therapies in favour of alternatives, and around 32% experience pressure from others to incorporate additional TCAM therapies alongside their mainstream therapies. Results of a chi-square test showed that significantly more private patients than government patients found it stressful deciding which treatments to use (Pearson’s Chi square = 22.828; p<.001). This is likely a reflection of the access to treatment options and involvement in decisions afforded private patients vs government patients, which is empowering albeit stressful.

4.4.2 Reported helpfulness of complementary therapies used

Those who had utilised complementary practices were asked to indicate whether they had found that specific complementary practise helpful. The data from these responses is presented in table 4.4.2.1 below.

Table 4.4.2.1: Reported helpfulness of complementary therapies used able.

	Number of patients who used it. *n*	Users who found it helpful. *n* (%)
TCAM practitioners		
Acupuncture	7	5 (71.43)
African Traditional	21	16 (76.19)
Aromatherapy	9	9 (100)
Ayurveda	3	2 (66.67)
BodyTalk	7	7 (100)
Chinese Medicine	4	3 (75)
Chiropractor	19	19 (100)
Homeopath	16	14 (87.5)
Kinesiology	2	1 (50)
Massage therapy	27	25 (92.59)
Naturopath	6	6 (100)
Physiotherapy	3	3 (100)
Reflexology	6	5 (83.33)
Reiki healer	5	4 (80)
Lifestyle factors and self-help practices		
Dietary changes		
Use of supplements	167	136 (81.44)
Cannabis oil	95	74 (77.90)
Exercise intervention	46	35 (76.09)
Yoga	99	91 (91.92)
Tai Chi	21	20 (95.24)
Relaxation Techniques	2	1 (50)
Meditation	16	15 (93.75)
Visualization	30	29 (96.67)
Emotional and spiritual support		
Spiritual healing ceremony/rite	22	21 (95.45)
Spiritual prophet	9	8 (88.89)
Prayer	270	266 (98.52)
Psychological counselling	28	28 (100)
Support Group	38	35 (92.11)
Music or art therapy	17	16 (94.12)

4.4.3 Reported patient experience of oncologist approaches to various complementary practices

As a further exploration into patient experiences of medical pluralism, questions were asked about the guidance received from the biomedical consultation setting regarding navigation of complementary practices. Patients were asked to indicate their oncologist's approach to six different categories of support practices. These were the inclusion of nutritional support practices; the management of supplement use; the use of medicinal cannabis; the role of alternative practitioners (like homeopaths or Chinese medicine practitioners); the incorporation of exercise; and psychological support. Figure 4.4.3.1 below provides an initial insight into patient reporting of their oncologist's approach to 6 different supporting practices. These results (which are both the government and private sector combined), indicate 'E' as the most frequently selected option for every kind of supporting practice ("It was never spoken about"). The next most frequently selected response for every supporting practice was 'B' ("Oncologist was supportive and carefully explained what I should or should not do"). However, these numbers are still low, with between 3% and 35% of patients reporting this as their oncologist's response.

A = Considered it important and referred me to specialists for support
B = Supportive and carefully explained what I should or should not do
C = Dismissive and unconcerned.
D = Asked me to leave it until my oncology treatments were completed
E = It was never spoken about.

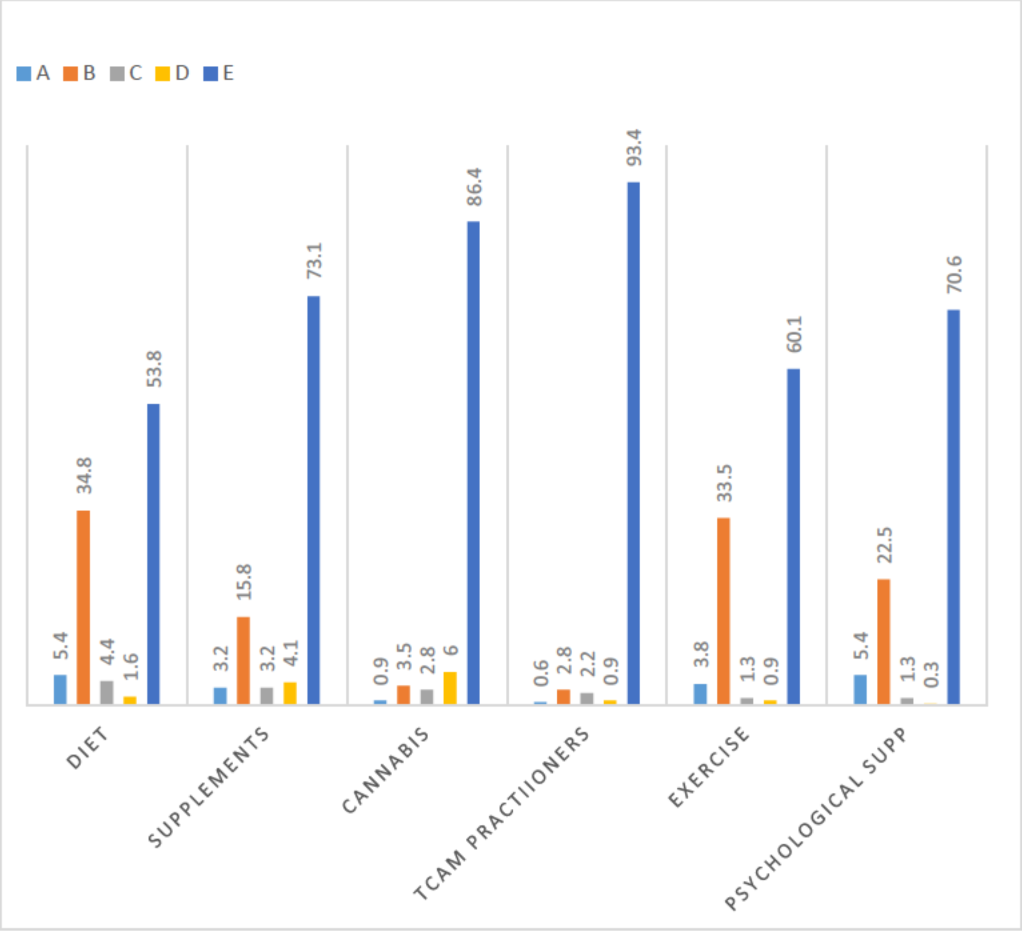


Figure 4.4.3.1: Bar graphs of patient reporting on oncologist approaches to supporting practices

These figures of the two cohorts combined are further elucidated by splitting up the responses of government and private patients. These frequencies and percentages are reported in table 4.4.3.1 below. Whilst noting where the highest proportions of responses fell overall (reflected in totals "T" in table 4.4.3.1), it is important to take cognisance of the differences in the distribution of reported oncologist approaches between government and private patients. Whilst the combined sample reported 'E' as the highest for all the categories, 'B' is the most reported approach within the private sector for diet, supplements, and exercise ("supportive and carefully explained what I should and should not do").

Table 4.4.3.1: numbers and percentages of patient reporting on oncologist responses to various supporting practices

	A Considered it important and Referred *n* (%)	B Supportive and carefully explained. *n* (%)	C Dismissive and unconcerned *n* (%)	D Asked me to leave it till after my treatments. *n* (%)	E Never spoke about it *n* (%)
Dietary approaches	G: 5 (2.23)	G: 70 (31.25)	G: 4 (1.79)	G: 0 (0)	G: 145 (64.73)
	P: 12 (13.04)	P: 40 (43.48)	P: 10 (10.87)	P: 5 (5.43)	P: 25 (27.17)
	T: 17 (5.38)	T: 110 (34.8)	T: 14 (4.43)	T: 5 (1.58)	T: 170 (53.80)
Use of Supplements	G: 2 (0.89)	G: 12 (5.36)	G: 2 (0.89)	G: 3 (1.34)	G: 205 (91.52)
	P: 8 (8.70)	P: 38 (41.30)	P: 8 (8.70)	P: 10 (10.87)	P: 28 (30.43)
	T: 10 (3.16)	T: 50 (15.82)	T: 10 (3.16)	T: 13 (4.11)	T: 233 (73.73)
Use of Medicinal Cannabis	G: 2 (0.89)	G: 2 (0.89)	G: 2 (0.89)	G: 3 (1.34)	G: 215 (95.98)
	P: 1 (1.09)	P: 9 (9.78)	P: 7 (7.61)	P: 16 (17.39)	P: 59 (64.13)
	T: 3 (0.95)	T: 11 (3.48)	T: 9 (2.85)	T: 19 (6.01)	T: 274 (86.71)
TCAM practitioners	G: 1 (0.45)	G: 1 (0.45)	G: 0 (0)	G: 1 (0.45)	G: 221 (98.66)
	P: 1 (1.09)	P: 8 (8.70)	P: 7 (7.61)	P: 2 (2.17)	P: 74 (80.43)
	T: 2 (0.63)	T: 9 (2.85)	T: 7 (2.22)	T: 3 (0.95)	T: 295 (93.35)
Incorporating exercise	G: 1 (0.45)	G: 52 (23.21)	G: 1 (0.45)	G: 0 (0)	G: 170 (75.89)
	P: 11 (11.96)	P: 54 (58.70)	P: 3 (3.26)	P: 3 (3.26)	P: 21 (22.83)
	T: 12 (3.80)	T: 106 (33.54)	T: 4 (1.27)	T: 3 (0.95)	T: 191 (60.44)
Psychological support	G: 8 (3.57)	G: 37 (16.52)	G: 1 (0.45)	G: 1 (0.45)	G: 177 (79.02)
	P: 9 (9.78)	P: 34 (36.96)	P: 3 (3.26)	P: 0 (0)	P: 46 (50.00)
	T: 17 (5.38)	T: 71 (22.47)	T: 4 (1.27)	T: 1 (0.32)	T:223 (70.57)
G = government patients (n = 224); P = Private patients (n = 92); T = total (n = 316)					

Referral percentages (column A) reported as low by private patients and very low by government patients. Worth noting is private patient referral for dietary advice (13%) and exercise advice (12%). Column 'B' ("carefully explained") has percentages between 0.5% (TCAM practitioners) and 31% (diet) for government patients and 9% (TCAM practitioners) and 59% (exercise) for private patients. Revisiting column 'E' ("never spoke about it") reveals disparate percentages between the government and private sectors, with higher percentages in the government sector, likely reflecting consultation time constraints of the government sector. Many categories still show high percentages, indicating no communication on the topic in those patients.

Patients were also presented with 3 statements regarding emotional support as well as guidance in nutrition and supplement use. Pearson's chi square test (or Fisher's exact test where necessary) was used to see if there was a relationship between patient's responses to these statements and their responses in 4.4.3.1 above. The results are presented in table 4.4.3.2 below, with significant associations in bold. As expected, significant associations were found between disagreement (strongly disagree/disagree) and category 'E' (it was never spoken about). In the case of emotional support, a significant association was also found between "strongly disagree" and category 'C' (dismissive and unconcerned). Conversely, significant associations were found between "strongly agree" (or "agree") and categories 'A' (referred) and 'B' (supportive and explained). In attempting to fully engage with the table however, it is also important to note that (although perhaps not statistically significant), there are those patients who feel they got adequate support even though falling in category 'C', 'D' and 'E', as well as those who did not feel they got the advice they needed even though falling in category 'A' and 'B'.

Table 4.4.3.2: Chi Square showing associations between patient responses to questions regarding sense of adequate support and actual support received.

Statements	Patient responses	Row %					Chi square	*df*	p-value
		A Referred	B Supportive/ explained	C Dismissive	D Asked to leave till after treatments	E Never spoke about it			
I got all the Emotional/ psychological support I needed.	Strongly Disagree	0	5.3%	**5.3%**	0%	89.5%	#	-	<.001
	Disagree	3.8%	9.6%	1.9%	**1%**	**83.7%**			
	Agree	**6.5%**	**29.3%**	0.8%	0%	63.4%			
	Strongly Agree	7.2%	**33.3%**	0%	0%	59.4%			
I got all the advice I needed on how to eat during & after treatments.	Strongly Disagree	0%	13.6%	9.1%	0%	**77.3%**	106.369	12	<.001
	Disagree	0.8%	9.8%	3.3%	0.8%	**85.2%**			
	Agree	**8.5%**	**53.8%**	4.6%	**3.1%**	30%			
	Strongly Agree	**12.2%**	**58.5%**	4.9%	0.0%	24.4%			
I got all the advice I needed on supplement use during & after treatments.	Strongly Disagree	0%	5.7%	2.9%	2.9%	88.6%	119.949	12	<.001
	Disagree	1.1%	4.4%	2.7%	2.2%	**89.6%**			
	Agree	4.1%	**37.8%**	**5.4%**	**9.5%**	43.2%			
	Strongly Agree	22.7%	50%	0%	4.5%	22.7%			

Fisher's exact test

4.4.4 Patient indications of need for increased guidance and support

Two hundred and ninety-four patients, or 93% of the sample indicated that they felt it was important to give cancer patients additional information and guidance to assist them in making choices about complementary healing therapies that are available to them. When asked whether they had had all the support and guidance they needed in various areas, many patients indicated that they would have liked more support. One hundred and twenty-three patients, or 39% of the sample indicated that they would have liked more emotional/psychological support (42% of government patients; 30% of private patients); 144 patients, or 46% of the sample indicated that they needed more support and guidance in dietary approaches (54% of government patients; 25% of private patients); 219 patients, or 69% of the sample indicated they felt a need for more guidance in the use of supplements (83% of government patients; 35% of private patients); and 160 patients, or 51% of the sample would have liked more advice on various therapies they could use to assist with side-effects and healing (60% of government patients; 27% of private patients). For each of these, the need for additional information was greater in the government sector).

4.4.5 Patient sense of their personal inclusion and role in their cancer journey

One of the core ideals of Integrative Oncology is the aspect of patient-centeredness and the role of the patient in their own healing journey. The integrative approach views the patient and practitioner as partners and places much store by empowering them to participate in their own healing journey in an active and informed way. Therefore, following on from the results in 4.4.3 and 4.4.4, it was fitting to examine responses of patients to some statements exploring the participants sense of their own role in seeking personal healing. These responses are outlined in table 4.4.5.1 below. These responses reveal that, for the majority of patients, there is a sense of personal inclusion and action in their healing journey. This is seen by the higher percentages of disagreement with the negative statements 1 to 4, together with the higher percentages of agreement with the positive statements 4, 5, 7 and 9. One cannot fully comprehend the data however, without being cognizant of those patients who disagreed with the positive statements and/or agreed with negative statements, indicating a sense of helplessness and lack of empowerment and an adequate sense of inclusion in their personal cancer journeys. The results also need to be interpreted with the understanding that they reflect subjective opinions of patients relative to their expectations and not necessarily objective measures.

Table 4.4.5.1: Patient responses to statements exploring aspects of personal inclusion.

Black = 162; Coloured = 9; Indian = 72; White = 73; Government hospital = 224; Private clinics = 92; Totals = 316	Disagree *n* (%)	Some of the time *n* (%)	Agree *n* (%)
1. “As a cancer patient I felt helpless. There was little that I could personally do, and I simply had to go along with the cancer doctors.	B: 112 (69.14) C: 6 (66.67) I: 44 (61.11) W: 38 (52.05)	B: 17 (10.49) C: 1 (11.11) I: 9 (12.50) W: 20 (27.40)	B: 33 (20.37) C: 2 (22.22) I: 19 (26.39) W: 15 (20.55)
	G: 148 (66.07) P: 52 (56.52)	G: 24 (10.71) P: 23 (25.00)	G: 52 (23.21) P: 17 (18.48)
	T: 200 (63.29)	T: 47 (14.87)	T: 69 (21.84)
2. During my treatment I felt that the tumor was the main focus, and not me.	B: 104 (64.20) C: 5 (55.56) I: 51 (70.83) W: 52 (71.23)	B: 14 (8.64) C: 1 (11.11) I: 4 (5.56) W: 11 (15.07)	B: 44 (27.16) C: 3 (33.33) I: 17 (23.61) W: 10 (13.70)
	G: 144 (64.29) P: 68 (73.91)	G: 19 (8.48) P: 11 (11.96)	G: 61 (27.23) P: 13 (14.13)
	T: 212 (67.09)	T: 30 (9.49)	T: 74 (23.42)
3. I felt too scared to make any decisions or do anything myself as I do not want to interfere with what the doctors are doing.	B: 108 (66.67) C: 5 (55.56) I: 44 (61.11) W: 48 (65.75)	B: 30 (18.52) C: 1 (11.11) I: 8 (11.11) W: 12 (16.44)	B: 24 (14.81) C: 3 (33.33) I: 20 (27.78) W: 13 (17.81)
	G: 145 (64.73) P: 60 (65.22)	G: 37 (16.52) P: 14 (15.22)	G: 42 (18.75) P: 18 (19.57)
	T: 205 (64.87)	T: 51 (16.14)	T: 60 (18.99)
4. I had many questions which I did not ask because I did not want to bother the oncologist. I tried to find answers myself.	B: 82 (50.62) C: 5 (55.56) I: 52 (72.22) W: 49 (67.12)	B: 46 (28.40) C: 3 33.33 () I: 8 (11.11) W: 15 (20.55)	B: 34 (20.99) C: 1 (11.11) I: 12 (16.67) W: 9 (12.33)
	G: 128 (57.14) P: 60 (65.22)	G: 50 (22.32) P: 22 (23.91)	G: 36 (16.07) P: 10 (10.87)
	T: 188 (59.49)	T: 72 (22.78)	T: 46 (14.56)
5. I felt that I was included in all decisions related to my care wherever possible.	B: 26 (16.05) C: 4 (44.44) I: 11 (15.28) W: 3 (4.11)	B: 21 (12.96) C: 0 (0) I: 15 (20.83) W: 6 (8.22)	B: 115 (70.99) C: 5 (55.56) I: 46 (63.89) W: 64 (87.67)
	G: 40 (17.86) P: 4 (4.35)	G: 34 (15.18) P: 8 (8.70)	G: 150 (66.96) P: 80 (86.96)
	T: 44 (13.92)	T: 42 (13.29)	T: 230 (72.78)
6. I felt adequately informed about what was happening and what to expect throughout my treatment.	B: 33 (20.37) C: 3 (33.33) I: 3 (4.17) W: 5 (6.85)	B: 15 (9.26) C: 1 (11.11) I: 7 (9.72) W: 8 (10.96)	B: 114 (70.37) C: 5 (55.56) I: 62 (86.11) W: 60 (82.19)
	G: 40 (17.86) P: 4 (4.35)	G: 18 (8.04) P: 13 (14.13)	G: 166 (74.11) P: 75 (81.52)
	T: 44 (13.92)	T: 31 (9.81)	T: 241 (76.27)
7. I was empowered by being directed to self-help approaches such as nutritional approaches, exercise, and support systems.	B: 74 (45.68) C: 4 (44.44) I: 25 (34.72) W: 23 (31.51)	B: 12 (7.41) C: 1 (11.11) I: 13 (18.06) W: 19 (26.03)	B: 76 (46.91) C: 4 (44.44) I: 34 (47.22) W: 31 (42.47)
	G: 102 (45.54) P: 23 (25.00)	G: 24 (10.71) P: 21 (22.83)	G: 98 (43.75) P: 48 (52.17)
	T: 125 (39.56)	T: 45 (14.24)	T: 146 (46.20)
8. I took control myself for a lot of things as I believe I am important in the healing process and cannot leave it all up to the doctors.	B: 19 (11.73) C: 3 (33.33) I: 12 (16.67) W: 14 (19.18)	B: 23 (14.20) C: 1 (11.11) I: 15 (20.83) W: 13 (17.81)	B: 120 (74.07) C: 5 (55.56) I: 45 (62.50) W: 46 (63.01)
	G: 33 (14.73) P: 15 (16.30)	G: 39 (17.41) P: 13 (14.13)	G: 152 (67.86) P: 64 (69.57)
	T: 48 (15.19)	T: 52 (16.46)	T: 216 (68.35)
9. I was treated as capable of being an integral part of my own healing.	B: 30 (18.52) C: 4 (44.44) I: 3 (4.17) W: 4 (5.48)	B: 16 (9.88) C: 1 (11.11) I: 12 (16.67) W: 7 (9.59)	B: 116 (71.60) C: 4 (44.44) I: 57 (79.17) W: 62 (84.93)
	G: 39 (17.41) P: 2 (2.17)	G: 26 (11.61) P: 10 (10.87)	G: 159 (70.98) P: 80 (86.96)
	T: 41 (12.97)	T: 36 (11.39)	T: 239 (75.63)

4.4.6 Patient interest in an Integrative Oncology centre

As a final question of the survey, patients were asked to indicate their interest in an integrative design to a treatment centre. They were asked whether, all else being equal, they would elect to attend an oncology centre offering integration of complementary practices. The responses are indicated below in table 4.4.6.1. 67% of the sample responded that complementary offerings would very likely affect their choice of oncology centre, and 13% said it might. A higher proportion of government patients were interested in the concept of an integrative centre.

Table 4.4.6.1: Patient indication as to whether integrative offerings would affect their choice of treatment centre.

	Very likely *n* (%)	Might *n* (%)	Unlikely *n* (%)	Stats
Black patients	**131 (80.86)**	10 (6.17)	21 (12.96)	χ^2=52.971 df=6 P<.001
Coloured patients	5 (55.56)	**3 (33.3)**	1 (11.11)	
Indian patients	37 (51.39)	6 (8.33)	**29 (40.27)**	
White patients	38 (52.05)	**21 (28.77)**	14 (19.18)	
Government patients	**167 (74.55)**	17 (7.59)	40 (17.86)	χ^2=25.346 df=2 P<.001
Private patients	44 (47.83)	**23 (25.00)**	**25 (27.17)**	
Totals	211 (66.77)	40 (12.66)	65 (20.57)	

The results of a Pearson's chi square test showed a significant relationship between race and interest in the concept of an integrative centre. A significant proportion of Blacks responded that the presence of integrative options would "very likely" affect their choice; a significant proportion of Whites and Coloureds responded that it "might"; and a significant proportion of Indians said that these offerings were "unlikely" to affect their choice of centre.

4.5 Summary of Chapter 4

This chapter presented the socio-demographic and clinical profile of the patient sample and then went on to explore the current practices in the use of TCAM alongside allopathic treatments. This incorporated a variety of lifestyle factors as well as visits to TCAM practitioners. Usage was presented as frequencies and percentages for the government cohort, private cohort and total sample. Besides prayer, Dietary interventions, supplements and exercise were amongst the most utilised lifestyle inclusions. African traditional healers, Massage therapists, Homeopaths and Chiropractors were amongst the most frequently consulted practitioners.

Pearson’s chi-square (or Fisher’s exact test, where necessary) were used to look for significant differences between government and private patient use of TCAM inclusions. These results revealed the disparities in the use of supporting therapies between government patients and private patients, with government patients significant for non-use of most lifestyle practices except prayer, and private patients significant for their use. Private patients also incorporated a wider range of consultations with TCAM professionals.

The chapter explored demographic factors associated with TCAM use, revealing significant associations between use of several different kinds of inclusions and educational level and income. Some of the most cited reasons for use were “doing all I could”, “emotional distress”, “increased immunity”, “need for more personal control” and “relief from side-effects”. Reasons for non-disclosure of use included not being asked, not feeling it was necessary, and being afraid.

The chapter also presented insights into patient experiences in navigating the pluralistic medical landscape, including stress in decision making, the helpfulness of complementary practices and oncologist approach to various supporting practices. The majority of patients reported that supporting practices (diet, supplements, exercise, psychological, TCAM practitioners) were not discussed during oncology consultations, and when they were, these conversations were initiated by the patient. Finally patient experiences of personal inclusion in their healing journey and interest in Integrative Oncology were presented.

5. ONCOLOGIST QUANTITATIVE RESULTS

In this chapter, the demographic and clinical profile of the oncologist sample will be presented. It will then outline some aspects of oncologist views and approaches towards inclusion of lifestyle and self-help practices as well as TCAM practitioner consults. Data on oncologist experiences with respect to management of patients' use of additional therapies will be presented, and the chapter will end by presenting oncologist views on Integrative Oncology.

5.1 Socio-Demographic and Clinical Profiles of the Oncologist Sample

A total of 19 oncologists consented to participate in the study. The greater proportion of these (73.7%; n = 14) were oncologists affiliated to one of the private practices across eThekwini. Of the remaining oncologists, 15.8% (n = 3) were affiliated with a government facility and 10.5% (n=2) practice at both private and government facilities. The demographic profile of the oncologist sample is presented in Table 5.1.1 below.

Table 5.1.1: Socio-demographic profile of the oncologist sample

19 participants	TOT *n* (%)
Age	
Less than 35	1 (5.3)
35-40	6 (31.6)
41-50	5 (26.3)
51-60	4 (21.1)
Older than 60	3 (15.8)
Gender	
Male	10 (52.6)
Female	9 (47.4)
Religion	
Atheist/Agnostic	4 (21.1)
Christian	8 (42.1)
Hindu	5 (26.3)
Muslim	2 (10.5)
Race	
Black	3 (15.8)
Coloured	1 (5.3)
Indian	8 (42.1)
White	7 (36.8)
World view	
Practical and logical and base understanding in scientific facts.	9 (47.4)
Intuitive and spiritual.	0
Mix of the above.	10 (52.6)
Had utilised TCAM for self personally.	
Yes	3 (15.8)

Table 5.1.2 outlines the factors related to the clinical practice of the oncologist sample, including number of years in practice and the nature of the practice with which the oncologists are affiliated.

Table 5.1.2: Clinical profile of the oncologist sample

Factors related to clinical practice	*n* (%)
Number of years in oncology practice.	
Still a registrar	1 (5.3)
Less than 5 years	3 (15.8)
5-10 years	7 (36.8)
11-20 years	3 (15.8)
More than 20 years	5 (26.3)
Nature of Practice.	
Government facility	3 (15.8)
Private practice	14 (73.7)
Work at government hospital as well as private practice	2 (10.5)
Working relationship.	
Share facilities and admin staff but work independently	4 (21.1)
Work as a team meeting regularly to discuss cases	13 (68.4)
I work independently in my own practice	2 (10.5)
Support services associated with practice.	
Nutritionist	11 (57.9)
Psychologist	13 (68.4)
Collaboration with alternate practitioners e.g. homeopath	0

5.2 Views and Practices of Oncologists Regarding Incorporation of Lifestyle and Self-Help Approaches

This section will present data on oncologist views and practices with respect to lifestyle factors including nutritional approaches, supplementation, exercise, and spiritual practices. Subsequent to this, data on oncologist knowledge of, and attitudes towards patient consults with TCAM practitioners will be presented.

5.2.1 Oncologist views on the role of nutrition in cancer management

When asked what role they believed Nutrition plays in oncogenesis and healing, 21.1% (n=4) of the oncologists stated they believed it only played a minimal role, whereas 78.9% (n=15) stated they believed it played a very important role. Around half of the oncologists (52.6%; n=10) indicated that they regularly refer patients for counselling on nutrition, whilst most others (42.1%; n=8) indicated that they personally counsel their patients on nutrition. One respondent (5.3%) felt it was unnecessary to counsel patients on nutrition if a preliminary assessment reveals a relatively healthy diet. Only two oncologists (10.5%) believed that food allergy testing could be an important tool for oncologists in order to implement specific nutritional changes in patients.

Many of the oncologists who responded to the survey (68.4% ;13) believe serum glucose, insulin resistance and IGF favour tumour formation; and 57.9% (11) believe that maintaining a low glycaemic load is an important consideration in diet and in enteral or intravenous feeding of oncology patients. Table 5.2.1 below indicates the role that the respondents believe is played by some of the dietary practices sanctioned by some alternative approaches. Chi square goodness of fit tests were done to see if a particular response was selected by a significant number of oncologists. These are indicated in bold. The following were considered to have "no role" by a significant proportion of the respondents: Maintaining an alkaline body environment, juicing, ketogenic diet, and reducing intake of dairy.

Table 5.2.1: Oncologists' views on the role played by specific nutritional approaches. Significant proportions in bold.

N=19	No role % (n)	Minor role % (n)	Very helpful % (n)	χ^2	df	p
Maintaining an alkaline body environment	**16 (84.2)**	3 (15.8)		8.895	1	**.003**
Juicing	**11 (57.9)**	6 (31.6)	2 (10.5)	6.421	2	**.040**
Ketogenic diet	**15 (78.9)**	3 (15.8)	1 (5.3)	18.105	2	**<.001**
Eliminating/reducing intake of dairy products	**11 (57.9)**	6 (31.6)	2 (10.5)	6.421	2	**.040**
Reducing intake of hormonally treated meat	4 (21.1)	8 (42.1)	7 (36.8)	1.368	2	.504
Using organically grown foods	5 (26.3)	9 (47.4)	5 (26.3)	1.684	2	.431
Reducing/eliminating alcohol intake	1 (5.3)	6 (31.6)	**11 (57.9)**	9.579	2	**.008**
Filtering water	7 (36.8)	8 (42.1)	4 (21.1)	1.368	2	.504
Plant-based wholefood diet	4 (21.1)	7 (36.8)	8 (42.1)	1.368	2	.504
Importance of a healthy body mass index		3 (15.8)	**16 (84.2)**	8.895	1	**.003**

Reducing or eliminating alcohol was considered important by a significant 58% of respondents, and the importance of a healthy body mass index by 84% of respondents. Other factors considered helpful, albeit by less than half the respondents included reducing intake of hormonally treated meat (37%) and use of a plant-based wholefood diet (42%). Precise reasons for views held were not investigated as part of this research.

5.2.2 Oncologist views role of supplementation in cancer management

Oncologist views on the role of supplementation in cancer management was divided. Just under half of the respondents (47.37%) believed `supplements do not play a major role in cancer management, whilst the other 52.63% disagreed with this. The majority (13; 68.42%) still felt it was important to discuss supplements with patients and address their use or non-use at different stages of the treatment journey. Eight oncologists

(42.11%) expressed hesitation in recommending supplements due to the potential pitfalls and complications when taken in conjunction with mainstream therapies and many oncologists (15; 78.95%) discouraged the use of vitamins and antioxidant supplements during chemotherapy and radiation. Five oncologists (27.8%) felt that an average nutritionist would not have the necessary training to guide oncology patients in supplement use. Table 5.2.2 below outlines the views of oncologists towards specific supplements. Chi-Square goodness of fit was done to determine is any responses were selected by a significant number of oncologists. The significant ones are indicated in bold. Those supplements considered "helpful" by a significant proportion of oncologists included omega 3; vitamin D; and folic acid. High dose vitamin therapy was considered "dangerous" by a significant proportion of oncologists. Several supplements were significant for the numbers of oncologists who selected "do not know", including resveratrol; sulphorophane; and astragalus.

Table 5.2.2: Oncologist views of various supplements in cancer management

	dangerous	Needs care	No effect	helpful	excellent	Do not know	χ^2	df	p
Multivitamins		4 (21.1)	5 (26.3)	10 (52.6)			3.263	2	.196
Omega 3		3 (15.8)	4 (21.1)	**10 (52.6)**		2 (10.5)	8.150	3	**.043**
Antioxidants	2 (10.5)	6 (31.6)	5 (26.3)	5 (26.3)	1 (5.3)		4.947	4	.293
Vitamin D	1 (5.3)	4 (21.1)	4 (21.1)	**9 (47.4)**	1 (5.3)		11.2	4	**.024**
Alkalinising agents	1 (5.3)	5 (26.3)	9 (47.4)			4 (21.1)	6.895	3	.075
High dose vitamin therapy	**13 (68.4)**	3 (15.8)	1 (5.3)	1 (5.3)		1 (5.3)	28.6	4	**<.001**
Curcumin		2 (10.5)	8 (42.1)	5 (26.3)	1 (5.3)	3 (15.8)	8.105	4	.088
Green tea/essiac tea		3 (15.8)	7 (36.8)	5 (26.3)		4 (21.1)	1.842	3	.606
Folic Acid	1 (5.3)	3 (15.8)	3 (15.8)	12 (63.2)			15.3	3	.002
Resveratrol	2 (10.5)	4 (21.1)	3 (15.8)	1 (5.3)		**9 (47.4)**	10.211	4	**.037**
Sulphorophane	3 (15.8)	1 (5.3)	3 (15.8)	1 (5.3)		**11 (57.9)**	18.105	4	**.001**
Astragalus	3 (15.8)	1 (5.3)	3 (15.8)	1 (5.3)		**11 (57.9)**	18.105	4	**.001**
Oestrogen metabol modulators	25 (6.3)	3 (15.8)	3 (15.8)	2 (10.5)		6 (31.6)	2.842	4	.585
Cannabis oil	4 (21.1)	5 (26.3)	2 (10.5)	7 (36.8)		1 (5.3)	6.0	4	.199

5.2.3 Oncologist views on the role of exercise in cancer management

To gain insight into the views of the oncologists on the role played by exercise in cancer management, participants were presented with six statements and asked to select their response in agreement or disagreement of the statement. These results are presented in table 5.2.3 below and indicate that most oncologists would support the critical role played by exercise in assisting patients to manage their cancer journey and in promoting health. Eighteen oncologists (94.73%) reported that they make a point of raising the topic with their patients due to the positive impact it can have. There was both concern that some patients may overemphasise rest, but also acknowledgement of the fact that many cancer patients are too ill to incorporate it. The majority (18; 94.73) also felt that exercise for cancer patients would need careful design and monitoring. Results of a Wilcoxon signed ranks test revealed that there was significant agreement with all but one statement.

Table 5.2.3: oncologist responses to statements concerning the role of exercise in cancer management.

	Strongly disagree	Disagree	Agree	Strongly agree	Z	p
I find that those patients who engage in regular physical activity deal better with therapy both physically and mentally			7 (36.8)	12 (63.2)	-3.963	**<.001**
Physical activity has cancer protective effects and the ability to affect survival rates.		1 (5.3)	9 (47.4)	9 (47.4)	-3.136	**.002**
I believe in the positive impact of exercise in cancer management to the extent that I make a point of raising the topic with my patients.		1 (5.3)	9 (47.4)	9 (47.4)	-3.710	**<.001**
I believe that many patients might overemphasise rest, with resulting increased levels of inactivity and decreasing fitness.		1 (5.3)	15 (78.9)	3 (15.8)	-3.750	**<.001**
Whilst the ideal might be that exercise has much to offer, the reality is that the majority of cancer patients are too ill to incorporate it into their life.		7 (36.8)	10 (52.6)	2 (10.5)	-1.410	.159
Exercise for cancer patients needs careful designing and monitoring.		1 (5.3)	13 (68.4)	5 (26.3)	-3.704	**<.001**

5.2.4 Oncologist views on the role of the mind and spirit in cancer

Although one oncologist amongst the respondents believed that the mind and spirit play no role in health and healing, the remaining 18 (94.7%) felt that these factors did play a role. All the participants believed it was part of the responsibilities of the oncologist to address the emotional state and needs of their patients. Table 5.2.4 presents oncologist views on the usefulness of some approaches addressing the mind and spirit. Some practices were considered “very helpful” by a significant proportion of the oncologists including counselling, support groups. These are indicated in bold with marginal significance indicated by a hashtag.

Table 5.2.4: Oncologist view of approaches addressing the mind and spirit.

	No experience of this	Not helpful	A little helpful	Very helpful		χ^2	df	p
Psychological Counselling			2 (10.5)	**17 (89.5)**		11.842	1	**.001**
Patient support groups			5 (26.3)	**14 (73.7)**		4.263	1	**.039**
Spiritual support			6 (31.6)	13 (68.4)		2.579	1	.108
Relaxation techniques			10 (52.6)	9 (47.4)		.053	1	.819
Visualisation techniques	5 (26.3)	2 (10.5)	5 (26.3)	7 (36.8)		2.684	3	.443
Meditation/ mindfulness	4 (21.1)	1 (5.3)	6 (31.6)	8 (42.1)		5.632	3	.131
Yoga	3 (15.8)	1 (5.3)	**9 (47.4)#**	**6 (31.6)#**		7.737	3	**.052**

5.3 Views and Practices of Oncologists Regarding Incorporation of TCAM Practitioners

This section will present data on oncologist knowledge, views and practices with respect to specialist TCAM fields and consultation with TCAM practitioners.

5.3.1 Oncologist knowledge, opinion of, and referral to various TCAM practitioners

Table 5.3.1 below outlines the oncologist knowledge concerning specific TCAM practitioners, together with their opinion of the practice and whether or not they refer patients to that kind of practitioner. Only a subset of the TCAM practitioners surveyed in the patient portion of the study are incorporated here.

5.3.1.1 Knowledge of specific therapies

Cumulatively, between 50% and 90% of oncologists described their knowledge as “very little” or “none” for all the TCAM fields included in this analysis. Chi-square goodness of fit tests were used to determine if a particular response option was selected by a significant number of oncologists. The significant numbers are indicated in bold with marginally significant numbers indicated by a hashtag. The significant responses included “very little” knowledge of ayurveda (p = .040); and “very little” or “adequate” knowledge of acupuncture (P= .008). The marginally significant responses included “very little” knowledge of homeopathy (p= .076); “adequate” knowledge of reflexology (p = .076); and “none” or “very little” knowledge of functional medicine (p = .052).

5.3.1.2 Opinion of specific therapies

Once again, the significant numbers are indicated in bold with marginally significant numbers indicated by a hashtag. Selection of “helpful” in relation to African traditional healer was significant in that it was only selected by one respondent (p = .029). Selection of “use with care” was significant in relation to homeopathy (p=.005) and naturopathy (p = .002). In several therapies, a dichotomy exists with a significant proportion of the respondents selecting “use with care”, whilst a significant proportion also selected “helpful”. These included ayurveda/traditional Indian medicine (p = .019); acupuncture (p = .005); and (marginally significant) functional medicine (p = .052). One oncologist found African traditional healers to be helpful, although the majority of responses were “use with care” or “harmful”. Alternative practitioners who prescribe medication were considered “harmful” or “use with care” by the greater proportion of respondents. This was particularly so for African traditional healers.

5.3.1.3 Recommendation/referral

The number of oncologists referring to alternate practitioners for integrated therapies are: 11 referred for acupuncture; 8 for reflexology; 7 for homeopathy; 6 for ayurveda; 4 to a Chinese medical practitioner; 4 to a functional medicine practitioner; 3 for naturopathy; and 1 to an African traditional healer. It is of interest to note that several of these categories are referrals to practices underpinned by philosophies different from the biomedical model. Merging data for sometimes/frequent referral, binomial tests were done to determine if a significant proportion of oncologists were for or against referral to that therapy. Those significant for non-referral were African traditional (p <.001); Chinese traditional medicine (p = .019); naturopathy (p = .004); and functional medicine (p = .019).

Table 5.3.1: Oncologist knowledge of, opinion of, and referral to various TCAM practitioners. Significant proportions at the .05 level are indicated in bold and marginally significant proportions by #.

		Knowledge of therapy % (*n*)				Opinion of therapy % (*n*)					Recommend/refer % (*n*)		
		none	Very little	adequate	good	Harmful / avoid	Use with care	Nonsense but harmless	helpful	excellent	never	sometimes	regularly
Prescribe meds to ingest	African traditional healer	5 (26.3)	8 (42.1)	4 (21.1)	2 (10.5)	8 (42.1)	10 (52.6)		**1 (5.3)**		18 (94.7)	1 (5.3)	
	Ayurveda practitioner (traditional Indian medicine)	6 (31.6)	**11 (57.9)**	2 (10.5)		3 (15.8)	**9 (47.4)**	1 (5.3)	**5 (26.3)**	1 (5.3)	13 (68.4)	6 (31.6)	
	Traditional Chinese medicine practitioner	8 (42.1)	9 (47.4)	2 (10.5)		4 (21.1)	8 (42.1)	1 (5.3)	6 (31.6)		15 (78.9)	4 (21.1)	
	Homeopath		**10 (52.6)**$^{\#}$	7 (36.8)	2 (10.5)	1 (5.3)	**11 (57.9)**	2 (10.5)	5 (26.3)		12 (63.2)	6 (31.6)	1 (5.3)
	Naturopath	5 (26.3)	**10 (52.6)**$^{\#}$	4 (21.1)		1 (5.3)	**12 (63.2)**	3 (15.8)	3 (15.8)		16 (84.2)	2 (10.5)	1 (5.3)
	Functional medicine practitioner	**9 (47.4)**$^{\#}$	**6 (31.6)**$^{\#}$	3 (15.8)	1 (5.3)	2 (11.8)	**8 (47.1)**$^{\#}$	1 (5.9)	**6 (35.3)**$^{\#}$		15 (78.9)	2 (10.5)	2 (10.5)
External	Acupuncturist	1 (5.3)	**9 (47.4)**	**8 (42.1)**	1 (5.3)	1 (5.3)	**7 (36.8)**	1 (5.3)	**10 (52.6)**		8 (42.1)	9 (47.4)	2 (10.5)
	Reflexologist	2 (10.5)	7 (36.8)	**10 (52.6)**$^{\#}$		2 (10.5)	3 (15.8)	6 (31.6)	8 (42.1)		11 (57.9)	7 (36.8)	1 (5.3)

5.3.2 Possible factors affecting inclusion and non-inclusion of TCAM practices by oncologists

The main reason given for non-referral to TCAM support practitioners and therapies was that oncologists felt incorporating these therapies “could potentially be counterproductive or even dangerous in conjunction with mainstream oncology treatments” and that “condoning them is not responsible medicine” (52.6%; n = 10). In addition, 42% (n=8) of the oncologists were of the opinion that “there is very little evidence for the efficacy and safety of TCAM use in oncology”. Three oncologists (16%) indicated that they did not feel it was their area of expertise or responsibility and so they therefore left it up to their patients to find TCAM therapies and practitioners should they so wish.

Influencing oncologist reserve about TCAM as a whole, is that oncologists are experiencing late presentation by patients. In addition, they are concerned about potential negative impact on prognosis. Twelve oncologists (63%) indicated they believed that there is an increase in the numbers of patients delaying commencement of mainstream treatments in order to try alternative therapies, which is of concern to them. Eighteen oncologists (94.73%) asserted that patients who elect sole use alternative medicine will have a worse prognosis, but only 3 (16.67%) felt the same about complementary use alongside mainstream therapies, although 9 oncologists (50%) did not know how complementary use might affect prognosis. Only 2 oncologists (10.52%) felt that TCAM therapies could extend survival when mainstream therapies are completed.

5.4 Oncologist Experiences of Pluralistic Landscape

5.4.1 Oncologist sense of being equipped to guide patients in TCAM

In addition to the data on knowledge of specific TCAM fields presented in 6.3.1 above, oncologists were also asked about their overall knowledge of TCAM practices in general. Out of the 19 oncologists that participated in the survey, 8 (42%) described their own knowledge of TCAM therapies as “adequate”. A further 42% indicated that their TCAM knowledge was minimal and that they often felt they needed to know more. The remaining 3 (16%) indicated that their knowledge was poor. Only two of the respondents (11%) had been exposed to any TCAM modules as part of their formal training and this was homeopathy. Self-rating of TCAM knowledge was unrelated to years in practice.

Oncologists were asked where they gained the TCAM knowledge they *did* have and could indicate more than one source. Sixty-three percent of the oncologists (n=12) reported learning about TCAM from journal articles; 53% (n=10) from their patients; 42% (n=8) from the internet; 37% (n=7) from media; 31% from oncology conferences and forums; 21 % (n=4) from causal interactions with peers; 21% (n=4) from TCAM practitioners and 5% (n=1) form a medical sales representative.

Although many oncologists felt they needed to know more, support of TCAM training through continuing professional development (CPD) was mixed. When asked whether they would attend CPD training in TCAM were it offered, 42% (n=8) stated that they would, whilst 58% (n=11) stated that they would not because it is not critical to their work and their time is pressurized.

5.4.2 Patient-oncologist communications about TCAM practices

Table 5.4.2.1 explores this oncologist opinion on guiding patients in TCAM by outlining their responses to various statements on this matter.

Table 5.4.2.1: Oncologist responses to statements about TCAM use.

	Strongly disagree	disagree	agree	Strongly agree	Z	p
The responsibility of the oncologist is allopathic oncology and not to guide patients in TCAM use.		7 (36.8)	10 (52.6)	2 (10.5)	-1.410	.159
It can be stressful when patients want to incorporate TCAM therapies as I feel they have little worth and the potential to interfere with mainstream therapies.		9 (47.4)	8 (42.1)	2 (10.5)	-.617	.537
I have a growing interest in the potential role that TCAM can play in oncology.	1 (5.3)	10 (52.6)	8 (42.1)		-.853	.394
I believe TCAM practitioners have a lot to offer, and I would like more opportunity for collaboration	2 (10.5)	7 (36.8)	10 (52.6)		-.220	.826
I encourage my patients to make use of TCAM therapies where possible.	3 (15.8)	**10 (52.6)**	6 (31.6)		-1.908	**.056**
Collaborating with TCAM practitioners and incorporating complementary support therapies has become routine practise for me.	4 (21.1)	**13 (68.4)**	1 (5.3)	1 (5.3)	-2.984	**.003**

It is of interest that 44% (8) of the oncologists indicated that they only discuss TCAM with their patients if the patient raises the topic, at which point they advise the patient according to their specific questions. The remaining oncologists indicated that they raise the topic with their patients, 17% (3) raising the topic in the first couple of visits and 39% (7) raising the topic along the treatment journey so that they know what the patient is doing and to ensure that the patients know what they can and cannot do.

About 63% of the oncologist sample are of the opinion that guiding patients in TCAM use is not the responsibility of the oncologist, and about half of the sample (53%) found it stressful when patients want to incorporate TCAM therapies. However, there were some indications of a growing interest in the potential role of TCAM (42%), an interest in increased collaboration (52%). The results of a Wilcoxon test showed a significant disagreement with the statement “Collaborating with TCAM practitioners and incorporating complementary support therapies has become routine practise for me”, and a marginally significant disagreement with the statement “I encourage my patients to make use of TCAM therapies wherever possible”.

When asked what the main therapies were that they receive queries about from their patients, the following responses were obtained from the oncologists:

- Cannabis was listed by the most oncologists (16 times).
- Alternative practitioners featured strongly, including homeopathy (listed by 7 oncologists); acupuncture (3) and ayurveda (2); reflexology (2); naturopathy (2); traditional healers (2) and chiropractic (1).
- Diet and nutrition queries were reported by 8 oncologists. These queries included what to eat or not eat; avoiding of sugar; the use of juicing; and creating an alkaline body environment through diet.
- Oncologists reported queries on supplements including vitamins; curcumin; immune boosters; and Sevenpointfive® wellness supplements.
- Queries on the use of herbal medicines was reported by 3 oncologists.
- Alternative cancer remedies such as artesunate; coffee enemas; vitamin C infusions; high dose vitamin therapy; ozone therapy and oxytherapy were also reported.
- Other supporting therapy questions reported included those on meditation and exercise.
- One oncologist stated that all patients want to know “what else can I do?”

5.5 Oncologist Views towards Integrative Oncology in South Africa

5.5.1 Initial insights into perceptions of Integrative Oncology

When asked to select the statement that best described their perceptions of Integrative Oncology, five out of nineteen oncologists (26%) selected the statement “Very positive I believe it is the way forward”, and ten oncologists (53%) selected the statement “Positive but tentatively so as there are many challenges to overcome”. Both these options were selected by a significant proportion of the respondents ($X^2(3) = 9.421$; $p = .023$). Three oncologists (16%) selected the statement “Negative and resistant to the idea as much needs to be investigated and proven first”, and one oncologist (5%) selected the statement “Very negative. I think the complications outweigh the benefits”.

Results of a Pearson's chi square test showed that a significant proportion of atheists were "negative and resistant to the idea", whilst a significant proportion of Christians were "very positive" (Fisher's exact = 13.551; p = .031). There was a partial significance in terms of race with Blacks and Coloureds being "very positive" about the idea and Indians being "tentatively positive" (Fisher's = 13.287; p = .055). No other significant relationships were noted between demographic and clinical variables, and perceptions of Integrative Oncology.

5.5.2 Views on incorporating TCAM into formal training

The sample was divided as to whether TCAM modules should be incorporated into formal oncology training, with 58% (n=11) indicating that they felt it should be included and 42% (n=8) indicating that they believed it was unnecessary. Those oncologists who felt it would be beneficial to incorporate TCAM modules into formal oncology training were asked to indicate aspects that they believed would be beneficial to include. Once again, each respondent could indicate more than one. Proposed aspects to potentially include in TCAM training are listed below in table 5.5.2.1 together with the percentage of oncologists who felt it would be beneficial to include in a TCAM module.

For this table, the responding sample size was 11 (those who believed that TCAM should be incorporated into formal training). Results of a binomial test showed that a significant proportion of the respondents selected "role of nutrition and lifestyle in oncology" (p=.012) and a marginally significant proportion selected "overview of main types of TCAM therapies" (p = .065) as beneficial content areas to include.

Table 5.5.2.1: Oncologist support of potential TCAM modules to incorporate into formal oncology training.

Possible content areas to include in TCAM module as part of formal oncology training	As a percentage of the sub-group of 11 who support TCAM training
	Indicated by n (%)
Overview of the main types of TCAM therapies (philosophies, evidence base, strengths; weaknesses and applications)	9 (81.8)
Role of Nutrition and lifestyle in oncology	**10 (90.9)**
Traditional medicines and oncology (African, Ayurveda, Chinese)	3 (27.3)
Mind and spirituality in health and illness	6 (54.5)
Environmental medicine (how environment affects disease)	3 (27.3)
How to manage oncology patient TCAM use	7 (63.6)

Integrative Oncology design	5 (45.5)

5.5.3 Views on the best Integrative Oncology model for the local setting

Eighteen oncologists went on to select the integrative model or approach that they felt would work best in South Africa. The responses of these 18 is shown in table 5.5.3.1 below. It is interesting to note that the two preferred models are in fact collaborative as opposed to integrative, although 17% selected an integrated team. The first option was selected by a marginally significant proportion of respondents ($X^2(3) = 7.778$; P = .051).

Table 5.5.3.1: Oncologist support of topics that could potentially be included in a formal TCAM module.

	Supported by % (n)
TCAM and allopathic healthcare practitioners work independently in different venues but form close collaborations and share information via formal communications.	**9 (50.0)#**
TCAM and allopathic healthcare practitioners work independently in a common venue (integrative healthcare clinic) and share information via formal communications.	1 (5.56)
Team of TCAM and allopathic practitioners work in a common integrative practise and meet regularly to discuss patients and make decisions regarding treatment plans.	3 (16.7)
A trained TCAM advisor who could co-ordinate TCAM referrals and queries in consultation with the oncologist.	5 (27.8)

5.5.4 Insights into oncologist views of the challenges for the growth of Integrative Oncology in the local setting

As a final question on the survey, participating oncologists were asked to state the possible reasons why the growth of Integrative Oncology is fairly slow in South Africa compared to some other places in the world such as Europe and the USA. Their responses are listed below:

5.5.4.1 Factors related to EBM, oncology guidelines and efficacy of TCAM

Seven out of the nineteen oncologists raised their concerns that TCAM lacks a strong evidence base and that they need to stick to evidence based medical practices (EBM):

- “There is inadequate science to support integrative practices”.
- “Lack of evidence of efficacy”; “no evidence”; “limited evidence”
- “Not reflected in international guidelines”.
- “It remains controversial even in the US and E.U.”
- “Maybe South Africans are more savvy!”

Some oncologists offered further opinions on other factors that could be related to resistance amongst professionals. Some were of the opinion that there was a lack of knowledge regarding TCAM:

- “Most oncologists lack knowledge of TCAM”.
- With the “lack of professional awareness” it remains “poorly understood”.

This poor understanding could be exacerbated by the characteristics of conservatism and lack of collaboration raised by others:

- “Collaboration is unfortunately not part of the ethos of medicine in South Africa”.
- “It may be part of a conservative mindset”.

Some oncologists raised the fact that oncologists are wary due to negative experiences:

- “Oncologists’ experience delay in presentation due to patients unsuccessfully trying alternate therapies”.
- “We have bad reports regarding African traditional healing”.
- One stated that they felt that “TCAM practitioners have no oncology knowledge and hence cannot expect to adequately guide oncologists”.

5.5.4.2 Systemic pressures and limitations

Several oncologists raised the systemic challenges of the oncology field in South Africa and KwaZulu-Natal:

- “There are limited oncologists resulting in significant pressures in just managing patients and their mainstream treatment protocols”.
- “Health care structure not geared for integrative health practise”.
- “Lack of adequate venues”.

5.5.4.3 Patient factors

Different factors related to patients were raised, related to cost of TCAM, as well as patient role in their own healing:

- Four oncologists referred to the “cost of treatments for patients” stating that “patients resist paying for additional services” and that “health care cost is prohibitive”.
- Patient adoption and compliance with additional therapies is driven by affordability and in South Africa the living standards measure (LSM) is highly variable.

Still with regards to patient factors, some oncologists reported lack of interest or even compliance to supportive therapies on the part of patients:

- “Patients are looking for one pill to fix all ills, less effort and less expense”.
- “Patients are not involved in personal care making it harder for the physician”.
- “Most often do not follow individualised dietary advice”.
- “There is a lack of public awareness and education”.

5.5.4.4 Of limited worth

There were also those who expressed the opinion that the impact of integrative therapies was limited and therefore not worth it:

- "Patient wellbeing may benefit from TCAM but empirical evidence for measurable improvement in health is lacking".
- "TCAM plays little or no role in treatment of cancer apart from psychological support".
- "Some areas such as nutrition are helpful, but many are not".

5.6 Summary of Chapter 5

This chapter began by presenting the demographic profile of the oncologist population. It went on to explore aspects of oncologist opinion and practice regarding TCAM use alongside allopathic treatments. Utilising nutritional and exercise approaches whilst supporting the psychological and spiritual wellbeing of patients was embraced by the majority of oncologists, indicating a belief in the holistic ideal of patient care. Opinion on the role of supplementation for most patients however remains divided. Integration of TCAM practitioner consultations was not well supported, although there are some referrals including ayurveda, acupuncture, reflexology, and homeopathy amongst others. There was however also evidence of interest in the potential offered by collaborations with TCAM practitioners.

The chapter presented some of the challenges and opportunities that the pluralistic medical landscape poses for practitioners. A slim majority felt that aspects of TCAM in oncology should be addressed in formal training to better equip oncologists in navigating the pluralistic landscape. Whist raising the challenges facing the growth of formal Integrative Oncology in the local setting, many oncologists were open to the concept of evidence-based Integrative Oncology. The chapter ended by laying out the models of integrative practice preferred by the oncologists for the local setting.

6. PATIENT QUALITATIVE RESULTS

Within the introduction to this thesis, the research question was articulated as follows: “What is the current status of Integrative Oncology in the local setting”? This needed to be explored in terms of which practices are being incorporated as well as in terms of personal lived experience (both positive and negative) of patients and oncologists navigating the local pluralistic medical landscape. After collecting quantitative data that gave insight into patient and oncologist choices and opinion, it was vital to turn to qualitative explorations in order to delve deeper into the lived experience of these two populations. The question at the outset of the qualitative phase was whether the personal narratives of the patients and oncologists would corroborate the quantitative data obtained thus far. However, in the spirit of qualitative enquiry, the researcher was open to new findings that might emerge from this phase. The qualitative approach to data collection and analysis was underpinned by narrative theory and phenomenology as described in the methodology.

6.1 The Interview Population and Domains of Enquiry

6.1.1 The interview population

Sixteen patients were interviewed, with each interview lasting between 1 and 1.5 hours. Despite multiple attempts to contact the government centre participants who had volunteered to be interviewed, only five were interviewed. The remaining eleven participants were from the private sector. Nevertheless, the qualitative analysis provides insight into patient lived experience of both groups in terms of the mainstream biomedical environment as well as complementary inclusions.

6.1.2 The domains of enquiry

The thematic analysis reported in this chapter reflects three main domains of enquiry as set out in figure 6.1 below. The first domain of enquiry incorporates themes which emerged out of patient narratives of lived experience in the mainstream oncology environment. These include lack of management and resultant difficulties of decision making during the initial weeks; the management of treatment side effects; the nature of the doctor-patient relationship; and an exploration oncologist attitudes towards incorporation of holistic and complementary practices.

The second domain of enquiry outlines patient inclusion of any TCAM modalities as reported during the patient narratives and subsequent probing. In doing this, any insights gained into the reasons why patients elected to incorporate these therapies or approaches will also be presented, as well as matters related to information sources used by the patients.

The third domain summarizes and expands on those elements which patients, from their lived experience, might consider as essential or truly worth incorporating in a more holistic vision for treatment of breast cancer patients. (Please note that the term “holistic” is retained here, as most of these views are currently reflecting a more widely holistic, yet not necessarily a fully integrated approach).

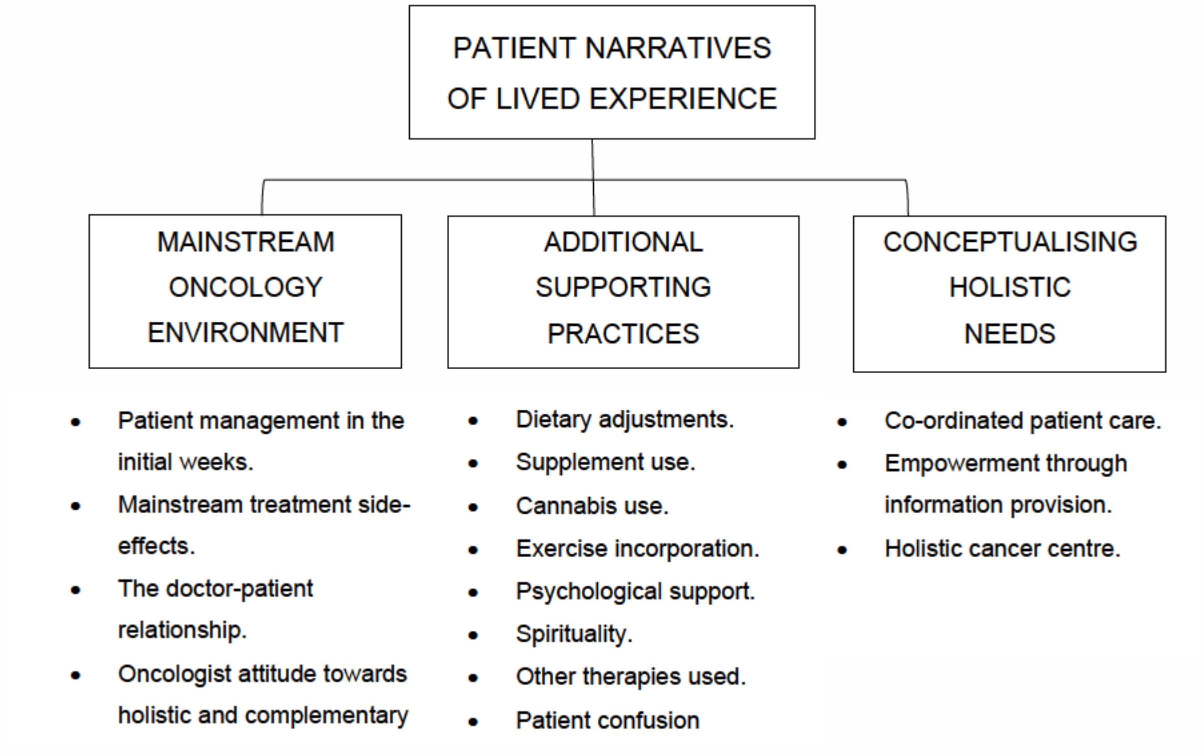


Figure 6.1: Outline of thematic areas which emerged from the patient qualitative data.

6.2 Domain 1: The Mainstream Oncology Environment

6.2.1 Patient management in the initial weeks

Participants related their personal stories of diagnosis (or misdiagnosis); the challenges associated with finding a suitable practitioner or clinic; as well as the confusion and stress inherent in making critical decisions regarding personal treatment options. The precise way that this occurs naturally differs a lot from patient to patient. The crises of these initial days speak to the need for streamlined processes as well as more guidance and support right from the beginning. It is interesting to note however, that those who contributed to this section of the discussion were from the private sector, whereas those in the specific public hospital used for sampling had been under the care of a multi-disciplinary team (MDT). One assumes this MDT would have effectively co-ordinated the processes and made joint decisions in the patient’s interests, eliminating some stress for the patient.

6.2.1.1 Co-ordination of processes from biopsy onwards

Several participants described the need for better co-ordination of the processes of biopsy, surgical decisions and oncology consultations, and a desire for provision of more information, support, and guidance in these early stages.

> *I personally know several people who have gone through this journey, where there was no one in control of the initial situation. Very often you are just being rushed along in a current of fear and each person is just dealing with one particular thing. So, you've got everyone just doing their own thing, and there's no co-ordination whatsoever. It's a mess! And it's terrifying because you are having to call everybody individually, you're having to think of everything that's going on, and there's a lot. You don't know that you can't just go to a general surgeon. If you have a mastectomy and there's no plastic surgeon there, you could end up being told that you can't have reconstruction because of the way the mastectomy was done. How are you supposed to know that? You get diagnosed…you're in surgery BAM!* (Participant 5: Private)

Biopsy results are generally delivered by the referring medical practitioner, which can prolong the period of uncertainty between biopsy and diagnosis. This induced anxiety in several participants, which was aggravated by a lack of adequate information and support at the critical point of diagnosis delivery. One participant suggested that this could potentially be alleviated by a centralised system of diagnosis delivery and guidance provision.

> *The waiting period was excruciating. It causes extreme amounts of anxiety because there is so much uncertainty. You are waiting to hear if you have cancer or not. …..when I got the results the doctor just said "Its cancerous. It is cancer". Full stop. No more details, nothing. …… I actually think that not having any more information made me go into worst case scenario. Precisely how the news is broken to you as a huge impact on you. There needs to be some sort of support when this news is shared with you, or information about where you can go to find out more or get the support you need.* (Participant 6: Private)

> *When you go to the biopsy place, you know nothing and are told nothing. They should cut that wait out. You need to know within 24 hours and the biopsy place should have [professionals with the relevant insight to guide you].* (Participant 2: Private at time of diagnosis)

6.2.1.2 Selecting one's oncologist

The critical decision of selecting an oncologist appears to occur in an ad-hoc manner. Some participants felt that this disempowered decision making added to their stress during the early days post-diagnosis because they had little to no information to guide them in making such a vital choice.

> *How do I know who to choose? Do I go by what my friends say to me? What happens to the person who doesn't have knowledgeable people to go and talk to about this important decision?* (Participant 6: Private)

> *Nobody told me about my options for oncologists or clinics. That shouldn't be! That information should be provided [in a more organised fashion, preferably at the beginning of the process].* (Participant 2: Private at time of diagnosis)

6.2.1.3 Critical treatment decisions

Some participants were also required to make decisions regarding different surgical options presented but did not feel adequately informed to do so. In the case of one participant, this resulted in regret about her decision to undergo a mastectomy.

> *You're scared and ill-informed, so you panic!! You just want the cancer gone! You don't realise that you actually have time to explore all your options. You're unsure of how safe a lumpectomy is or how the different type of cancer affects your options. I opted for a mastectomy yet afterwards the oncologist they said I was too hasty, and they could have saved my breast. Total and utter regret! My decision turned out to be regretful because I wasn't informed or guided at the outset.* (Participant 2: Private at time of diagnosis)

> *There was this sense of great urgency to deal with the cancer right away. It was a I was left to my own devices to find information and make decisions. In retrospect, I would have appreciated more knowledge from a medical person or direction to people who could advise me.* (Participant 6: Private)

> *They needed to do surgery immediately. I was told that I needed to decide whether I wanted a lumpectomy or a unilateral mastectomy. I don't even know the difference between any of them or what each could meant for me in the future and needed more information, but I was mute and just sat there nodding. Fortunately, he looked up at one point and he just saw my face and he made the decision to put on the brakes. He suggested that I see my oncologist first to get more insight to help me make the decision. The oncologist said that I wasn't going to have any surgery until they knew what was going on in my entire body. You can't just go and cut out the tumour not knowing anything about the rest of the body. It could be a primary source, or it could be a secondary source of cancer. She wanted me to go for chest X-rays, ultrasounds, bloods etc. and it was just coming at me. My oncologist phoned the surgeon to tell him that there was no way there was going to be any surgery. So, all surgery was off the cards and over the next month I started having just barrage of tests.* (Participant 13: Private)

Where professionals collaborated on vital decision making, participants reported a positive experience and comfort in their treatment decisions.

> *My oncologist put me in contact with the breast surgeon and they were amazing. They both sat with me and explained what decisions I needed to make. It was stressful and you are processing so much.* (Participant 3: Private)

> *Presenting all the evidence, my oncologist strongly advised a mastectomy, but they gave me time to decide. I had time to process, and I had time to get ready for that so by the time I had it, I was kind of mentally prepared for it. Though you can never be 100% prepared for it.* (Participant 5: Private)

> *The surgeon explained very nicely what they were going to do. He and the oncologist had discussed it and between them they decided that, as I was stage 1, the best approach would be to do a lumpectomy.* (Participant 10: Private)

6.2.1.4 A time of vulnerability and exploration of pluralistic health offerings

Participants expressed feeling vulnerable during the initial stage of their diagnosis. For some this vulnerability led to an exploration of alternative or additional treatment options.

> *Initially I also went to see a lady who does natural therapy. She owns a health shop. I asked her what alternatives there were if I chose to not have the operation and the radiotherapy.* (Participant 10: Private)
>
> *During that month before I had my surgery, I looked into a lot of alternative therapies.* (Participant 5: Private)
>
> *My first thought was to choose alternative therapies. There was also pressure from friends around me and other medical people. It was a very stressful time. I felt very conflicted. I think my resistance came from Mr Google. I read about the potential side effects and that made me think that surely there has to be a more natural way to do this.* (Participant 8: Private)

6.2.2 Mainstream treatment side effects

Participants highlighted side effects of mainstream treatment practices such as surgery, chemotherapy, and radiotherapy, as well as their struggles in managing these side effects, sometimes without adequate support.

6.2.2.1 Post-surgical challenges

Some patients in the private sector sometimes found themselves dealing with post-surgical matters alone, unsure of where to get support.

> *I had no follow-up from the surgeon at all. Eventually, I had to find a way through Googling to see what wound dressings would work.* (Participant 9: Private)

6.2.2.2 Radiation side-effects

Most participants reported extreme fatigue and skin irritation while undergoing radiotherapy, Advice on how to manage the skin irritation varied between oncologists with conflicting messages.

> *With the radiation it was just exhaustion.* (Participant 8: Private)
>
> *My radiation knocked me for a six and I had to stop early without completing all the cycles.* (Participant 9: Private)
>
> *I had been told that I mustn't get water on the radiation area, but towards the tail end of the radiation I did. The next thing my skin bubbled. It looked like it had been roasted in a fire. It was a crust, and it was hard and cut into the inner part of the flesh. That was very painful.* (Participant 12: Private)
>
> *I'd been told with radiation that you mustn't get it wet, but interestingly, my oncologist said "That's rubbish. Just have your shower as normal and as long as you don't rub the skin, everything will be fine". I had no damage.* (Participant 8: Private)

Three participants reported what they believe are long-term effects of their radiation, including plural effusion, a heart murmur, lung fibrosis and rib pains.

> *I had to have a pacemaker and instead of taking 45 minutes, it took three hours 45 minutes because all my veins where I had the radiation were brittle and the surgeon struggled to insert the pacemaker. He had to go through the back of my heart. And when this was going on I was thinking "well, what else is damaged inside me that I don't know about"? You know, what else has this radiation done?* (Participant 1: Private)

6.2.2.3 Chemotherapy side-effects

Chemotherapy use was associated with temporary side effects such as rashes, headaches, nausea, and exhaustion, as well as permanent adverse effects like bone deterioration. For one participant the side effects were so severe that she was advised to discontinue treatment.

> *With Chemo I just remember feeling dreadful. Sick and utterly exhausted.* (Participant 5: Private)

> *I was getting terrible migraines and we discovered I had osteopenia and cervical disc displacement from chemo.* (Participant 13: Private)

> *I didn't actually make it through the chemo. I got this rash all over my body. We had a week's break to see if it subsided and then I had another dose and then it just flared up again.* (Participant 7: Private)

6.2.2.4 Hormone therapy side-effects

Several participants spoke at length about the debilitating effects of ovarian oblation and chronic oestrogen deprivation, with some feeling that it was the worst of the mainstream therapies for them in terms of impact on quality of life.

> *I started a course of Zoladex. The injection is huge and painful, and I bled. It was awful! The side effects of [being starved of oestrogen] were just so debilitating. The worst thing I have ever experienced in my life!! I honestly thought I was dying. I had only had two months and was supposed to have two years. I phoned my oncologist one day and told her "I'm not doing this anymore. I don't even know who I am. I'm in the darkest place I've ever been in my life. I'm a tough person, but that can't even pull me out from where I am". My body was decrepit. It felt old. My knees and ankles hurt. I could barely stand on my feet when I woke up in the morning. I feel like I can't stand up without a walker. I couldn't sit down for too long because my body started to feel like it's seizing up. I felt like I was losing my mind. I was in forced menopause, and it was just too much! If I take everything into account that I have been through, I have found the menopause to be the worst part. It has got to be the brain fog and the hot flashes. And my hot flashes are so painful that it feels as if someone is tazering me. The heat comes, and I feel like I'm going to either faint, throw up or lose my mind, and it's violent. It's really violent.* (Participant 13: Private)

> *The side effects of Anastrozole were terrible for me. Virtually everything that they're tell you can happen, actually happened to me. I really went through a bad time. I lost my hair, I was having terrible night sweats, and I got arthritic pain and eye degeneration.* (Participant 10: Private)

6.2.3 Doctor-Patient relationship

Participants from both the private and public sector highlighted the importance of the doctor-patient relationship and the impact it had on their treatment journey.

6.2.3.1 The impact of the relationship on experience

Most of private patients who were interviewed described their oncologists as exceptional people, who genuinely cared about their patients. The oncologists listened to their patients and devoted considerable time to address their concerns and offer support. For some participants, however, this dissipated over time.

> *I found her kind and enthusiastic and she really cares personally about every patient.* (Participant 1: Private)

> *He was always open to listen to me and I never felt rushed in the meetings ever. He always took time to see how I was doing and asked me questions.* (Participant 3: Private)

> *I received massive emotional support from my oncologist. I felt 100% supported to the point that I knew I could call out of consulting hours. I still have [my oncologists] private number and I'm not the only one.* (Participant 5: Private)

> *When I first went to my new oncologist, my first appointment with her took an hour and a half. Even my follow-up consultations can last an hour She's open to discussing things. She is so humane.* (Participant 9: Private)

The nature of the relationship was not as consistent in the public sector. One public participant bonded with her oncologist. So much so that despite the traumatic reason for the relationship, looked forward to their appointments. However, others found it difficult to establish a relationship, due to the challenges of rotating oncologist duties in the public setting. A third described an impersonal and uncaring environment at an outlying public hospital.

> *I actually still miss seeing her. I think she made my journey easier. It's more than just the job that she does in terms of the surgery, it's the interaction. It's the relationship between patient and doctor. She really does care and takes her job seriously. That made a big difference to my experience. I actually looked forward to going to oncology. You know you have to wait for a long time for them to call your name for your appointment, but I didn't mind because it was so nice to see her and to chat with her.* (Participant 11: Public)

> *Another thing that worries me is how Oncologists keep changing. I can't really say which one is my doctor. I consult with whichever Oncologist is on duty at that time. Today you see this doctor, in the next visit you see another one and so on. Sometimes I am instructed to go to one hospital and sometimes I am instructed to go to another hospital. That really troubles me, and I feel like it has a huge impact on patient care or our recovery as patients. I feel like it results in some of us not being cured from breast cancer, because you end up not knowing who your Oncologist is really. Till to date, I have no idea which one is my Oncologist. Each time I go I consult with a different Oncologist, which means that the last Oncologist that saw how bad my condition was the last time, won't get to see how much it has progressed. So that he/ she can come up with a solution.* (Participant 14: Public)

6.2.3.2 Oncologists responses to patient queries

While most participants reported their oncologists as taking the time to carefully answer patient queries, many reported feelings of being overwhelmed by the complex terminology and amount of information.

> *There were times when I wanted answers but still couldn't really understand the jargon. My oncologist is like a walking medical dictionary.* (Participant 13: Private)

> *That first visit to my oncologist, she shared a textbook rendition of everything that is breast cancer and what oncology is etc. It was overwhelming. I had the feeling of trying to take it all in but not knowing what she was saying. Once you leave your doctors rooms, it's your own recall that you rely on and you're in such a strange state of mind, you really don't remember everything. So, in later consultations, I would take a notepad and ask the oncologist if I could make notes because I forget these things. And subsequent to that I even started to record our consultations.* (Participant 6: Private)

When patient queries were ignored, one participant reported feeling frustrated and disempowered by the power dynamic and rushed engagement, leaving without having her questions answered.

> *I feel that some oncologists are not happy to listen to the patient. They are the powers that be. My first oncologist never really addressed my concerns; he didn't really answer my questions. You would go in and he would be talking. I would try to get some questions in and try to engage him on things that I've researched, but without success. I would sometimes email him ahead of time and ask him to look at something, but he would never even touch on those aspects. He might promise to get back to me but would never do so.* (Participant 9: Private)

6.2.3.3 A relationship requiring mutual confidence and trust

Participants described their breast cancer journey as a vulnerable time where utmost confidence in one's oncologist was important. This confidence was earned through honesty, evidence of excellent professional abilities, as well as genuine caring.

> *I had complete faith in [my oncologist]. I would say that building that trust was just as important as the treatment she was giving me. I needed that trust to feel that I was going to make it through this journey. And that respect is earned. You could see that her concern was my health. It wasn't her image or anything of that sort, it was a case of "You are the most important person to me. You're you are my patient", and she would convey that in the way that she spoke to me; in the way that she would research with me; and in the way that she took all the time to explain to me why I'm experiencing what I'm experiencing. Even now, in the follow up surveillance consultations, she would carefully explain the longer-term side-effects to me. She deals with it case by case because she said that no two breast cancer patients are the same, but she would make you feel that she had done research on your particular case and was not just dealing with you as she would with any breast cancer patient. In retrospect, I realize just having that confidence in my oncologist was just so phenomenally important. I think that doubting my oncologist would have just added to my anxiety.* (Participant 6: Private)

> *You have different family members, friends and professionals telling you different things and you have to decide who you are going to trust and put your faith in.* (Participant 13: Private)

One participant spoke about how a breach of trust came when critical truths about the histology report were dismissed and when treatment choices were later proven incorrect.

> *You can understand and have sympathy for the fact that that they have to follow the standard of care. However, some are not even doing that properly. I was not told the truth about the histology results. I was not offered radiation but later found out that I should have been, and I was offered chemotherapy when chemotherapy would not work on my kind of cancer. Either they knew that the chemo didn't work for my specific cancer, or they didn't know, but both cases would be cardinal sins for an oncologist.* (Participant 9: Private)

In spite of commenting on good relations with oncologists, two participants also admitted to not being completely honest with their oncologists.

> *I made the decision on my own, without anyone influencing me, that I needed to take back my life. I decided that I was going to be the one in control. I needed quality of life, and I wasn't getting that on the medication. I stopped taking any kind of medication [including IC3]. I also went to the gynaecologist because my menopause was so severe, and the gynaecologist was reluctant to give me hormonal patches but gave me a script to use after I had run it past my oncologist. But I was naughty and went and got it. I know what risks I am prepared to take. I'm going back to the gynaecologist in May and if I ever need to tell her I'm off IC3 and on patches I will, but at this point she doesn't know.* (Participant 13: Private)

6.2.3.4 Patient and doctor as collaborators in healing

Three participants spoke about collaborating with their oncologists in researching aspects of their personal care. Naturally this kind of doctor-patient partnership in information-gathering and exploration is only possible with patients who have some form of advanced academic training, as was the case in all three of these participants. However, it is commendable that the oncologists were willing to engage in this mutual exploration for the benefit of these patients (and possibly future patients). It is especially interesting because in these instances some integrative choices were being explored and incorporated.

> *I became the second explorer with her. She would discuss all my options, giving me the pros and cons and again considering me and my particular case. To me that was important. The decision making was very much done together. She has a very conversational way of engaging, and helping you deal with your reality whilst feeling confident that you can rely on the information that she is sharing with you which is so important. She asked me to please send her whatever I was reading. I would write to her, and she would write back to me, and we would share research articles. And in this way we moved from patient and doctor to information-sharing friends.* (Participant 6: Private)

> *I had come across an approach to cancer called "a Metabolic approach". I studied it in great detail and did a diagrammatic summary of how it worked. It is based on certain off-label drugs and supplements, and I didn't want to just take them unsupervised. When I went to see my oncologist, I showed it to her and explained a bit about how it worked. She was supportive but said I must wait until after radiation, at which point she was very, very helpful.* (Participant 9: Private)

> *I have my PhD so I know how to do research and I would read up on the internet, find out what I needed to do and chat to him about it. He would say to me "yes, no, do this". So, we had a little team going between him and I. it was very good. I think I was quite blessed in the experience that I had.* (Participant 3: Private)

6.2.4 Oncologist attitude towards holistic and complementary therapies

In speaking about how discussions on medical pluralism and incorporation of complementary therapies are received in the mainstream oncology environment, patients reported that mainstream discussions usually dominate. Discussions on aspects of holistic care such as nutrition and supplement use, inclusion of exercise and consideration of psychological wellbeing were often lacking, and examples of intentional integration by the oncologist were very limited. The integration of other complementary/alternative therapies such as acupuncture was extremely rare. In terms of discussions on all these matters, whether holistic or integrative, for the most part, these only happen when initiated by the patient, and responses ranged from very negative to quite receptive. (Please note that reporting on the differing levels of guidance patients received in holistic inclusions will be further elucidated in the second domain of enquiry 6.3 below).

6.2.4.1 Mainstream treatments dominate discussions

Most of the patient and oncologist discussions centered around mainstream medical treatment and not complementary holistic or integrative practices.

> *In my engagements with the oncologist and the oncology environment, the focus was mainly on the mainstream treatments. There's so much information that has to be communicated just with regard to these. It's massive!! They're trying to get you through that, and they've got 17 other patients at the same time. It is a time thing, but I never felt if I asked a question or brought something up that I was dismissed.* (Participant 5: Private)

6.2.4.2 Range of oncologist responses

Participants described a wide variety of oncologist attitudes to complementary practices. These attitudes ranged from complete opposition to support, with some oncologists advising patients to only utilise these practices after the completion of conventional treatments to avoid any potential interactions. One participant reported a negative experience where her oncologist suggested that the reoccurrence of her cancer was due to her use of complementary therapy. Although there were rare instances, where oncologists were open to exploring the introduction of other supporting therapies in a formal integrated fashion, there were no reports of a fully holistic and integrated experience by any of the participants.

> *He was not supportive. I went in with all my nutraceuticals, but when I spoke about them, he just said I was wasting all my money. And speaking about diet as well he would just say "Just cut out sugar a little bit, that's probably a good idea" but was [very off hand]. So, I had to explore the [complementary] therapies on my own.* (Participant 8: Private)
>
> *My first oncologist was entirely closed to complementary therapies. When you mention anything that is not conventional standard of care, he said he would come back to you but never did. When my cancer returned and I called him, he immediately attacked me saying it was due to the complementary therapies I had utilised. I was very angry because in fact the original histology report has stated that the tumour "abutted the deep excision margin" and I had queried both him and the surgeon repeatedly about tumour being left behind.* (Participant 9: Private)
>
> *Often when I asked [my oncologist] about things they would say there's not enough information. We don't know how this affects things. We don't know. And in the absence of that knowledge, we just have to avoid things. We know that when we add things to the chemo it can affects the chemo efficacy. We want full efficacy so don't take something else.* (Participant 5: Private)
>
> *I always spoke to my oncologist about all the different things I did, and she was always very supportive. Everything went through her, even the illegal stuff [cannabis]. For example, the other thing the blood lady said is that I should have Epsom salts baths and soak in them for 20 minutes and I checked with [my oncologist] and she said it was fine, but just to leave it till a few days after the chemo. She was always receptive and happy to discuss them. She referred me to the psychologists, and she also*

> *referred me for the genetic testing for nutritional approaches and to the dietician..* (Participant7: Private)
>
> *My new oncologist will discuss anything that you ask her, but she also assiduously follows standard of care approach. She is very au fait, in many instances, with natural substitutes that can be taken in lieu of cancer drugs, and she understands a lot of the biochemical reactions and so forth.* (Participant 9: Private)
>
> *My daughter is a qualified homeopath and came with me to the appointments and my oncologist was extremely open to collaborating with her in supporting me through this journey. I found her very, very, very open. Really fantastic. She also supported my use of IC3 instead of hormone blockers and said that as long as I let her monitor me, she was very happy with it.* (Participant 1: Private)

6.3 Domain 2: Additional Supporting Practices Reported

The supporting practices most frequently reported as being utilised by participants were dietary approaches, use of supplements, exercise, and psychological support. Many of these contribute to the holistic ideal whilst not deviating from the world of biomedicine. There was also reporting on the successful use of homeopathy, chiropractic, and energy healing practices such as BodyTalk. The confusion of navigating medical pluralism was expressed by many patients.

6.3.1 Dietary adjustments

The overwhelming majority of participants adopted dietary changes to seek wellness and support healing as part of their response to their cancer diagnosis. For some this included the incorporation of more fruit and vegetables with the exclusion of unhealthy options, while for others this included extensive reading and professional consultation. The need for better information provision to clear up confusion was expressed by both public as well as private participants.

6.3.1.1 Shifting the healthy eating patterns

Simple self-directed changes in favour of healthy eating were initiated by many participants. Several also utilised juicing or nutritional shakes to increase nutritional intake, with two participants doing so at the instruction of their oncologist.

> *I really started eating right. I had a lot of vegetables and fruits and really stuck to it. I stopped fizzy drinks and* mostly drank water. *I also drank warm water and fresh lemon juice every morning.* (Participant 11: Public)
>
> *Following my oncologists advice, I did juicing every day right through all my treatments. I must tell you; I looked better than I've ever looked before during that process. I got nice and thin and had a glowing skin so there was that benefit.* (Participant 1: Private)

6.3.1.2 Dietary eliminations

Sugar was widely viewed as something that should be avoided by cancer patients, yet participants could not meaningfully explain why this was the case. One mentioned getting the information on the matter from Google whilst another referenced their oncologist, stating that the oncologist said that "sugar feeds cancer".

> *Before diagnosis I used to drink a lot of cold drinks and eat a lot of chocolates. But when I was diagnosed I stopped all sugar completely. I actually went on Google, and I did a lot of research. A lot of it said stop sugar and that's what I did. When patients hear that they have cancer, I would say they need to stop the sugar. That's the killer.* (Participant 11: Public)

> *She said cut out all sugar. So even in the juicing, no apples. She said sugar feeds cancer.* (Participant 1: Private)

Three participants eliminated alcohol during treatments under instruction from their (different) oncologists.

> *That was the first thing my oncologist said to me. He said "I know you love your alcohol, but I need you to stop drinking from today. There will be no more alcohol".* (Participant 3: Private)

Several participants considered meat potentially problematic and practiced various levels of exclusion, including vegetarian and vegan diets. In some cases, where participants were concerned about the lack of protein or other nutrients, participants elected to consume hormone free meat which was viewed as less toxic.

> *I felt that I didn't want to have any hormones added to my body. I cut out meat and soya.* (Participant 2: Public)

> *I eat as clean a meat as I can find. I try and buy game because I feel they are wild animals that haven't been in any toxic environment.* (Participant 7: Private)

> *I went completely vegan and extreme on that side. Then I actually wasn't that healthy because I wasn't having the time to really plan my meals properly. After a conversation with my oncologist and a bit of anaemia. I'm not mostly plant based but I'll have an ostrich steak and I've relaxed a little bit.* (Participant 5: Private)

6.3.1.3 Dietician consultation

When seeking formal dietary guidance, not all patients found dietician consultation useful. However, private participants who visited nutritionists specialising in oncology support expressed greater levels of patient satisfaction due to the use of genetic tests to guide individually tailored recommendations.

> *I had genetic tests done to explore lifestyle aspects such as nutrition and based on the results of that test, she put me on a diet. She looks into aspects of relevance to cancer, inflammation, supplements and all those sorts of things. She was able to use my data and plan dietary approaches specifically tailored to me in consultation with [my oncologist].* (Participant 13: Private)

6.3.1.4 Reasons for using dietary approaches

For most participants, nutritional concerns and adaptations were underpinned by a firm belief that these choices were important for healing and wellbeing. Reasons for this varied but included factors such as BMI, potential toxicity, oestrogen-sensitivity, and general inflammatory processes into consideration in their approach. One participant described taking charge of her diet as ways to assert some control over her body in a life-threatening situation.

> *I think a lot has to do with what you're eating. Chemo definitely helps but it is also how you eat and how you look after your body that counts. Even for Christmas time I didn't have the Christmas fare. I set my mind that I'm going to get better.* (Participant 11: Public)
>
> *We're trying our best to detoxify our bodies, because we are exposed to so many toxins from chemo.* (Participant 2: Public)
>
> *I think that because of how I was eating, [I had far less nausea].* (Participant 3: Private)
>
> *I was trying to control this disease to prevent another recurrence. Learning about and utilising nutritional approaches was a means to control the situation. You're in freaking survival mode. I was looking for information, but I was panic seeking information. It was a case of "help me so I can survive", not "help me so that I can live a healthy life whilst I am alive".* (Participant 5: Private)
>
> *I did a Gene-pro test where it indicated that I'm very bad at detoxing. I realised pretty quickly that I needed to lose a little bit of weight as I was on the top end of the BMI. Weight loss became more of a health thing rather than a vanity thing. Then cutting out preservatives and additives too. On the converse I was also reading about the benefits of certain things and filling my body with more good stuff. It's to keep the general inflammation of the body down. Avoiding foods that you are intolerant or allergic to is important because of the inflammation that your body will constantly be in if you're having things that you are intolerant to which I think must affect the way your body can heal or deal with disease. So, it's one of my main tools. Feeding my body with as many nutrients and qualities of natural foods as I know I can.* (Participant 7: Private)

Although most participants viewed dietary changes as beneficial, a minority of participants were confident that the mainstream treatments were sufficient and dismissed the role that diet might play in their healing or wellbeing.

> *I'm not good with changing my diet and I haven't been careful with the kind of careful healthy choices I should make. But when my Letrozole finishes, I won't have that crutch of protection and I have to be worried about what I stuff into my face. At the moment I feel that the Letrozole is taking care of me inside [as far as recurrence is concerned]. I feel that when the Letrozole finishes, that my anxiety of a recurrence will increase, and I will need to adopt other approaches to keep my health. Participant 12: Private*
>
> *I experienced a fellow patient eating suckers. I told her it's not a good idea, but she dismissed it by saying that she was doing chemo, and that's good enough.* (Participant 7: Private)

6.3.1.5 Information seeking and provision

Private and public participants described different levels of both information seeking and information provision. There was a notable difference between the public and private sectors for both patient and practitioner engagements with the matter. Only one of the public sector participants received any guidance and it was minimal. Otherwise, public participants gained information via the use of the internet or ad hoc information sharing between patients in the clinic.

> *Nobody said anything about changing my diet. I was never told that I needed to stop eating this type of food and start eating that type of food. I was not advised.* (Participant 14: Public)

> *I just did research myself on Google and listened to videos of doctors talking about things and made my own decisions on diet etc. Then I tried to help fellow patients, people I could see were doing things incorrectly. One gentleman was eating chips and drinking coke and I tried to tell him it was not good because Coke has a lot of sugar in it and to start eating healthily. Some other ladies helped me with their health tips, and I exchanged my health tips.* (Participant 11: Public)

> *There was only this one nurse that was a little bit informative. But only if you asked. If you sat there ill informed, nobody really came to us and said anything.* (Participant 2: Public)

A public sector patient who a chef by vocation highlighted the need for additional guidance, as fellow breast cancer patients, desperate for information, sought advice from her.

> *They were turning to me because I've got a very good nutritional background because I'm a chef and I'd be very vocal. And if I'm speaking to the lady next to me, everybody is all ears. And the patients next to me made like a sort of group. People look for me when I came there. They wanted to sit next to me. I just felt that that people are starting to Google stuff, and I said to them that once you start Googling, you're all going to be misled. They were trying to get informed on their own by Googling and being very misled like "don't eat fruit". All facts about nutrition should come from the hospital and the hospital only.* (Participant 2: Public)

There was limited reporting of nutritional guidance at private oncology centres, although in some cases, helpful booklets were provided. A notable exception was by the oncologist who made referrals to a dietician specialising in patient oncology support. The same oncologist utilised nutrition as the first choice of action when blood cell counts were low, with a successful outcome.

> *We didn't [speak about nutrition], and I think I think maybe that's where they fall down a bit. My oncologist never discussed nutrition with me. All he basically said was that I must take vitamin D3 and was very adamant that alcohol can be detrimental to one's recovery but didn't speak to other aspects.* (Participant 10: Private)

> *I was given a booklet with basic nutritional information and was told to stay away from red meat because of hormonal injections given to cattle; eat lots of fresh vegetables; have less salt and sugar; eat oily fish and drink plenty of water.* (Participant 4: Private)

> *When I was doing the third or fourth Taxol my white blood cell count went quite low. My oncologist told me to eat lots of beetroot and broccoli and by the next week it was back to normal, and I was able to have my chemo.* (Participant 3: Private)

Several private patient participants sought out nutritional information via the internet, social media, and books. The wide array of information, however resulted in confusion as to which advice to follow.

> *I went into a frenzy of reading everything that I possibly could.* (Participant 9: Private)

> *I got my information from TV, Wikipedia, the Internet, but primarily from books. As a retired Librarian, I have done a lot of reading.* (Participant 4: Private)

> *I used internet and books. You just have to pick up YouTube on your device and there's so much stuff. Internet, and books. I did a lot of reading. I read a book about dairy and the China study which linked dairy in the Western diet to breast cancer and there's another book which talks about disease and inflammation and food.* (Participant 7: Private)

> *I had read so much about cancer, but there are about just as many approaches as there are cancers.* (Participant 9: Private)

> *When diagnosed I was trying to get rid of toxins and I didn't know what I could eat. I went through my whole kitchen and took out all the bad foods. Everything looked like poison to me. Everything!* (Participant 5: Private)

One private patient participant who had studied in the alternate field spoke about her approach which was to starve cancer through various pathways though nutritional choices combined with off label drugs, an approach she started after treatments under the guidance of her oncologist (see later as well under "supplements").

> *According to "The Metabolic Approach" research, if you starve cancer of glucose, it's going to move onto glutamine or fatty acids. That is the basis of the whole metabolic approach. 78 to 80% of the metabolic approach involves starving cancer of glucose, glutamine, and fatty acids. So, your next question would probably be "then, what can one eat in terms of your macros". The thing is you can eat sensibly and can eat all your macros, perhaps with the exception of the simple carbs but the off-label drugs will block the ability of the cancer to feed.* (Participant 9: Private)

In spite of access to quality resources and doing lots of reading, even the private patients spoke to the confusion that can arise and the need for guidance. Management of one's diet was viewed as complex with challenges in terms sustainability of changes as well as managing nutritional needs while undergoing chemotherapy. It was also noted that dietary requirements are not fixed and changed during different phases of treatment. This meant that diet could become an area of unbalanced hyperfocus.

> *The patients that had no appetite or the patients that couldn't get their nutrition, their full balance of nutrition. Not because they don't want to eat. It's because they don't have a zest to eat. They're sick. They're nauseous for days and can't eat. So how do the people [who can't eat] get nutrition? That's what I want to know. They could just get sicker and weaker.* (Participant 2: Public)

> *But I'm not going to guilt myself about it or about that odd slice of chocolate cake because life needs to be happy also and there's a little bit of happiness in that. I can do everything I can within my power to be healthy and living life, but I can't be a cancer patient every living moment being about what I am eating.* (Participant 5: Private)

6.3.2 Use of Supplements

6.3.2.1 Different inclusions and reasons

About half the participants referred to supplementation during their interview, including both private and government patients. This ranged from use of a basic multivitamin, through to fairly complex supplementation for the specific purpose of combating side effects or correcting for deficiencies as part of a tailored solution. The specific reasons for taking supplements included nausea (from chemotherapy); skeletal issues (caused by hormone blocking drugs); compromised immunity; depressed mood; fatigue; body toxicity; and addressing the underlying metabolic disturbances of cancer.

> *I'm a reasonably health-conscious person so I do take a lot of vitamins. It was definitely part of my approach to cancer, to keep up those vitamins.* (Participant 10: Private)
>
> *I did a lot of supplementations. Vitamins have been a big and consistent part of my journey.* (Participant 12: Private)
>
> *I found Essentiale to be utterly transformative in terms of [chemotherapy side effects]. It's milk thistle which is a liver support. I tell other people having chemo to take that and they've all said it makes a big difference.* (Participant 5: Private)
>
> *The metabolic approach incorporates ways of starving the cancer and there are different natural and pharmaceutical compounds that can do that, but they need to be used together because all the different cancer metabolic pathways need to be blocked.* (Participant 9: Private)

6.3.2.2 Companies promoting supplements

In some cases, supplements were taken under guidance of external private companies. These included companies who specialised in tailored supplementation for cancer patients and those who offer vitamin drips.

> *I did live blood analysis, where they take your blood and look at it under a microscope. The consultant got me onto quite high levels of vitamin B6 and fish oil and my mood and my tiredness improved. Their whole model is supplementation because I do think it is how they make their money, but it really did help. Even now I take the B6 and the fish oil, and I always have a stash of the vitamin C and the olive leaf tincture for detox. Participant 7: Private*
>
> *One of the key people that really helped me was from [a large nutraceutical company]. I know it's a commercial business selling supplements, but they have someone dedicated to oncology and she was absolutely brilliant. I had a blood test done for Vit B, Vit D and other things and then she advised me and gave me program of stuff to take, and I really stuck to it (Vitamin D, Vitamin B and then the green tea supplement (as an antioxidant) and Salvestrol that is very good and then omega as well. You take a lot of omegas). It was interesting over that time as we did more blood tests, to see how things were improving. She was just really good at what she did and supportive too.* (Participant 8: Private)

At times participants felt mislead by the marketing of expensive products that claimed to be effective against cancer.

> *I was doing the 50g vitamin C drips every two weeks or so. But I found a European study that found that for drips to be effective, it has to be three times a week at 50g or more. At that point it would have worked out to about R22 000 per month, and it would not be paid by medical aid. A lot of the drip bars that have opened, I have found, are giving miniscule amounts of vitamin C and touting this as a cancer treatment and in actual fact it could be causing more harm than good.* (Participant 9: Private)

Another participant from the public hospital reported using a product marketed as a stem cell supplement and claiming to be effective against a wide range of diseases, including cancer.

> *There's something that I used called Super Life. They told me that it cures cancer. The only problem is that it is an expensive medicine.* (Participant 14: Public)

6.3.2.3 Oncologist guidance

Oncologist guidance regarding supplements was very limited and centred around the inclusion of vitamin D and exclusion of vitamin C and E. Guidance concerning supplement use during treatments was essentially cautioning against use until treatments were completed. A public participant called for more detailed explanation about specific supplements rather than a blanket instruction to avoid all supplements during treatments.

> *One vitamin my oncologist insist I take is vitamin D3 for the bones, because you can definitely end up with bad osteo-arthritis, and that is exactly what I have. Of course, I have to have blood tests done every time I see him and then he checks my Vitamin D3 levels.* (Participant 10: Private)

> *The people in the chemo room would say "you mustn't take any supplements or anything like that because it might interfere with your treatment". I don't know how true that is. It's just a statement in the air. If you say to me "oh you can't take calcium" or "you can't take chromium". There should be information. We want information. You need to verify what you're saying. You need to say "oh, you can't take it because, you know what, calcium does this and that in the body when it's mixed with Amoxil". You need to verify what people mustn't do in terms of the treatment they're getting.* (Participant 2: Public)

On the other hand, another participant expressed reluctance to do anything independently, being happy to exercise complete exclusion of even basic supplements unless taken under the guidance of her oncologist.

> *And I am so aware now of the balance and control I now have on the oestrogen and don't feel I want to tamper with it. I don't want to take the risk of trying anything. I don't want to take responsibility on my own for that. If I were to feel that I might need something, I think I would have that discussion with my oncologist. I'm not going to experiment with anything unless I've has that discussion with my oncologist.* (Participant 6: Private)

One widely read participant incorporated a complex system of nutrition, supplementation and off label drugs which she initiated after the active treatments. This personal initiative was overseen and monitored by her oncologist.

> *In terms of the metabolic approach, I take certain off-label drugs. Largely it is supplements like curcumin and green tea and olive leaf and berberine. I get the information for supplementation from peer reviewed journals. We discussed it and she decided she would help me along as much as I needed, provided I kept her in the loop, and it doesn't clash with anything that she has to do by way of treatment.* (Participant 9: Private)

Three participants under the care of the same oncologist utilised Indole-3-carbinol as a natural alternative to hormone-blocking therapy. Two participants found the supplement satisfactory, but one participant discontinued use without disclosure to her oncologist.

> *The thought of Tamoxifen became a nightmare. I read everything possible about alternatives to tamoxifen. I think [my oncologist] realized how important it was to me and put me onto IC3 instead. We continued to look at oestrogen levels as she lowered the levels of indole-3-carbinol.* (Participant 6: Private)

> *My oncologist prescribed me something that is more of a natural alternative [IC3]. But was taking it but I still felt terrible, and I actually took the whole bottle and threw them in the bin. I didn't tell [my oncologist].* (Participant 13: Private)

6.3.3 Use of Cannabis

Nine participants referred to cannabis during their interview. Six of these patients utilised cannabis; two of them expressed that they wanted to use it but were cautioned against it; and one decided independently not to use it to be as moderate and normal in their practices as possible. There were different oncologist approaches to cannabis use described by the participants.

6.3.3.1 Reasons for cannabis use and non-use

Participants took cannabis with the hope that it would fight the cancer at a biological level, assist with insomnia, anxiety, and pain. In most cases, they were influenced to do so by friends and fellow patients, with limited access to reliable information.

> *At that time, everybody was talking about Cannabis and swearing by the efficacy of it. So, I tried it.* (Participant 12: Private)

> *I did start this medicinal cannabis. I didn't know what the composition was. I was just taking it because someone said take it. The person who brought the cannabis was a chemist, so he had some information, but he was also very anti-allopathic treatments, so I didn't like that. There was a conflict of views. I think everyone wants to give you their advice. You want to do the best thing you can to survive, but there's not enough information to know how it works. I believed it could help me battle the disease. I wanted to do whatever I could to rectify a system, a feeling, a thing that was out of control. I just felt like… "I can't control this", "What am I going to do?", "I have to do something". So, this was [one of] the things I did.* (Participant 5: Private)

> *I live on cannabis and have done so from the moment I was diagnosed. My husband wanted me to take it as he believes it can help fight the cancer, so he brought it up in one of my early appointments [and the oncologist supported its use]. I've been taking it for five years now and find it a great support. I mainly take it at night to help me sleep. Menopause can give you terrible insomnia and I was never the greatest sleeper to start off with. Sleep is absolutely imperative to me and I just can't cope without it. So, I rely on the cannabis.* (Participant 13: Private)

> *During chemo, [my oncologist] wanted to put me on sleeping tablets and I was trying to reduce as much toxicity as possible, so I discussed with her the possibility of taking cannabis as a way to sleep and reduce my anxiety rather than the sleeping tablets and she was fine with that. You just literally take like a pinhead size. I would take it just at bedtime to help me to sleep, which was working quite well for most of my treatment. There is definitely a place for it. Not just in the relaxing sleeping effects but also in the biological consequences that you read about in the studies and stuff it could be quite a good [drug].* (Participant 7: Private)

Participants who elected not to take cannabis did so due to concerns of lack of efficacy or potential interactions with conventional treatments. The underlying reasons for use or non-use were essentially the same: giving one's body the best chance against the cancer whether, according to the participant, this would best be achieved by inclusion or exclusion.

> *I didn't do the cannabis oil. A lot, a lot of the patients there do take it. I'd say probably quite a few of them are on the cannabis oil. I just chose not to because I was worried about it interfering with my chemo. That was my biggest fear. I was scared that it would counteract something, so I thought let me rather just leave it out.* (Participant 3: Private)

6.3.3.2 Sources of cannabis

It should be noted that some of the participants were utilising cannabis prior to legalization in South Africain September 2018, which meant illegally sourcing it from friends.

> *A friend of mine had sent me a bottle of cannabis oil drops. She dispenses from her supply and sells them in thin little vials for R10.* (Participant 12: Private)

> *I was told that [a particular pharmacy] sells that a medicine made from traditional/Zulu tobacco [cannabis].* (Participant 15: Public)

> *At first it was like really kind of cloak and dagger, in the stairwell, a thousand rand in your pocket kinda stuff, because it wasn't legal.* (Participant 5: Private)

6.3.3.3 Experiences using cannabis

While some participants reported positive experiences regarding anxiety and sleep, there were challenges with accurate dosing which could result in hallucinogenic effects or feeling 'high'. There were some reports of negative side effects, generally related to inaccurate dosage control of the cannabis.

> *It does help me sleep but I do experience nausea and dizziness as side effects. I have to be careful when I take it and how much I take.* (Participant 13: Private)

> *I found it quite tricky to get the amounts right. An extra little bit would come out of the syringe, and I would take it and then I'd be stoned.* (Participant 5: Private)

> *I must admit I don't think I'm a candidate for it, because I started having hallucinations even though the cannabis was supposed to exclude the THC.* (Participant 12: Private)

6.3.3.4 Oncologist guidance

When oncologists discussed cannabis use with the participants, it was always upon initiation by the patient. Oncologists expressed divergent views, with some participants reporting that their oncologists condoned cannabis use during their active treatments, whilst others were cautioned against use during conventional treatments.

> *She was actually quite supportive of it. She had her own research on cannabis and so she was happy for me to take it even during treatments to help me sleep.* (Participant 7: Private)

> *[When we asked the oncologist about it, she] responded positively and told me to start taking it straight away so that my body could become accustomed to it before all my treatments started.* (Participant 13: Private)

> *I did ask him once about using cannabis. He said to me, no, under no circumstances can I use it, because cannabis would interfere with his treatment. He made it very clear to me that there was no way that I*

> *would be allowed to go onto cannabis, and that if I choose to go onto cannabis, then I must stop the treatment, because the one would be interfering with the function of the other.* (Participant 10: Private)

> *I asked my oncologist, and he strongly advised me not to mix my medications and to wait for the five years of Letrozole to be completed. He didn't want the potential interactions between the cannabis and the Letrozole. I was committed because he was sincere in saying what he believed. I gave the cannabis to an elderly relative who was also diagnosed.* (Participant 12: Private)

6.3.4 Incorporation of Exercise

Approximately half of the participants incorporated some form of exercise intervention which was, in most cases, gentle (for example walking, yoga or Pilates). Those who made exercise an integral and important part of their journey, spoke to the tremendous benefits they had gained from this, with five referencing the positive impact it had on their mental wellbeing in addition to the physical benefits. While exercise allowed participants a sense of normality, for some the ability to continue was curbed by the side effects of active treatments. Only one participant was encouraged to keep active by their oncologist, however the focus was on shoulder mobility to prevent long term restriction from radiation damage. Most exercise was self-directed, although two participants utilised a biokineticist to get tailored advice.

> *I went for walks a lot of people after [treatments] can't move their arms, but I did the [arm exercises]. I had to prove I could. I think that continuing life as normal was very important for me. My biggest fear was being treated as a cancer patient. I didn't want to be labelled, and so I just wanted to carry on being a normal person. I didn't want to go into that little cocoon, so exercise helped. And it also helped proving to other people that I was normal. Participant 1: Private*

> *I promise you I would not have managed, and I would never had made it had I not been into my exercise. I would definitely advise that exercise is vital.* (Participant 13: Private)

> *The most important thing, even while I was having chemo, I went to the gym. I felt it was important for the detoxing and to avoid swelling. And it absolutely helped me psychologically! Your mind is off cancer.* (Participant 2: Public)

> *What had happened was that the Aromatase inhibitor had really caused arthralgia. I felt debilitated! I was being woken from sleep in the middle of the night from the pain. Every morning was an ordeal, even getting my feet on the ground, because it was so sore and unbearable and then hobbling about like I was 90 years old. A few weeks into resistance training, it started to improve and its made a big difference.* (Participant 8: Private)

Some participants spoke about the challenges to incorporating exercise which were mainly side effects of biomedical treatments.

> *For about six months after radiation, I was absolutely not capable of doing much at all. It hit me very, very badly.* (Participant 9: Private)

> *After the lumpectomy, I ended up with quite a serious infection at the wound and it was horrible, so for a long time I didn't do any exercise. It took me a while to get back to it.* (Participant 8: Private)

> *My implants cause quite a lot of pain and discomfort, so my training has had to change completely.* (Participant 13: Private)
>
> *I have osteoporosis, so my feet are collapsing, and they give me a lot of trouble.* (Participant 4: Private)

6.3.5 Psychological support

Many narratives gave insights into the kinds of emotional trauma patients suffer, and the challenges they and their families face which could be, or were in fact, ameliorated by the support and guidance of a psychologist. Of the sixteen patients interviewed, six reported attending formal counselling sessions with a professional. Several of the participants who did not receive psychological counselling stated that their need for emotional support was met through partners, friends and, in some cases, support groups.

6.3.5.1 Crisis of diagnosis

Diagnosis was viewed as a time of uncertainty and extremely stressful for not only the patients but also their loved ones. Participants felt overwhelmed about how to process the news as well as lost as to how to tell those closest to them. This was identified as key time where additional support would be beneficial.

> *Initially it's such a fearful experience because the unknown is very frightening. At the beginning, whether you show it or not, you go into a decline.* (Participant 1: Private)
>
> *I have never seen my husband that affected by anything. It was just as though everything was shattered. No matter where we looked, everything had changed. We didn't know what to expect or what to think. We just knew that I had been diagnosed with cancer. I think the shock had just frozen us both. Precisely how the news is broken to you as a huge impact on you. There needs to be some sort of support when this news is shared with you, or sharing of information about where you can go to find out more or get the support you need.* (Participant 6: Private)

Participants expressed feeling overwhelmed by many emotions including guilt and a fear of being a burden on their family, wondering what they could have done differently to prevent the disease.

> *During the period after my diagnosis, I really started questioning my life.* (Participant 10: Private)
>
> *I realized that I'm not going through all this alone. My family are going through this with me, and I felt so guilty. I felt as though I had put myself in this position and now was putting my husband, my son and all those who loved me, through this agony and pain with me. Suddenly you go through this re-examination of your life.* (Participant 6: Private)

6.3.5.2 Distress of active treatments

Emotional and psychological challenges related to the period of active treatments include the turmoil in going through a barrage of treatments; a lack of processing time, potential disfigurement and emotional loss associated with a mastectomy; fear of death; and the side effects of both chemotherapy and hormone blocking therapy such as depression and cognitive decline. Participants expressed a lack control over anything that was happening to them. (Loss of breasts will be dealt with under a separate heading).

> *Once you go into the rollercoaster of the various diagnostic explorations and treatments, they put you on this machine and then they slot you on the next machine, but it's not personal. You are just this person with cancer, and they just slot you along like a little train journey and I just think you're really in that crisis mode. And the handling isn't gentle. They're hurried, they're rushed. They don't see a person as a human being, and I think that's very demoralizing.* (Participant 1: Private)
>
> *I was terrified. Everything was just moving out of control. I felt like deer caught in the headlights and didn't know where to turn. I would feel like I'd handled the worst part, only to find out that it wasn't the worst part, and to discover that now I've got to go through more physical trauma, another obstacle to overcome. And there was no waiting to get your head around it. So, there was a huge lack of processing for me. It was just rolling with the punches and dodging bullets. In hindsight, it was very traumatic! And as you go, you just drag your family with you because no one else has the chance to process the whole thing either.* (Participant 13: Private)
>
> *At the time, you are processing so much. For me it was an absolutely crazy rollercoaster ride.* (Participant 3: Private)
>
> *I don't know whether it was just the long-term effects of chemo and or impact of what the two Zoladex injections had done to me, but I just wasn't coming out of the darkness, and I wasn't coming out of that tremendous ailing feeling that I had physically and psychologically. My mind was dark, and nobody could understand. It was the loneliest journey you could ever go on. My mind felt like it was failing.* (Participant 13: Private)

6.3.5.3 Grappling with a new identity

Participants struggled with the change of identity of becoming a 'cancer patient'. Physical changes like hair loss due to chemotherapy were difficult to hide and participants felt that people engaged with them in a different manner as they themselves did not know what to do.

> *Straight away people put you into a box and that's what you are now. Everyone looks at you as a cancer patient and it's a label.* (Participant 1: Private)
>
> *I felt that people were looking at me strange and they weren't prepared to confront me and ask how I was doing or if everything was OK. Nobody wanted to interact with me. They just side-stepped me and that was traumatic. I remember going to [the psychologist] and just crying and saying that people just look at me funny like I'm an alien to them. Even now, people don't know how to ask and just say "thinking of you" or "can I bring you something" or just some support. I felt that people's view of me had changed. Whether it was true or not I don't know. It was how I felt.* (Participant 7: Private)
>
> *When a person goes through chemotherapy, you must you go through this dreadful trauma of losing your hair. That for me was a big, big, big, big, big, big, big traumatic experience. Not just me. Ask anyone.* (Participant 2: Public)
>
> *One's cancer journey is also a long road of introspection, figuring out yourself. Who are you post cancer. You think nothing is going to change but after a diagnosis, you're never the same. I remember sitting there crying in the psychologist's rooms and saying that I thought cancer had changed me. The therapist said to me "Listen to me carefully. Cancer changes you! Do you not think for one moment it possibly could not." You need to look within yourself spiritually and emotionally, to understand how best to get through the traumas and injury.* (Participant 13: Private)

Participants described the trauma associated with the mutilation and/or loss of a breast/s, and how these impacts one's identity as a woman. While psychotherapy helped some participants to process these emotions, others were left to find their own way post-mastectomy with a view to feeling whole again, regaining their feminine dignity and navigating sexuality post cancer. Many did not receive guidance regarding prostheses.

> *When I initially went for counselling before the surgery, it was about the amputation. I was less worried about the actual cancer, and more worried that they were going to chop up my body. I believed that I was going to feel mutilated and didn't know how I was going to live with that. After the operation there was mourning, but interestingly enough up until the point when I had my reconstruction. Even though it's not perfect, somehow it just fixed something. I can't say I'm not reminded of it every day because I always will be, but it's not so bad now. After coming to terms with the mastectomy, the focus shifted to the fear of death…just like the overriding thing at a point, and still is.* (Participant 5: Private)

> *You are being totally disfigured. When you look into the mirror and you see what your breast looks like after that operation, it's very difficult. It must be 10 times worse after a mastectomy, but my whole breast has been totally mutilated. I now don't look in the mirror at all.* (Participant 10: Private)

> *A woman's breast is her sexual heart. It's something that makes you feel desirable as a woman. If you're in a relationship or if you're single and looking for a partner, how do you move on? How do you tell this partner that you've had a mastectomy? I'll use me for example because I'm single. I'm dating a guy at the moment but we're not intimate or anything because of this. So, there are people who need to accept this and how do you get people to accept this? You want to be accepted as a woman without a breast. That's why breast cancer survivors also need to be counselled regarding these matters. How do you find somebody who is mature enough? When you meet someone you don't tell them that you don't have a breast. You've got this prosthetic breast on, and you look all beautiful in pictures and how they see you. They fall in love with you, but you're too scared to tell the guy that you don't have a breast. It's an issue. Women need help on how to move forward in your relationship. Your husband and the family also need acceptance. Does he still desire you the way he desired you prior to your breast being removed? I'm talking post treatment when your hair has grown back but you still don't have a breast. You want to move on. You want to still feel like a woman again. Emotionally and spiritually within yourself in terms of your self-esteem you're not healed. We need to have that kind of information or that kind of assistance in terms of guiding women to make them feel like a woman again. I'm healed sitting here but I've got no breast and I'm full of scars. When you look at the scar on the outside when you're changing or having a bath, your scar opens on the inside. You look at yourself and you don't feel desirable at all! You've healed and "a breast is just a breast. But it's an intimate part of your body that's lost. It's not like he lost a finger. It's different. It's completely different and you will only feel that when it happens to you. And I don't know how to express to you in words how a woman feels when they undress. Once you're all dressed and covered, people out there don't know but the sad secret is that you know.* (Participant 2: Public)

6.3.5.4 Family struggles

Whilst some participants reported that they relied on their family for emotional support, this was not always the case. Some participants felt isolated from family members that either didn't understand their trauma or were unable able to process their own emotions regarding the disease. At times, this resulted in the patient trying to be strong for the family member, rather than caring for their own mental health.

> *When I was diagnosed, my husband just pulled away even more. He doesn't deal well with his own feelings and so he couldn't actually get in touch with the reality of my diagnosis. My youngest daughter*

> *developed severe separation anxiety. She couldn't sleep in her bed anymore. Her panic attacks are still so debilitating that some days she can't get up for school. My oldest tends to deal with everything on her own and internalizes everything. She started to self-harm. She started to cut herself. And that was one of my darkest hours ever. So, looking at things from my experience, the family needs help as much as the patient.* (Participant 13: Private)

6.3.5.5 Living in fear of cancer returning

Once in remission, participants struggled with the ever-present possibility of the cancer returning, trying to lead a normal life whilst being constantly aware of its fragility.

> *It's also still in the back of my mind. It is like that for any cancer patients. We know how easily the cancer can come back. We've all seen the realities of it.* (Participant 13: Private)

> *Most people probably don't think about their demise every day, but I do. I think it's something that makes you wake up, but it also is quite a burden. It keeps you alive, but it keeps you anxious. So, if you have not stared death in the face, you have no idea what that feels like, and you cannot know until you actually do stare death in the face. Once your life has changed in a second, you know it can happen on any day, and then you worry about those days. If I get any little ache or pain, I think the cancer had spread and have to talk myself through it. So, therapy helps with that as well.* (Participant 5: Private)

6.3.5.6 Sources of support

Some participants substituted or supplemented psychotherapy with support from fellow breast cancer patients who could empathise with them in a way that others could not. Others avoided survivor support groups due to fears of negativity or further labelling.

> *What I also did when I finished my treatment was to join a cancer support group. You share what you've been through, and you listen to what everyone else has been through, or is going through, and then you realize that you're not the only one that's going through all this.* (Participant 10: Private)

> *A fellow patient encouraged me to join the Cancer Support group that she had joined. I was actually not that keen because I was concerned about it being a negative space. I wondered if I put myself in a position like that, whether it would be traumatic for me. I just felt I didn't need more darkness, and I also didn't know if I could carry other people's burdens. But what struck me the most about my Cancer Support group was the fact that there was the exact opposite. There was actually too much positivity. I felt that everybody needed to come with their A-game and be all chipper and chirpy. But I joined the group and I have actually grown to love them all. We laughed a lot and sometimes cried, and we have watched people die, and watched others survive.* (Participant 13: Private)

> *Along my journey I met a lot of friends, and we formed a little group. We still chat now and again on WhatsApp. We share ideas about diet and share problems. Hearing their problems made my problems less.* (Participant 11: Public)

> *I just wanted life to be, as I said before "normal". I didn't want to think about cancer and talk about cancer. I tried going, I did try. I just found that everybody was talking about themselves and, I might sound strange, but for me saying "I'm a cancer survivor" felt like another label. I don't want to be labelled. And I didn't want to sit and talk about being sick or all the problems associated with that. I didn't want it. I just wanted life to be, as I said before "normal". I didn't want to think about cancer and talk about cancer.* (Participant 1: Private)

While some participants reported that they relied on their family for emotional support, this was not always the case. Some participants felt isolated from family members that either didn't understand their trauma or were unable able to process their own emotions regarding the disease. At times, this resulted in the patient trying to be strong for the family member, rather than caring for their own mental health.

> *My one daughter.... she actually didn't want to know this was me. She found it difficult. She was avoiding the whole subject and not wanting to think about it.* (Participant 1: Private)

> *The support that I was getting from home was enough because my sister was there. And my husband was there supporting me as well. But I do believe there is a need for structured support programs. Sometimes we would have conversations amongst each other as patients. And often at times I would realise that some individuals do not even have support from their families. For instance, there would be a patient who comes for their treatment, and they are so weak. You can see that they are really sick and can barely walk, but they came to hospital alone. No family member accompanied them, even though someone should have come with them. Perhaps she needs some emotional support, but she has no one who can offer that. She has no one who can walk this journey with her. (Participant 16: Public)*

Some participants felt that loved ones were also coping with the trauma of the diagnosis and that professionals with experience or training in psycho-oncology were better equipped to support patients in a less emotional manner. Participants generally reported positive experiences with psychotherapy and felt it helped them to process their personal trauma and gave them emotional strength. Only one participant had been referred to the psychologist by her oncologist. This psychologist worked in conjunction with the oncologist as part of the practise. Several participants referred to additional steps they took to manage their stress, reporting positive impacts of life coaching, trips to nature, mindfulness, journalling, and creative processes like art.

> *I think there is a lack of understanding and support for the needs of patients and their families. People need to be taken through the process properly.* (Participant 13: Private)

> *I think the weight of the emotional stuff should be taken to a professional. Partners and friends can't carry it all. Most definitely. They should be part of the team. There is definitely a role for psychotherapy on this journey. It's been absolutely integral to my coping and healing.* (Participant 5: Private)

> *During that time, I was seeing a psychologist recommended by the oncologist who actually practiced at the oncology practice. She was a cancer specialist psychologist.* (Participant 7: Private)

6.3.6 Spirituality

Approximately half of the participants referred to the positive role that spirituality played in their journey. For some, spirituality offered comfort at difficult times, while others felt guided to the information they needed.

> *I am definitely spiritually inclined. I have a belief in, and connection with the divine and my spirituality supported me in this journey a lot.* (Participant 12: Private)

> *I am an individual that prays often. I also went to church for prayers and the congregants of the church use to pray for me.* (Participant 15: Public)

> *I started reading a lot of books on religion. This reading started pushing me into seeking something more than what I had experienced in life thus far and I ended up joining a church.* (Participant 10: Private)
>
> *I went to two psychics and they both said my cancer won't come back.* (Participant 1: Private)
>
> *I have faith and I pray. I believe emphatically in the power of the mind, the power of the spirit, the power of the body and the power of your attitude.* (Participant 13: Private)
>
> *I have never prayed so hard in my life and there was a strange kind of strength. It was definitely a spiritual thing. Waiting to be wheeled into the operating theatre, I had resigned myself to [place myself into God's hands and trust that he would look after me].* (Participant 6: Private)
>
> *I started delving into meditation. After I had healed a bit from my second operation, I was thinking about what to do next and decided to just "put it out there" to find guidance asking the universe to point me in the right direction. And the next day, I came across this book [how to starve cancer using the metabolic approach]. I started reading it and what unfolded for me was the paradigm I had so desperately been looking for, for so many years. And so, for me, in a sense, it was beyond an epiphany, and it created a framework to me to understand how cancer needed to be approached.* (Participant 9: Private)

6.3.7 Other additional therapies

While participants spoke at length about the holistic inclusions of diet, supplements, exercise, and spirituality, there were fewer examples of patients integrating other TCAM practices. There were instances of consultations with chiropractors, energy healers, acupuncturists, homeopaths, and massage therapists. Two participants spoke about actively seeking to eliminate toxins from their environment as an additional approach in managing their cancer.

The participants who utilised chiropractic treatment, did so for musculoskeletal issues, energy balancing and emotional support. Both reported a positive experience. These same participants also utilised energy healers and found it very physically and emotionally helpful.

> *I had chiropractic treatments. It is just so good for the alignment and has been an important part of my cancer journey. It affects muscular-skeletal function as well as energy flow. I intentionally do it for both reasons. You can actually feel the release of stuck energy.* (Participant 12: Private)
>
> *I went to a chiropractor who specialises in craniosacral acupuncture and more energy-derived interventions. I saw him every two weeks the whole way through my treatments. It definitely helped.* (Participant 7: Private)
>
> *I have a lot of healing done by [an energy healer]. She does a combination of meridian therapy and Reiki therapy. Afterwards you can really feel that you have had a treatment. I see her when I need her every few months. I have found it very helpful.* (Participant 12: Private)

Five of the patients interviewed had utilised homeopathy as an adjunctive therapy to help them with side effects from the conventional treatments. These participants reported that their homoeopaths had told them to comply with their oncologist’s instructions and to inform them of the complementary treatment.

> *Homeopathy was most definitely my biggest supporting therapy. I was prepared for the worst and pleasantly surprised. My skin was not damaged by the radiation, and I did not get tired at all.* (Participant 1: Private)
>
> *Shortly after my diagnosis, I went to see a homeopath. He said that he could help me with the side effects of treatments like skin eruptions, but that I must follow the prescribed treatment plan of the oncologist. I appreciated his frankness and his honesty, and that I wasn’t given false hope of an alternative.* (Participant 6: Private)
>
> *I went to for general healing and emotional support for the trauma and for side effects (for sleep I was having trouble sleeping). It was just always another support mechanism.* (Participant 7: Private)

Although massage was the highest reported inclusion by private patients in the quantitative phase of the research, in the qualitative phase only three participants reported its use. Two referred to lymphatic massage, one to reflexology and one to massage for fascia release. One of these participants is a trained somatology practitioner and chooses to do lymphatic massage on her own breast and arm, whilst for another participant, their oncologist cautioned against lymphatic massage during chemotherapy.

> *My ankles got quite swollen, and I had lymphatic swelling in my one arm from the mastectomy. The nurses at the oncology centre asked me if I had thought of reflexology or lymphatic massage. My oncologist was a bit worried about doing lymphatic massage during chemotherapy, but he approved the reflexology. AAAh it was amazing!!* (Participant 3: Private)

6.3.8 Confusion in navigating pluralism

Participants expressed a desire to explore as many treatment options as possible to fight their breast cancer but described the pluralistic medical landscape and all its offerings as overwhelming and confusing.

> *I personally added these extra things that because if you are diagnosed with a disease, you want to try everything or anything that could possibly help you recover.* (Participant 15: Public)
>
> *I think I turned to these extra practices out of necessity as well. Let's face it, if we take a look at the stats on cancer, they're not the best. There is no magic bullet as far as cancer treatments go. But then I've also realized, looking at things objectively, there isn't a magical magic bullet on the natural side either. You get a lot of fly-by-night doctors that are claiming to have ways to get rid of cancer. A lot, a lot of natural stuff is touted, and people are dragged into it, and they are misled.* (Participant 9: Private)
>
> *Knowing what to do and not do is so confusing. Just doing what you’re doing for the mainstream treatments and feeling so [absolutely terrible] is tough. And people did tell me to do other things Everyone knows how to fix you. Everybody. Everybody!! It's natural for people to run around and want to take things to help themselves so they need information on what to do or not do.* (Participant 5: Private)
>
> *There were so many conflicting pieces of information. Everything is so unfamiliar that you just feel extremely, extremely vulnerable.* (Participant 6: Private)

6.4 Domain 3: Conceptualizing Holistic Needs

The themes and supporting quotes reported in the first two domains have provided numerous insights into what participants did or would like to have included in their cancer journey. Most participants felt the need to augment their mainstream treatments, to support healing, but experienced confusion when navigating the pluralistic environment. While there were efforts among oncologists to provide patients with additional information and referrals when necessary, participants in this study called for better empowerment through information provision and support in holistic lifestyle choices and practices. Also present, although less prevalent, were patients' considerations of those complementary therapies that could be considered more integrative than simply holistic. This chapter will now present some of the excerpts which throw additional light on these and other matters related to the patient vision of the holistic ideal.

6.4.1 Co-ordinated patient care

Although many public patients receive the co-ordinated care of a multi-disciplinary team, patient narratives revealed that many public and most private patients do not. This added to the stress of making important decisions at in the early phases of treatment. Two participants suggested that there should be better co-ordination and guidance available for patients as early as from the point of scans and biopsies, and that oncology centres should have a case manager who would act as a central contact point for patients, especially as regards integration of supporting therapies at critical times.

> *You need coordination of many people in a team. A general surgeon, a plastic surgeon, an oncologist, and somebody overseeing all of these other people. The amount of ball dropping that happens within that sequence is of concern. Just having someone within that sequence of events who can oversee all that and connect all those people together....a centre that you go to that has the ability to coordinate or put you in touch with what best suits your lifestyle with regards choice of oncologist and advice about alternative therapies. If things are being overseen from early, then integration of supporting therapies at critical times becomes easier. I had a physiotherapist who was contracted to my oncology centre, so straight after my mastectomy she came straight to the hospital.* (Participant 5: Private)

> *In the early days, patients need someone to allay their fears. I think someone to sit and talk to you. If things can be explained very clearly in layman's terms from the beginning and options laid out so you don't have to go and try to research it all yourself. So that you're empowered to make decisions. (Participant 8: Private)*

6.4.2 Empowerment through information provision

Many patients called for better empowerment through provision of information and recommendations.

> *There is the need for more guidance because people don't know. A kind of a go-to place would be lovely, where information and recommendations are available to guide people and help them in their*

> *whole treatment journey. The kind of support that can be given to women going through cancer treatments, when they are feeling so lost and disenfranchised.* (Participant 3: Private)
>
> *Patients need advice in terms of what you can do or can't do. I was given a few bullet points but when you read those, there are so many questions that arise. Patients need someone who can actually sit with them after their or treatment and explains things carefully, and who you can contact if you need something or have a query.* (Participant 8: Private)
>
> *I think it would be nice to have an inventory available of all the people who can give you help like counsellors, nutritionists, Reiki and so on.* (Participant 4: Private)
>
> *There were no clear guidelines for nutrition or anything to do with exercise or anything else. I would have loved more support and advice there.* (Participant 7: Private)
>
> *Nothing was said by any of the Oncologists about any additional things that I can do.* (Participant 14: Public)
>
> *We never got guidance about additional factors like lifestyle from these oncologists. The information is not enough make progress on decisions on lifestyle; food choices; and how to prevent cancer the next time. We just live in limbo hoping nothing happens.* (Participant 2: Public)

Whilst information provision in many areas is of great importance, it is also important to consider the timing of information according to the changing needs of patients along the cancer continuum.

> *I was given this booklet, but it was the most depressing booklet I've ever read. I came home, read it and I threw it in the bin. I thought I'm not even looking at this again. It was very depressing. It was like "preparing to die" and "writing your will". I think it's one of the most terrible things to give someone newly diagnosed with cancer. You don't want to read all that stuff at that point. It should be talking about the possibilities and supporting practices in order to make it less of a threatening thing. Outlining the most positive way to deal with it, so you don't just go into this decline.* (Participant 1: Private)

6.4.3 A holistic cancer centre

Participants identified participants lifestyle and self-help approaches, including nutritional support practices, exercise, mind-body practices (including yoga), massage and psychological support as beneficial inclusions to a holistic oncology centre. This would allow for case management that was tailored to the individual. One participant spoke to the need for integration of evidence-based therapies such as homeopathy or mistletoe therapy.

> *A holistic unit needs different kinds of professionals there to help you such as a nutritionist and physiotherapist, but also promotion of additional practices like mindfulness, exercise etc. but all in parallel with the medical interventions.* (Participant 8: Private)
>
> *For me, all the different approaches (like exercise; breathing techniques; massage; yoga and meditation) help. I absolutely think these sorts of things should be part of a holistic plan. And definitely the psychological aspect needs support too. It becomes very overwhelming.* (Participant 13: Private)
>
> *I think for holistic care, it needs to take everything into consideration. Definitely some kind of dietician or nutritionist needs to be involved. They should have some kind of psychologist or counselling available, and yoga would be amazing. Also, lymphatic massage or even just massage treatment that*

> *you could go to where they know how to do it. I really think it would have such a huge benefit and wish more people would be open to this kind of thing.* (Participant 3: Private)

In addition, participants called for participant support with basic practical challenges such as wound management and prostheses sourcing to alleviate stress.

> *Even something simple like wound management. You know, when I left the hospital, had no idea what to do. I tried to do all for myself, and at times it was really difficult. And then I ended up with infection. These basic practical things lead to and compound the emotional stresses.* (Participant 8: Private)

> *What about prosthesis? Nobody ever came to me and said, oh, we are offering these prosthetic breasts. I just stumbled on that. Nobody even told me that you can get one at the hospital now. They were giving all these soft ones. Yeah, my thing is this. Hospitals get funded. Why can't they give woman dignity and give them proper prosthetic breasts while waiting for reconstruction operation?* (Participant 2: Public)

Participants described their 'ideal' holistic cancer centre as a place of positivity, where the patients could feel 'normal' and would focus on the improvement of health rather than the fighting of disease.

> *We need to be challenging and encouraging people to carry on living a normal life. Draw people into things where they could do positive things. If people can just see a future and see that life can be normal.* (Participant 1: Private)

Finally, several participants acknowledged that one carries a cancer diagnosis forever, which calls for support beyond active treatment. This is a time when patients attempt to regain their strength, process their trauma, and learn to live fully and healthily as a cancer survivor, yet it was reported as the time when patients felt the sudden loss of formalised support due to being declared disease free.

> *I definitely felt the need for more support when the treatments fell away. When they told me I'll now have an oncology visit every six months, I thought "What are you talking about every six months? Who's going to look after me?". I had been looked after through my mainstream treatments and knew that my body still needed support. I was out of the storm of panic, out of the race for survival. I wanted to live a healthy calm, peaceful life but there was no support anymore. So, I think maybe there needs to be that sort of support system for when you finish your mainstream treatments would make a lot of sense, and you could give it your full attention.* (Participant 5: Private)

6.5 Summary of Chapter 6

Chapter 6 outlined the thematic areas (together with supporting quotes) that emerged from the patient qualitative data. These were presented according to the three domains of enquiry: The patient experiences in the mainstream oncology environment; the use of additional supporting practices by patients; and the patient conceptualization of holistic needs.

In the first domain, participants reported a need for more co-ordination and support in the very early days, from biopsy, through critical treatment choices and selection of oncologist. It was revealed as a time of vulnerability and exploration of pluralism. They also spoke to the well-known side effects of mainstream treatments which continue to cause suffering, which for some is debilitating. The doctor-patient relationship came through strongly in the patient narratives as being of great importance, whether impacting their experience positively or negatively. Genuine care, ample unhurried time investment and thorough addressing of patient questions and concerns were core needs in the relationship. Participant reporting made it clear that most oncologists remain very strongly in the biomedical model, with a focus on mainstream treatments and very limited inclusion of holistic practices, or integration of complementary therapies. However, several narratives did reveal that some oncologists are open to exploring supporting therapies whether biomedical or from the world of alternative medicine. Some were even willing, where the patients have suitable capacity, to engage with them as partner in decision making wherever possible and as co-researchers in exploring some aspects of the ever-growing evidence base.

The second domain gave insight into the many efforts on the part of patients to include holistic practices as well as additional therapies that they believed would improve both physical and emotional recovery. There was a marked difference between public and private participants in terms of information provision, information seeking as well as actions taken with respect to nutrition. Besides a shift to healthier choices, participants also reported elimination of certain foods including sugar and meat, believing that these can impact oncogenesis. There was limited oncologist instruction regarding diet, and most participants incorporated dietary changes in a self-directed fashion, although a few were referred to dieticians. Within these referrals, dieticians specialising in oncology proved to be the most helpful. Most participants interviewed believed diet to be important in managing their cancer journey. However, navigating this alone via different sources of information from friends, fellow patients and the internet resulted in conflicting recommendations. There was a call by many of participants for more clarity regarding nutrition, and a reassurance that they are approaching things correctly and not excluding important or even critical considerations.

Interviews also revealed a variety of patient approaches to supplement use. Some simply used basic supplementation whilst others either consulted with supplement companies or did their own reading to explore the use of supplements in fighting cancer. There were instances of misguided use such as vitamin C infusions or stem-cell supplements claiming to cure cancer. Supplement use was with a view to supporting the body in fighting the cancer or combatting specific side effects of the treatments. In one case, a complex metabolic approach was being utilised as a biochemical approach to curbing oncogenesis. There was once again limited guidance from the oncology practitioners regarding what to include or avoid. Thus many of the patients interviewed made independent choices, utilizing personal knowledge/reading, or advice of supplement companies. As was the case for diet, there was a call for better and more comprehensive advice regarding supplements and their safe integration into cancer management.

All participants had heard about cannabis and made a personal choice for or against its use. When excluded, this was done with the intention of maximising healing. When included, it was also done with the intention of maximising healing. In addition, it was used for coping with side effects of cancer and its treatments. All cannabis conversations with oncologists were initiated by the patients and oncologist views on its use were divergent. Sources of the cannabis were varied and sometimes questionable, as was dosage. Some negative side-effects were experienced by several patients.

In terms of psychological support, every patient interview included reference to the emotional distress associated with the cancer diagnosis, treatment, and post-treatment recovery. Management of this distress varied from individual to individual. For some, emotional support needs were fulfilled by family and friends, and/or support groups. For others, professional counselling was a vital part of coping and healing along their journey. Challenges included the crisis of diagnosis, the rapid rollercoaster ride of treatments without time for processing, dealing with a changed identity, particularly in the case of mastectomy patients, and living with the fear of the cancer returning.

Where exercise was incorporated it was viewed as very beneficial and even imperative inclusion. Narratives spoke strongly to the psychological journey patients experience and the great need for psychological support at different times of the process. Spirituality was also a very important aspect for many participants. In these practices we see patients actively striving to include holistic practices. Aside from these, patients also incorporated consultations with therapists outside of the mainstream arena with a view to supporting healing. Participants found the pluralistic medical landscape to be confusing and the lack of information provision regarding additional approaches and supporting practices to be disempowering.

The third domain presented insights into patient views on what is needed for holistic patient-centred care. These views revealed that the need for better patient support begins at diagnosis, where coordination of processes and guidance in choices is lacking for private patients. The domain then went on to present patient quotes that emphasised the need for empowerment through better information provision. It continued by elucidating patient views on the kinds of offerings a holistic cancer centre should include, which echoed the same holistic inclusions reported in domain two.

7. ONCOLOGIST QUALITATIVE RESULTS

In this chapter, oncologist interview data will be presented according to the main domains of enquiry as presented in 7.1 below. Summaries of findings, together with supporting quotes, will be organized under headings sub-headings that reflect the domains of enquiry as well as themes which emerged during analysis.

7.1 The Interview Population and Domains of Enquiry

7.1.1 The interview population

Five of the original 18 oncologists consented to be interviewed, with each interview lasting between 1 and 1.5 hours. Four of the oncologists were from the private sector and one was from the government sector, although all had experience working in the government sector. Numerous attempts to obtain further participation were unsuccessful. However, upon analysis, saturation was evident, lending the necessary trustworthiness to the findings.

7.1.2 The domains of enquiry

The thematic analysis reported in this chapter reflects four main domains of enquiry as set out in figure 7.1 below. The first domain of enquiry was the holistic considerations that came through strongly in the patient interviews. Starting with exploring oncologist views on the role of diet and supplements in oncology, the first domain went on to explore oncologist views of the role of exercise, psychological and spiritual support. The researcher also needed more insight into oncologist opinion on, and experiences of, TCAM practitioners. This was with a view to ascertaining whether oncologists felt these practitioners have a role to play in oncology. This formed the second domain of enquiry. The third domain of enquiry concerned oncologists' opinion of the formalized field of Integrative Oncology, and whether they believe there is potential for its growth in the local setting. Lastly, due to the disparate nature of medical services in the country, as well as the disparity of TCAM usage patterns revealed in the quantitative phase of the research, it was decided to ask for comment on the divide between the government and private sector. This was with a view to supporting the quantitative findings with deeper insights from these experienced professionals. This formed the fourth and final domain.

The resulting oncologist narratives were dense and contained valuable insights. Where longer extracts were imported, this was to maintain context, provide detail, and reflect the fullness of the professional opinion of these critical role-players in the oncology arena.

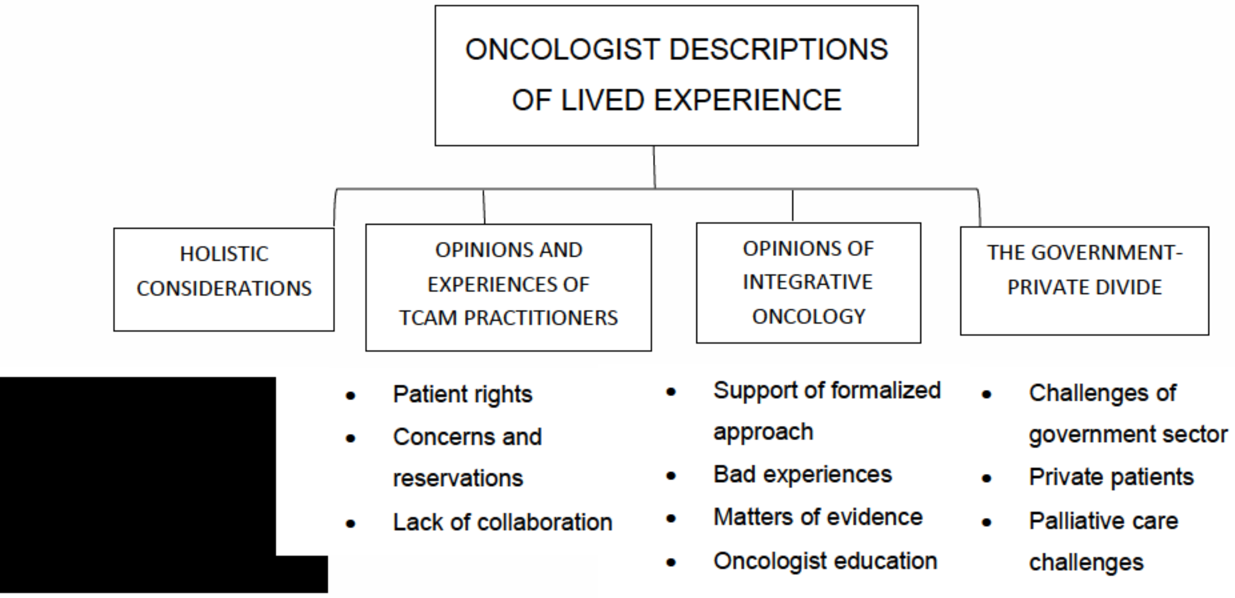


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Figure 7.1: Outline of thematic areas which emerged from the oncologist qualitative data.

7.2 Domain 1: Holistic Considerations

7.2.1 Nutrition

7.2.1.1 The importance of nutrition in oncology

There was a consensus amongst most practitioners that good nutrition has an important role to play in oncology, and that for anyone, good health relies on good nutrition.

> *I think diet does play an important role. I think just overall from a health perspective, nutrition is extremely important. With cancer in particular, nutrition plays a very vital role.* (Oncologist 3)

The large metabolic impacts of the cancer itself, as well as the impacts of the biomedical treatments, were raised as critical factors underpinning the significance of nutrition in oncology, and the importance of addressing it with every patient. There is a need to ensure that the patient remains in a relatively good nutritional state as you cannot treat a malnourished patient. It is important both in tolerance and recovery.

> *I do believe diet plays a very strong role in tolerating and recovering from treatments. But it does not directly impact the cancer and the cancer cells.* (Oncologist 4)

> *Nutritional support is important in order to maintain the BMI within normal range as well as maintaining muscle mass. It's very important to understand that cancer changes the metabolism.*

> *Cancer puts the body into a catabolic state. It robs the body of nutrients for its own needs and can severely deplete the nutritional status of the body. We need to compensate for that catabolic state because you cannot treat a malnourished patient. If a patient is severely malnourished, we need to admit them to hospital to give them nutritional support to strengthen them for treatment. A patient in a better nutritional state tolerates treatment much better. We are giving the body poisons, so we need a good body composition to stand up to that toxicity. There is likely also a need for increased metabolic intake to maintain the energy index for the purposes of fighting the cancer.* (Oncologist 5)

The role played by diet in preventing cancer was raised by two oncologists, with one stating that it is a more important consideration in the preventive setting than in the therapeutic setting, as at that point, the “horse has bolted”. Once there is a cancer diagnosis, there are “other considerations”.

> *Patients take a lot of interest in the dietary aspects. Unfortunately, I think it's too little, too late. A lot of them think that they can influence the growth of the cancer through diet, and they can’t. A lot of the dietary advice out there should be put into a preventative context. Diet does play a role in the development of cancer, but once it's developed, the horse has bolted. The cancer is there and you’re not going to change the behavior of the cancer through diet.* (Oncologist 4)

7.2.1.2 Management of nutritional considerations

When the topic of nutrition was raised, most of the oncologists interviewed spoke of an awareness of the fact that many patients have questions and concerns regarding what needs to be done, or what can be done, in this area. There was also an acknowledgement of the plethora of, often misguided, information to be found in the media, and that this can be confusing for patients. One oncologist expressed the opinion that it is an area where patients can gain a sense of control in a disease that has made them feel out of control.

> *Interestingly, Nutrition is probably one of the first questions that comes up when you've discussed the treatment plan with the patient. It is one of the biggest factors that patients and their families are very concerned about from the beginning of the journey right through into palliative care.* (Oncologist 2)
>
> *Over the years I've learned to expect that patients will ask about it. Patients will Google, they'll talk with family, friends, etcetera and there's a lot of incorrect information that can also be channeled through via those ways. So, I think it's something that should be addressed and it's very important.* (Oncologist 3)
>
> *I think patient’s need for dietary intervention is largely driven by the fact that it gives them a sense of control over a disease that has made them feel out of control. Nutrition is something that they can control, and I think that's where a lot of the focus comes from. And I'm not saying that it's not important. I think that good nutrition is important. There's no question about that.* (Oncologist 1)

When referring to management of nutritional considerations in patient care, several oncologists mentioned referring to, or collaborating with, registered dieticians, believing that these professionals have a vital role to play in oncology. They felt that where possible, this should be a dietician specializing in oncology nutrition, as it has unique challenges. Whilst dietician consultation was considered the ideal way to manage the nutrition of patients, it was acknowledged that this is not always possible due to various limitations. This is especially the case in the public/government sector where system constraints curtail access. There was the opinion that most practitioners in their field would speak to their patients about nutrition themselves, but that this tends to be general as it is difficult to manage the detailed specifics of all patients. These conversations are limited, especially in the government sector, where time constraints result in very limited patient education.

> *I have dieticians working with me to guide my patients in different nutritional aspects and every patient of mine has a dietician consultation. Every patient! For those patients who are hospitalized, it is also a standing order that my patients see the dietician whilst in the ward….I believe dieticians have a very important role to play in oncology.* (Oncologist 5)
>
> *I regularly collaborate with a nutritionist, and I think it should be standard…But unfortunately, not all medical aids allow for it, so there have been some patients who haven't benefited from having even that little bit of input to help them understand the role of diet and nutrition.* (Oncologist 2)
>
> *Addressing nutrition in the public sector is even more difficult. This is because of the tremendous lack of resources and difficulty in accessing dietitian appointments for the number of patients that we have. …We do get asked questions on nutrition ….but we often have to bring it down to a few-minute talk…I really feel that we don't do it justice. …There is a lack of knowledge for patients as a result. When trying to get an appointment for the dietitians, we are often told that they are resource-constrained and to only send the patients that really require them the most. (Oncologist 2)*
>
> *I do believe all oncologists will give some dietary advice themselves, but I think we keep it quite broad and general….I absolutely think there is a need for nutritionists specializing in oncology…Cancer puts a unique metabolic strain on the patients and the dietitians or nutritionists can support that. Nutrition is a very broad topic. Everything from high performance sport to our cancer patients. I don't think anyone can claim to know everything about all those specializations. If they do make such a claim, perhaps they do not completely understand the complexities of the topic.* (Oncologist 4)

7.2.1.3 Dietary exclusions

Regarding the dietary exclusions that some patients practice, the oncologists referred repeatedly to the lack of adequate evidence. One oncologist highlighting the potential for misinterpretation of epidemiological nutrition studies that "have a number of potential flaws" whilst "it's very difficult to do randomized control studies with anything nutritional". None of the oncologists interviewed believed that hormones in certain foods such as meat and dairy were of real concern. The notion that "sugar feeds cancer" was addressed as an "urban myth" and an "oversimplification" within a complex metabolic picture. The oncologists emphasised instead the links between all high glycaemic load foods, the constant cycles of insulin spikes and eating, potentially resulting in insulin resistance, high insulin levels and obesity, which are true concerns in oncology. Linked to this, one oncologist raised the issue of ketogenic diets, stating that, whilst they can be helpful in the preventive setting, cancer patients are already in a ketogenic state and ketogenic diets could make things worse.

> *My field of interest is breast cancer, and the only really consistent dietary factor that seems to be a risk factor is alcohol and none of the other things that are routinely talked about on the Internet are likely to be realistic factors. it's a very complex area, from the point of view that scientifically determining the impact of nutrition is difficult and is mostly done through epidemiological studies which have a number of potential flaws in them….What we understanding more and more is that*

> *obesity is the major driver. ..if we can control weight post diagnosis it does reduce the risk of relapse. Sugar is a big thing on the Internet, but it's largely, I think, misinterpreted. This whole concept that sugar feeds cancer is a is a total oversimplification of things. …The primary problem was high glycaemic index foods is that you end up eating a lot more of them because you get hungry again quickly, and with these high insulin levels, a lot of that blood glucose is then converted into fat. So, it's coming back again to the whole obesity story. The second part is that having high glycaemic index foods and the resultant stimulation of the pancreas results in insulin resistance. You end up with a higher level of circulating insulin and there are some cancers that have insulin-like growth factors. So that may not be good for certain cancers.* (Oncologist 1)

> *Exclusion of meat or dairy due to hormones is nonsense. Exclusion of sugar is also utter nonsense. The cancer will utilise other pathways to produce sugar on its own. Whether you starve yourself of sugar or not, you produce glucose from fats and from proteins. So starving cancer of sugar is a gimmick. It's another urban myth. Patients must eat a balanced and healthy diet.* (Oncologist 5)

> *Fasting has health benefits but you have to use your head.…If you are dealing with patients already in a ketogenic state due to cancer, this is pure nonsense. It will not help cure the cancer. It will make things worse.* (Oncologist 5)

Some patients reported doing food intolerance tests. These were with a view to avoiding any foods to which they are intolerant in order to avoid increased levels of circulating inflammatory cytokines that may result. Whilst this is theoretically sound and conceivable that it might contribute, oncologists did not believe it would play a big role, as carcinogenesis is multifaceted and complex. Once again, the lack of supporting data was highlighted. Some oncologists felt that food intolerances are overemphasised by many people, and none of them advocate consideration of food intolerances in their management of patients at this point. Obesity was once again referenced as a more important consideration with regard to increased levels of inflammatory cytokines.

> *Inflammatory cytokines certainly may play a role. Again, it is important to revisit the concern of high glycaemic index foods, fat tissue and obesity in this regard. Inflammatory cytokines tend to be released in higher quantities in obese patients. Whether this is meaningfully altered by dietary intolerances or not, I don't know.* (Oncologist 1)

7.2.1.4 Cachexia and patients who struggle to eat

Whilst acknowledging the need for good nutrition, oncologists are also cognizant of the fact that some patients simply struggle to eat, losing their “appetite for everything” and that flexibility is needed in nutritional advice in favour of “basic concerns like calorie intake”.

> *I think one needs to be really careful in the dietary advice you'd give because you might actually hinder basic concerns like calorie intake. I think it's far more important that they get calories than worrying about in precisely what form they get those calories.* (Oncologist 4)

7.2.1.5 Nutrition as an alternative treatment is dangerous

One oncologist was concerned about “crooks out there” who claim to be able to treat cancer through modification of diet, having had some patients who deteriorated when under care of such alternative practitioners. This oncologist was of the passionately expressed opinion that “people have to discriminate between approaches used for prevention, for treatment and for support! We must compartmentalize between these three!”.

> *Nutrition does play an important role in cancer management, but a collateral role, certainly not as a treatment per se. There are crooks out there who claim to treat and kill cancer through modification of diet. Sometimes the recommendations are extremely hard to follow and often patients cannot adhere to the strict diet. …Today I saw someone who was completely emaciated down to skin and bone and dying from hunger because she was only consuming 400 calories per day according to guidelines from someone who was treating her….People need to discriminate between approaches used for prevention, for treatment and for support! We must compartmentalize between these three.* (Oncologist 5)

7.2.1.6 Need for better advice in this arena

One oncologist spoke to their feeling that there more that could and should be done to educate and guide patients in this arena, that “it should be a priority for all patients who are going through a cancer journey” and that, ideally, “a dietician should be an integral part of the multidisciplinary team” from the first day when treatment decisions are being made. Another oncologist acknowledged that although patient questions and concerns about nutrition are valid, the medical profession does not have all the “proper answers”.

> *I think as oncologists…we often tend to put it more secondary to the treatment. We tend to focus more on nutrition and refer to a dietician in those patients where the gastrointestinal system is affected….But it's not only important for these patients. It should be a priority for all patients who are going through a cancer journey. They need the guidance and the education. I think a dietitian should be an integral part of the MDT.* (Oncologist 2)

> *Asking what they should eat is not a stupid question, but the problem is that we don’t have proper answers for them.* (Oncologist 5)

7.2.2 Supplements

7.2.1.1 A common patient question but unnecessary in most patients

Just as it was with nutrition, supplementation was reported as a “very common question” and therefore something that seems to be important to patients. Oncologists believed supplementation to be an “important consideration”, but naturally more critical in those patients who are depleted. However, for an average patient, supplementation was generally considered unnecessary, as “supplementation in the absence of deficiency is not beneficial”. Oncologists would support supplementation “in the right patient” but generally were not opposed to patients using a good multivitamin, so long as it did not include large doses of antioxidants. One oncologist raised the lack of evidence and that, except for a few specific recommendations and exclusions, there is in fact “very little in the way of good guidance and very little in the way of positive evidence that it makes a difference”.

> *Supplements are a very common question.* (Oncologist 3)

> *Supplements are an important consideration. Cancer patients on treatments can have deficiencies. Looking at the individual needs, good nutritional supplementation can help. Keep in mind that the cancer robs the body of nutrients and so food supplements are helpful.* (Oncologist 5)

> *There has quite recently been a very large metanalysis published which suggested that that vitamin supplementation in the absence of deficiency is not of any benefit in any respect. So, if patients are deficient in vitamins, supplementation is definitely helpful but outside of that there are questions.* (Oncologist 1)

> *Guidance on general supplementation is lacking. Other than some well-recognised oncology-related deficiencies, there is very little in the way of good guidance and very little in the way of positive evidence that it makes any difference.* (Oncologist 4)

7.2.1.2 Dietician monitoring of supplementation

The need for some more specialised care and supplementation in some patients (for example those with cachexia) was mentioned, highlighting the vital role a dietician plays in such instances.

> *For patients who are battling, we usually recommend that they see a dietician because they would be able to tailor supplements catering to specific deficiencies and needs. It may not necessarily be your generic supplements that you buy off the counter, but rather specific types of feeds/formulations fortified for such use.* (Oncologist 3)

7.2.1.3 Specific well-recognised deficiencies

Oncologists spoke about those critical deficiencies which have been identified in cancer patients and incorporated into general guidelines (notably vitamin D), further evidence of the manner these professionals practice according to evidence-based medicine. One oncologist raised current explorations into microbiota and their potential role in carcinogenesis and consideration in management of the cancer patient.

> *There are some very specific deficiencies that some of our patients develop and there are clear guidelines on supplementing those patients. Our breast cancer patients who go on to aromatase inhibitors, there's clear guidance that they need to go on a vitamin D and the calcium supplement. It's proven to reduce the fracture risk for the patients. Some of the patients become iron deficient so we keep an eye on iron levels, and absolutely they need to be supplemented. And folic acid for patients receiving methotrexate. If you don't take that supplement the chemotherapy is highly toxic but if you take the supplement, you're quite fine.* (Oncologist 4)

> *Linked to the whole issue of what cancer patients should be eating, is the question of the role of microbiota which is a common denominator currently being explored. It appears important but we don't yet know how to address it. …The chemotherapy and antibiotics we give can also disrupt this in patients, killing protective bacteria. Keeping microbiota balanced is very important so I encourage people to try replacing their gut flora using yoghurt or kefir..I also find that it helps with the chemotherapy-induced diarrhoea.* (Oncologist 5)

7.2.1.4 Reservations about supplement use

The oncologist interviews revealed that one of the main concerns for patients on active treatment is potential drug interactions. Intake of additional oral formulations carries the risk of increased toxicity and can negatively affect outcome through different mechanisms. Another big consideration is antioxidants which patients want to take during active treatment which is counterproductive because many treatments rely on oxidation to kill the cancer cells. One oncologist specifically mentioned the importance of patients being transparent about anything additional they are taking so that these issues can be prevented. One oncologist summed it up by saying the "lack of proven benefit to the patient, and a theoretical risk that you could be negatively impacting on the cancer treatment" it is best to avoid many supplements during active treatment.

> *I would also caution them against going onto multiple different types of vitamins because there are concerns about interactions and side-effects……But importantly, you need the patients to be transparent with you because some of them might be …over-supplementing. As much as it's good to have nutrients, excess can also be associated with toxicity as well.* (Oncologist 3)
>
> *There is competition for liver enzymes and the liver cannot cope with detoxifying the chemotherapy drug as well as herbal medicine. I need to know everything they are having, and I prefer they avoid all herbal things. If they want to go the herbal route then I'm not going to forbid that, but not together with mainstream treatment. They must choose.* (Oncologist 5)
>
> *There is a theory out there that you can influence malignant processes in the body by taking antioxidants. A lot of the patients take a variety of antioxidants (sometimes, in high doses) in the hope that they can affect the cancer growth. The problem is that a lot of our cytotoxic drugs and even our radiotherapy relies on an oxidation process to kill off the cancer cells. So, in theory, by taking a lot of antioxidants, you could negatively impact the effectiveness of the anti-cancer treatment. … So, in a setting where there is lack of proven benefit to the patient, and a theoretical risk that you could be negatively impacting on the cancer treatment, we would then rather give the advice for blanket avoidance.* (Oncologist 4)

Some of the challenges raised in connection with supplementation were the size of the industry, its relative lack of regulation, and the sometimes-misleading nature of the marketing. Three oncologists spoke to such concerns and how they can influence patients, touting safety on the basis of being "natural" and offering "cure", both of which are dangerous misconceptions.

> *One needs to be careful. Supplements are a huge industry and alternative health products can bypass regulations and sell rubbish. They also make all sorts of claims such as "Lycopene supplements help cure prostate cancer" etc. which is utter rubbish.* (Oncologist 5)
>
> *People have this idea that natural or herbal medicines are safe.* (Oncologist 5)
>
> *I think the need for supplements is overemphasized to the patients in the lay press. This places pressure on patients.* (Oncologist 4)

7.2.1.5 Checking patient supplements

Two oncologists spoke about going through bottles of supplements that patients bring in order to check ingredients. Whilst they exercise this caution, it can be cumbersome and get out of hand. One oncologist felt strongly that navigating such use with patients can take up "an unnecessarily disproportionate amount of time", especially when considering that for the average patient they are of "little relevance" in comparison to other aspects of management.

> *Trying to navigate this with patients takes up an unnecessarily disproportionate amount of time….I'm trying to say that nutrients play a very small role, but the patient wants to spend two hours discussing his supplements and I actually think it's of very little relevance and significance. And the same goes for the nursing staff. They often get caught up in a long, somewhat pointless discussions….Patients sometimes put the emphasis in the wrong place.* (Oncologist 4)

7.2.3 Cannabis

7.2.3.1 Increasingly prevalent and of concern

Cannabis production, promotion and use is increasing and for this reason, the subject was specifically raised with the oncologists during interviews. Oncologists are aware that its availability and use is on the increase.

> *Unfortunately, there is a lot of information out there promoting the use of cannabis by cancer patients. We can't be ignorant to the fact that people will use it and that it's becoming more and more available.* (Oncologist 3)

> *I know that half patients use it, and the other half will never tell you. It's reality. I've been in this world long enough to realize that.*(Oncologist 5)

7.2.3.2 False claims and a lack of rigorous evidence

The problem of a lack of rigorous evidence was raised in connection to cannabis and, in particular, the problem of curative claims based on in vitro as opposed to in vivo studies. Given the heterogenous nature of cancer and its very varied treatments, clinical trials to validate claims and eliminate potential pitfalls would need to be huge. Adding to this problem is the fact that the manufacture of cannabis is unregulated, detailed knowledge of its active substances is inadequate, and dosages unclear.

> *In our practice we practice according to level one evidence-based medicine. We do not have that level or quality of scientific information to actively promote the use of cannabis.* (Oncologist 3)

> *The concern is that, even if there is an impact on tumour cell turnover in vitro, that may not necessarily translate into improved outcome in vivo. Unless you've got randomized studies of treatment with cannabis versus treatment without, you will not know whether you are possibly undermining the effectiveness of the treatment. …There may be some little trials with 20 patients, but those are totally statistically meaningless, especially in a disease as heterogeneous as breast cancer. A problem is that it's been recommended for absolutely everything.* (Oncologist 1)

> *Unfortunately, a lot of the Cannabinoids that patients are using come from questionable sources. They are made in garages etc. and so this becomes quite a difficult area to recommend.* (Oncologist 1)

7.2.3.3 Patients being treated with curative intent

All but one of the oncologists interviewed discouraged the use of cannabis by patients on active treatment with curative intent.

> *My approach is that, in patients that are being treated with curative intent (for example adjuvant therapy with curative intent), I advise against it. The reason for this is two-fold. One is that to date*

> *there has been no evidence that its actually an effective therapeutic tool (other than in vitro studies which are very limited in their value), and there has been some evidence of harmful effects (for example, prostate cancer is treated with hormonal therapy).* (Oncologist 1)
>
> *The literature that I was reading really spoke a lot of the benefit in terms of the pain control and anti-anxiety effects. To date, I still have not seen literature that can show evidence of its anti-cancer effect in aiding cure. So, for those reasons I'm not at a point where I am comfortable using it in the radical setting.* (Oncologist 2)

7.2.3.4 Palliative setting

Where most oncologists were more comfortable with their patients using cannabis was the palliative setting, where biomedical options for aspects such as pain control and nausea had proven ineffective.

> *Where I do say that I am comfortable with patients using it if they wish to, is obviously in the palliative setting. If it does alleviate nausea and anxiety and gives them a general sense of well-being, then that's fine. But even there, I have concerns regarding source etc.* (Oncologist 1)
>
> *If a patient is experiencing very severe pain (and I'm talking more in the palliative setting) I do allow it. I have read some literature of the beneficial effect of cannabis in pain control, and so I certainly do allow it there. Sometimes the patients bring it up, but even if the patients don't bring it up, I sometimes offer it as an alternative option or one of the treatment options should they want to try it during their journey. So really for me it's use is in the setting of more advanced cancer and as part of a pain control mechanism.* (Oncologist 2)

7.2.4 Exercise

7.2.4.1 Exercise in oncology management

When asked about the role of exercise in oncology, all oncologists were strong advocates for its inclusion as an integral part of a patient journey. However, whilst it was considered important and therefore encouraged, time constraints often do not allow for formal discussions or monitoring. One oncologist even encourages exercise in weaker patients, including physiotherapy consultations to encourage walking if necessary.

> *I think exercise is another imperative part of the journey. You can't actually look at cancer management without involving exercise because it plays a major role. …Once again, it is more difficult again in the public sector where you have limited resources and limited caretakers in the MDT. I do believe with everything in me that it should be there.* (Oncologist 2)
>
> *I think that exercise should always be advocated. Obviously, it needs to be tailored to the individual in terms of what they can cope with etcetera… but it should be advocated in patients with early diagnosis, and even patients that are on active treatment.* (Oncologist 3)

7.2.4.2 Ways in which exercise helps cancer patients

All oncologists spoke to the many physical and emotional benefits for the cancer patient to be found in exercising. This was for all patients, but especially so in patients whose treatment compromises bone, muscle, and cardiovascular health.

> *There's a lot of research exploring the role of physical exercise, especially in breast cancer patients. I think we all know that exercise has benefits on so many levels, from your endorphin release to making you feel better and obviously improving the strength and fitness of your body. It also does a lot for the mental health as well to be honest.* (Oncologist 3)
>
> *Exercise also assists on a social level. The patients' well-being benefits from exercise. Going for a good walk either with family or friends adds psychological support in the process. There is definitely a sense of well-being through exercise.* (Oncologist 4)
>
> *Exercise is actually the best way to combat fatigue.* (Oncologist 5)

7.2.5 Psycho-spiritual

The oncologists interviewed recognised the trauma that a cancer diagnosis brings, and the importance of psychological support. Oncology was described as an "empathetic profession" where oncologists need to monitor and manage more than physical aspects of patient wellbeing. Besides dealing with emotions such as fear and anxiety, psychological support was described as assisting patients in setting goals, pulling them out of hopelessness and helping them find a will to live, or on the other hand, accepting inevitable death. Some oncologists mentioned that not everyone is suited to psychological counselling and that one needs to be able to read their needs.

Oncologists noted the role that spirituality plays in cancer. One stated that patients who have a "solid religious conviction and active spiritual life deal better with the whole cancer process" from diagnosis through to death. Another oncologist expressed the opinion that the spiritual ambit is missing in oncology care at the moment, going on to say that "humans need an esoteric part in their approach to life" and that it helps cancer patients find "calm and balance and an increased sense of control".

Psycho-spiritual aspects require a sensitivity on the part of the oncologist, knowing what a patient's beliefs are, what motivates them, and thus being able to provide support and referral if needed.

> *Psychological support is so important. In the private sector, I do insist that my patients see a psychologist, just for a once off.* (Oncologist 2)
>
> *I have a psychologist I work with and refer to, but I often find that people don't like going to a psychologist for some reason. Many seem to have a pre-conception that makes them reluctant. You need to read the patient and determine which way you need to help them. Someone may be suited to it and someone else not.* (Oncologist 5)
>
> *The spiritual or esoteric ambit is missing at the moment. Rituals are very important for people….Humans need an esoteric part in their approach to life. It is a part of being human and helps*

> *us succeed and live life. When we are in danger we need it even more, so cancer patients are looking for this even more than healthy people. They are terrified and these spiritual practices give them calm and balance.* (Oncologist 5)
>
> *From experience, patients who have a solid religious conviction and an active spiritual life deal better with the whole cancer process. They deal better with the diagnosis and in the palliative setting they are far more accepting and at ease with the process they are going through.* (Oncologist 4)

7.3 Domain 2: Opinions and Experiences of TCAM Practitioners

The responses to questions regarding the role of TCAM practitioners in oncology brought responses that reflected a knowledge that patients have the right to seek out TCAM practitioners and that many do. There was the opinion that these practitioners may have a useful role to play in oncology, but this opinion was not without concern and reservations regarding the risks.

7.3.1 Recognition of patient right to explore various healing options

Oncologists recognise the right of patients to explore various healing options, and that these options are often important to their patients. Several stated that they believe TCAM practitioners have worthwhile skills to offer the oncology arena.

> *I do really believe that every patient should have the right to explore the various options because we all have different beliefs, different ways that we brought up and even differing spirituality. But there are risks and cautions that need to be considered.* (Oncologist 2)
>
> *I think the alternative practitioners do play a big role in a lot of our patients. Many of our state patients place great store by and depend on the opinion of traditional healers or spiritual healers.* (Oncologist 3)
>
> *I believe there is a role for TCAM practitioners. Some of these practitioners, and homeopaths in particular, have a slightly different approach to their patients. They seem to take the time and the patients appreciate that.* (Oncologist 4)

Some oncologists are comfortable with their patients incorporating practices, as long as they are not going to negatively impact outcome, and as long as the mainstream biomedical treatment plan is not interrupted. If these things make patients feel better, even if by placebo effect, they will support it, although not necessarily promote incorporation of it themselves.

> *We must remember that these things can also have a placebo effect. Patients can feel better when they do something else. If a patient believes something is helping them, that belief can make a difference for them. I don't simply dismiss everything as rubbish because if it is not harming, it may help the patients feel better. Use visualization techniques but use the proven therapies too. Don't make promises and unproven claims of cure, and don't interrupt the proven mainstream therapies!* (Oncologist 5)

7.3.2 Concerns and reservations

Having expressed the openness to the potential role of TCAM practitioners in oncology, oncologists are naturally concerned about the potential risks involved, which include critical delays in the commencing of biomedical treatments, and the potential for additional therapies to impact mainstream therapies adversely, particularly via drug interactions. Lack of disclosure was problematic in many instances. There were also concerns about those who tout some alternatives praying on the desperation and vulnerability of cancer patients and their families.

> *What ends up happening, and we see it very often in the state hospitals, where a patient is on a very tight timeline to get started on treatment, but they would default for a month because they wanted to try out alternative practices. Then they end up coming to us with their disease very much advanced and it puts us in a difficult situation.* (Oncologist 3)
>
> *Taking herbal medicines as a cancer patient can have detrimental effects on the liver. We cannot even know how many people could have died because of taking traditional herbal medicines.* (Oncologist 5)
>
> *When the TCAM practitioner is giving the patients remedies that they are ingesting it is potentially problematic. Oncologists are not familiar with all the ingredients in alternate offerings, and as cancer treatments also come from lots of plants varieties and things like that, one worries about interactions on a cellular level. I have no issue with things like acupuncture or aromatherapy massages.* (Oncologist 3)

When asked about their opinions of TCAM practitioners the first and immediate response from several oncologists concerned adverse reactions occurring in patients who used traditional medicine (and in one case herbs recommended by a Homeopath). In all these instances, the use had also been undisclosed and even denied upon initial enquiry. Worries about undisclosed use of TCAM practitioners (as in the case of supplements) is the risk of increased toxicity and/or drug interactions between mainstream treatments and medicines dispensed by a TCAM practitioner. In contrast, TCAM practitioners such as acupuncturists or massage therapists are not of concern, or perhaps even interest to many oncologists.

> *We get medical crises…with unexplained hepatic or renal dysfunction and it eventually comes out that they did seek assistance elsewhere and were taking different types of herbal remedies etc. whilst still under our care. One cannot generalize and say that all the alternative therapies are bad. What I am saying is that we just need to be cautious because the treatment we administer is toxic treatment as well, so we have to be respectful of that.* (Oncologist 3)
>
> *Fairly often patients will come in critically ill with metabolic acidosis and have clearly had some form of traditional muti and it will come out eventually that they did. But even when they are critically ill, there is an enormous amount of denial as to whether they have done so.* (Oncologist 1)

One oncologist spoke about how his experiences have led him to be very wary of “crooks” preying on the vulnerability of patients and their families. This oncologist elaborated on how unproven claims of cure are made for what are essentially fads or gimmicks, and how patients can be brainwashed into believing these claims. Interestingly, this oncologist stated that he felt it was primary caregiver's neglect in addressing the patient role in their personal healing journey which creates a gap that patients will seek to fill in other ways.

> *Unfortunately, there's often scope for exploitation in the form of desperation on the part of the patient.* (Oncologist 4)
>
> *Many of these alternate offerings on the market also play into the need of patients and their families to do extra things that they believe will help them to get better. Many doctors are rushed and neglect the importance of the patient role in their personal healing. That is a problem because patients really want to do something to help themselves. Not addressing this creates the space for alternate offerings. There are gimmicks and scams out there. I'm very sensitive to crooking and there is a huge gap for crooks in the oncology arena.* (Oncologist 5)

7.3.3 Lack of collaboration

Amongst those interviewed, there was negligible evidence of any collaborations with TCAM practitioners outside of a psychologist and dietician.

> *In terms of collaboration, I do not actively collaborate but neither do I actively avoid it. I know they are out there and there is space for everyone.* (Oncologist 4)
>
> *The dietician and the psychologist are standard for me (at least once-off), but there is no one else that we are using. We've got our nurse navigators who are kind of help patients navigate through the journey. They do a little bit of a counselling, a little bit of the education but other than that no.* (Oncologist 2)
>
> *In the state sector we don't have opportunity to collaborate with any alternate practitioners.* (Oncologist 3)

Two oncologists raised the opinion that more open communication is needed, wondering if there isn't a "better and more consultative way" to approach patient use of different healing options. This is needed in terms of the professionals as well as the patients. TCAM practitioners need to be more respectful of the mainstream therapy protocols and risks of patients incorporating additional therapies, and patients need to be open about what they are utilising thus ensuring comprehensive and informed management with everyone "on the same page". It may even be that the additional treatments are helping the patient, but the oncologists cannot know this as they are uninformed about what the patient is doing.

One oncologist spoke about a "good working relationship" with local homeopaths and is comfortable with his patents seeing them. Although no formal collaboration is taking place, he believes there is mutual respect between the practitioners and that his relationship with his patients is open enough for them to feel comfortable informing him of their visits to TCAM professionals.

> *I believe that as oncologists we need to be open to the personal need of patients being able to visit all other forms of alternative medicine. I just wonder if there's a better and more consultative way that*

> *we can do it, because I know that not all alternative healers are necessarily using potentially harmful things (like things that you are ingesting for example). But I certainly think it's something that we need to be open to.* (Oncologist 2)

> *I usually tell patients that I don't have a problem with them consulting alternative practitioners but express the need for these alternative healers to also be respectful of the patient's diagnosis, and the management and treatment that we have planned for them. Generally, if we've got active treatment planned for a patient that we know is going to help them and make a difference, then we would advocate following that path exclusively during active treatment…It would be nice if the other practitioners/healers actually made contact with us, so they know what it is we're doing…We need to be on the same page.* (Oncologist 3)

> *I believe that patients feel bad to tell their oncologists that they're going to see someone else or that they are using something else. Even the CBD oil. Often, you'll find out down the line from, my chemo sisters or someone else that a patient is using something else…But I don't see it like that. I'd prefer to know. I think it makes the journey better when everything is on the table. There can be various different ways that alternative options could be integrated into the treatment, and for me, as long as the safety can be taken into account then I would be comfortable. However, I don't know how we do that.* (Oncologist 2)

7.4 Domain 3: Opinions of Integrative Oncology

7.4.1 Support for a more formalised approach to integration

Several oncologists expressed an interest in the field of Integrative Oncology. These oncologists recognised the potential that a formalised evidence-based integrated approach could hold for assisting patients and oncologists to safely navigate pluralistic offerings. One oncologist felt that it might possibly address some of the broader unmet needs of patients, enhance healing or provide support when coming up against limitations of mainstream biomedicine, whilst also increasing collaboration and mutual learning between medical fields. The difficult and complex road to achieving this was spoken about by interviewees, raising the need for formalization of guidelines, practitioner registrations, and trustworthy affiliations. Also emphasised repeatedly across interviews, was the ever-present need for quality evidence. One oncologist took a step back and spoke about the lack of even the basic holistic offerings for patients such as dieticians, psychologists, and palliative care. This oncologist expressed the opinion that we need to "get the basics right first" before venturing into the complex field of Integrative Oncology which is "still in its infancy". However, whilst acknowledging the immense challenges that it would entail, it was viewed by the majority as a worthwhile and possibly necessary avenue to explore.

> *I would support a move in that direction because, whether we advocate it or not, we know that a decent proportion of our patients will still seek out additional therapies. So again, it's about educating everyone and maybe there's a lot that we can learn from the alternative therapies that can enhance and complement our practice, especially because there are still a large number of cancers that we can't cure. There are a large number of palliative patients for whom we are very helpless when it comes to assisting or supporting. So definitely there's room where we can collaborate, and I think it is an avenue*

> *that should be explored. In the South African context, I think it's doable, but it will probably work better in the private sector, just because within the state sector there are so many shortfalls, even just within our own Department of Health, and branching out would place more pressure on an already constrained system. I think it's it would be nice to pilot it first and probably best if it could start off as a pilot in the private practice arena first, then hopefully it could spill over to the rest of the country from there.* (Oncologist 3)

> *I think it is possible, but I think it might take a lot of work. It would have to be officially and formally organized via a sort of memorandum, etcetera. Another problem is that when it comes to alternative practitioners, there has to be some sort of formal registration, training and affiliation so we know who we can trust as well. Obviously, it will be very difficult to just plan organize something of this nature overnight on a large scale. I'm glad that there's somebody looking into this, because as much as we have our challenges, evolution and progress is very important. It has to start somewhere, even if it's just on a parallel platform initially. If the foresight and thinking isn't there, then nothing will happen. Somebody has to get going with these types of things and that's the only way we'll ever really progress.* (Oncologist 3)

> *I believe it has potential, but it depends on what exactly is going to be included, and the rules and guidelines that will govern such practice. It has to be based in evidence (EBM). This is extremely important because a lot of harm has been done when it is lacking.* (Oncologist 5)

> *I think it has a long way to go. I would say that integrative medicine in South Africa is still in its infancy. Integrative medicine needs to be firmly established first before offering Integrative Oncology. And I think there's a lot more to be done on the conventional side first. ..We've got a long way to go before we start thinking about alternatives. Can we just get the basics right first?* (Oncologist 4)

7.4.2 Bad experiences with Integrative practitioners

Some oncologists interviewed had had bad experiences with integrative practitioners. These practitioners promoted themselves as offering Integrative Oncology solutions for patients when in reality they were not practicing Integrative Oncology at all but offering a sort of “fringe oncology” consisting of alternatives to proven biomedical treatments. These offerings attract a certain kind of patient and can have potentially dire consequences.

> *There are so-called integrative practitioners out there that I've had extremely bad experiences with, where they recommend and use treatments that are really not proven and patients avoid treatments that are of value because the alternatives are more attractive, either from a side-effect profile or just because of where the patient is situated mentally. And there are potential disasters as a result.* (Oncologist 1)

> *In my catchment area there are one or two general Integrative practitioners and I do have patients that have consulted them. I think a lot of the people that promote themselves as practitioners of Integrative Oncology often practice a sort of fringe oncology which is not evidence-based. It's not supported by large trials or by any of the big professional authoritative bodies. These kinds of fringe practices and practitioners who have put themselves out there as integrative practitioners in oncology have unfortunately given Integrative Oncology quite a bad name and it's going to take a lot of work to undo.* (Oncologist 4)

7.4.3 Lack and limitations of evidence

All the oncologists spoke, often at great length, about the lack of quality evidence which they believe is the greatest challenge to the growth of Integrative Oncology. Not only does there have to be good evidence that a modality is effective, but there also needs to be evidence that there is not going to be any negative impact on outcome. Some interviewees expressed the belief that too many studies in the alternative space are anecdotal or compromised by bias and lack of standardization. The variety of cancers and their tendency to respond differently was cited as an extremely problematic consideration, as it means that immense clinical trials are needed to truly prove efficacy and eliminate risks. Were quality evidence available, oncologists would be willing to embrace and integrate complementary approaches.

> *It’s difficult for me to be open to patients utilising additional treatments because I operate on an* evidence-based a*pproach. The difficulty that that I have … is the challenge of a lack of evidence-based data either with the combinations, or the treatments alone. But where there is evidence, I'm very happy to embrace it. For example, I send quite a lot of patients for acupuncture for hot flushes because there is randomized data that shows that it is an effective modality and it's got it's not going to have any negative impact on outcome. But if a patient has got hot flashes and they go to the health shop, they may be given all sorts of phytoestrogens, which may alleviate the hot flashes, but have the potential to actually result in a in a in a worse outcome. So, there are situations where the alternative therapies have got some proven efficacy and are safe, but the difficulty is that with most of these things, there just isn't that evidence available. I don't understand why many of these alternative approaches are not investigated more. It's all anecdotal evidence and anecdotal evidence is totally meaningless in the oncology space.* (Oncologist 1)

> *I think the evidence for integrative medicine in general is a bit questionable. The level of evidence that is seen as acceptable is quite low in the integrative environment and it just doesn’t stand up to rigorous evaluation. Particularly in oncology, and certainly in the chemotherapy environment, the clinical trials are incredibly rigorous. We really have very demanding clinical trials and that is the standard by which we work. ..So, it’s difficult to see integrative medicine fitting into oncology just because of the level of evidence.* (Oncologist 4)

7.4.4 Holistic and integrative theory and oncologist education

One oncologist raised the matter of medical education of oncologists and the fact that no modalities outside biomedicine are incorporated into the curriculum. As a result, oncologists can find themselves inadequately prepared to navigate the pluralistic environment with their patients. This oncologist felt that the curriculum needed to address holistic and integrative knowledge to fully equip oncologists to better serve their patients.

> *In our training in oncology, there is only really a focus on the biomedical field and our knowledge of the other domains that are available out there is absolutely limited, and I think to our detriment at times, because when you are counselling patients, you've got to have some knowledge of these things and I feel it is lacking. … Sometimes you know too little about something … and that also can make*

> *patients feel uncomfortable as well when the oncologist doesn't know what other avenues are available. I think the biggest factor from our side as oncologists is probably going be education. The more we are educated about the various other holistic treatments that are available, the more we can be informed and educate and guide our patients as well. I think there certainly is a possibility for growth. Knowing the oncology domain, I feel that it may be met with a bit of resistance. However, I think it is integral and could grow, especially if it could be introduced into formal training of oncologists.* (Oncologist 2)

7.5 Domain 4: The Government-Private Divide

7.5.1 Challenges facing the government sector oncology

The request for interviewees to comment on the government-private divide elicited lengthy and passionate responses from most oncologists. All had experienced the challenges on every level within the government sector of oncology care. Some of these challenges concerned the situation and agency of the patients themselves, others concerned the primary healthcare clinics where many cancer patients start their journey, and yet others concerned the distract and regional hospitals where patients present for treatment.

The difficulties experienced by patients at a personal level were largely related to poverty. Patients battle to get from their homes to treatment facilities due to distances and lack of transport. They do not have basic amenities like running water and electricity. Many patients also have low levels of health literacy, being ignorant about cancer as a disease and/or associating stigma with the disease.

The limitations and pressure on primary health care clinics also contribute to inequalities in care. There is inadequate staffing, and insufficiently proficiency in cancer screening, leading to delays and misdiagnoses. The inadequate staffing and resultant pressures on oncologists are also a real challenge at district and regional hospitals. This leads constraints on the time practitioners are able to spend with each patient, a less than ideal situation for both caregiver and patient. Lack of adequate and well-maintained equipment for both diagnosis and treatment, as well as pressures on pathology labs, leads to delays in proper diagnosis and rollout of treatment plans. A system under such constraints allows only for a "mass production" approach in which state of the art treatments available to private patients simply aren't available to government patients. In addition, patients with medical emergencies are being turned away due to no available beds, and late-stage patients sent home with very little palliative support. These examples illustrate how some of the basic elements of oncology care are under pressure in the government sector, making the more holistic offerings or integrative approaches of secondary importance. Despite the challenges, the view was expressed that more can and should be done to provide basic human care to the government patients. One oncologist had a different take on the public sector hospitals after interning in a different province, having found multidisciplinary professionals in place and an efficient referral system, both of which have been lacking in their experience of the private sector, where much-needed support systems are often lacking and practitioners “operate in silos”.

> *Unfortunately, in the public setting, there are lots of challenges and it's at every level… A large majority of our patients come from backgrounds where poverty is an issue... There's the issue of access to healthcare and accessing healthcare timeously. …Then obviously factors linked to lack of education or ignorance of the disease.… Then it comes to our district and regional hospitals where resources are a problem. The need for functional CT scans etcetera which are important for staging cancer, to have a jacked-up pathology system and efficient surgical services so you can get biopsies done and followed up on timeously. These are continuous challenges and all of it unfortunately contributes to delaying presentation. Then .. we are left with the impossible task of trying to perform miracles on patients who are presenting to us at a much later stage than they should.* (Oncologist 3)

> *The public setting is geared towards mass production and not the individual patient. If a patient doesn’t fit the average patient profile but is treated with an average one-size-fits-all treatment plan, they can die. …It also has very limited resources. Many modern medicines are not available to the public patient. There are delays in patient appointments that impact progression of the disease. Consultation time to engage with the patient is extremely limited and resources are inadequate. Maintenance is also a big issue; facilities and equipment aren’t maintained. …Organization is very bad and so much money is wasted. So much money! I found it very difficult to deal with how the mass-production approach and many limitations lead to short-changing of the patients.* (Oncologist 5)

> *There are major challenges in the public sector. I really feel we do not do enough for our public sector patients and that more could be done. There are tremendous time pressures and constraints. For example, you may only spend 5 minutes with the patients because you have 30 patients to go through….Then there are instances when you get a patient that comes in extremely sick and with a medical emergency such as spinal cord compression, but there are no beds, and you have to send that family home. …Sometimes patients present with stage 4 disease, but we cannot offer them proper palliative care. Although we have a lack of resources, I think that even despite this, there is more that we can offer our patients in terms of the basic care and holistic support. We’re not asking for the big drugs or major things but just basic needs.* (Oncologist 2)

7.5.2 Additional insights into private patient health-seeking

In speaking about discrepancies between the private and public sector, one oncologist raised some additional possibilities of why private patients utilise more complementary practices. The considerations raised were increased access to the internet and thus information as well as conspiracy theories. Another possibility raised was a shift away from paternalistic medicine amongst these patients. Then naturally the matters of access and knowledge which are higher in the private sector.

> *I think there is a disparity there in a sense in that first world people have certainly over time showed an increased leaning towards complementary and often non-evidence-based therapies. I think part of the reason is access to Internet, exposure to conspiracy theories and also just general pendulum of life where people go from one extreme to the other and it seldom stops in the middle for some reason. So, there's a time when everything is paternalistic medicine, and then there's some resistance to that and it sort of swings all the way the other way and ideally we need something in between. But I also think*

> *that in the public sector, the patients don't have the luxury of many of the treatments or modalities that are available outside evidence-based medicine, just from a cost point of view and from an access point of view or even a knowledge point of view. But I think the involvement of traditional healers is actually quite significant in the public sector. I think it's been shown that the number of people using alternative therapies, whatever they are, is very much higher than it is reported to the to the practitioners for fear of them being unhappy or whatever. I think that when it comes to traditional healers, I think those sorts of people are very reticent to admit that they are seeing a traditional healer.* (Oncologist 1)

7.5.3 Deficiencies of palliative care

Four oncologists raised palliative care as a critical area that is currently lacking in both private and government sectors. The main Hospice that had served the area has closed and many patients do not get the support they desperately need at this final and difficult part of their cancer journey. Some oncologists felt that this was an indication that integrative practices were a long way from being incorporated, as even the basics such as palliative care are still insufficient. Other oncologists felt that it is precisely in such situations that complementary or alternative options might be able to offer some solutions.

> *There are people and their families going through the palliative process who need some sort of support and there's zero support available. It is tough. It is really tough. I feel that so much more needs to be done just on a human level. Sometimes patients come, possibly travelling about 4 hours to get to the clinic. They come to see us for the first time only to be told that they have stage four disease and that they are not well enough for care. They've come this long way, and they are going home without any form of support just because we can't offer any. It is very sad.* (Oncologist 2)

> *There are obviously challenges from the palliative point of view. Our palliative services have a long way to go before we can actually offer patients proper palliation. Before we can even evolve to the point of considering holistic and integrative practices, there's so much of the basic factors that needs to be considered.* (Oncologist 3)

> *Palliative care should be very supportive and include emotional, psychological, and physical support, explaining options for end-of-life care. But for many patients in our country, it is a case of telling them there is nothing we can do, giving them morphine and sending them home. That is not palliative care. Every stage of a cancer journey is important.* (Oncologist 5)

7.6 Summary of Chapter 7

Responses to the first domain of enquiry revealed that oncologists believe in the importance of the holistic considerations of diet, psychological support, exercise, and spiritual support. There was consensus regarding the valuable contribution of a healthy diet in assisting the body cope with the negative metabolic effects of cancer and mainstream treatments. Whilst many oncologists collaborated with dieticians as part of their management approach this was generally prioritized for gastro-intestinal patients. Approaches such as dietary exclusions, and food intolerances were not considered to be of value, although foods with a high glycemic load were considered problematic due to their impact on insulin levels and resistance, and potential to bring about weight gain. Supplementation was considered important for patients with specific deficiencies or where recommended but not for patients who are getting adequate nutritional intake, and the risk of interaction of herbal supplements and biomedical treatments was a concern. The increased use of cannabis was acknowledged as an area of concern, with most oncologists discouraging its use by patients receiving active treatment with curative intent, whilst supporting its use in patients battling the effects of end-stage disease. Exercise was considered extremely helpful although consultation time does not allow for formal discussions and monitoring. Psychologists realized the trauma of a cancer diagnosis and journey and thus the importance of psychological support. However, it seems that most patients did not make ongoing use of psychological counseling. The spiritual ambit was seen as significant, with patients of faith coping better with all aspects of their cancer journey. Some interviewees felt that the spiritual dimension is often lacking.

The second domain of enquiry (opinions of TCAM practitioners and their role in oncology) revealed that oncologists supported the patients' right to explore various healing options yet held reservations due to lack of evidence and the potential for adverse reactions. Oncologists felt that whilst some TCAM practitioners practiced safe modalities, many did not understand the complexity of oncology. There was no reported collaboration with TCAM practitioners, but several oncologists felt there was a need for more open communication and mutual respect.

The third domain of enquiry (Opinion on Integrative Oncology) elicited mixed responses, with some oncologists showing an interest in the potential of evidence-based integration, and others having already had bad experiences with integrative practitioners who make unproven claims and practice "fringe oncology".

A common touchpoint for all oncologists was the need for all practice to rest on quality scientific evidence. Several felt there is currently a lack of evidence supporting integrative approaches and raised the rigor of clinical trials needed to ensure both effectiveness and safety. However, in the presence of adequate evidence, oncologists expressed a willingness to embrace and integrate complementary approaches.

Oncologists detailed the challenges of the government sector at all levels, pointing the difficulty of providing good oncology care in public facilities. These issues illustrate the need for improving basic care before addressing the complexity of integrative offerings in the public setting.

8. DISCUSSION

The aim of this research was "to investigate perspectives on the challenges and opportunities for pluralistic integrative management of the breast cancer patient in eThekwini, within the context of the disparate nature of the South Africa society". Essentially it sought to contribute to the understanding of patient and practitioner engagement with the pluralistic landscape of South Africa as it pertains to oncology, and specifically breast cancer patients and their oncologists. It sought first to gain insights into current practice and lived experience on the part of both patients and oncologists, and then to explore the feasibility of a vision of Integrative Oncology in the local setting.

This discussion will begin by exploring various aspects of the results presented in chapters 4 to 7, triangulating findings where possible across the data sets with a view to determining where the different data sets corroborate, conflict with, or explain one another. These key findings will be elucidated by comparisons and insights from the existing body of literature. The discussion will then seek to determine where the local oncology landscape is situated in terms of holistic and integrative practice, highlighting opportunities and challenges that emerged in the findings, and appraising the feasibility of formalised Integrative Oncology in the local setting going forwards.

8.1 Current Practise and Lived Experience

8.1.1 Dietary approaches

Diet has been demonstrated to play a role in carcinogenesis, treatment tolerance and survival of cancer patients (Vrieling *et al.* 2013; George *et al.* 2014; Dandamudi *et al.* 2018; Foroutan-Ghaznavi *et al.* 2022; Reitz *et al.* 2022). In the current study, dietary modification accounted for the most highly utilised lifestyle inclusion at 53% (47% government patients; 67% private patients). It is pertinent to note that dietary modification was significant for inclusion by private patients and significant for non-inclusion by government patients ($p < .001$), with odds ratios suggesting that the sociodemographic factors of education level and income as the most likely explanation for this discrepancy.

The use of dietary modification by patients was corroborated by the feedback obtained during the patient qualitative phase where the majority of interview participants referenced using such modifications as a tool to battle the disease. In both the survey and interviews, the patients who adopted dietary modifications described a conscious shift to healthy eating patterns, incorporating more fruit and vegetables and reducing or eliminating processed foods. Many of the choices described were in keeping with the dietary patterns recommended to improve treatment tolerance and reduce cancer mortality (Vrieling *et al.* 2013; Wiseman 2019; Foroutan-Ghaznavi *et al.* 2022; Reitz *et al.* 2022).

Dramatic reduction or elimination of specific food groups was practiced by some patients including sugar (44%); red meat (27%); carbohydrates (19%); dairy (10%) and alcohol (14%), choices which were once again mirrored in the qualitative phase. The reported reduction in the intake of certain food groups, including meat, dairy, and alcohol, is supported by the recommendations of the Continuous Update Project (CUP), which through rigorous analyses has attributed plausible potential causality in cancer to these dietary factors (Wiseman 2019). Patient avoidance of refined carbohydrates and sugars was attributed by many of them as being because "sugar feeds cancer". However, oncologists challenged this oversimplification and pointed rather to insulin resistance and weight gain (increasing body mass index (BMI)) as the problematic consideration with these foods. This is supported by the CUP research which suggests that the hyperinsulinemia, increased oestradiol and inflammation associated with greater body fatness could carry plausible causality in cancer (Wiseman 2019). The concern with adiposity/obesity and BMI is in consensus with research associating these factors with increased mortality and recurrence in breast cancer patients (Chan *et al.* 2022).

Interviews revealed how patient dietary modifications were underpinned by a firm belief that this holistic inclusion could support treatment tolerance, enhance healing, and impact outcome. Patient understanding of the reasons for this ranged from basic (*"I think a lot has to do with what you're eating."* Participant 11: Public), to fairly complex and theoretical (*"To keep the general inflammation of my body down."* Participant 7: Private) (*"According to 'The Metabolic Approach', if you starve cancer of glucose, it's going to move onto glutamine or fatty acids."* Participant 9: Private). A need for personal control was also reported by one interviewee as her reason for adopting dietary interventions (*"I was trying to control this disease"* Participant 5: Private). Interestingly, this was also proposed by an oncologist as a possible motivation for patients incorporating dietary approaches (*"I think patients need for dietary intervention is largely driven by the fact that it gives them control over a disease that has made them feel out of control."* Oncologist 1). This was not presented as a criticism, but rather as an explanation. One of the core aims of Integrative Oncology is giving patients a sense of personal empowerment, with a view to being "active participants during and beyond cancer" (Witt *et al.* 2017). Nutrition is a vital area where precisely such empowerment can occur.

An overwhelming majority (79%) of the oncologists who participated in the survey, stated that they believe nutrition plays a very important role in oncology. This was echoed in the interviews where oncologist participants emphasised the role of nutrition in treatment tolerance and recovery and spoke to the unique needs that arise in cancer patients. Around half the oncologists (53%) indicated that they regularly refer patients to dieticians for guidance, and 42% indicated that they counsel patients themselves. Many patients received some sort of dietary guidance from their clinics (31% of the government patients and 44% of the private patients), yet there was still a strong call by both private and government patients for better information provision in this arena.

In spite of oncologists' opinion on the importance of nutrition in oncology, the majority of dietary modifications appeared to be self-directed, especially amongst the government cohort. More than half of the patients surveyed reported that diet was never mentioned (65% of government patients; 27% of private patients; 54% of the total patient sample). Several patients who were interviewed spoke to the plethora of conflicting information in the media which creates confusion and adds to stress, highlighting the need for clear guidelines and support from professionals. Patients seeking better nutritional guidance has been reported in previous research (Lopez *et al.* 2017). Oncologists were aware that this is an area where patients needed and sought guidance. Several described nutritional queries as "common" and "expected". Two oncologists interviewees (one working in the private sector and one in the government sector) expressed the opinion that, whilst most oncologists give some dietary advice, such advice is generally quite broad and limited. For this reason, oncologists also emphasised the important contribution of dieticians, with several stating that every patient should receive nutritional counselling at least once and preferably all along the cancer continuum. Challenges to this ideal included medical aid in the private sector and capacity constraints in the government sector. A minority of patients reported visits to a dietician (1% government patients and 27% private patients), some of whom consulted dieticians specialising in oncology, with the latter being reported as resulting in more tailored solutions and science-based recommendations.

Nutrition has been shown by ongoing metanalyses to be a proven strategy in increasing treatment tolerance and improving patient outcome, decreasing breast cancer mortality and all-cause mortality (Vrieling *et al.* 2013; Reitz *et al.* 2022). Increasing health literacy in this area also has the potential to give the patient personal control during a time when they feel a lack of control, empowering them to become active participants in their own healing and wellbeing (Abrams and Weil 2014). Conversely, as reported by an oncologist in this study, some alternative dietary approaches followed with the best of intentions can caused more harm than good. Given the impact that the correct nutritional approaches can have on the cancer continuum, the fact that its role was never mentioned to over half the patient participants in this study, highlights this as an area needing better management. Given the constraints currently on oncologists, such information may need to be conveyed in another form such as hospital podcasts or mini booklets. As expressed by one oncologist interviewee: "*more could and should be done for patients in this arena….It should be a priority for all patients who are going through a cancer journey"* (Oncologist 2).

8.1.2 Supplements

Supplements are amongst the most used inclusions amongst cancer patients worldwide (Strizich *et al.* 2015; Alsharif 2021). Whilst promoted as “natural” and “safe”, supplement use can be a minefield for potential interactions with mainstream treatments (Terrie 2017; Fasinu and Rapp 2019). In the current study, supplement use was reported at 30% (21% government patients; 53% private patients). Once again, the government sector figures showed significance for non-use whilst the private sector showed significance for use (p <.001). The most commonly reported supplement was a multivitamin (24%) followed by vitamin D (11%) and omegas (10%). Of interest was 7% of patients utilising Indole-3-Carbonol (an alternative to hormone therapy). Of concern were high dose vitamin therapy reported at 3%, antioxidant tablets reported at 9%, and antioxidant teas reported at 9%. Patient use of supplements was supported by patient narratives in the qualitative phase, where half of the interviewees referred to supplement use. Multivitamin use was common in the narratives, but there were also reports of a wide range of other supplements including omegas, detoxing formulas, antioxidant use (including vitamin C drips), liver support, and a stem cell supplement. Two patient narratives spoke about consulting with supplement companies who provided tailored plans incorporating various supplement recommendations. Both the quantitative and qualitative data reported patients adopting supplement use as a way to support their body in fighting the disease, increasing their immunity, and combatting side-effects such as nausea and depression. More than half (54%) of the patients who used supplements reported that they did not disclose their use to their oncologist.

Oncologist interviews revealed different approaches to supplement use. The survey showed divided opinion on the usefulness or risk of many supplements. Only a few supplements were supported or regarded as dangerous by statistically significant proportion of oncologists. These were Omega 3 and Vitamin D (considered helpful), and high dose vitamin therapy (considered dangerous). All oncologists acknowledged the complexity supplements as well as their potential for good or harm. They also recognised that patients turn to supplements as an additional tool but often in a misguided fashion (such as wanting to use antioxidants or supplements that affect the immune system).

Supplements (including vitamins and minerals, herbal remedies, and antioxidants) have been reported as the most utilised inclusion by cancer patients (Strizich *et al.* 2015; Alsharif 2021; Krejbich and Birringer 2022). Supplements carry the risk of overuse and misuse, as well as the risk of potential interactions with mainstream drugs, and yet many are important in general health and particularly in nutritionally compromised patients who can have deficiencies, making management essential (Rock *et al.* 2022). Guidance on supplement use (along with advice on holistic health and diet) has been reported as one of the most common concerns amongst cancer patients (Lopez *et al.* 2017).

The majority of oncologists who participated in the survey (68%) reported discussing supplements with their patients. However, this is likely more a reflection of the private sector as a large proportion of patient participants reported that supplements were never spoken about (92% government; 30% private; 74% total). Both the responses in the survey as well as patient narratives spoke to very limited guidance on supplement use, with many being requested to follow a blanket exclusion until active treatments were completed. This was corroborated in the oncologist survey where 79% of the respondents stated this as their preferred approach during active treatments yet was raised as a limited and frustrating approach by some patients in their interviews. Around one third (35%) of the private patients, and the vast majority (83%) of the government patients indicated that they had needed more guidance in supplement use. Oncologists spoke to the challenge posed by the size of the supplement industry, the relative lack of regulation, and unfounded promises such as safety of the basis of the constituents being "natural or of potential "cure". Whilst there are oncologists who try to oversee patient use of supplements by examining ingredients, navigating the complexity of this can use up a "disproportionate amount of time" on what, for most patients, is of limited clinical benefit. This is the most likely motivation for a blanket exclusion during active treatments. Given the growing size and the nature of claims made by the supplement industry (whether founded and unfounded), addressing supplement use is important for all cancer patients, both during active treatments and beyond.

Cannabis was used by 28% of private patients and 8% of government patients (excluding drinking of cannabis tea). It was referred to by just under half of the patients during interviews with two thirds of those having used it (one third of the interview sample). Patients took it in the hope that it would fight the cancer, but also to assist with side effects such as pain, insomnia, and anxiety. Cannabis has been found to alleviate cancer-related problems such as fatigue, anxiety and pain (Abu-Amna *et al.* 2021). Claims of cure however, remain unfounded extrapolations of in-vitro studies (Maida and Daeninck 2016).

Oncologist interviews revealed that practitioners are aware of cannabis use becoming increasingly prevalent amongst patients. Oncologists are also aware than whilst many will use it, most will not reveal their use. This was supported by patient survey data showing that only 44% of those who used cannabis disclosed this use to their oncologists. Discussions between patient and practitioner regarding cannabis appear to be fairly rare. Eighty six percent of the patients who participated in the survey stated that cannabis was never spoken about with their oncologist. Patient interviewees also stated that when spoken about, they were the ones to raise the topic. Patients reported oncologist opinion to be divided, with some being relaxed about its use throughout active treatments, and others strongly discouraging its use. All but one of the oncologists interviewed discouraged use during active treatment, although acknowledging it has a place in the palliative setting when biomedical control of side-effects is ineffective. Oncologist interviews revealed the main reasons for caution as being false claims by proponents of cannabis, lack of regulation, and potential for drug interactions. This is corroborated by research indicating that there are currently few controls on the formulation and sale of cannabis (Al-Hamdani *et al.* 2021), and that it has the potential to interfere with mainstream treatments (Bodine and Kemp 2022). Caution remains the prudent approach. Given the fact that many patients do not disclose use, it is important that the oncologist raise the topic in order to provide the necessary insights and cautions.

8.1.3 Exercise

Exercise holds the potential to impact the cancer patient in many positive ways, from mitigation of side-effects (such as muscle wasting, cardiorespiratory deconditioning, pain, anxiety and sleep disturbances) through to rehabilitation and increased survival (Abrams and Weil 2014; Torregrosa *et al.* 2022). The survey revealed that whilst 67% of private patients incorporated exercise as part of their personal approach to cancer, this was the case for only 16% of government patients (government patients significant for exclusion and private patients significant for inclusion $p<.001$). Half of the patients interviewed during the qualitative phase also incorporated some form of exercise. The types of exercise incorporated by patients included walking, gym/resistance training, Pilates, yoga, and tai chi. These patients spoke to the tremendous physical and mental benefits this brought them. They spoke about exercise assisting them to maintain strength and mobility, whilst curbing pain and lymphedema. They also spoke about the psychological improvement it brought about, allowing them to feel “normal”.

All oncologists who participated in the survey reported that, in their experience, patients who engage in regular physical activity deal better with therapy both physically and mentally. All but one agreed that physical activity has cancer protective effects and the ability to affect survival rates (95%). Likewise, all but one agreed that cancer patients tend to overemphasise rest, resulting in decreased activity levels, yet also acknowledged that there are constraining factors which impact patients’ ability to be active. Oncologist interviews reinforced these views with oncologists referring to exercise as an “imperative” and “critical”, and something that should always be advocated. With the exception of one oncologist, all respondents reported that they make a point of raising the topic with their patients. The patient survey reflected 33% of patients reporting conversations (and/or referrals) with their oncologist about exercise (70% private patients; 23% government patients). Recognising the importance of exercise together with the fact that many patients overemphasise rest, researchers have set out to determine barriers and enablers for cancer patients (Avancini *et al.* 2020). Treatment side-effects and procedures formed the barriers as one would expect. strategies that strongly encouraged patients to exercise included the addressing of the medical role of exercise by the professionals, social support from family and friends, selecting enjoyable exercise, and setting goals. Additional factors that improved patient participation were the availability of a specialised consultant, individually tailored plans and access to suitable facilities (Avancini *et al.* 2020).

Torregrosa *et.al.* (2022) describe the physiological effects of exercise on the body as it pertains to the systemic and micro-environment of cancer, presenting both theory and supporting research. Based on their findings, they propose that exercise is the most promising way to improve the care of cancer patients (Torregrosa *et al.* 2022). These same researchers found that, despite the extensive evidence of the positive impact of exercise for the cancer patient, only 1 in 2 patients were participating in any form of exercise or were exposed to guidance regarding its incorporation as a tool in managing the disease (Fortin *et al.* 2021). The current research reports better figures than these for the private setting and worse figures for the public setting. Given the many advantages of exercise, as well as the relative ease with which a simple exercise program can be incorporated by most patients, information regarding why and how to incorporate physical activity should be actively promoted amongst patients, especially in the government sector. Once again, due to constraints on oncologists, information sharing would likely take the form of pamphlets, podcasts or mini presentations.

8.1.4 Psychological support

As reported in the literature review, there are many factors that contribute to depressive symptoms in breast cancer patients. Around 25% of cancer patients suffer from depression yet only around 5% of that 25% consult a professional (National Cancer Institute 2023b). The presence of depression in cancer patients is of concern as meta-analyses have demonstrated a link between depression and elevated mortality, even after correcting for confounding medical variables (Pinquart and Duberstein 2010).

The quantitative phase of the current research did not delve into whether people suffered from depression, but simply whether they received psychological counselling or support. Nine percent (9%) of the total sample reported visiting a psychologist (4% of government patients; 22% of private patients), and 12% of the total sample reported participating in a support group (4% of government patients; 32% of private patients). Once again, the private sector data was significant for use and the government sector data significant for non-use ($p <.001$). The qualitative phase found half of the participants (8 of the 16 patients) speaking at length about the emotional distress associated with different aspects of cancer, both for themselves and for their families. The crisis of diagnosis was described as a very frightening time filled with numerous negative emotions and thoughts. They went on to detail the distress of active treatments, both how they felt out of control when on this “rollercoaster”, as well as how treatment side-effects impacted them psychologically. This was especially poignant when interviewees were describing their battle with their new identity as a cancer patient, and with the bodily changes and mutilations that result from some of the treatments including surgery and endocrine therapy ("*You are being totally disfigured*" Participant 10: Private). Finally, interviewees who had been declared disease-free, spoke to the burden of living with the ever-present knowledge that their cancer could return. Many of these experiences, and reported reasons for psychological distress, were in keeping with findings in previous research. Currin-McCulloch *et al.* reported patients' distress at diagnosis and through the treatment processes, including body-image post surgically. In addition they referred to issues of existentialism and fears of death, all of which were reported by patients in the current study (Currin-McCulloch et al. 2021). Other researchers also referenced the sense of loss, endocrine therapy and its side-effects, disruption of life plans, changes in body image and self-esteem, compromised mental function and fear of death (Niedzwiedz *et al.* 2019; Bolte 2020; Currin-McCulloch *et al.* 2021; Fortin *et al.* 2021; National Cancer Institute 2023b). It is interesting to note that at 40% of survey respondents, "emotional distress" was the second most frequently cited reason for patients turning to TCAM, although the precise inclusion may not necessarily have been consulting a psychologist.

In the oncologist survey, all respondents agreed with the statement that it was the responsibility of the oncologist to address the emotional state and needs of their patients, and all but one believed that the mind and spirit play an important role in health and healing. The majority (68%) of oncologists reported that their practice was affiliated with a psychologist. In the oncologist interviews, participants described psychological support as a "critical" part of management, speaking to the need for practitioners to be sensitive to the psychological wellbeing of their patients. They acknowledged the impact of a cancer diagnosis and journey on the mental health of their patients and expressed the firm believe that psychologists have a vital role to play. One oncologist also expressed the opinion that counselling is not only for working through negative emotional aspects of a cancer journey, but also to set goals and bring hope. In the patient survey, 4% of government patients and 10% of private patients reported being referred by their oncologists for counselling. It is worth noting that two of the oncologists interviewed mentioned their experiences of many patients being reluctant to go for counselling, attributing this to possible negative preconceptions or associations with counselling. Costs associated with psychological support were also raised as problematic for many patients, with medical aid limitations (in the case of private patients), and capacity constraints (in the case of government patients) making access to counselling difficult if not impossible for many. Some of the patients interviewed reported turning to family, friends, and support groups for alternative sources of support. However, two of the patients interviewed felt strongly that professional support was better for the patient and their family, bringing insights and objectivity that family cannot offer.

In summary, a cancer journey brings experiences and physiological changes that can greatly impact the mental health of both the patient and their family. Even more critical, is the impact that patient metal health can have on cancer outcome. Yet 80% of government patients and 50% of private patients (70% of the total sample) reported in the current survey that psychological issues were never discussed. Although a deeply personal area of care, every patient should be made aware of how their emotional health can impact their outcome and be given the opportunity to avail themselves of formalised professional support at different times in the cancer continuum should they need it.

8.1.5 TCAM practitioners

Patient visits to at least one TCAM practitioner was reported at 13% for government patients and 53% for private patients. In the case of government patients, this was mostly to African traditional healers (9%), but also included Chinese medicine, chiropractic, homeopathy, ayurveda, and acupuncture. In the case of private patients, the most utilised modality was massage therapy (29%) followed by chiropractic (18%) and homeopathy (16%). Acupuncture, aromatherapy, ayurveda, BodyTalk, Chinese medicine, kinesiology, naturopathy, reflexology and reiki were also reported. Private patients were significant for use and government patients for non-use of TCAM consultations (p <.001). Use of TCAM practitioners was corroborated in the patient interviews, where there were instances of these patients visiting acupuncturists, homeopaths, chiropractors, massage therapists and energy healers. These TCAM practitioners were consulted for side-effects such as musculoskeletal issues, emotional trauma, sleep disturbances as well as for radiation burn prevention. The patients who utilised these therapies reported finding them very helpful.

Whilst some oncologists participating in the survey reported that their oncology practices are affiliated to a psychologist and/or a nutrition specialist, all oncologists reported no current affiliation or ongoing formal collaboration with any TCAM practitioners, a finding corroborated in the interviews. The reported frequencies of oncologists recommending or referring to TCAM practitioners was fairly low but notably not absent. The vast majority of oncologists selected “never” when asked if they ever recommend or refer to: African traditional healer (95%), Ayurvedic practitioner (68%), Traditional Chinese practitioner (79%), Homeopath (63%), Naturopath (84%), Functional medicine practitioner (79%), Acupuncturist (42%) and Reflexologist (58%). However, the remaining percentages of these responses reflect oncologists that *do* refer or recommend these practitioners to their patients on occasion, with one (and in some cases two) oncologist/s reporting that they regularly refer patients for homeopathy, naturopathy, functional medicine, acupuncture, and reflexology.

The main reason for non-referral was the potential for counterproductive or dangerous medical interactions with mainstream therapies, believing that referral is “not responsible medicine” (52% of respondents), a finding duplicated in the interviews. In addition, the matter of reliable evidence was highlighted in the survey, with 42% of the respondents feeling that there was “little evidence of efficacy and safety of TCAM use in oncology”. The majority of oncologists (63%) were of the opinion that there is an increase in the numbers of late presentations and delaying of mainstream treatments attributable to patients wanting to try alternative approaches first. Oncologist knowledge of the different therapies remains low with a significant proportion of oncologist reporting that they have “very little knowledge” for most TCAM fields in the survey. Whilst knowledge remains low, caution (and possibly exclusion) is likely to remain the prudent and default approach for oncologists towards most TCAM fields.

Oncologist interviews threw additional light on their experiences and resulting opinions. Interviewees expressed support of the right of patients to explore different healing options. In addition, some were open to the potential role that certain TCAM practitioners might be able to play in oncology. In the survey, 8 oncologists (42%) expressed interest in the potential role that TCAM practitioners could play in oncology but the remaining 11 disagreed (58%). During interviews, most oncologists displayed cognizance of the need for mutual respect between mainstream and TCAM practitioners and one oncologist expressed the opinion that more open communication, and a more consultative approach, could benefit both practitioner and patient. Given that oncology patients are receiving proven and critical treatment protocols, TCAM practitioners also need to respect these and refrain from administering treatments that could interfere with these protocols. In the interviews, several oncologists spoke about the negative experiences with patients who had used African Traditional healers alongside active biomedical treatments, as well as experiences of unproven claims and exploitation. Previous research elsewhere in the world has reported very similar findings, with professionals holding different views on the value and place of TCAM, resulting in them attributing it varying levels of legitimacy (Siegel *et al.* 2016). In addition, that while some health professionals may express some of support for TCAM, that this is limited by questions of efficacy and concerns regarding claims of jurisdiction (Siegel *et al.* 2016).

When patients were asked if TCAM specialists/practitioners were discussed during oncology consultations, 93% of patients (98% government patients; 80% private patients) reported that TCAM practitioners were never spoken about. This is concerning given that many cancer patients, finding themselves in a pluralistic medical landscape, choose to access treatment from additional TCAM practitioners. The self-reported Oncologist knowledge of TCAM fields was mostly limited. This is confounded by what oncologists deem to be inadequate evidence of efficacy, as well as negative personal clinical experiences. These experiences lead many oncologists to be wary of TCAM practitioners occupying a place in oncology. However, there remains amongst some an openness to the potential role that some TCAM practitioners could play. Specialist TCAM fields however remains largely unspoken about with most patients.

8.2 Factors Associated with Patient TCAM Use

8.2.1 Demographic factors

Previous research from elsewhere in the world has shown that TCAM use by cancer patients is generally associated with higher education levels, higher employment status/income levels, and access to medical aid (Wanchai, Armer and Stewart 2010; Chang *et al.* 2011; Saquib *et al.* 2011; Tautz *et al.* 2012; Saghatchian *et al.* 2014; Oyunchimeg *et al.* 2017; Yalcin *et al.* 2017; Gall *et al.* 2018; Hammersen *et al.* 2020; Dehghan *et al.* 2023). The current research found the same associations: Inclusion of TCAM consultations, dietary approaches, supplement use, cannabis use, inclusion of exercise, relaxation techniques and psychological support were all significantly associated with post-schooling education, higher levels of income, and access to medical aid. Spiritual support practices were associated with no education (or primary level education only) and were significant for non-use amongst those in higher income brackets.

All the inclusions listed above were also significantly associated to patients being treated at private facilities. This is likely due to the fact that the treatment centres (government vs private) reflect the disparate socio-economic profiles of the patients, with those attending the private facilities having higher education levels, higher income, and access to medical aid. Besides the agency gained through a strong financial situation, there is likely also disparity of agency in terms of literacy and access to health information (see below under 8.2.3).

8.2.2 Personal motivations

The most highly cited reason for inclusion of TCAM practices by the patients in this study was “doing all I could” (68% of question respondents). This gives insight into the patients’ sense of needing to ensure they were doing all in their power to combat the disease and support healing, an insight firmly corroborated in both patient and oncologist interviews. Of a similar nature is the patients’ desire for more personal control (23% of question respondents). A need for more control was also reported as a reason for TCAM use in a 2020 systematic review. This same review also reported that tradition was a significant factor motivating TCAM use for African patients (Tangkiatkumjai, Boardman and Walker 2020a).

In the current study, twenty-nine percent of the question respondents also stated that the TCAM practices were included because they were “part of [the patient’s] culture”. Research into TCAM use by indigenous populations has described it as being much more than just a treatment for physical symptoms, but rather as intrinsic to their wider belief system, a connection to their community and culture, and as having spiritual and emotional benefits (Gyasi *et al.* 2016; Gall *et al.* 2018). Cultural diversity was shown to play a role in cancer patients’ choice of TCAM. Jones et al. described Chinese patients as favouring herbal medicines, African Americans using spiritual healing, and Caucasians favouring the use of several methods including physical therapies, dietary approaches, massage, and acupuncture (Jones *et al.* 2019). It could be argued that the racial associations between the inclusion or non-inclusion of certain TCAM approaches by the patients in this study could be influenced by culture. For examples, significant inclusions for the Black patients included African traditional healer consultations and spiritual approaches, whereas significant inclusions for the White patients included TCAM consultations (excluding African traditional healers), cannabis, exercise, and relaxation approaches.

The second most cited reason for TCAM use was “emotional distress” (40% of question respondents), 23% cited the desire to “increase immunity” and 19% the need for relief from side-effects. These reasons have frequently been cited in previous studies, and thus form core matters of relevance to clinicians when discussing patient needs and TCAM practices (Saghatchian *et al.* 2014; Kessel *et al.* 2016; Farahani *et al.* 2019a; Wode *et al.* 2019).

8.2.3 Information seeking and sources

Navigating a pluralistic landscape and making treatment decisions is recognised as a potential source of stress for cancer patients as they seek to inform themselves and adopt practices that might be of benefit (Reyna *et al.* 2015; Horneber *et al.* 2018; Currin-McCulloch *et al.* 2021). One’s ability to do this depends on one’s level of health literacy. “Centers for Disease Control and Prevention” defines personal health literacy as “The degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others”. It requires not only an ability to access appropriate health information, but also to correctly understand it and make well-informed decisions (Centers for disease control and prevention 2023). Dehghan *et al.* (2023) found a significant and direct relationship between the use of additional TCAM inclusions, and higher health literacy of patients (Dehghan *et al.* 2023). There are other factors that affect information gathering and decision making. Previous research has noted that cultural differences appear to impact health information-seeking more than level of education. For example, they reported that White patients preferred unbiased, scientific information from reputable sources such as medical journals and institutions, that Japanese patients utilised the commercial sources such as television and TCAM providers, and that Asians and Pacific Islanders favoured social sources of information (friends and other cancer patients) (Jones *et al.* 2019).

The quantitative phase of the current study revealed both cohorts citing the use of multiple sources (both formal and informal) for gathering of TCAM information. Whilst elsewhere in the world, the internet and social media are the largest sources of TCAM information, followed by friends and family, the most cited source of TCAM information in the current study was family (42% of question respondents) and friends (40% of question respondents). This was followed by 24% respondents citing use of the internet, and 21% saying they got information from fellow patients. Notable differences between the two cohorts were reflected in the proportion of patients reporting that they chose thri current TCAM practices due to having grown up using them (44% of government respondents; 21% of private respondents), as well as those reporting obtaining information from their oncologists (10% of government respondents and 34% of private respondents). The percentage of patients citing their oncology practitioner as the source of TCAM information is fairly low. A high need for TCAM information amongst cancer patients, combined with a failure to consult with the primary oncology physician has been previously highlighted (Tautz *et al.* 2012). The qualitative phase of the current study confirmed the use of a variety of sources used when seeking TCAM information. In addition, the narratives revealed a notable difference between the agency and activity in information gathering between patients in the two cohorts. Private patients appeared to read widely and consult professionals more regularly, whilst public patients gained limited information from the internet and mostly relied on superficial ad hoc information sharing amongst patients.

Research into the statistics of a patient call centre elsewhere in the world suggest that many patients have unmet information needs (Horneber *et al.* 2018). Provision of quality evidence based TCAM information for cancer patients has been a consistent call from journal articles (Wanchai, Armer and Stewart 2010; Tautz *et al.* 2012; Saghatchian *et al.* 2014; Horneber *et al.* 2018; Wode *et al.* 2019). Both the quantitative and qualitative phases of the current study also highlighted a call from patients for better information provision, especially in the government sector. Ninety-three percent of the patient sample thought it was important to provide cancer patients with additional information and guidance to assist them in making choices about complementary healing therapies. Sixty nine percent of the sample expressed needed more guidance on supplement use (83% government patients; 35% private patients); 51% of the sample would have liked more advice on complementary therapies to assist with side-effects and healing (60% government patients; 27% private patients); 46% of the sample indicated needing more guidance in dietary approaches (54% government patients; 25% private patients); and 39% indicated they would have liked to receive more emotional/psychological support (42% government patients; 30% private patients). It is worth noting that the percentages of patients who reported needing more information were consistently higher in the government sector where oncologist time and patient literacy are both constrained. Ensuring dissemination of appropriate information for patients in the government sector brings unique challenges that require unique solutions. These solutions would need to be sustainable, accessible, understandable for the layman, culturally sensitive, and preferably available in the home language of the patient (Centers for disease control and prevention 2023).

Patient interviews described the confusion of navigating pluralism: *"Knowing what to do and not do is so confusing….It's natural for people to run around and want to take things to help themselves so they need information on what to do or not do"* (Participant 5)*. "There were so many conflicting pieces of information"* (Participant 6). Many called for better empowerment through provision of information: *"There is the need for more guidance because people don't know. A kind of go-to place would be lovely, where information and recommendations are available to guide people and help them in their whole treatment journey"* (Participant 3). *"The information is not enough to make progress or decisions on lifestyle, food choices and how to prevent cancer the next time. We just live in limbo hoping nothing happens"* (Participant 2:).

8.2.4 TCAM disclosure and the doctor-patient relationship

TCAM use by oncology patients has been reported to be higher than the general population, and even as high as 90% in some countries (Kleine Wortmann *et al.* 2016; Alsharif 2021). Many studies also report high levels of non-disclosure of TCAM use by patients, a matter of concern given that certain TCAM inclusions are not suitable for concurrent use with mainstream oncology treatments (Tautz *et al.* 2012; Naja *et al.* 2015; Oyunchimeg *et al.* 2017; Roumeliotis, Dostaler and Boyd 2017; Yalcin *et al.* 2017; Sarada *et al.* 2021). In the current study, levels of non-disclosure had a wide variation for different inclusions. The following percentages of non-disclosure were reported for practices that might affect clinical management: 47% of those using dietary approaches, forty six percent of those using supplements, 56% of those using cannabis, 67% of those consulting a naturopath, 75% of those who used Chinese medicine; 43% of those who used acupuncture, 31% of those using homeopathy, and 100% of those using African traditional medicine.

Previously outlined reasons for patient non-disclosure of additional therapies include lack of enquiry by the medical professional, patient anticipation of disapproval, perceived disinterest on the part of the professional, perceived lack of information/knowledge of the medical professional, and the belief that disclosing use was not necessary (Wanchai *et al.* 2017). The reasons for non-disclosure in the current study were similar to those reported by Wanchai *et al.* with 47% stating that they were not asked; 33% stating that they did not feel it was necessary; 10% citing fear of disapproval; and 10% stating they tried but sensed disinterest on the part of the professional. It is of interest to note that a larger percentage of government patients felt it was not necessary to tell their oncologist about additional inclusions (41%GOV vs 17%PVT) and that they were afraid (14%GOV vs 2%PVT) whereas the perception of limited interest on the part of the professional was cited by a higher percentage of private patients (3%GOV vs 23%PVT).

From the point of view of the medical professionals, speaking about TCAM is hampered by many factors. A literature review by Stub *et al.* summarised four factors which make medical professionals reluctant to speak about TCAM. These were differences in philosophical values and ideas of what constitutes treatment; adverse effects that can occur with concurrent use; lack of adequate scientific evidence of efficacy; and lack of knowledge of treatments on the part of the practitioners (Stub *et al.* 2016). The oncologist reservations reported in the current study mirror these same factors (as also reported in 8.1.5 above). Over half of the oncologists (56%) in the current study reported that they raise the topic of TCAM inclusions with their patients, and eight oncologists (44%) indicated that they will only discuss TCAM with patients if the patient raises the topic. In the patient survey, over 80% of patients who had TCAM discussions with their oncologists reported this as being initiated by the patient. These figures may be partially explained by the oncologist survey feedback where twelve of the nineteen oncologists (63%) stated that they believed that the responsibility of the oncologist is mainstream treatments and not to guide patients in TCAM use (The remaining 7 (37%) however, disagreed with this statement). One also needs to bear in mind that, whilst many of the oncologist respondents in this survey were working in private practise, many of the patient respondents were from the government sector where time and staffing constraints impact patient consultation experiences. *"There are tremendous time pressures and constraints…you may only spend five minutes with a patient because you have 30 patients to go through"* (Oncologist 2).

The critical role of the doctor-patient relationship is emphasised by advocates of Integrative Oncology, believing that it has become devalued in pressurised contemporary medical settings (Abrams and Weil 2014). In an article exploring the changing nature of the doctor-patient relationship, In the current study, the majority of patients spoke very highly of their oncologists and explorations revealed many relationships of mutual respect, compassion and excellence that had a positive impact on the patient's experience. Even though TCAM discussions were limited, patients from the private sector spoke about unhurried engagement and personalised care, with few even reporting collaborative explorations into treatment options. The government patients expressed respect, yet also revealed how the doctor-patient relationship was hampered by the fact that oncologists keep changing. *"Oncologists keep changing. I can't really say which one is my doctor. ..Sometimes I am instructed to go to one hospital* *and sometimes I am instructed to go to another hospital. That troubles me and I feel like it has a huge impact on patient care”* (Participant 14).

Many studies call for more open discussions on TCAM between practitioners and their patients, believing that an atmosphere of openness and understanding will allow patients to feel comfortable discussing their choices (Fremd *et al.* 2017; Roumeliotis, Dostaler and Boyd 2017; Wanchai *et al.* 2017; Horneber *et al.* 2018; Wode *et al.* 2019; Alsharif 2021). Along with this call, is also a call for improving awareness of TCAM amongst oncologists (Fremd *et al.* 2017; Roumeliotis, Dostaler and Boyd 2017; Paepke *et al.* 2020). Health care professionals often feel that they do not have adequate knowledge to discuss TCAM (Chang *et al.* 2011). In the current study, whilst 42% of the oncologists described their knowledge of TCAM as “adequate”, a further 42% admitted that they often felt they “needed to know more” and 3% described their knowledge as “poor”.

In the interviews, one oncologist referenced the lack of any formal training in holistic and alternative treatments, a deficit which the interviewee felt compromises their ability to adequately guide patients. This interviewee was of the opinion that oncologist education would be integral to any growth of Integrative Oncology. The survey showed that only two oncologists (11%) had been exposed to TCAM modules as part of their formal training, and eleven out of the 18 oncologists (61%) believe that some elements of TCAM knowledge should be incorporated into formal training. Of those who felt inclusion into formal training would be helpful, a significant number of respondents (10 oncologists) supported the incorporation of training on the role of nutrition. Nine (82%) supported training on an overview of the main types of TCAM therapies and seven (64%) supported training on how to manage patient TCAM use. Less than half of the respondents said that they would support TCAM training as part of CPD. Whilst 58% were in support of the inclusion of TCAM modules in formal oncology training, 42% deemed it unnecessary.

8.3 Integrative Oncology

8.3.1 The status quo

Integrative Oncology is a field of cancer care that utilises an evidence-based combination of conventional therapy with complementary interventions from different traditions, in order to improve quality of life, optimising health, and clinical outcomes across the cancer care continuum (Abrams and Weil 2014; Witt *et al.* 2017). It seeks to address the whole person living with and beyond cancer, supporting the natural healing power of the body, stressing the importance of lifestyle, honouring the role of the doctor-patient relationship and empowering people to become active participants in their own health and healing (Abrams and Weil 2014; Witt *et al.* 2017).

The discussion thus far has been focussed upon revisiting current practice and lived experience of patients and oncologists. Both the quantitative and qualitative results indicate that oncologists support the important role of lifestyle in the management of cancer. In the private sector, several oncologists provide basic nutritional information and there is referral to dietary and psychological professionals where deemed necessary, rare inclusions in the constrained government sector. However, the majority of the triangulated evidence supports the view that the ideal of formalised Integrative Oncology, as defined by international organizations promoting the field, is currently not being practiced in eThekwini. Whilst many patients are seeking to embrace holistic lifestyle approaches (e.g., nutrition, supplements, exercise, relaxation, and psycho-spiritual approaches) most of these are self-directed as formal guidance from their oncology clinic is often lacking. Navigating the plethora of information and making independent decisions has been reported as confusing and overwhelming, and there is a widespread patient call for more guidance on lifestyle inclusions from the mainstream environment. In addition, whilst some patients are turning to TCAM practitioners (e.g., homeopathy, chiropractic, acupuncture, African traditional healers, and naturopaths), there is once again very little information about the potential benefits or risks of these inclusions, and collaboration between the oncologists and TCAM practitioners is uncommon or absent.

Qualitative explorations revealed that there are oncologists who recognise that a formalised evidence-based integrated approach could be beneficial for both practitioners as well as patients, addressing currently unmet needs and assisting safe navigation of a pluralistic landscape, avoiding dangers whilst harnessing the benefits of complementary therapies. When asked in the survey to select the statement that best described their perceptions of the field, five out of 19 oncologists (26%) selected the statement “very positive. I believe it is the way forwards”. Ten oncologists (53%) selected the statement “positive but tentatively so as there are many challenges to overcome”. These two statements both reflect support of the concept of Integrative Oncology, and it is worth noting that collectively, the number of oncologists who selected one of these two statements represent the vast majority (79%) of oncologists who participated in the survey.

However, not all oncologists respond positively to the idea of integrative practice. Three oncologists (16%) selected the statement “negative and resistant to the idea as there is much to be investigated and proven first”, and one oncologist (5%) selected the statement “very negative as the complications outweigh the benefits”. As in 8.1.5 above, interviews revealed how these reservations on the part of oncologists are rooted bad experiences with patients who incorporated additional therapies, as well as lack and limitations of evidence. Many of the bad experiences related during interviews concerned toxicity resulting from concurrent use of African Traditional Medicine, an issue of concern as disclosure levels are very low. However, there were also instances of patients opting for therapies such as extreme diets, and fad offerings. One oncologist expressed the opinion that people currently promoting themselves as practitioners of Integrative Oncology in South Africa actually practice a non-evidence-based “fringe oncology”. This oncologist stated that fringe practitioners and practices punted as “Integrative Oncology” have given Integrative Oncology a bad name which will take a lot of work to remedy.

Although one of the main precepts of Integrative Oncology is that it rests on Evidence Based Medicine (EBM), evidence was repeatedly referred to by oncologists both during the quantitative phase (in the open-ended questions), as well as in the qualitative phase. Lack and/or limitations of evidence was cited as the main reason these oncologists were not in favour of an integrated approach. One oncologist spoke to the massive size of clinical trials required in oncology for the mainstream treatments, which is lacking in the potential role for complementary and alternative therapies in oncology.

8.3.2 Challenges and opportunities

The dynamic complexity of a pluralistic medical landscape brings with it undeniable challenges and opportunities for medical systems, providers, and patients. Integrative Oncology, as a field of practice that has its roots in and draws on medical pluralism, likewise faces the same challenges and opportunities. In exploring patient and oncologist navigation of the local pluralistic medical landscape, the current research has not only gathered insights into practice and lived experience, but in doing so has also gleaned a clearer understanding of some of the challenges and opportunities with respect to the growth of Integrative Oncology in the local setting. This chapter will now end by outlining these challenges and opportunities in terms of the systemic factors, factors relating to oncologists, and those relating to patients. These factors are also summarise in Table 8.3.2.1 below.

8.3.2.1 Systemic

The biggest systemic challenge in the local setting is the disparate socio-economic nature of medical services in South Africa, and therefore the capacity to provide integrative holistic practices for the majority of breast cancer patients. All through this study, the disparity has been clearly evident. Government facilities are challenged in terms of funding and therefore staff appointments and treatment protocols. There are currently limitations on mainstream biomedical treatments, placing doubt on the feasibility of the more complex and holistic model of Integrative Oncology.

In this digital age of social media, there is a plethora of information and misinformation, both highly available and difficult to navigate. There are many practices and practitioners promising unproven results and these pose potential threats to patients, oncologists, and the reputation of Integrative Oncology. Many of these practices are marketed under the banner of “Integrative Oncology” yet involved no collaboration with mainstream providers and do not uphold the principles of Integrative Oncology. Regulation of the abundance of alternative medical provision, including manufacture and sales of products is very difficult to manage. However, whist these factors make the TCAM world that lies outside of mainstream oncology a confusing and potentially dangerous space, it is an argument in favour of the controlled evidence-based formalization of Integrative Oncology. Failure to address possible patient use of TCAM and/or placing blanket exclusions on TCAM use is not serving patient needs, leaving them uninformed and disempowered.

On the positive side, true Integrative Oncology which incorporates mainstream as well as evidence-based complementary offerings is growing as a field, resulting in a concerted international effort to provide both the necessary scientific evidence base together with guidelines for clinicians and patients. Studies are demonstrating worthwhile improvements in quality of life for patients, but also the impact that some inclusions can have on outcome. As a richly pluralistic landscape, South Africa recognises and validates many alternative health professions. This holds potential for those seeking to explore Integrative Oncology practise in a more formalised way.

8.3.2.2 Oncologists

Oncologists in the local setting are few and thus are already overworked by the current and increasing oncology burden in the country. Simply managing mainstream treatments is a mammoth task. TCAM is a vast and dynamic field, and oncologists do not receive any formal TCAM training. Many feel they lack adequate knowledge to properly assist patients in navigating holistic inclusions and TCAM offerings. Limited time and TCAM knowledge in turn results in limited patient-practitioner communications. This leaves patients with unmet information needs and aspects of care which they feel are lacking. Oncologists have experienced the negative side of unsafe TCAM use. They have had to deal with later presentations in instances where patients initially refused mainstream treatments. In addition, they have experienced toxic reactions when patients use herbal remedies alongside mainstream therapies without disclosing use. These experiences make have resulted in oncologists being very wary of TCAM as a field. Several oncologists are of the opinion that most TCAM offerings are of limited worth, and that evidence is insufficient to warrant investment of time and money.

Many oncologists, however, already embrace the need for holistic approaches, seeking ways to incorporate them more actively, and some remain open to the potential for other integrative practices and TCAM practitioner collaboration when supported by adequate evidence and when their inclusion does not involve risk. For those oncologists wishing to offer their patients more, there are TCAM inclusions and lifestyle support practices that could be offered to patients by way of enhancing care without compromising treatment protocols. This would naturally start with health literacy on the basic theory and guidelines for holistic practices and possibly consultations with these professionals (nutrition; exercise; relaxation technique training; psycho-oncology support). Integrative Oncology opens up channels of communication between mainstream and TCAM practitioners, as well as between oncologists and their patients. This in turn increases trust and decreases risk.

8.3.2.3 Patients

The socio-economic status and limited literacy (and therefore health literacy) of a large majority of cancer patients negatively impact their personal agency. However, the importance of health literacy in these patients remains critical and presents a challenge that would need to be surmounted in creative ways such as the use of videos, podcasts, or trained advisors who communicate important messages to patients in culturally sensitive ways. Lack of patient-practitioner communication, and fear or ignorance on the part of the patients, contribute to non-disclosure of TCAM inclusions by patients, which in some instances carries risk (for example when involving herbal products).

Integrative Oncology offers patients holistic care that assists them in navigating the risky landscape of medical pluralism whilst addressing unmet needs. Increasing health literacy through knowledge of the benefits and risks of the main TCAM inclusions can empower patients to become more involved in their personal healing. Very importantly, this empowerment also reduces the risk of self-directed inclusions that could be counter-productive or even dangerous. Integrative Oncology also seeks to empower patients not only for their treatment journey, but beyond through the whole cancer continuum whether living as a survivor or dealing with end stage disease. Whilst adoption and compliance will always be hampered by many variables including socio-economic status, these cannot begin to be achieved without adequate health literacy.

Table 8.3.2 1: Challenges to, and opportunities for the growth of Integrative Oncology in the local setting

	Challenges	**Opportunities**
Systemic	• Disparity of South African medical services. • Plethora of information and misinformation. • Regulation of TCAM. • Funding limitations.	• The growth of Integrative Oncology as a field with evidence and guidelines. • South Africa recognises many alternative fields which are available for formal integration.
Oncologists	• Constrained numbers of oncologists and increasing cancer burden resulting in high pressure working environment	• Many oncologists are open to holistic and integrated inclusions given the evidence of benefit without risk.

	- No formal training in TCAM and knowledge is limited. - Patient-practitioner conversations do not take place. - Have experienced negatives in terms of late presentations and concurrent undisclosed use. - See most TCAM as lacking evidence and of very limited worth.	- Integrative Oncology offers professionals opportunity for a team-approach. - Strengthening of patient-practitioner trust and communication. - Opportunity to position the practice as offering more than mainstream biomedical treatments.
Patients	- Patient health literacy - Lack of disclosure - Adoption and compliance limited by aspects such as socio-economic status.	- Patients holistic needs met. - Benefit from open communications where health literacy is increased. Patients are empowered to become part of own healing journey through and beyond treatments. - Controlled approach protects from dangerous self-directed choices.

The play of factors in the local pluralistic medical landscape offers numerous challenges to the growth of Integrative Oncology in its fullness. However, the same landscape also appears to offer opportunity for both practitioners and patients. Patients will continue to explore this landscape in their efforts to do what they can in their personal capacity to gain control and seek healing. Professionals cognizant of patients seeking a more holistic and integrated approach, can draw on the growing evidence base of Integrative Oncology research to maximise patient care.

9. CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

9.1 Summary of the Study Findings

Formalised Integrative Oncology is currently not evident in Oncology care in eThekwini. There are, however, oncologists who strive towards a holistic model of patient care and who are open to other evidence-based inclusions and collaborations. With the disparate nature of medical provision in South Africa, the government sector holds more challenges for both oncologists and patients, making the private sector more suited to the growth of Integrative Oncology.

Whilst there are numerous challenges to the growth of Integrative Oncology in the local setting, the potential benefits warrant thorough, open, and informed consideration. As central players, oncologists offer valuable insight into the feasibility, limitations and challenges present in an already constrained system. Their opinions, however, remain divided on the usefulness of Integrative Oncology as a model for managing patient care. Whilst many oncologists acknowledge limited personal knowledge of TCAM, reservations were also based on their previous negative experiences with patient TCAM inclusions (mostly African traditional healers) and the promotion of products or modalities with unfounded claims of healing.

This study found however, that despite some reservations and concerns, many oncologists see the value of and need for collaborative, and integrated patient care. It has also demonstrated that despite seeking better support and calling for more guidance, many patients remain disempowered by lack of knowledge. In the absence of doctor-patient communication and guidance, these patients adopt self-directed choices which may negatively impact patient outcomes.

Evidence-based health literacy and the active inclusion of relevant holistic practices should ideally be part of the management of all cancer patients. This includes an understanding of the potential impact of lifestyle factors such as diet and exercise on patient outcome. Dissemination of accessible, reliable, evidence-based information about these and other potential TCAM inclusions/exclusions remains a priority in order to facilitate open and informed patient-practitioner discussions and optimise patient outcomes.

9.2 Study Recommendations

The following recommendations have emerged from the findings of this research study.

Recommendation 1: The incorporation of TCAM information in the continued professional development (CPD) and education forums of oncology professionals, including oncologists and nurses caring for patients.
This could include various topics such as the basic understanding of the different types of TCAM practices and their potential role or risk for cancer patients; discussions on how best to manage oncology patient TCAM use; and explorations of the theory and practise of Integrative Oncology. These voluntary CPD sessions would be with a view to facilitating open evidence-based patient-practitioner discussions, thereby improving patient disclosure of TCAM usage, and empowering patients to make informed decisions and play an active role in their own healing .

Recommendation 2: The inclusion of oncology-specific continued professional development for other related disciplines such as dietetics, exercise and psycho-oncology.
This would aim to provide discipline-specific guidance on the holistic management of cancer patients, and better equip these providers to participate in increasing patient health-literacy in these vital arenas.

Recommendation 3: The foundation of a multidisciplinary Integrative Oncology forum.
This group could collate and share high quality Integrative Oncology resources and distribute them to interested parties. This forum would also allow for support between different health professions interested in integrated holistic patient management, and optimisation of cancer patient quality of life and health outcomes.

Recommendation 4: When designing universal health care programmes, as envisioned by the National Health Insurance (NHI) Bill, the National Department of Health should consider piloting a multidisciplinary Integrative Oncology centre.
Should this pilot be successful, the Integrative Oncology model could be included in the roll out of universal health care and ease the burden on the public sector oncologists while improving patient care

9.3 Recommendations for Future Research

This research explored a previously uncharted landscape. While it provides initial insight into TCAM use in eThekwini breast cancer patients, there is a need for future research into the potential for Integrative Oncology in South Africa:

First, this study was limited to breast cancer patients. Future studies should be conducted to investigate TCAM use by patients with other types of cancer in eThekwini.

Second, this study was limited to the eThekwini municipality. Future studies should be conducted to investigate TCAM use by breast cancer patients in other South African municipalities. This should include a focus on rural areas where African traditional medicine use is prevalent.

Third, this study did not include an investigation of the management of cancer patients by TCAM practitioners themselves. Future studies should be conducted to close this gap in available evidence.

Fourth, this study was a broad overview of TCAM use by breast cancer patients. Further in-depth studies should be conducted into the use of the specific modalities by cancer patients across the country.

9.4 Limitations of this Study

Several limitations of this study should be acknowledged.

First, as the study included participants from a single municipality the findings cannot be regarded as generalizable.

Second, as the study was limited to breast cancer patients the findings may not be representative of patients with other types of cancer.

Third, there were sampling constraints to this study. Due to privacy restrictions and COVID-19 restrictions, convenience and snowball sampling were necessary. Unfortunately, the final sample is not demographically representative of breast cancer patients in the municipality or country.

Finally, while most studies are conducted with the assumption of participant honesty and transparency, it should be acknowledged that some participants may experience varying levels of unease or anxiety around balancing their desire to ‘please’ the researcher and, simultaneously, to not ‘betray’ those who are responsible for their care. The extent to which information has been distorted or withheld in response to such tensions is impossible to determine post-hoc. The design of future studies within this domain is recommended to take this more subtle consideration into account.

9.5 Conclusion of the Study

Medical pluralism is a vast arena, and the field of Integrative Oncology is complex. This study sought to explore patient and practitioner choices and lived experience within the local pluralistic landscape. It also sought to ascertain the status of Integrative Oncology practice in eThekwini, and broadly identify challenges and opportunities for its future application. Future research opportunities, such as those identified in this chapter, should add to these findings to develop a deeper and more nuanced understanding of what is a vast area of investigation. Notwithstanding the limitations of the study, the four data sets emanating from the research endeavours outlined in this thesis, have resulted in useful insights into the practice and lived experiences of oncologists and breast cancer patients in eThekwini. They have also provided rich elucidation of the current challenges and opportunities that the local pluralistic landscape presents to the growth of Integrative Oncology in the local setting, and fertile insights for the philosophical and practical investigation of a critically important, promising, and multi-disciplinary clinical field.

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11. APPENDICES

11.1: Insight Into The Researcher

(This section is included for readers interested in my personal position within the debates of the health seeking landscape, and on how I came to hold this position).

Childhood medical landscape.

I was born and raised in a middle-class family in the suburbs of East London and Johannesburg, South Africa. The time was one of simple living and simple choices. The medical system of the middle class was based on the Western biomedical model, and this system provided our family with all the medical insights and care we needed, from birth, through childhood illnesses, to assisting with the elderly. Reference books and articles we might have turned to when seeking information were based on this same model.

We practiced wholesome holistic living, with nutritional and exercise considerations as important contributions to health and wellbeing. I also came from a long line of devout Christians and embraced spirituality as vital in the journey of life. I do vaguely recall there being a very limited presence of the rare alternate practitioner but was never exposed to them as part of my care and was firmly rooted in the biomedical model of understanding when approaching disease and health.

Tertiary education and lecturing.

Having an interest in the scientific and medical fields, I went on to obtain a Medical BSc (Hons) at the University of the Witwatersrand, before taking up a position of lecturing Anatomy, Physiology and Histology in the department of Basic Medical Sciences, at what was then Technikon Natal. I was put in charge of lecturing several courses to students studying homeopathy and chiropractic, and through these interactions, started to be exposed to the ideas and practices of alternate medical fields.

Use of Homeopathy.

When I was married and had my three children, I continued to follow the Western biomedical practices within my own family. However, at one point I was not happy with the high frequency of tonsillitis being suffered by my then two-year-old son, with recurrences almost every month throughout that year. Nor was I happy about the frequency of antibiotics I had to administer to bring him relief. It was suggested at that point that he have a tonsillectomy. I requested that I be given the opportunity to consult with a homeopath as a last resort before the operation. This consultation concluded with me leaving the rooms with three tiny sachets of white powder to be given that evening and the next day. My son recovered from that infection within a couple of days, never had tonsillitis again, and still has his tonsils. This revolutionary experience resulted in my bringing all three children up on Homeopathic treatments for their childhood ailments. I also used it myself and clearly recall a rare episode of very uncomfortable and painful sinusitis physically dissipating on the way home after taking one powder at the homeopath.

I had always been a person who placed my faith in scientific evidence and based my understanding on the biomedical model. That being said however, I have also always been a spiritual person aware of realities that lie outside of what we can see with our biological senses or explain with our current theoretical models. For this reason, I was not opposed to embracing practices that were underpinned by theories outside of the biomedical model such as energy fields, or the body's own capacity for self-healing.

This did not mean that I turned my back on biomedicine. The biomedical evidence base is compelling, and it has more than won its place of prominence in the medical landscape through scientific study and major successes in many arenas. I do feel however, that even with its success, it is still limited in its capacity to support all forms of suffering, to heal the whole person, and does not always address the root cause of disease. I was open to incorporating a gentler form of healing that could make a difference and support the body's innate healing capacity where possible.

My personal cancer journey.

I lived a demanding and stressful life, working in a full-time academic post in a rapidly changing academic landscape, running a home, and raising three children. Possibly due to these high levels of stress and neglect of myself within the scope of these demands, my health took a major turn for the worse.

When, at 42, I was diagnosed with breast cancer, it was the biomedical model in which I placed my faith to battle the disease that threatened to take me from my family. In a surreal state of shock, I went through the full gamut of biomedical treatments. This began with a lumpectomy, rapidly followed by a mastectomy (due to surgical incision through two high-grade tumours that had not shown up on the mammogram). After recovery from the surgery, my first five rounds of chemotherapy began. At that point, an MRI revealed problems with the contralateral breast, and I had a second mastectomy plus a further five rounds of chemotherapy. Subsequent to this, five weeks of daily radiation were administered, followed by two years of monthly Zoladex injections and five years of Tamoxifen taken concurrently.

I firmly believe that these treatments saved my life and are the reason I was able to continue to be a functional member of society and watch my children grow into wonderful young adults. However, there is no denying that the treatments were emotionally and physically brutal, with numerous harsh side effects, that at times have been debilitating. One never fully recovers from such an onslaught against one's body and personal identity. Whilst being grateful to still be alive, the numerous physical and emotional scars are undeniable and over a decade later, I still deal with the numerous side-effects of a body starved of every source of oestrogen. I have battled weight gain, lack of the vigour I once enjoyed, painful joints, and compromised cognitive function. I have had to navigate all treatments and side effects whilst continuing to meet the demands of full-time lecturing which included getting a master's degree, and now a PhD.

The challenges of medical pluralism for patient and oncologist.

I have great respect for the oncologists who bravely tackle this awful disease on the part of so many patients and their families. Oncologist numbers are limited, and cancer is increasing. This places these professionals under tremendous stress within their working environment and challenges the facilities of both the private and public sectors, with extreme constraints on the latter. These challenges are most likely the main reason for a dearth of support and guidance in areas such as nutrition, exercise, emotional/psychological guidance, and helpful complementary practices. These aspects are often peripheral conversations intruding into the main pressures of care, if they happen at all. This leaves patients journeying through a brutal regime and seeking solutions to the accompanying problems in their own way, utilising their own social capital and background knowledge.

During my journey, I felt that I needed more support. I would go to the consultations with my questions regarding topics such as supplements or side effects. These would be patiently addressed by the man who saved my life, but I felt that we both needed support in addressing the wider complexity that is the world of the cancer sufferer. Privileged enough to have a basic training in the medical space and to have access to knowledge through books and the internet, I, like so many others, did much of my own research. Many family members and friends also offered advice and reference materials. Whilst I had some agency, it led me down overwhelming and confusing paths. At the same time, I was aware of those who navigate the journey without agency and may remain ignorant to those wider factors which could support them in their quest for healing.

I had found myself in a pluralistic medical environment and was navigating its complexity by myself. The numerous options and plethora of information was overwhelming and despite all my knowledge and social capital, I found it to be a difficult terrain. Issues of capacity and approach made the oncology system limited in being able to guide me in my journey to health and strength. I experienced how conflicts of opinion and diverse views of healing leave the patient feeling alone in their health-seeking decision making, with intolerant opinions on both sides failing the patient in the middle. There were times when I felt that it would be easier to be ignorant to all the complementary and holistic approaches. To simply deal with the biomedical treatments and side effects without wondering what else I could and should be doing to deal with what had happened to get me to this point, and what was to happen going forwards.

Based on my readings, I tried to incorporate the best nutritional approaches I could, to include more exercise and spirituality into my life, and to approach my life in a more holistic fashion. I did blood tests to determine the foods to which I was allergic, and which could be increasing inflammatory processes within my body. I explored the detrimental effects of chronic stress on the body and the helpful effects of exercise and relaxation. At different points and for different reasons, I went for treatments with a Reiki healer, a Homeopath, an Acupuncturist, and a BodyTalk practitioner which I believe had a big effect on my physical well-being. Looking back, I realise that I would have really benefitted from some psycho-oncology with a counsellor specifically trained in guiding people in dealing with the emotional impact of the disease.

I now live with a constant awareness of the sword of Damocles that hangs over my head and want to do all I can to prevent it's dropping. The stressful environment of the modern world does little to reassure me that I will not face a repeat of my experiences, and the current biomedical oncology environment does little beyond the initial harsh treatments and follow-up scans to ensure that I don't. In fact, after these treatments, many find themselves thrust back into "normal life" with little to no support or guidance, whilst feeling far from normal.

Finding a way forward.

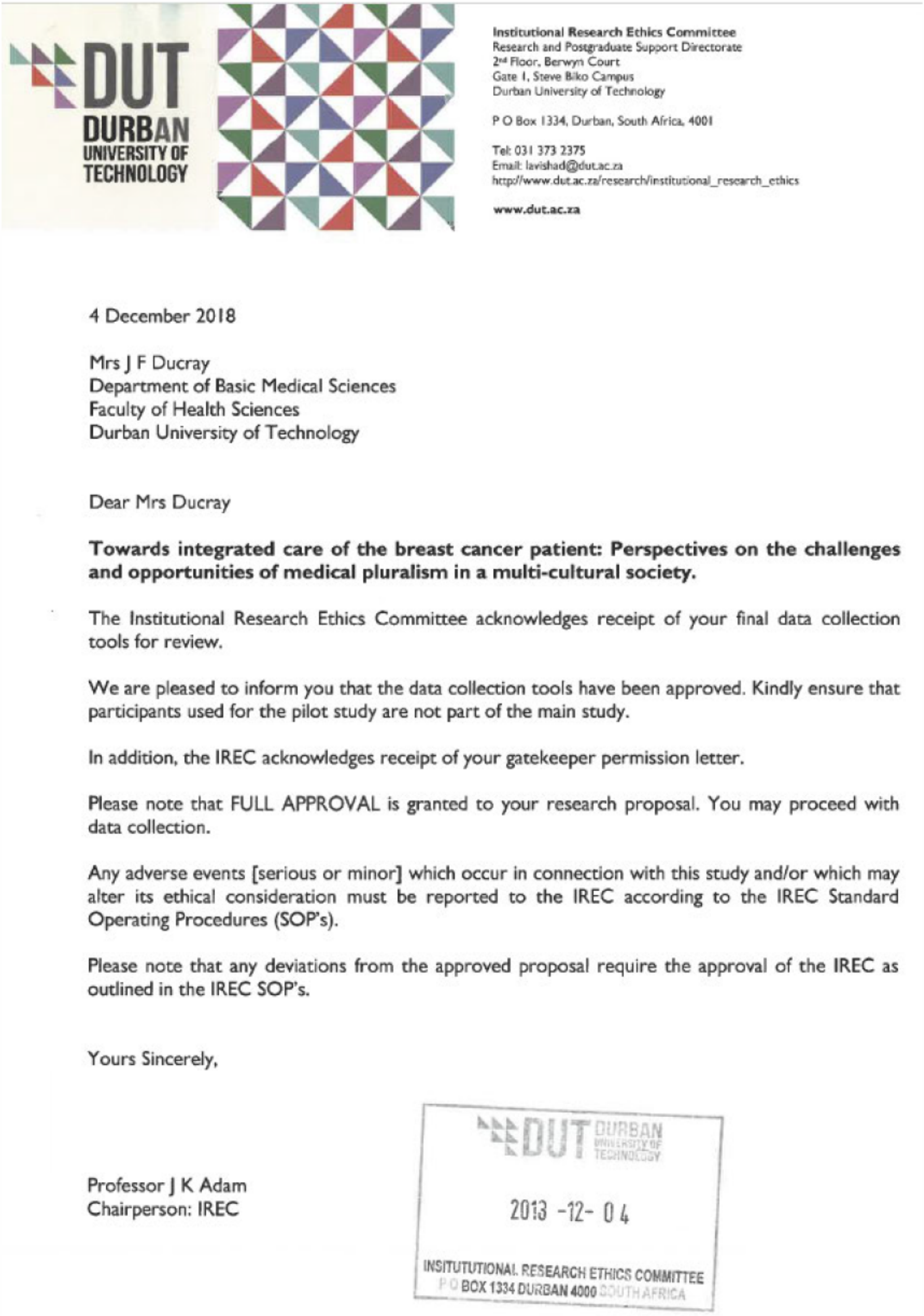
Amidst the many challenges of disease and medical pluralism, there are numerous people working towards creating a better experience for the cancer patient, both during and after treatments. These professionals, from different backgrounds and theoretical frameworks, are committed to being open-minded whilst maintaining high standards of ethical behaviour. They are building the evidence base in a collaborative integrated fashion, so that the future will see an oncology landscape that can even better assist the healing and long-term health of those who are suffering. Because of my personal journey, my position in the health-seeking debate is with these people, defined in whatever way best represents their united efforts. For me it is the growing field of Integrative Oncology that holds the potential to fill the broader and currently unmet needs of cancer patients.

Engaging in this research has taken me back into the oncology environment physically and emotionally, albeit this time as a researcher. I have encountered feelings I did not anticipate as I revisited the brave patients and oncologists of this battleground. Sights and smells brought waves of (undeniably psychosomatic) nausea in the clinics, and I often found myself weeping during transcription of the brave and difficult patient narratives.

The undeniable challenges of health care (notably in oncology and particularly in the post-Apartheid developing and still disparate country that is South Africa), make many aspirations of Integrative Oncology seem unattainable. Yet mankind is always called to look forwards and upwards to what could be better in the future, albeit attained through numerous small steps taken over generations of committed people. My small contribution to this end is why I embarked on this thesis.

11.2 Ethics Forms

11.2.1 Ethics clearance letter



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TECHNOLOGY

Institutional Research Ethics Committee
Research and Postgraduate Support Directorate
2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa, 4001

Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

4 December 2018

Mrs J F Ducray
Department of Basic Medical Sciences
Faculty of Health Sciences
Durban University of Technology

Dear Mrs Ducray

Towards integrated care of the breast cancer patient: Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.

The Institutional Research Ethics Committee acknowledges receipt of your final data collection tools for review.

We are pleased to inform you that the data collection tools have been approved. Kindly ensure that participants used for the pilot study are not part of the main study.

In addition, the IREC acknowledges receipt of your gatekeeper permission letter.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC Standard Operating Procedures (SOP's).

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely,

Professor J K Adam
Chairperson: IREC

DUT DURBAN UNIVERSITY OF TECHNOLOGY
2013 -12- 04
INSITUTUTIONAL RESEARCH ETHICS COMMITTEE
P O BOX 1334 DURBAN 4000 SOUTH AFRICA

11.2.2 Gatekeeper request for private clinic

DUT
DURBAN
UNIVERSITY OF TECHNOLOGY
INSTITUTIONAL RESEARCH ETHICS COMMITTEE

26 November 2019

Request for Permission to Conduct Research Survey

To whom it may concern

My name is Mrs Jennifer Ducray and I am a lecturer and PhD student at the Durban University of Technology. The research I wish to conduct for my Doctoral thesis involves investigations into the patterns of use of traditional complementary and alternative medical therapies (TCAM) by breast cancer patients. Besides exploring what TCAM therapies patients are using, I will also be investigating the factors affecting their choices and the opinions and experiences of oncologists with respect to such use. The title of the thesis is “Towards integrated care of the breast cancer patient: Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.”

I am hereby seeking your consent to place flyers in your waiting area (see attached) for the voluntary participation of breast cancer patients.

I have previously provided the practice with a copy of my proposal, copies of the data collection tools and consent forms to be used in the research process, as well as a copy of the approval letter which I received from the Institutional Research Ethics Committee (IREC). However, should you require these to be provided again please do not hesitate to request them.

You can grant the gatekeeper permission by using the attached gatekeeper permission letter.

If you require any further information, I can be contacted at JenniferD@dut.ac.za. Thank you for your time and consideration in this matter.

Yours sincerely,

____
Jennifer Ducray
Durban University of Technology

11.2.3 Gatekeeper request for public/government hospital

Medical management
Albert Luthuli Hospital
Private Bag X03
Mayville
4058

20 November 2018

Request for Permission to Conduct Research Survey

To whom it may concern

My name is Mrs Jennifer Ducray and I am a lecturer and PhD student at the Durban University of Technology. The research I wish to conduct is for my Doctoral thesis and involves investigations into the patterns of use of traditional complementary and alternative medical therapies (TCAM) by breast cancer patients. Besides exploring what TCAM therapies patients are using, I will also be investigating the factors affecting their choices and the opinions and experiences of oncologists WRT such use. The title of the thesis is “Towards integrated care of the breast cancer patient: Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.”

I am hereby seeking your consent to conduct some of this research at the Breast cancer facility attached to your institution. The investigations will be done in consultation with the relevant staff in charge of the breast clinic and will involve inviting breast cancer patients to consider participating in a questionnaire. The correct ethical principles of voluntary participation and confidentiality will be adhered to. In addition I would greatly appreciate the invaluable voluntary participation of the oncologists at the practice through filling in an oncologist questionnaire.

I have provided you with a copy of my proposal which includes copies of the data collection tools and consent forms to be used in the research process, as well as a copy of the approval letter which I received from the Institutional Research Ethics Committee (IREC).

If you require any further information, please do not hesitate to contact me at JenniferD@dut.ac.za. Thank you for your time and consideration in this matter.

Yours sincerely,

____

Jennifer Ducray
Durban University of Technology

11.2.4 Flyers used in private practices

Have you received treatment
for breast cancer
in the last 5 years?

Dear patient

My name is Jenny Ducray. I am a breast cancer survivor and currently conducting research exploring the personal choices of breast cancer patients regarding the use of any additional approaches for their health and well-being. This could include things like regular exercise, nutritional factors, supplements, counselling, mindfulness, traditional healers, homeopathy, cannabis products etc. Your personal choices (even if they were to exclude any additional practices) are of great relevance to my research.

If you are willing to fill in a 15min confidential questionnaire, you can participate by **scanning the QR code below**.

Alternatively, you can access the survey at the web address **https://ee.humanitarianresponse.info/x/#VoP5K9jH**

If you have questions, or would prefer to complete a paper version, my contact details are as follows:

Cell: 0723650158

Email:JenniferD@dut.ac.za

Work land line: 031 373 2396

11.2.5 Information and consent for patients completing questionnaires

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INSTITUTIONAL
RESEARCH
ETHICS
COMMITTEE

LETTER OF INFORMATION FOR PATIENTS COMPLETING QUESTIONNAIRE

Title of the Research Study: Towards integrated care of the breast cancer patient:
Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.
Principal Investigator/researcher: Mrs Jennifer Ducray (MMedSci)

Co-Investigators/supervisors: Prof AHA Ross (DTech, MTech, PG Dip, BMus); Prof CC Jinabhai (BSc, MBChB, M Med (CM) FFCH (CM) MD)

Brief Introduction and Purpose of the Study: There are many different kinds of health treatments available in South Africa. When diagnosed with an illness such as cancer, patients often have to decide what treatments they should include or exclude. This research study is exploring what alternative therapies breast cancer patients are choosing to use either instead of, or together with their mainstream therapies as part of managing their breast cancer. The insights from this study will contribute to the discussions on the role of alternative therapies in cancer management as well as the growth of integrative oncology practice in South Africa.

Ethical approval details: This research project has been approved by the Institutional Research Ethics Committee (IREC) of the Durban University of Technology (DUT). The ethics reference number for the project is IREC 043/18 and the Research Ethics Administrator can be contacted on 031 373 2375.

Participation: Participation in this research study is completely voluntary. Only female patients over the age of 18 who were diagnosed with cancer in the last 10 years and have received treatment for breast cancer in the last 5 years from a center in the greater Durban area may participate in the patient Questionnaire.

Outline of the Procedures: The part of this research project that you are agreeing to take part in, is a survey consisting of questionnaires. About 350 patients and 40 oncologists will be answering these questionnaires. The questionnaires will include a few basic questions about your cancer, and questions on the kinds of extra treatments you used for helping fight your cancer or manage side-effects. The time taken to complete a survey should be 15-20 minutes. (This survey will be followed at a later stage by small discussion groups and some personal interviews for those who might be interested to take part further. If you are interested in participating in these parts of the study, please indicate this on the last page of the questionnaire).

Risks or Discomforts to the Participant: This questionnaire should not result in discomfort of any sort. There are really no right or wrong answers, so please feel completely comfortable when making your selection of answer or describing your feelings. If any questions made you feel uncomfortable or if you need advice, please speak to one of the researchers using the contact details at the end of this information sheet.

Benefits: This research is being conducted towards a PhD and the researchers hope to publish findings in medical journals. There is no immediate gain for the patient participating in the study, but the insights gained from the study will hopefully assist future patients and oncologists in managing treatment options.

Withdrawing from the Study: You may choose to withdraw from the study at any point, and there will be no negative consequences should you choose to do so.

Payment: Participation in the questionnaire is completely voluntary and patients will not receive any payment for participating.

Costs of the Study: Your participation in this questionnaire will not result in any costs for you.

Confidentiality: All information from the questionnaires will be stored in a way that ensures that your participation and answers remain confidential. The only page that will display your details is the consent form which will be stored separately from your questionnaire. Answers from the questionnaires will be entered into a computer. No identifying data such as name and contact details will be entered together with the data. Your answers will be pooled together with answers from other patients to form data that will then be analysed. Only the researchers and Ethics committee may access the research records. The pooled data and analyses will be the property of DUT and used for medical publications and presentations. Data will be stored for five years after which it will be destroyed by shredding (in the case of paper questionnaires) and digitally destroyed using Windows “data-wiper” (in the case of electronic data).

Persons to Contact in the Event of Any Problems or Queries:
Main researcher (PhD student): Mrs Jennifer Ducray (tel no 031 373 2396 email jenniferd@dut.ac.za)
Main supervisor: Professor Ashley Ross (tel no 031 373 2620 email ashleyr@dut.ac.za)
Institutional Research Ethics Administrator: Ms Lavisha Deonarain (tel no 031 373 2375 lavishad@dut.ac.za)
Complaints can be reported to the Director: Research and Postgraduate Support, Prof Carin Napier on 031 373 2577 or carinn@dut.ac.za

Research reference number:

CONSENT

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Mrs J Ducray, about the nature, conduct, benefits and risks of this study –
  Research Ethics Clearance Number:___________________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me should I so wish.

Full Name of Participant _________________________ Date ____________ Time ________ Signature/Right Thumbprint ___________________

I hereby confirm that the participant above has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher _____________________ Date ____________ Signature ________________________

Full Name of Witness (If applicable) _____________________ Date ____________ Signature ________________________

11.2.6 Information and consent for oncologists completing a questionnaire

LETTER OF INFORMATION FOR ONCOLOGISTS COMPLETING QUESTIONNAIRE

Title of the Research Study: Towards integrated care of the breast cancer patient: Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.

Principal Investigator/researcher: Mrs Jennifer Ducray (MMedSci)

Co-Investigators/supervisors: Prof AHA Ross (DTech, MTech, PG Dip, BMus); Prof CC Jinabhai (BSc, MbChB, M Med (CM) FFCH (CM) MD)

Brief Introduction and Purpose of the Study: There are many different kinds of health treatments available in South Africa, both from professionals and in health shops. When diagnosed with an illness such as cancer, patients often find themselves having to decide what treatments or health practices they should include or exclude. This research study is exploring what alternative therapies breast cancer patients are choosing to use together with their mainstream therapies as part of managing their breast cancer. These alternate therapies include some more widely accepted therapies (such as special diets or physiotherapy) as well as therapies which would be considered to fall outside of mainstream medicine (such as traditional medicine, acupuncture or homeopathy). Besides looking at what additional approaches cancer patients are choosing to use, the study will also investigate the opinions of oncologists towards such use. It will explore how the array of complementary and alternative therapies affect the experiences of the patient, both positively and negatively. The insights from this study will contribute to the discussions on the role of alternative therapies in cancer management as well as the growth of integrative oncology practice in South Africa.

Ethical approval details: This research project has been assessed and approved by the Institutional Research Ethics Committee (IREC) of the Durban University of Technology (DUT). The ethics reference number for the project is IREC043/18 and the Research Ethics Administrator can be contacted on 031 373 2375.

Participation: Participation in this research study is completely voluntary. For the patient aspects of the study, only female patients over the age of 18 who have received treatment for breast cancer in the last 5 years from a practitioner in KZN may participate. For the oncologist aspects of the study, only oncologists who practice in KZN may participate.

Outline of the Procedures: The research project will take place in two stages. Firstly, a survey consisting of questionnaires will be conducted amongst breast cancer patients and oncologists. Approximately 350 patients and 40 oncologists from the greater Durban area will be answering questionnaires. This is the stage you are currently agreeing to take part in. The questionnaires will include questions concerning your views on the role of nutrition, supplements and exercise in cancer. It also includes questions concerning any TCAM training you may have received or would be interested in receiving; and your views on integrated oncology. The questions related to race and culture will only be used to assist the researchers in interpreting your choices. The time taken to complete a survey should be 15-20 minutes. This survey will be followed at a later stage by personal interviews for those who might be interested to participate further. If you are interested in participating in the later phases, please indicate this on the last page of the questionnaire.

Risks or Discomforts to the Participant: As this interview is seeking insight into current practice and opinion of oncologists WRT TCAM, it may elicit feelings of discomfort. Please be as honest as possible and feel free to express your opinions openly, as your views are critical to the understanding of the role of TCAM in oncology in South Africa. Confidentiality is an ethical priority for the researcher and procedures have been put into place to ensure confidentiality (see below).

Benefits: This research is being conducted towards a PhD and the researchers hope to publish findings in peer-reviewed journals. There is no immediate gain for the patient participating in the study, but the insights gained from the study will hopefully assist future patients and oncologists in managing numerous therapeutic options.

Withdrawing from the Study: You may choose to withdraw from the study at any point, and there will be no negative consequences should you choose to do so.

Remuneration: Participation in the questionnaire is completely voluntary and participants will not receive any payment for participating.

Costs of the Study: Your participation in this questionnaire will not result in any costs for you.

Confidentiality: Participation will be kept completely confidential, and all information from the questionnaires will be treated with respect and stored in a way that ensures the information remains confidential. The only page that will display your details is the consent form which will be handed in and stored separately from your questionnaire. Answers from the questionnaires will be entered into a computer and an extra copy on a separate hard drive. No identifying data such as name and contact details will be entered together with the data. Your answers will be pooled together with answers from other oncologists to form data that will then be analysed. The computer files will have a password known only to the researchers. Only the researchers and Ethics committee may access the research records. The pooled data and analyses will be the property of DUT and used for medical publications and presentations. No personal questionnaires will be presented, only pooled data. Data will be stored for five years after which it will be destroyed by shredding (in the case of paper questionnaires) and digitally destroyed using Windows "data-wiper" (in the case of electronic data).

Persons to Contact in the Event of Any Problems or Queries:
Main researcher (PhD student): Mrs Jennifer Ducray (tel no 031 373 2396 email jenniferd@dut.ac.za)
Main supervisor: Professor Ashley Ross (tel no 031 373 2620 email ashleyr@dut.ac.za)
Institutional Research Ethics Administrator: Ms Lavisha Deonarain (tel no 031 373 2375 lavishad@dut.ac.za)
Complaints can be reported to the Director: Research and Postgraduate Support, Prof Carin Napier on 031 373 2577 or carinn@dut.ac.za

Research reference number:

CONSENT
Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Mrs J Ducray, about the nature, conduct, benefits and risks of this study –
  Research Ethics Clearance Number IREC043/18,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

____________________	__________	____________________
Full Name of Participant	Date	Signature

I, Jennifer Ducray, hereby confirm that the participant above has been fully informed about the nature, conduct and risks of the above study.

____________________	__________	____________________
Full Name of Researcher	Date	Signature

11.2.7 Information and consent for patients participating in an interview

LETTER OF INFORMATION FOR PATIENTS PARTICIPATING IN AN INTERVIEW

Title of the Research Study: Towards integrated care of the breast cancer patient: Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.

Principal Investigator/researcher: Mrs Jennifer Ducray (MMedSci)

Co-Investigators/supervisors: Prof AHA Ross (DTech, MTech, PG Dip, BMus); Prof CC Jinabhai (BSc, MbChB, M Med (CM) FFCH (CM) MD)

Brief Introduction and Purpose of the Study: There are many different kinds of health treatments available in South Africa. When diagnosed with an illness such as cancer, patients often have to decide what treatments they should include or exclude. This research study is exploring what alternative therapies breast cancer patients are choosing to use either instead of, or together with their mainstream therapies as part of managing their breast cancer. The insights from this study will contribute to the discussions on the role of alternative therapies in cancer management as well as the growth of integrative oncology practice in South Africa.

Ethical approval details: This research project has been assessed and approved by the Institutional Research Ethics Committee (IREC) of the Durban University of Technology (DUT). The ethics reference number for the project is IREC 043/18 and the Research Ethics Administrator can be contacted on 031 373 2375.

Participation: Participation in this research study is completely voluntary. Only female patients over the age of 18 who were diagnosed with cancer in the last 10 years and have received treatment for breast cancer from a center in the greater Durban area may participate.

Outline of the Procedures: The part of this research project that you are agreeing to take part in, is a personal interview which forms the second phase of the study, with the first being the questionnaire. The interview will be about your personal cancer journey and include any activities or treatments patients use to help fight their cancer or manage side-effects. We are also interested to understand why patients make the choices that they do, and what sources of information they are using to find the information they need. Feel free to share personal experiences, both positive and negative with respect to therapies you used. The time taken for the interview should be about one hour.

Risks or Discomforts to the Participant: This discussion should not result in discomfort. There are really no right or wrong comments, so you should feel completely comfortable when making your contribution to the discussion or describing your feelings. Your sharing will help give us insights into patient experiences. However, if any aspect of the group discussion makes you feel uncomfortable, please confide in the focus group facilitator. You may also contact one of the researchers using the contact details at the end of this information sheet should you need to speak about anything.

Benefits: This research is being conducted towards a PhD and the researchers hope to publish findings in peer-reviewed journals. There is no immediate gain for the patient participating in the study, but the insights gained from the study will hopefully assist future patients and oncologists in managing numerous therapeutic options.

Withdrawing from the Study: You may choose to withdraw from the study at any point, and there will be no negative consequences should you choose to do so.

Remuneration: Participation in the focus group is completely voluntary and patients will not receive any payment for participating other than R50 contribution towards personal transport to and from the group discussion.

Costs of the Study: Your participation in this focus group will not result in any costs for you.

Confidentiality: The group discussions will be recorded and transcribed into a typed document by the reseacher. The transcribing will not make use of individuals' names but rather "participant 1" etc. All information from the focus groups will be stored in a way that ensures the information remains confidential. The only page that will display your details is the consent form which will be handed in and stored separately. No identifying data such as name and contact details will be entered together with the data. The data from all focus groups will be analysed by the researcher and if we use your comment as an example in the research write-up, it will not be associated with any personal identifying data. Hard copies and spare hard drive will be stored in a locked filing cabinet and the computer files will have a password known only to the researchers. Only the researchers and Ethics committee may access the research records. The pooled data and analyses will be the property of DUT and used for medical publications and presentations, with presentations and publications ensuring that any comments quoted as examples cannot be linked to any one participant. Data will be stored for five years after which it will be destroyed by shredding (in the case of paper transcripts) and digitally destroyed using Windows "data-wiper" (in the case of electronic data).

Persons to Contact in the Event of Any Problems or Queries:
Main researcher (PhD student): Mrs Jennifer Ducray (tel no 031 373 2396 email jenniferd@dut.ac.za)
Main supervisor: Professor Ashley Ross (tel no 031 373 2620 email ashleyr@dut.ac.za)
Institutional Research Ethics Administrator: Ms Lavisha Deonarain (tel no 031 373 2375 lavishad@dut.ac.za)
Complaints can be reported to the Director: Research and Postgraduate Support, Prof Carin Napier on 031 373 2577 or carinn@dut.ac.za

DUT DURBAN UNIVERSITY OF TECHNOLOGY INSTITUTIONAL RESEARCH ETHICS COMMITTEE

Research reference number:

CONSENT
Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Mrs J Ducray, about the nature, conduct, benefits and risks of this study –
  Research Ethics Clearance Number:___________________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me should I so wish.

Full Name of Participant	Date	Time	Signature/Right Thumbprint

I hereby confirm that the participant above has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher	Date	Signature
Full Name of Witness (If applicable)	Date	Signature

11.2.8 Information and consent for Oncologists participating in an interview

LETTER OF INFORMATION FOR ONCOLOGISTS DOING AN INTERVIEW

Title of the Research Study: Towards integrated care of the breast cancer patient: Perspectives on the challenges and opportunities of medical pluralism in a multi-cultural society.
Principal Investigator/researcher: Mrs Jennifer Ducray (MMedSci)

Co-Investigators/supervisors: Prof AHA Ross (DTech, MTech, PG Dip, BMus); Prof CC Jinabhai (BSc, MbChB, M Med (CM) FFCH (CM) MD)

Brief Introduction and Purpose of the Study: There are many different kinds of health treatments available in South Africa, both from professionals and in health shops. When diagnosed with an illness such as cancer, patients often find themselves having to decide what treatments or health practices they should include or exclude. This research study is exploring what alternative therapies breast cancer patients are choosing to use together with their mainstream therapies as part of managing their breast cancer. These alternate therapies include some more widely accepted therapies (such as special diets or physiotherapy) as well as therapies which would be considered to fall outside of mainstream medicine (such as traditional medicine, acupuncture or homeopathy). Besides looking at what additional approaches cancer patients are choosing to use, the study will also investigate the opinions of oncologists towards such use. It will explore how the array of complementary and alternative therapies affect the experiences of the patient and oncologist, both positively and negatively. The insights from this study will contribute to the discussions on the role of alternative therapies in cancer management as well as the growth of integrative oncology practice in South Africa.

Ethical approval details: This research project has been assessed and approved by the Institutional Research Ethics Committee (IREC) of the Durban University of Technology (DUT). The ethics reference number for the project is IREC043/18 and the Research Ethics Administrator can be contacted on 031 373 2375.

Participation: Participation in this research study is completely voluntary. Only oncologists who practice in KZN may participate in the oncologist aspects of the study.

Outline of the Procedures: The research study has two stages. The first stage, a survey consisting of questionnaires has already been completed. The data from these investigations have been analysed and the researcher is now beginning to interview patients and oncologists one-on-one in order to gain more insights. You are being requested to participate in a private recorded interview with the researcher. The interview will be about your views towards the use of TCAM therapies by patients, and the factors that influenced your views. The researcher is also interested to know your positive and negative experiences in relation to TCAM use in oncology, and your opinion of integrative oncology. The time taken for the interview should be about 30-45mins.

Risks or Discomforts to the Participant: This interview is seeking insight into current practice and opinion of oncologists WRT TCAM. Please be as honest as possible and feel free to express your opinions openly, as your views are critical to the understanding of the role of TCAM in oncology in South Africa. Confidentiality is an ethical priority for the researcher and procedures have been put into place to ensure confidentiality (see below).

Benefits: This research is being conducted towards a PhD and the researchers hope to publish findings in peer-reviewed journals. There is no immediate gain for the participant, but the insights gained from the study will hopefully assist future patients and oncologists in managing numerous therapeutic options.

Withdrawing from the Study: You may choose to withdraw from the study at any point, and there will be no negative consequences should you choose to do so.

Remuneration: Participation in the questionnaire is completely voluntary and participants will not receive any payment for participating.

Costs of the Study: Your participation in this questionnaire will not result in any costs for you.

Confidentiality: Participation will be kept completely confidential, and all information from the interviews will be treated with respect and stored in a way that ensures the information remains confidential. The only page that will display your details is the consent form which will be stored separately from interview transcriptions. No identifying data such as name and contact details will be entered together with the data. Your answers will be pooled together with answers from other oncologists to form data that will then be analysed. The recorded and transcribed computer files will have a password known only to the researchers. Only the researchers and Ethics committee may access the research records. The pooled data and analyses will be the property of DUT and used for medical publications and presentations. Data will be stored for five years after which it will be destroyed by shredding (in the case of paper questionnaires) and digitally destroyed using Windows "data-wiper" (in the case of electronic data).

Persons to Contact in the Event of Any Problems or Queries:
Main researcher (PhD student): Mrs Jennifer Ducray (tel no 031 373 2396 email jenniferd@dut.ac.za)
Main supervisor: Professor Ashley Ross (tel no 031 373 2620 email ashleyr@dut.ac.za)
Institutional Research Ethics Administrator: Ms Lavisha Deonarain (tel no 031 373 2375 lavishad@dut.ac.za)
Complaints can be reported to the Director: Research and Postgraduate Support Dr Linganiso (031 373 2577) or researchdirector@dut.ac.za

DUT DURBAN UNIVERSITY OF TECHNOLOGY
INSTITUTIONAL RESEARCH ETHICS COMMITTEE

Research reference number:

CONSENT
Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, Mrs J Ducray, about the nature, conduct, benefits and risks of this study – Research Ethics Clearance Number:____________________,
- I have also received, read and understood the above written information (Participant Letter of Information) regarding the study.
- I am aware that the interview will be recorded and transcribed by the researcher.
- I am aware that the results of the study, will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher and have been assured that it will be stored in a manner that protects confidentiality.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

____________________	__________	______	_______________
Full Name of Participant	Date	Time	Signature/Right Thumbprint

I, Jennifer Ducray, hereby confirm that the participant above has been fully informed about the nature, conduct and risks of the above study.

__________________	__________	____________________
Full Name of Researcher	Date	Signature
__________________	__________	____________________
Full Name of Witness (If applicable)	Date	Signature

11.2. Tools Used in Quantitative and Qualitative Data Collection

11.2.1 Patient questionnaire

The use of Traditional, Complementary and Alternative therapies (TCAM) in Breast Cancer: PATIENT SURVEY

A: GENERAL AND DEMOGRAPHIC INFORMATION

A1. Please state your Age

____

MARK THE RELEVANT
BOX WITH A CROSS

☒

A2. Religious/cultural background

☐ 1 Atheist or Agnostic
☐ 2 Buddhist
☐ 3 Christian
☐ 4 Hindu
☐ 5 Jewish
☐ 6 Muslim
☐ 7 Shembe
☐ 8 Other (please specify):……………………………………………………………………..

A3. Race/ethnic group (for statistical purposes)

☐ 1 Asian
☐ 2 Black African
☐ 3 Coloured
☐ 4 Indian
☐ 5 White
☐ 6 Other (please specify):…………………………………………………………………..

A4. Highest level of education

☐ 1 No formal schooling
☐ 2 Primary school
☐ 3 Secondary school
☐ 4 Apprenticeship or trade certificate
☐ 5 University undergraduate degree or diploma
☐ 6 Postgraduate degree

A5. What is your current marital status?

☐ 1 Single
☐ 2 Permanent relationship (Married (traditional, religious or court); partnership)
☐ 3 Divorced
☐ 4 Widowed
☐ 5 Other (please specify):…………………………………………………………………

A6. Combined monthly income of your household

☐ 1 R1- R1500
☐ 2 R1501-R5000
☐ 3 R5001-R10 000
☐ 4 R10 001- R20 000
☐ 5 R20 001- R40 000
☐ 6 More than R40 000

A7. Do you have medical aid?

☐ 0 No
☐ 1 Only hospital cover
☐ 2 Yes

A8. What is your employment status?

☐ 1 Unemployed
☐ 2 Housewife/Homemaker
☐ 3 Self-employed
☐ 4 Employed
☐ 5 On Pension
☐ 6 Other (please specify):………………………………………………………………

A9. **Indicate how you would describe your view of the world and life.**

☐ 1 I am very practical and logical and base my understandings in scientific facts
☐ 2 I am intuitive/spiritual and open to possible realities other than what we see
☐ 3 I am a mix of both the descriptions above

B: MEDICAL FACTORS RELATED TO BREAST CANCER

B1. State the age you were at your first diagnosis of breast cancer. __________

B2. Have you experienced a period of remission (being completely clear of cancer) followed by a return of cancer?

☐ 0 No
☐ 1 Yes

B3. Where did/do you receive the main treatment for your cancer?

☐ 1 Government hospital.
☐ 2 Private oncology centre.

B4. How far did your cancer spread?

☐ 1 I do not know
☐ 2 Cancer was only in my breast
☐ 3 Cancer was found in my lymph nodes
☐ 4 Cancer has been found in other organs like my liver, lungs or bones (stage 4).

B5. Tick which of the following treatments you have/are/will be receiving (<u>Tick all that are relevant to you</u>)

Surgical treatments

- ☐ Lumpectomy (lump removed but kept breast) B 5.1 0/1
- ☐ Mastectomy (whole breast removed) B 5.2 0/1
- ☐ Both breasts removed B 5.3 0/1

Non-surgical treatments

- ☐ Radiation therapy B 5.4 0/1
- ☐ Chemotherapy B 5.5 0/1
- ☐ Hormone-blocking injections (capsules injected into skin of tummy about once a month to supress hormonal function e.g. Zoladex®) B 5.6 0/1
- ☐ Hormone-blocking tablets (daily tablets to block hormone receptors in the body e.g. Tamoxifen® or Arimidex®). B 5.7 0/1

C: MAINSTREAM VS TCAM

In this Questionnaire, **"Mainstream"** treatments refer to widely accepted biomedical treatments used by Western medical doctors such as:

- Pharmaceutical drugs
- Surgery

Which in the case of cancer would include:

- chemotherapy
- radiation therapy

MAINSTREAM

"TCAM" Stands for Traditional, Complementary, and Alternative Medical practices. TCAM includes a wide array of approaches and healing practices not generally considered to be a standard part of medical treatment.

TCAM can include biomedical support therapies like:

- Nutritional approaches to health and healing
- Exercise
- Psychological counselling and stress relief

But can also include alternative healing practices such as:

- Homeopathy
- African traditional healers
- Acupuncture
- Chinese traditional medicine
- Ayurveda
- Spiritual and energy healing
- Mind-body techniques

TCAM THERAPIES

C1: How would you describe your choice of treatments <u>BEFORE</u> your cancer diagnosis?

- ☐ 1 I mostly chose mainstream treatments
- ☐ 2 I mostly chose TCAM/alternative forms of healing
- ☐ 3 I used a mix of mainstream and TCAM/alternative treatments

C2. Once you knew you had cancer, which of the following best describes your FIRST thoughts about the treatment you wanted to receive?

☐ 1 I wanted to use mainstream treatments
☐ 2 I wanted to try alternative treatments rather than mainstream treatments
☐ 3 I wanted to combine both mainstream and TCAM treatments
☐ 4 Nothing (no treatments). I was scared and did not go to either for a while.

C3. Did you delay mainstream cancer treatments in order to try TCAM/alternative treatments and then ended up using mainstream treatments later?

☐ 0 No
☐ 1 Yes

C4: Have you at any point felt pressure from friends or family to utilise TCAM treatments <u>IN PLACE OF</u> mainstream treatments?

☐ 0 No
☐ 1 Yes

C5: Have you at any point felt pressure from friends or family to use TCAM treatments <u>IN ADDITION TO</u> your mainstream treatments?

☐ 0 No
☐ 1 Yes

C6. Please indicate your response to the following statements regarding possible stress involved in deciding between treatment options for your cancer.

	Strongly disagree	disagree	agree	Strongly agree
Having to decide **between mainstream and TCAM/alternative** treatment options added to my stress. C6.1	1	2	3	4
Deciding **which specific mainstream** treatments to use added to my stress. C6.2	1	2	3	4
Deciding **which specific TCAM** treatments to use added to my stress. C6.3	1	2	3	4

C7. If you have used TCAM treatments (whether alone or together with mainstream treatments), please tick the statements that reflect your reasons. (If you never used TCAM treatment approaches for your cancer, then skip to question C8 below.)

- ☐ I used them because of my fear of mainstream treatments. C7.1 0/1
- ☐ These alternative treatments are part of my culture. C7.2 0/1
- ☐ I wanted to do everything I could to fight the cancer so was willing to try anything. C7.3 0/1
- ☐ I wanted greater personal control over my treatment. C7.4 0/1
- ☐ They are easily available. C7.5 0/1
- ☐ I could not afford the mainstream treatments. C7.6 0/1
- ☐ To relieve emotional/psychological distress (depression/anxiety etc).C7.7 0/1
- ☐ I felt my lifestyle could be to blame and I needed to change that dramatically. C7.8 0/1
- ☐ My family wanted me to use alternative treatments. C7.9 0/1
- ☐ To strengthen my immune system. C7.10 0/1
- ☐ To help my body detox and heal from the mainstream treatments.C7.11 0/1
- ☐ I needed help with physical side-effects of my mainstream treatments (e.g. nausea, pain, hot flushes etc). C7.12 0/1
- ☐ Other (please specify):………………………………………………………………… C7.13 0/1

C8: If you have never used any TCAM therapies together with or in place of mainstream therapies, please tick the statements that reflect you reasons.
(If you DID use TCAM therapies then skip to question D over the page).

☐ I only did what my oncologist told me to do, which did not include alternative therapies. C8.1

☐ I believe it is dangerous to mix mainstream therapies and alternative therapies. C8.2

☐ I thought the other therapies might decrease effectiveness of the main ones. C8.3

☐ I simply never considered anything else. C8.4

☐ I did not think I could not afford extra treatments. C8.5

☐ My oncologist asked me not to. C8.6

☐ Other (please specify)…………………………………………………………………………………… C8.7

In column (i), please place a **tick next to all the therapies you have used** since your cancer diagnosis.

For **each therapy you used** (i.e., where you have put a tick), please **also answer questions in columns (ii), (iii) and (iv).**

D: TCAM PRACTITIONERS	(i) Tick those therapies you have used since your diagnosis? (tick √)	(ii) Had you made use of this kind of treatment before your cancer diagnosis? (Yes or no)	(iii) Is your oncologist aware that you used/use this treatment? (Yes or no)	(iv) How helpful did you find this treatment? (Tick relevant answer).		
				I don't know	A little helpful	Very helpful
1. Acupuncture						
2. Aromatherapy						
3. Ayurveda (traditional Indian)						
4. BodyTalk						
5. Chinese herbal doctor						
6. Chiropractor						
7. Homeopath						
8. Inyanga/Sangoma						
9. Iridologist						
10. Kinesiology						
11. Massage therapy						
12. Naturopath						
13. Reflexology						
14. Reiki healer						
15. Unani						
16. Other (specify)						

If you have not used any of the therapies listed in this table, continue on to the next page.

In column (i), please place a **tick next to all the therapies you have used** since your cancer diagnosis.

For **each therapy you used** (i.e., where you have put a tick), please **also answer questions in columns (ii), (iii) and (iv).**

E: SELF HELP PRACTICES AND SPIRITUAL APPROACHES	(i) Tick those therapies you have used this since your diagnosis? (tick √)	(ii) Had you made use of this kind of treatment before your cancer diagnosis? (Yes or no)	(iii) Is your oncologist aware that you used/use this treatment? (Yes or no)	(iv) How helpful did you find this treatment? (Tick relevant answer).		
				I don't know	A little helpful	Very helpful
1. Special dietary changes						
2. Supplements						
3. Cannabis oil						
4. Regular exercise						
5. Yoga						
6. Tai Chi						
7. Relaxation techniques						
8. Meditation						
9. Visualization						
10. Spiritual Prophet						
11. Spiritual healing ceremony or rite						
12. Prayer (self or others)						
13. Psychological counselling						
14. Cancer Support group						
15. Music or art therapy						
16. Other (specify)						

If you have not used any of the therapies listed in this table, continue on to the next page.

F: DIETARY FACTORS

This section has some more specific questions related to diet and supplements

F1. Did you alter your diet in any way after being diagnosed with breast cancer?

- ☐ $_1$ I changed my diet dramatically.
- ☐ $_2$ I changed my diet a little.
- ☐ $_3$ I wanted to change my diet but special food was too expensive.
- ☐ $_4$ I don’t believe diet plays a role in cancer.

F2. Did you visit a dietician in relation to your cancer?

- ☐ $_0$ No
- ☐ $_1$ Yes

F3. Did you have genetic testing done for food allergies/intolerances as part of your approach to health after your cancer diagnosis?

- ☐ $_0$ No
- ☐ $_1$ Yes

F4. Please tick any of the following which you have used as part of fighting your cancer

- ☐ Juicing F4.1 0/1
- ☐ Decreased/eliminated sugar F4.2 0/1
- ☐ Decreased/eliminated red meat F4.3 0/1
- ☐ Decreased carbohydrates F4.4 0/1
- ☐ Decreased/eliminated dairy products F4.5 0/1
- ☐ Increased cruciferous vegetables such as cauliflower/broccoli F4.6 0/1
- ☐ Choosing organically grown food where possible F4.7 0/1
- ☐ Decreased/eliminated processed food F4.8 0/1
- ☐ Decreased/eliminated alcohol F4.9 0/1
- ☐ Other (specify)………………………………………………………………………. F4.10

F5. Please tick any of the following supplements you have used as part of fighting your cancer

- ☐ Multivitamin F5.1 0/1
- ☐ High dose vitamin therapy e.g. vit C injections F5.2 0/1
- ☐ Antioxidant (e.g. co-enzyme Q10, selenium, vit C, melatonin) F5.3 0/1
- ☐ Extra omega 3 e.g. fish oil F5.4 0/1
- ☐ Green tea F5.5 0/1
- ☐ Essiac tea F5.6 0/1
- ☐ Folic acid/folate F5.7 0/1
- ☐ Alkalinising powder or bicarb F5.8 0/1
- ☐ Additional vitamin D F5.9 0/1
- ☐ IC3 (indole-3-carbinol) F5.10 0/1
- ☐ Cannabis oil F5.11 0/1
- ☐ Other (please specify)________________________________ F5.12 0/1

G : COMMUNICATION / ONCOLOGIST INVOLVEMENT AND TCAM GUIDANCE

G1: If you used TCAM therapies, how did you first find out about them? (Tick all that apply)

☐ I grew up using them G1.1 0/1
☐ Friends G1.2 0/1
☐ Family G1.3 0/1
☐ Fellow patients G1.4 0/1
☐ My oncologist G1.5 0/1
☐ My family GP G1.6 0/1
☐ My alternate practitioner G1.7 0/1
☐ Salesperson in a shop (e.g., health shop) G1.8 0/1
☐ Magazine G1.9 0/1
☐ TV G1.10 0/1
☐ Internet G1.11 0/1
☐ Other (please specify):………………………………………………………………….. G1.12 0/1

G2: If you chose to NOT to tell your oncologist about some of the TCAM therapies you utilise/d please state the reason by ticking the block/s that apply:

☐ I don't feel it is necessary for my oncologist to know G2.1
☐ My oncologist did not ask me G2.2
☐ I am afraid to tell the oncologist about my other treatments G2.3
☐ I started to bring it up but sensed limited interest and/or knowledge G2.4
☐ Other (please specify):…………………………………………………………………….G2.5

G3: If you DID discuss TCAM therapies with your oncologist, who brought up the topic first?

☐ 1 I brought up the discussion
☐ 2 My oncologist brought up the topic

G4: How would you describe your oncologist's approach towards the following:

	Considered it important and referred me to specialists who could assist	Supportive, and carefully explained what I should or should not do	Dismissive and unconcerned. I could do what I liked except for certain things	Asked me to leave it until my oncology treatments were completed	We never spoke about it
	4	3	2	1	0
1.Nutritional changes					
2.Supplements (vitamins and minerals)					
3.Medicinal cannabis					
4.Alternative practitioners such as herbalists/homeopaths					
5.Exercise					
6.Psychological support					

H: PATIENT ROLE IN THE HEALING PROCESS

Please indicate whether you agree or disagree (and to what extent) to the each of the statements below by placing a tick in the relevant column.

	Strongly disagree (never) 1	Disagree (hardly ever) 2	Some of the time 3	Agree (lots of the time) 4	Strongly agree (most of the time) 5
1. As a cancer patient I felt helpless. There was very little I could personally do, and I simply had to go along with the cancer doctors.					
2. During my treatments I felt/feel that the tumour was the main focus and not me.					
3. I was/am too scared to make decisions or do anything myself as I did not want to interfere with what the doctors were doing.					
4. I felt that I was included in all decisions related to my care wherever possible.					
5. I felt adequately informed about what was happening and what to expect throughout my treatment.					
6. I was empowered by being directed to self-help approaches such as specific nutritional changes, exercise and support systems.					
7. I took control myself for a lot of things as I believe I am important in the healing process and cannot simply leave things up to the doctors.					
8. I had many questions which I did not want to bother my oncologist with, and so I tried to find answers myself.					
9. My oncologist treated me as capable of being an integral and important part of my own healing.					

I: PATIENT VIEWS ON INTEGRATIVE ONCOLOGY

Integrative Oncology combines elements of both modern medicine and complementary Or traditional healing approaches. This generally includes nutrition and psychological approaches, as well as evidence-based alternative therapies, with a view to treating the whole person, maximising patient care and minimising risk.

I1: Please indicate your responses to the statements below by placing a cross in the relevant column.

	Strongly disagree	disagree	agree	Strongly agree
	1	2	3	4
1. I was given all the emotional/psychological support I have needed. (For stress/anxiety/depression)				
2. I had all the guidance I needed in how to eat during and after my treatments.				
3. I had all the guidance I needed in which supplements to use during and after treatments.				
4. I felt that my whole person was receiving care, and not only the tumour.				
5. I was well advised on various therapies to use to assist with side-effects and healing.				
6. I felt that my cultural background and beliefs were important to my oncologists.				
7. I believe it is important to give cancer patients additional information and guidance in making choices concerning all the alternative healing therapies on offer.				

I2: Imagine you were looking for an oncologist for the first time and had to choose between two equally good oncology practices. Both of them have excellent mainstream therapies but one also includes additional therapies and TCAM guidance, would this affect your choice at all?

☐ 1 Very likely. Were this to exist, an integrated oncology centre would be the ideal for me.

☐ 2 This might affect my choice of where to go but is not very important.

☐ 3 This would not affect my choice of oncologist at all.

Continued research

Thank you so much for giving of your time to take part in this survey. Your contribution is greatly appreciated.

This research is continuing with some small group discussions as well as one-on-one interviews. These will be in order to get more insights into patient experiences, practices, beliefs and challenges in their treatment journey.

If you are willing to participate in either of these, whether you chose to include alternate approaches or only use traditional treatments, please fill in your details below so that the researchers can contact you to arrange a meeting. If not, you may leave this section blank.

If you would prefer, you can remove this page and hand it in separately in order to maintain the anonymity of this questionnaire.

I am willing to take part in continued research for this investigation by being interviewed by the researcher. In order to arrange this, the researchers can contact me as follows:

Name____

Cell number____

Alternate contact number ____

Email address____

11.2.2 Oncologist questionnaire

Integrating the use of Traditional, Complementary and Alternative therapies (TCAM) in Cancer Care: ONCOLOGIST SURVEY

A: GENERAL AND DEMOGRAPHIC INFORMATION

☒

MARK THE RELEVANT
BOX WITH A CROSS

A1: Your Age

☐ 1 <35
☐ 2 35-40
☐ 3 41-50
☐ 4 51-60
☐ 5 >60

A2: Gender

☐ 1 Male
☐ 2 Female

A3: Religious/cultural background (listed in alphabetical order)

☐ 1 Atheist or Agnostic
☐ 2 Buddhist
☐ 3 Christian
☐ 4 Hindu
☐ 5 Jewish
☐ 6 Muslim
☐ 7 Traditional African spiritualism
☐ 8 Other (please specify):……………………………………………………

A4: Race/ethnic group (listed in alphabetical order)

☐ 1 Asian
☐ 2 Black African
☐ 3 Coloured
☐ 4 Indian
☐ 5 White
☐ 6 Other (please specify):……………………………………………………………………..

A5: Have you ever used healing approaches that lie outside of mainstream biomedicine for your personal health and wellbeing?

☐ 0 No
☐ 1 Yes

A6. Indicate how you would describe your view of the world and life.

☐ 1 I am very practical and logical and base my understandings in scientific facts.
☐ 2 I am intuitive and spiritual and open to possible realities other than what we can see.
☐ 3 I am a mix of both the descriptions above.

B: FACTORS RELATED TO QUALIFICATION AND PRACTICE

B1: Institutions where qualifications were obtained

B1.1 Undergraduate medical degree was obtained from:

University…………………………Country…………………Year…………………

B1.2 Oncology specialisation was obtained from:

University………………………….Country…………………Year…………………

B2: Number of years in oncology practice

☐ 0 Still a registrar
☐ 1 < 5 years
☐ 2 5-10 years
☐ 3 11-20 years
☐ 4 > 20 years

B3: Nature of oncology practice to which you are affiliated

☐ 1 Urban private oncology centre.
☐ 2 Urban oncology centre linked to government hospital.
☐ 3 Rural or small-town private oncology centre.
☐ 4 Rural or small-town oncology centre linked to government hospital.
☐ 5 Other (please specify):……………………………………………………………………..

B4: How would you describe the working relationship between the oncologists in your practice?

☐ 1 We share the same facilities and admin staff, but mostly work independently unless there is a particularly difficult case.
☐ 2 We work as a team, meeting regularly to discuss cases.
☐ 3 Not applicable as I work privately (but have colleagues I can speak to if necessary).
☐ 4 Other(please specify):…………………………………………………………………..

B5: Does the oncology practice where you are based include any of the following? (Mark all that apply)

☐ 1 Nutritionist
☐ 2 Psychologist
☐ 3 TCAM links (e.g., collaboration with a homeopath; Chinese medical practitioner etc.)

Please Specify…………………………………………………

C: TCAM PRACTITIONERS

C1: Below is a list of some TCAM practitioners offering services in the greater Durban area. For each discipline, please indicate how you would rate your knowledge of the discipline; how you would feel about your patients using it and also whether you would refer patients to these practitioners.

	Knowledge of therapy				Opinion of therapy					Recommend/refer		
	none	Very little	adequate	good	Harmful / avoid	Use with care	Nonsense but	helpful	excellent	never	sometimes	often
	1	2	3	4	1	2	3	4	5	1	2	3
C1.1 African traditional healer												
C1.2 Ayurveda (traditional Indian medicine)practitioner												
C1.3 Traditional Chinese medicine practitioner												
C1.4 Homeopath												
C1.5 Naturopath												
C1.6 Acupuncturist												
C1.7 Reflexologist												
C1.8 Functional medicine practitioner												
C1.9 Unani/Tibb medicines												
C.1.10 Chiropractic												

C2: If you never refer outside of mainstream medical therapies, please select reason/s below (you may select more than one):

☐ I do not feel it is my area of expertise or my responsibility and I therefore leave it up to my patients to find TCAM therapies and practitioners should they so wish. C.2.1 0/1

☐ I find it difficult to accept healing beliefs that fall outside of the bio-medical model. c.2.2 0/1

☐ I feel that alternate therapies could potentially be counterproductive or even dangerous C.2.3 0/1 in conjunction with mainstream oncology treatments. Condoning them is not responsible medicine.

☐ I do not have TCAM practitioners that I feel comfortable referring to. C.2.4 0/1

☐ There is very little evidence for the efficacy and safety of TCAM use in oncology. C.2.5 0/1

Mainstream medical therapies include those commonly accepted by the Western medical fraternity and based on a biomedical model of understanding such as physiotherapy.

D: The role of nutrition in oncology

D1: Do you believe that nutrition plays a role in oncogenesis and healing?

☐ 0 No.
☐ 1 Yes, but only a minimal role.
☐ 2 Yes, a very important role.

D2: Do you think it is important to provide nutritional counselling for cancer patients?

☐ 0 No, I would rather they sustain their energy eating what appeals to them.
☐ 1 No, as long as a preliminary assessment reveals a relatively healthy diet.
☐ 2 Yes, I counsel my patients on nutrition.
☐ 3 Yes, I refer my patients for counselling on nutrition.

D3: Do you believe food allergy testing as a tool for specific nutritional changes could be an important tool for the oncologist?

☐ 0 No
☐ 1 Yes

D4: Do you believe that raised serum glucose, insulin resistance and IGF favour tumour formation?

☐ 0 No
☐ 1 Yes

D5: Do you believe that maintaining a low glycaemic load is an important consideration in diet and enteral or intravenous feeding of oncology patients.

☐ 0 No
☐ 1 Yes

D6: Below are nutritional approaches sanctioned by some TCAM practitioners. Please indicate your opinion on the role of the following by placing a cross in the relevant column.

	No role	Minor role	Very helpful
	0	1	2
D6.1 Maintaining an alkaline body environment			
D6.2 Juicing			
D6.3 Ketogenic diet			
D6.4 Eliminating/reducing intake of dairy products			
D6.5 Reducing intake of hormonally treated meat			
D6.6 Using organically grown foods			
D6.7 Reducing/eliminating alcohol intake			
D6.8 Filtering water			
D6.9 Plant-based wholefood diet			
D6.10 Importance of a healthy BMI (body mass index)			

E: THE ROLE OF SUPPLEMENTATION FOR CANCER PATIENTS

E1: Please indicate your response to the statements below by placing a cross in the relevant column:

	Strongly disagree 1	Disagree 2	Agree 3	Strongly agree 4
E1.1 Supplements do not play a major role in managing cancer, so I do not focus much on supplementation.				
E1.2 I discourage use of extra vitamins and antioxidants during chemotherapy and radiation.				
E1.3 I believe that there is a good argument for cancer patients to maintain high levels of antioxidants.				
E1.4 Supplement advice is very important, and I make a point of encouraging the use of specific supplements in my cancer patients whilst discouraging use of others.				
E1.5 I believe that vitamin intake in conjunction with mainstream therapies has so many complications and potential pitfalls that I hesitate to recommend supplementation.				
E1.6 I do not believe that a nutritionist has the necessary training to guide oncology patients in the use of supplements and vitamins. I believe this would require special training.				

E2: Please indicate your opinion on the role of the supplements listed below in the management of cancer patients.

	dangerous 1	Needs care 2	No effect 3	helpful 4	excellent 5	Do not know 6
E2.1 Multivitamins						
E2.2 Omega 3						
E2.3 Antioxidants						
E2.4 Vitamin D						
E2.5 Alkalinising agents						
E2.6 Very high dose vitamin therapy						
E2.7 Curcumin						
E2.8 Green tea/essiac tea						
E2.9 Folic Acid						
E2.10 Resveratrol						
E2.11 Sulphorophane						
E2.12 Astragalus						
E2.13 oestrogen metabolism modulators e.g. I3C (indole 3 carbinol)						
E2.14 Cannabis oil						

F: THE ROLE OF EXERCISE IN CANCER MANAGEMENT

Please indicate your response to the statements below by placing a cross in the relevant column:

	Strongly disagree 1	Disagree 2	Agree 3	Strongly agree 4
F1. I would describe myself as a physically active person.				
F2. I find that those patients who engage in regular physical activity deal better with therapy both physically and mentally				
F3. Physical activity has cancer protective effects and the ability to affect survival rates.				
F4. I believe in the positive impact of exercise in cancer management to the extent that I make a point of raising the topic with my patients.				
F5. I believe that many patients might overemphasise rest, with resulting increased levels of inactivity and decreasing fitness.				
F6. Whilst the ideal might be that exercise has much to offer, the reality is that the majority of cancer patients are too ill to incorporate it into their life.				
F7. Exercise for cancer patients needs careful designing and monitoring.				

G: THE ROLE OF THE MIND AND SPIRIT IN HEALING

G1: Do you believe that the mind and spirit play an important role in health and healing?

☐ 0 No
☐ 1 Yes

G2: Do you believe it is the role of an oncologist to address the emotional states and needs of their patients?

☐ 0 No
☐ 1 Yes

G3: Have you found any of the following to be helpful for your patients?

	No experience of this (0)	Not helpful (1)	A little helpful (2)	Very helpful (3)
G3.1 Psychological Counselling				
G3.2 Patient support groups				
G3.3 Spiritual support				
G3.4 Relaxation techniques				
G3.5 Visualisation techniques				
G3.6 Meditation/mindfulness				
G3.7 Yoga				

H : Patient role in the healing process and doctor-patient relationship

Please indicate your response to the following statements by placing a cross in the relevant column.

	Strongly disagree 1	Disagree 2	Agree 3	Strongly agree 4
H1. Oncology is streamlined and I can give the same care to my patients with a similar outcome whether I see them for 15mins minutes or 45mins.				
H2. An oncologist needs to focus more on the tumour/disease and less on the individual.				
H3. As a busy professional I sometimes find that patient questions and deliberations take up valuable time and can be frustrating.				
H4. I ensure that my patients are fully informed about what is happening and what to expect throughout their treatment.				
H5. Patients are more than capable of being an integral part of their own healing and I try to empower them to be that.				
H6. The doctor-patient relationship is of critical therapeutic importance to my purpose.				

I: Patient-oncologist communications regarding TCAM

I 1: Please indicate your level of communication with your patients about TCAM

- ☐ 1 I only discuss TCAM if the patient brings it up and if they do, I advise them according to their specific questions.
- ☐ 2 I always bring up a discussion on TCAM with my patients within the first few consultations.
- ☐ 3 I refer to TCAM along the treatment journey so that I know what the patient is doing and so that the patient knows what they can or cannot do.

I 2: Main therapies you receive questions about

Please state the top four TCAM therapies you receive enquiries about from your breast cancer patients:

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

I 3: Please indicate your opinion regarding your role in guiding patients in TCAM use, by rating your response to the statements below:

	Strongly disagree	disagree	agree	Strongly agree
	1	2	3	4
I3.1 The responsibility of the oncologist is allopathic oncology and not to guide patients in TCAM use.				
I3.2 It can be stressful when patients want to incorporate TCAM therapies as I feel they have little worth and the potential to interfere with mainstream therapies.				
I3.3 I have a growing interest in the potential role that TCAM can play in oncology.				
I3.4 I believe TCAM practitioners have a lot to offer, and I would like more opportunity for collaboration				
I3.5 I encourage my patients to make use of TCAM therapies where possible.				
I3.6 Collaborating with TCAM practitioners and incorporating complementary support therapies has become routine practise for me.				

J: TCAM AND BREAST CANCER OUTCOMES

Please indicate your opinion of the following statements by marking the appropriate column.

	Strongly disagree	Disagree	Agree	Strongly agree	Do not know
	1	2	3	4	5
J1. There is an increase in the numbers of patients delaying the commencement of mainstream treatments in order to try alternate therapies.					
J2. There is good scientific evidence proving that patients who elect sole use alternative medicine will have a worse prognosis (shorter survival).					
J3. There is good scientific evidence proving that patients who elect to use TCAM alongside allopathic treatments will have a worse prognosis.					
J4. TCAM therapies can extend survival when mainstream therapies are completed.					

K: TCAM training

K1: How would you rate your understanding of the various TCAM therapies and their use in cancer?

☐ 1 Good
☐ 2 Adequate
☐ 3 Minimal and often feel I need to know more
☐ 4 Poor

K2: Were you exposed to any TCAM modules as part of your formal training

☐ 0 No
☐ 1 Yes (Please specify):……………………………………………………………

K3: Do you think there should be TCAM modules as part of oncology training?

☐ 0 No
☐ 1 Yes

K3.1 If yes, indicate which of the following you think should be included.

☐ Overview of the main types of TCAM therapies (philosophies, evidence base, strengths, weaknesses and applications). K3.1.1 0/1
☐ Role of nutrition and lifestyle in oncology. K3.1.2
☐ Traditional medicines and oncology (African, Ayurveda, Chinese). K3.1.3
☐ Mind and spirituality in health and illness. K3.1.4
☐ Environmental medicine (how environment affects disease). K3.1.5
☐ How to manage oncology patient TCAM use. K3.1.6
☐ Integrative Oncology design. K3.1.7
☐ Other (please specify):…………………………………………… K3.1.8

K4: Where have you gained the TCAM knowledge you DO have? (You may select more than one)

☐ Journal articles K4.1
☐ Oncology forums/conferences K4.2
☐ Media K4.3
☐ Internet K4.4
☐ Medical sales representatives K4.5
☐ Casual interactions with peers K4.6
☐ From my patients K4.7
☐ TCAM Practitioners K4.8
☐ Other (please specify):………………………………………………….. K4.9

K5: Would you attend CPD training in TCAM were it offered?

☐ 0 No, I know enough.
☐ 1 No, it is not critical to my work and my time is pressurised.
☐ 2 Yes

L: Views on integrated oncology

L1: Which of the statements below best describes your perceptions of integrative Oncology?

Integrative Oncology is when mainstream medical treatments are utilised, but a strong emphasis is also placed on other aspects such as nutrition, lifestyle and

☐ 1 Very positive. I believe it is the way forward.

☐ 2 Positive but tentatively so as there are many challenges to overcome.

☐ 3 Negative and resistant to the idea. Much needs to be investigated and proven first.

☐ 4 Very negative. I think the complications outweigh the benefits.

☐ 5 Other (please specify):………………………… ………………………

L2: In your opinion, which of the scenarios below would be the best approach to integrative oncology in South Africa?

☐ 1 TCAM and allopathic healthcare practitioners work independently in different venues but form close collaborations and share information via formal communications.

☐ 2TCAM and allopathic healthcare practitioners work independently in a common venue (integrative healthcare clinic) and share information via formal communications.

☐ 3 Team of TCAM and allopathic practitioners work in a common integrative practise and meet regularly to discuss patients and make decisions regarding treatment plans.

☐ 4 A trained TCAM advisor who could co-ordinate TCAM referrals and queries in consultation with the oncologist.

☐ 5 Other (please specify):…………………………………………………………….

L3: Integrative oncology centres and approaches are growing rapidly in countries such as America and Europe, but this growth is not as rapid in South Africa.

Please list some of the main factors you believe could be reasons for this:

____

____

____

____

____

____

____

____

Continued research

Thank you so much for giving of your valuable time to take part in this survey. Your contribution is greatly appreciated.

If you are willing to participate in an interview, please fill in your details below so that the researcher can contact you to arrange a meeting. If you would prefer, you can remove this page and hand it in separately in order to maintain the anonymity of this questionnaire.

I am willing to take part in continued research for this investigation by taking part in an interview. In order to arrange this, the researcher can contact me as follows:

Name____
Cell number____
Other contact____

11.2.3 Patient interview guide

Note: During reflexive practice following initial interviews, it was established that the patients have a story they need to tell. Whilst we are seeking to answers specific questions, they are seeking to tell their story. Thus, it was decided to allow their personal narrative to unfold. However, the need to enter and explore specific domains for the research questions remains important. Therefore, whilst the patient participant is narrating their journey, the researcher needs to be tracking the addressing of the various domains and questions, seeking to provide appropriate and well-timed probes or to ask additional yet-unanswered questions when appropriate (possibly even at the end of the narrative). A domain map of these questions can be used during the narration to mark off areas covered in the narration and make notes of probes or additional questions to ask at the appropriate time.

Welcome and initial thanks: I'd like to welcome you today and thank you very much for your willingness to contribute to this research, both by participating in the survey, which was the first phase of this research, and now for making yourself available for this interview which is the second phase of the research. From the information you have received about the research so far, you would have a good idea of what it is about.

ASK ABOUT RECORDING AND PUT RECORDING ON

Consent: For the purposes of ethics, I would like to confirm that you understand the purpose of this research (that the information is going to be collated into journal articles and a PhD dissertation) and you are happy to support that. I also need you to confirm that you realize this interview is being recorded and transcribed, but that it will be treated with complete confidentiality. When transcribing the interviews, names will be replaced with research numbers, so all identifying characteristics will be removed from the reporting (waited for verbal consent).

Areas to be explored: Just to give you an indication of what my research is exploring in this interview, I am interested in three main areas, or "domains of enquiry".

- The first area is going to be looking for information on any I **supporting activities** that you utilised in order to help you on your cancer journey.
- We're also going to explore the **doctor-patient relationship.** What was the nature of that relationship for you? And in terms of supporting practices, was your oncologist open to discussing them, did you get support/encouragement/guidance/referral etc.?
- Lastly, from the discussion thus far (and likely based on some of the main areas your raised as possible challenges), we're going to look at your views of what you think the **ideal holistic treatment approach** might look like.

Starting the conversation: So, if you could just start by telling me basics of your clinical experiences. Along the way we will explore what your needs, challenges and choices were. You can start by telling me about your diagnosis and what happened after that.

DOMAIN 1: YOUR PERSONAL CANCER JOURNEY AND EXPERIENCES IN THE MAINSTREAM ONCOLOGY ENVIRONMENT

- Tell me about your personal cancer journey, starting with your diagnosis.
- What was the nature of your relationship with your oncologist?
- What was their approach to holistic practices? (Nutrition, supplements, exercise, and psychological support)
- What kind of information were you given about additional things you could do?
- Did they refer you to other practitioners for support with health or healing? (Who, why)
- Are there any areas where you felt that you needed more information or support?

DOMAIN 2: ADDITIONAL SUPPORTING ACTIVITIES AND CHOICES

Many patients will naturally speak about additional therapies etc. during their narrative but if not, ask specifically for these.

- Tell me about any additional things you did to assist with seeking health and wellbeing or to assist with side effects. Probe and explore specific examples:
    - Diet; dietary exclusions or special practices; visits to dietician.
    - Supplements; cannabis; exercise.
    - Other practitioners e.g., traditional healers; homeopath; energy healer; stress relief practices; psychological support.
- Where did you get the information from?
- Did you find this helped you? In what way?
- If a patient did not use any additional practices, then try to ascertain why.
- Is there a reason you chose to not include any extra practices.
    - May need to probe for Information access, money, oncologist instruction etc.

DOMAIN 3: HOLISTIC AND INTEGRATED CANCER PROGRAM

- In your opinion, what would the ideal of and integrated holistic care look like?

Thanks and closing: Thank you so much for that. Is there anything else you feel you would like to add to what has been said thus far? If there is anything else you think of and would like to add to what you have said, then please feel free to contact me. I also want you to know that if this time of sharing your experiences leads to any distress or concerns, that you must also feel free to contact me. You have my cell-phone number, and I am happy for you to make contact should you need to.

So once again, my very grateful thanks for your participation and sharing of your experiences and insights, both in the questionnaire and the interview. I really appreciate your contribution and I wish you everything of the best (and especially the best of health) going forwards. Enjoy the rest of the day. Thank you. Goodbye.

11.2.4 Oncologist interview guide

Welcome and initial thanks:

I'd like to welcome you today and thank you very much for your willingness to contribute to this research, both by participating in the survey, which was the first phase of this research, and now for making yourself available for this interview which is the second phase of the research. From the information you have received about the research so far, you would have a good idea of what it is about.

Areas to be explored: Just to give you an indication of what this interview will cover, we are going to be exploring four main areas, or "domains of enquiry".

- The first domain of enquiry is looking at your views on the inclusion of holistic practices. This includes nutrition, supplements (including your views on cannabis) as well as exercise and psychological support.
- The use of alternative therapies such as homeopathy, African medicine etc. by patients and whether you feel there is any role for these modalities in oncology.
- Your views on Integrative Oncology (positive or negative) and the factors supporting or constraining its growth in SA.
- The discrepancies between the private and public/state sector

ASK ABOUT RECORDING AND PUT RECORDING ON

Consent: For ethics, please could you confirm that you understand the purpose of this research (that the information is going to be collated into journal articles and a PhD dissertation) and that you are happy to be a participant. I also need you to confirm that you are aware that this interview is being recorded and transcribed, but that it will be treated with complete confidentiality. I will be storing the recordings in a folder only accessible by myself and when transcribing the interviews, names will be replaced with research numbers, so all identifying characteristics will be removed from the reporting.

Wait for verbal consent.

DOMAIN 1: VIEWS ON THE ROLE OF HOLISTIC PRACTICES IN ONCOLOGY

- I want to start with **NUTRITION** because it was biggest area where I was getting responses and queries from patients. The quantitative phase of the research showed that 40% of government patients and 67% of private patients are adopting dietary approaches as part of their personal management of their cancer. I think they are being exposed to a lot of nutri-babble from each other, from friends, from the Internet, and are needing to process and navigate all of that. Quite a large proportion of the patients expressed a need for more guidance in nutrition and supplement use.
- Could you comment on t**he role, if any, played by nutrition in the battle against cancer**?
- **How do you manage the nutritional aspects** of your patients?
    - Many patients choose to omit specific food groups such as **dairy and meat** in order to avoid hormones and especially **sugar or carbs** which they believe supports carcinogenesis.
- Could you **give your opinion on these dietary exclusions** as a tool in cancer management?
    - Some patients were using **food sensitivity tests** or intolerance testing through genetics, I believe (from interviews) because they were trying to avoid inflammatory cytokines or inflammatory processes that could result at the cellular level.
- Could you comment on **whether you think food sensitivities are an important consideration**. Is there a possible role being played by inflammatory processes resulting from these intolerances and could these be impacting epigenetics over time?
    - Do you think there is a role for **nutritionists specializing in the oncology continuum** Different during different stages of the cancer journey?

- **SUPPLEMENTS**: About 20% of government patients and 50% of the private patients in my study were using supplements and once again also felt that guidance was needed. It seemed from the earlier phases of the research that for many patients, a blanket exclusion is requested of all supplements during the active biomedical treatments.
- Can you comment on **whether you believe supplements are important as part of oncology management**.
- Can you comment on the tendency for blanket exclusion.
- **How do you manage supplement use?**
    - And whilst we are speaking about taking extra supplements, can you speak briefly about **cannabis**? 30% of the private patients and 10% of public patients said that they used it or were using it, obviously for various reasons.
- Can you comment on your experience with patient use of cannabis and the approach you take when patients are wanting to use it?

- Whilst we're in the ambit of holistic care, I'd like your professional opinion on the role of **exercise and then Psychological/spiritual support.**
- Are they of any great importance and do you think the formal oncology environment has any responsibility towards patients in these two arenas?
- How do you approach these aspects with your patients?

DOMAIN 2: VIEWS ON ROLE OF ALTERNATIVE PRACTITIONERS AND MODALITIES IN ONCOLOGY

SA, like many places in the world, has a very pluralistic medical landscape. This is being navigated by patients and therefore also their primary medical practitioners. Evidence shows that cancer patients are more likely to utilise one or more alternate practitioners (homeopathy, energy healers, traditional healers, chiropractors etc) as they battle side effects on mainstream treatments or seek health and healing.

- Can you comment on your **opinion of the role, negative or positive that TCAM practitioners** bring to the oncology arena or share any good or bad experiences you've had with patients incorporating them.
- Do you currently **collaborate** with any alternative practitioners (Why, , who, How)

DOMAIN 3: VIEWS ON INTEGRATIVE ONCOLOGY AND POTENTIAL FOR ITS GROWTH IN SA

As you know, Integrative Oncology as a field, seeks to formally incorporate more holistic practices. It also seeks to incorporate alternative therapies alongside conventional therapies where possible, preferably collaborating with alternative practitioners, whilst still upholding a commitment to evidence-based medicine.

- Can you comment on your **opinion of Integrative Oncology as a field**/ as an approach.
- Do you believe there is a **potential for the growth of Integrative Oncology in this country**?
- What in your opinion are the **challenges and opportunities for such growth**?

DOMAIN 4: DISCREPENCIES BETWEEN THE PUBLIC AND PRIVATE SECTOR

Given the history and nature of South Africa, I sampled from both and am often juxtaposing the two sets of data. The private patients seem to have access to and utilise the holistic and complementary practices more. Maybe if you can just comment on your experiences of the challenges facing patients and oncologists in the public setting.

- Could you comment on some of the **discrepancies you have experienced between the public and private sectors, and the challenges facing the public sector**.
- I would assume that the luxury of holistic treatments or integrative practices has even more challenges. **How realistic is the idea of more holistic and Integrative Oncology management in the public setting**?

So once again, my very grateful thanks for your participation and sharing of your experiences and insights, both in the questionnaire and the interview. You have said so many valuable things in this time that I've had with you, and I really appreciate your contribution. Enjoy the rest of the day. I will be sending through the transcript for you to read and have the opportunity to add to or change should you wish. If there is anything else you think of and would like to add to what you have said, then please feel free to contact me.
Thank you. Goodbye.

11.3. Conference Presentations to Date

- Ducray, J.F., Ross, A H.A., Jinabhai, C. (2021) Patterns of use of complementary practices amongst female breast cancer patients living in eThekwini, KwaZulu-Natal, South Africa. Society for Integrative Oncology 18th international conference. Baltimore, Mayland/ Virtual. Awarded 2021 SIO scholarship.

- Ducray, J.F., Ross, A.H.A., Jinabhai, C. (2022) Oncologist views on patient use of complementary practices, and opinions on the potential for the growth of Integrative Oncology in eThekwini, South Africa. Society for integrative Oncology 19th international conference. Scottsdale, Arizona /Virtual. Awarded 2022 SIO scholarship.

- Ducray, J.F., Ross, A.H.A., Jinabhai, C. (2023) Patterns of use of complementary practices amongst female breast cancer patients living in eThekwini, KwaZulu-Natal, South Africa. Surgical Research Society of South Africa 50th research symposium. University of KZN medical school South Africa.

Sceales Antrobus Prize for best presentation SRSSA 2023

Won the Sceales Antrobes prize for best presentation at the 50th Surgical Research Society of Southern Africa. Received funding to represent SRSSA at the 19th Annual Academic Surgical Congress in Washington DC in 2024.