DISSERTATION/THESIS

TITLE

EXPLORING THE IMPORTANCE, MEANING AND EXPERIENCE OF HOPE FOR ADULT PATIENTS WITH ADVANCED CANCER AND THEIR FAMILY CAREGIVERS IN KWAZULU-NATAL

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DECLARATION

I, *Dr Colleen Shan Cox,* hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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“Hope itself is like a star – not to be seen in the sunshine of prosperity,
and only to be discovered in the night of adversity.”
Charles Spurgeon (1834-1892)

“For I know the plans I have for you,” declares the Lord, “plans to prosper you and not to harm you, plans to give you hope and a future.”
Jeremiah 29:11 (NIV)

“Let us hold unswervingly to the hope we profess, for He who promised is faithful.”
Hebrews 10:23 (NIV)

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
BHI	Brief Hope Intervention
CALM	Managing Cancer and Living Meaningfully Intervention
CANSA	Cancer Association of South Africa
CH	Chatsworth Hospice, Durban
CNR	Cancer Nutrition and Rehabilitation
COVID-19	Coronavirus Disease 2019
DT	Dignity Therapy
GCP	Good Clinical Practice
GSE	General Self-Efficacy
HIP	Hope Intervention Program
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
HREC	Human Research Ethics Committee, University of Cape Town
IALCH	Inkosi Albert Luthuli Central Hospital, Durban
KZN	KwaZulu-Natal
LWHP	Living With Hope Program
NGO	Non-Governmental Organisation
PLWA	People Living With AIDS
PPS	Palliative Performance Scale
PRP	Palliative Rehabilitation Program
QODD	Quality of Dying and Death Questionnaire
QoL	Quality of Life
RCT	Randomised Controlled Trial
SA	South Africa
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SOP	Standard Operating Procedure
STROBE	Strengthening The Reporting of OBservational Studies in Epidemiology
UK	United Kingdom
US	United States

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ABSTRACT

Background: The importance of hope for patients with cancer and other life-threatening illness has been widely reported in international literature. Hope enhances patients' quality of life and facilitates coping. Towards end-of-life, hope is typically directed at "being" rather than at "doing", and at preparing for a peaceful death. Patients and their families reportedly look to healthcare professionals to give them hope. In South African palliative care settings, patients describe their need for psychosocial and spiritual care and for their hope to be upheld. There is however not a clear understanding of what hope means in the South African healthcare setting, particularly around issues such as "hope for a cure" and "false hope". Also, while several hope-fostering interventions have been validated internationally, the benefits of such interventions in South Africa are unknown.

Aim: The study aimed to describe the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal (KZN).

Method: Two study sites in KZN were chosen, a state hospital oncology unit and a hospice. The study followed a qualitative descriptive cross-sectional design, involving in-depth analysis of semi-structured interviews with patients with advanced cancer and their family caregivers. Each patient and their family caregiver were managed as a dyad. Questions around the importance, meaning and experience of hope were explored. Data collection continued via purposive sampling until data adequacy was achieved. Data were coded and analysed thematically. Data were also analysed in the context of the clinical, socio-economic and cultural contexts of the patients and their caregivers.

Results: The study sample included 11 patients and 11 family caregivers. Purposive sampling achieved variance in most clinical and socio-economic factors. Identified limitations of the study however included the lack of young adults in the study sample, and that each study participant had a religious affiliation, either Christian, African Ancestral, Hindu or Muslim. Despite wider screening, there were no atheist or agnostic participants. There was unanimous affirmation from all patients and caregivers that hope was important to them, particularly in the face of a cancer diagnosis or caregiving role. Thematic analysis of the meaning of hope revealed a strong correlation with spirituality, human connection and support, and physical and psychological comfort. Hope was also associated with psychological fortitude, having a goal and purpose, and living well while being ready to die. The study demonstrated the tension of oscillating between hoping for a cure and accepting a poor prognosis. As with meaning, the hope experience was strongly influenced by spirituality, human connection and support, and physical and psychological comfort. The role of overcoming previous adversity as a source of hope for most participants was an unexpected finding. Almost all participants expressed a preference for truthful communication regarding their diagnosis or prognosis and described how hope assisted them to cope with bad news and to reach acceptance. Participants described how doctors and nurses can give hope to patients and families.

Conclusion: The study confirmed the importance of hope in assisting patients with cancer and their family caregivers to cope and to live well in the face of life-threatening illness. Interventions including H – human connection and support, O – (reflections on) overcoming previous adversity, P – physical and psychological comfort, and E – existential or spiritual support, are expected to enhance hope for patients with cancer and their family caregivers in the South African setting. Further research to validate hope-fostering interventions in South Africa is recommended.

CHAPTER 1

INTRODUCTION

1.1 Overview

This chapter introduces the area of research, namely the exploration of hope for patients with advanced cancer and their family caregivers. The chapter gives the definitions relevant to the topic of research and introduces the theory relating to the importance, meaning and experience of hope in palliative care.

1.2 The relationship between palliative care, quality of life and hope

1.2.1 Defining palliative care

According to the World Health Organization, palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering, by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”(1) Improvement in the quality of life (QoL) of patients and families facing serious illness, such as advanced cancer, is therefore a primary goal and a core outcome of good palliative care.

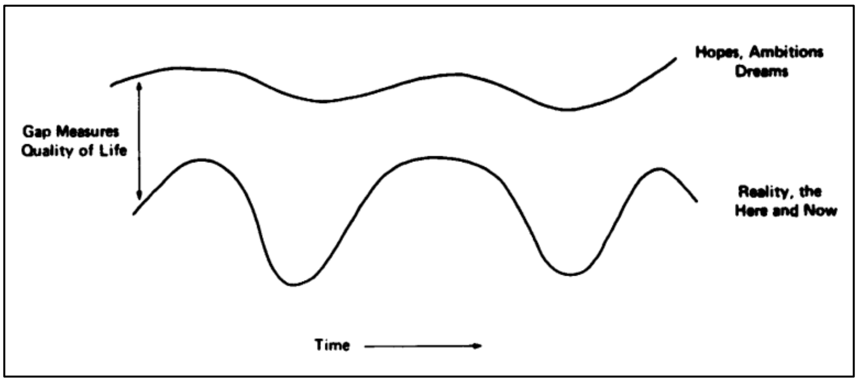
1.2.2 Palliative care improves the quality of life of patients with advanced cancer

Over the past decade in particular, it is becoming increasingly evident that, while improved disease-free survival, progression-free survival and median survival are fundamentally important when making decisions regarding the treatment options for patients diagnosed with cancer, QoL is likewise a significant end-point.(2) Currently patient-centred care, considered a key component of high-quality patient care(2-4), seeks to improve QoL by identifying and addressing patient and family needs in a holistic manner; these needs may be physical, psychological, social and/or spiritual, and may change over time.(2)

The integration of early palliative care in the management of patients with advanced cancer is internationally accepted as best oncology practice, particularly when the disease is considered incurable and/or where there is a significant symptom burden.(2, 4-8) Studies confirm that palliative care integration into standard oncology care significantly benefits patients with advanced cancer.(4, 7-9) Patient benefits include longer median survival, less depression and anxiety, enhanced QoL, reduced medical resource utilisation, greater prognostic understanding, better advance care planning, lower futile chemotherapy utilisation, and ultimately improved end-of-life experiences for patients and their families.(4, 7-9)

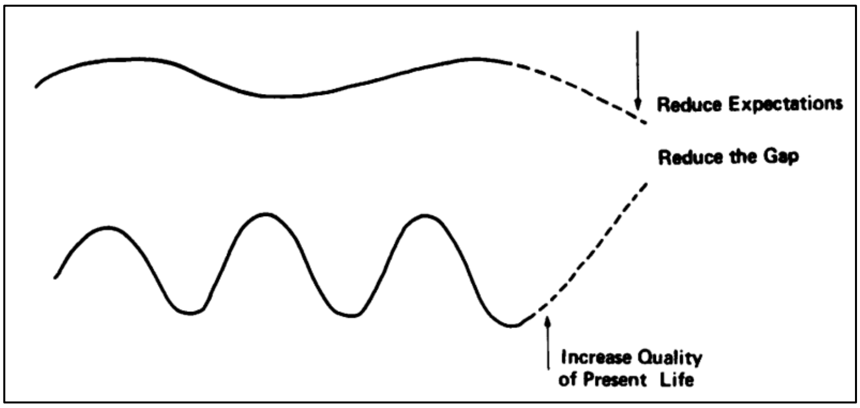
1.2.3 Defining quality of life

Twycross, considered a leader in palliative medicine(10), states that QoL "relates to an individual's overall subjective satisfaction with life, and is influenced by all aspects of personhood: physical, psychological, social and spiritual".(11) Twycross suggests that QoL reflects the gap between an individual's present experience and current aspirations.(11) This gap, first proposed by Calman in 1984(12) and referred to in palliative care literature as the Calman Gap(12, 13), relates an individual's present reality to their personal hopes for the future, dreams and ambitions (see Figure 1).(12) Calman proposed that good QoL results when an individual's present reality meets and fulfils his hopes, while poor QoL results from a wide divergence between hopes and present reality (see Figure 1).(12) Presenting the Calman Gap in graphical form illustrates how palliative care aims to narrow the gap and improve QoL firstly by improving a patient's circumstances, and secondly by modifying his expectations or aspirations, i.e. by maintaining realistic hopes (see Figure 2).(11, 12)



Ref: Calman(12)

Figure 1. Graphical representation of the Calman Gap between hopes, ambitions and dreams (top) and present reality (bottom). The Calman Gap, the gap between these lines, is inversely related to quality of life.



Ref: Calman(12)

Figure 2. Enhanced quality of life represented by narrowing the Calman Gap, as unrealistic expectations are reduced (top) and present reality improved (bottom) by palliative care.

1.2.4 Hope strongly influences quality of life when facing serious illness

Hope has been identified as one of the most essential aspects of living and coping with a serious illness such as cancer and can significantly affect the way one copes in the face of uncertainty, adversity and loss.(14) Hope ignites an inner strength which enables one to look beyond one's pain, suffering and turmoil and to rather focus on that which is considered realistically possible, and provides an opportunity for personal growth.(14) Hope strongly influences well-being and QoL in all stages of health and illness.(14-17) In contrast, hopelessness negatively impacts physical, psychological and spiritual well-being and significantly impairs QoL.(14)

1.2.5 Defining hope

Although hope has been defined in many ways, Dufault and Martocchio's definition of hope from 1985 remains relevant in current healthcare literature.(18-20) Dufault and Martocchio defined hope as "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which, to the hoping person, is realistically possible and personally significant".(14, 16-20)

A more practical definition of hope was given by Snyder.(21, 22) According to Snyder's Hope Theory, first described in 1991, hope can be defined as the perceived ability to produce pathways to achieve desired goals, and to motivate oneself (which he termed "agency") to use those pathways in pursuit of the desired goals.(21) Snyder suggested that hope can be learned, for example through watching others, or through psychotherapy.(21) Snyder's definition also suggests that a person can influence the desired outcomes through personal ability or strength.(18)

Ref: Corn et al(22)

Figure 3. Representation of Snyder's Hope Theory and the relationship between goals, pathways and agency in defining hope

Hope, by definition, is goal-directed and future-focused. In healthcare, hope is typically directed at cure from illness, but even patients not expecting a cure from their disease can experience hope.(15)

1.2.6 Hope as a component of palliative care

Perhaps one might rightly question whether hope can truly exist in the face of incurable illness and death. The importance and existence of hope for patients with life-threatening disease, even at the end-of-life stage, has however been widely reported in the literature.(14-17, 23-28) Hope for the patient with advanced disease can be directed at "being" rather than at "doing", and at preparing for a peaceful death.(15, 17)

Maintaining hope should be an important component of palliative care which, by definition, aims to reduce suffering and to improve QoL for patients facing life-threatening illness and their family members.(1) Indeed, patients and their family members reportedly look to their doctors and other healthcare professionals to give them hope.(18, 20, 29-33) The palliative care team, in response to this need, and with the intention of reducing suffering and improving well-being, should therefore include interventions which foster hope in their care plans for their patients and their family members.

1.3 The importance of hope in palliative care

1.3.1 Defining the importance of hope in palliative care

Importance can be defined as "a quality or aspect having great worth or significance".(34) Here hope will be described as important for well-being, disease recovery and personal growth. Hope is a significant determinant of QoL in various stages of health and illness, including the dying phase. It is important to maintain hope when communicating bad news. Hope has also been determined to be an important aspect of caregiving.

1.3.2 Hope as important in health and in illness

The World Health Organization reported that psychosocial dimensions of well-being such as hope and hopelessness can have striking effects on disease susceptibility, disease recovery and overall survival in patients with cancer, AIDS and heart disease(35) and that "patients and physicians have begun to realise the value of elements such as faith, hope and compassion in the healing process”(35).

Numerous systematic reviews confirm the important role played by hope in the healthy(36), the elderly(37), the mentally ill(38), the acutely ill(39), the chronically ill(16, 36) and in the palliative care setting(15, 26, 30, 36, 40-48). Hope has been studied in patients with cancer more than in patients with any other diagnosis except mental illness(14, 38), and especially researched in the advanced cancer setting(18, 19, 26, 33, 40-47). When faced with life-threatening illness such as cancer, maintaining hope assists with the endurance of suffering, and facilitates coping and psychosocial adaptation to a changed reality.(25, 49) Hopeful patients have also been shown to follow management recommendations more diligently, and have a better tolerance for treatment adverse effects than non-hopeful patients.(29)

1.3.3 Hope as important at the end-of-life

Kübler-Ross’ five stages of denial, anger, bargaining, depression and acceptance are widely recognised as important, albeit non-linear, phases of grief during the stages of dying and death.(48, 50) What is less well known or acknowledged is that Kübler-Ross, in her seminal work “On death and dying”(50), originally published in 1969, stressed the importance of hope for dying patients, to which she devoted a chapter of her book. Reflecting on the voiced experiences of more than two hundred patients facing imminent death, Kübler-Ross stated, “The one thing that usually persists through all these stages is hope”(50) (see Figure 4).

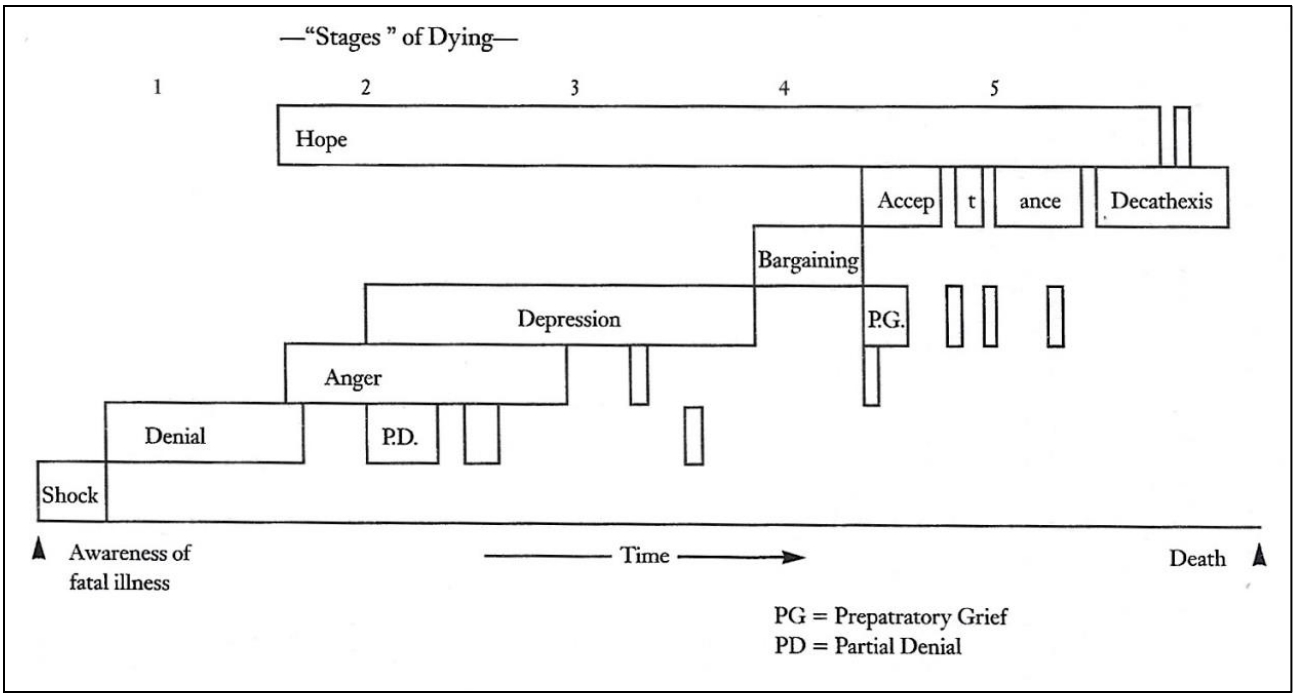


Figure 4. Representation of the "stages" of dying Ref: Kübler-Ross(50)

Kübler-Ross, as cited by Herth and Cutcliffe(48), discovered that maintaining hope is important for patient comfort and function at the end-of-life.(48) Here hope is quite clearly framed in terms of *quality* of life, and not life over death.(48, 51) As death is faced, hope helps to reshape the dread of dying and to rather focus on achieving meaning in life in the time that remains.(20)

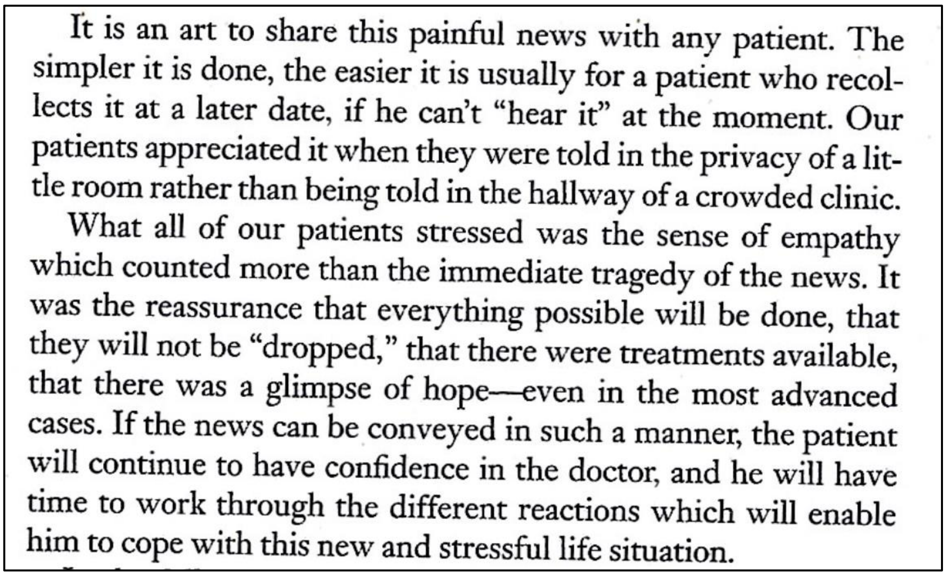
1.3.4 Hope as an important aspect of spirituality

Hope is seen as an important element of spirituality, fundamental for the spiritual well-being of patients and a valuable outcome of spiritual healthcare interventions.(52) Spirituality is a vital part of the whole person, and can be defined as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."(53, 54) Through this definition, one may appreciate the close relation between spirituality and hope in terms of seeking meaning and purpose, in the foundations of faith and religion, and in relationships with self, others, and the significant or sacred. Relating to spirituality, hope is to be found in encouraging patients to focus on important relationships and beliefs, attainable goals, and seeking value and purpose in life.(52) Hope and meaning are closely linked. Indeed, hopeful thought appears to be an important component of the perception that life is meaningful.(52) Hope is considered central to many religions, but the transcendent or spiritual aspect of hope reaches beyond religious activity, to be found in a connectedness with something or Someone greater than self, and finding meaning in difficult times, which often transcends human explanation.(52)

Hope is identified as a key spiritual need of many dying patients.(15, 20) Hope forms an important component of pastoral care, particularly for patients experiencing pain and distress.(55-58) Guidelines for healthcare chaplains describe hope as an essential patient need, list hope as part of patient assessment profiles and an important aspect of patient management plans.(59) Hope forms part of patient assessment and/or management plans in the chaplaincy care guidelines in Belgium(60), Canada(61), Netherlands(62), United Kingdom (UK)(63)and United States (US)(64, 65).

1.3.5 Hope as important in coping with bad news

For patients with cancer, irrespective of stage, hope has been identified as an essential component of coping with bad news.(31) Patients describe the importance of balancing hope with honesty when bad news is delivered regarding disease progression or poor prognoses.(30, 32) Receiving bad news often causes significant emotional distress, and physicians worry that giving truthful prognostic information takes away hope for patients and family members.(17, 29, 31, 32) Most patients and their family caregivers however prefer truthful prognostic information, but delivered with empathy and sensitivity.(17, 29-32) The manner in which information is given is described by patients and caregivers as just as important as, or more important than, the content.(30) Kübler-Ross in 1969 reported that delivering “painful news” with empathy and the reassurance of non-abandonment allowed patients the opportunity to cope with the news and to maintain hope, “even in the most advanced cases”(50) (see Figure 5).



It is an art to share this painful news with any patient. The simpler it is done, the easier it is usually for a patient who recollects it at a later date, if he can't "hear it" at the moment. Our patients appreciated it when they were told in the privacy of a little room rather than being told in the hallway of a crowded clinic.

What all of our patients stressed was the sense of empathy which counted more than the immediate tragedy of the news. It was the reassurance that everything possible will be done, that they will not be "dropped," that there were treatments available, that there was a glimpse of hope—even in the most advanced cases. If the news can be conveyed in such a manner, the patient will continue to have confidence in the doctor, and he will have time to work through the different reactions which will enable him to cope with this new and stressful life situation.

Ref: Kübler-Ross(50)

Figure 5. Excerpt from "On death and dying" on maintaining hope for patients while delivering bad news

Despite discussing prognostic and end-of-life issues, many patients are able to maintain a strong sense of hope, particularly when their healthcare providers assist them in exploring and facilitating realistic and meaningful forms of hope, such as symptom control, supportive relationships, finding peace, purpose and meaning, and supporting their spirituality.(29, 30, 32) Having accurate information also assists patients and families with decision-making and realistic planning for their future.(17) Patients and their family caregivers expect their healthcare practitioners to play a vital role in nurturing and sustaining their hope in discussions around diagnosis and prognosis(30, 31), to offer them emotional support(31) and to emphasise what realistically can be done(32).

A minority of patients and family members however prefer non-disclosure, and find hope in avoiding the medical facts.(29, 30) It is important for healthcare workers to respect individual preferences, which are often culture-specific(17, 31), regarding diagnostic and prognostic disclosure.(29-31)

1.3.6 Hope as important for family caregivers

Palliative care aims also to support and to relieve suffering for family members.(1) Within the palliative care setting, family caregivers are broadly defined as family and/or friends who provide unpaid ongoing assistance to a person nearing or at end-of-life.(66) Caring for a loved one is considered a “life transition”(66) and has been associated with significant disruption, caregiver burden and distress.(17, 66-68) Hope is an important element in assisting family members to cope in their care-giving role and to establish a new normal(15, 17, 66, 67, 69) and also in supporting their loved one to maintain hope(17). Hope has been expressed as important by family caregivers regardless of age, relationship or setting.(67) Family caregivers seek hope from healthcare providers through demonstrating true interest and concern, being given helpful, accurate, practical information and addressing their fears and concerns.(17)

The caregiver’s well-being is a central factor in providing effective end-of-life care to their loved one in the home setting.(66, 68) Well-being for caregivers is significantly correlated with hope.(68) Hope is foundational in alleviating the potential suffering associated with end-of-life care and allows family members to cope as their loved one dies, and in their bereavement.(66, 68)

A systematic review undertaken by Sterckx et al to determine the impact of high-grade gliomas on patients and their family caregivers found hope an important expressed need.(70) Patients with high-grade gliomas have a particularly poor prognosis and significant caregiver dependence.(70) The review described how patients find it especially difficult to lose their independence and autonomy.(70) Caregivers struggle to cope with increasingly all-consuming responsibilities for the patient with progressive glioma.(70) Some caregiver experiences however were satisfying, particularly where they felt supported.(70) Hope was identified as an important need for both patients and caregivers, especially at disease progression; other expressed needs were information and support.(70) The authors suggest however that further research be undertaken to better define caregivers’ needs regarding hope, such that interventions can be aligned accordingly.(70)

1.4 The meaning of hope in palliative care

1.4.1 Defining the meaning of hope in palliative care

Meaning can be defined as “the idea that is represented by a word, phrase, etc” or “the idea that a person wants to express by using words, signs, etc”.(34)

Within the context of adult patients with advanced cancer and their family caregivers, the word “hope” can be interpreted in different ways. For some seeking guidance to navigate the bewildering territory of life-threatening illness, hope has been likened to a radar guiding a ship on a stormy sea.(71) For some patients with advanced illness, to have hope means simply a realistic desire to feel better, to experience relief from pain and suffering, to live day by day, to plan for a peaceful death, to look ahead to a better life after death, and to envision a happier future for their families.(23, 24) For family caregivers, hope may mean setting their sights on a better future for the person being cared for.(69) Focusing on achieving a future good reportedly fosters an inner strength which encourages caregivers to continue caregiving.(69)

1.4.2 The tension of hope

For many patients and family members however, “hope” may focus only on cure of their illness. It has been suggested that, particularly in Western society, the meaning of hope has been over-medicalised and is more often associated with “hope for a cure”.(51) Duggleby suggests that societal discourse, such as found in newspapers and magazine articles, influences the meaning of “hope” for persons with cancer.(51) The media tends to portray “hope” very narrowly as synonymous with “hope for a cure”, which causes confusion and distress for patients with advanced cancer, whose own discourses of hope may focus more broadly on comfort, peace and meaningful relationships towards the end-of-life.(51)

A tension may therefore be experienced by patients and family members who continue to hope for a cure, while slowly coming to accept the eventual inevitability of their death.(23) Patients and family members describe oscillating between hope, hopelessness and despair.(36, 72) A metaphor describing the dichotomy and dynamics of moving between hope, hopelessness and despair is that of voices of a singing choir, where voices either sing together, alternate or sing their own melody.(72)

1.4.3 The protective yet fragile nature of hope

It has been suggested by Paul, who researched the role of hope in Canadian patients experiencing a recurrence of their cancer, that hope acts as a veneer(73), defined as "a thin layer of a superior substance laid over an inferior substance"(74). The veneer metaphor describes both the protective and the fragile nature of hope.(73, 74) The veneer of hope varies in strength and integrity along the patient's cancer trajectory, and may erode during times of disease progression such as at the diagnosis of first cancer recurrence, causing disengagement and overwhelming suffering of the self below.(73) Through a process of redefining objects of hope, the hopeful veneer is remodelled to support the rebuilding of the self below, involving reframing of self-identity, re-establishing a new normal and re-engagement in living.(73, 74)

1.4.4 Potential for mutually exclusive meanings of hope

Nierop-van Baalen et al undertook a qualitative study in Europe whereby 76 patients with advanced cancer were interviewed regarding the meaning of hope.(33) Meaning of hope for patients was linked to the desired object or outcome. Interestingly, desired outcomes were sometimes mutually exclusive, for example hoping simultaneously for recovery as well as for a peaceful death. In these instances, hope for cure, even though admittedly less realistic to the patient, gave energy to pursue treatments, healthy diets and alternative therapies, and assisted patients in dealing with the present difficult reality.(33)

Similarly, Buckley and Herth interviewed 16 patients receiving palliative care in England, 14 of whom had advanced cancer.(75) Almost half of the patients interviewed (seven) talked of hope for a cure, while also acknowledging their poor prognosis. The authors noted the dynamic nature of the hope experience, and that episodes of loss of hope were transient. Meaning of hope for these patients included being optimistic, having the love of family, living in the present, making the most of each day, and coping with the end stages of illness.(75)

1.4.5 Differences in meaning of hope between healthcare professionals and patients

Nierop-van Baalen et al further explored the differences in the meaning of hope between healthcare professionals and patients.(19) Focus group discussions were held with multidisciplinary team members caring for patients with palliative care needs, aiming to explore how “hopeful” patients with advanced cancer were managed. Health professionals typically associated “hope” with “cure”, and were distressed by perceptions of “false hope” in patients, labelling such hopeful patients as “difficult” or “irrational”.(19) Patients with advanced cancer however typically described hope more broadly in social, psychological and spiritual terms, and not necessarily in expectation of a cure. The authors suggest that it would be helpful to differentiate patients’ expectations from their hopes, and that illness-related expectations be communicated truthfully while maintaining the integrity of the patient’s hope. A helpful approach would be to give honest prognostic information to patients, but to say, “I hope with you”.(19) The authors suggest that the meaning of hope for healthcare professionals differs between countries and that further research be undertaken to explore how healthcare professionals view hope and manage hopeful patients, particularly in non-Western countries.(19)

1.5 The experience of hope in palliative care

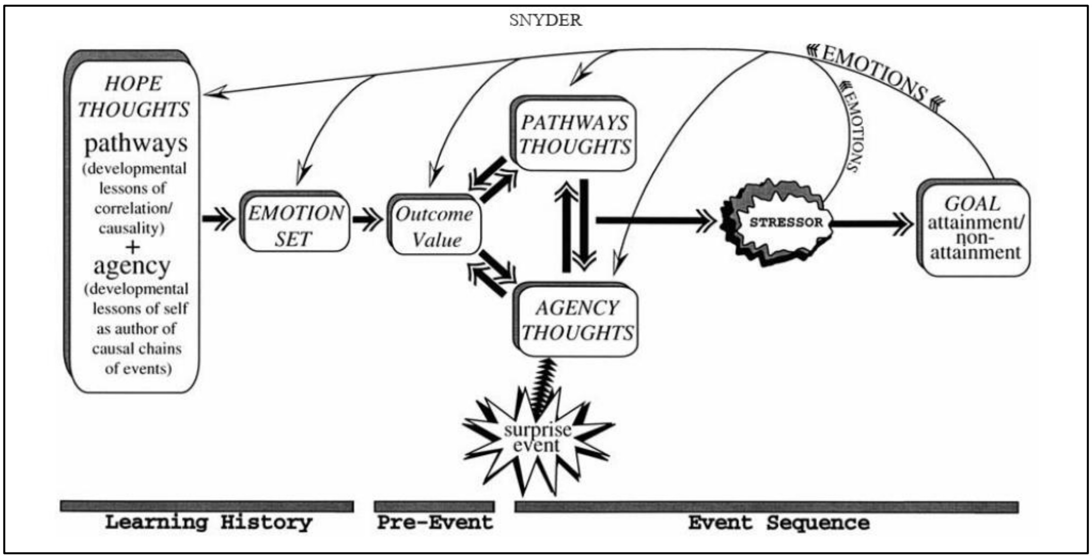
1.5.1 Defining the experience of hope in palliative care

Experience can be defined as “something personally encountered, undergone, or lived through”.(34) Dimensions of hope are complex and experiences can be physical, intellectual, psychological, social or spiritual in nature.(36, 76) Typically the hope experience is manifested emotionally and behaviourally.(77) In the palliative care literature, hope exists at the interface between the psychological and spiritual dimensions of well-being, and is associated with meaning, purpose, beliefs and goals in life and death.(15, 78, 79) Components, such as hope, experienced in the psychological and spiritual dimensions of well-being influence one another, for example hope experienced in the spiritual dimension can have a powerful effect on ameliorating psychological distress.(78)

1.5.2 Hope theories in palliative care

Snyder, an American psychologist, formulated a hope theory in the mid-1980's, based on the premise that hope necessitates something to hope for, i.e. a goal.(22) Snyder's definition of hope, first published in 1991, linked having a goal to the two inter-related cognitive processes of pathways thinking and agency thinking (self-motivation).(21) Snyder described his Hope Theory more fully in 2002, postulating that man's actions are primarily goal-directed and that goals are cognitively-derived and pursued.(21) Lazarus, as cited by Snyder(21), suggested that hope arises fundamentally when current life circumstances are unsatisfactory. Snyder suggests that in such distressing circumstances, hope might bestow a "repair" function where goals are chosen to fill an existing void.(21) Other important hope categories involve "maintenance" goals of day-to-day living and "enhancement" goals which build on current agreeable conditions.(21)

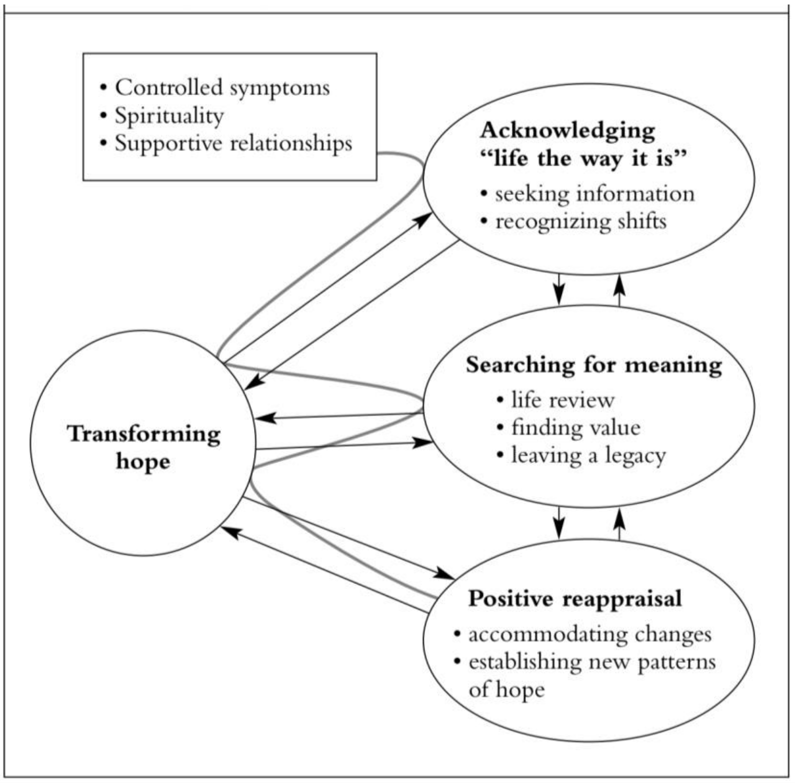
In Snyder's Hope Theory model, "pathways" refers to the route(s) taken by an individual to reach a pre-determined goal. High-hope people typically consider alternative strategies when meeting resistance, have greater confidence, persistence and flexibility regarding choice of routes taken, and choose pathways or mechanisms that have been beneficial in the past.(21, 22) "Agency" is the self-motivation or inspirational thoughts required to motivate a person to reach a goal, particularly when goal-pursuit is difficult.(21, 22) These cognitive concepts of the hope model are however influenced by emotions, stressors and surprise events, which can modify the person's success in attaining goals and in maintaining hope (see Figure 6).(21)



Ref: Snyder(21)

Figure 6. Schematic representation of Snyder's Hope Theory model demonstrating factors influencing the cognitive concepts of agency, pathways and goals

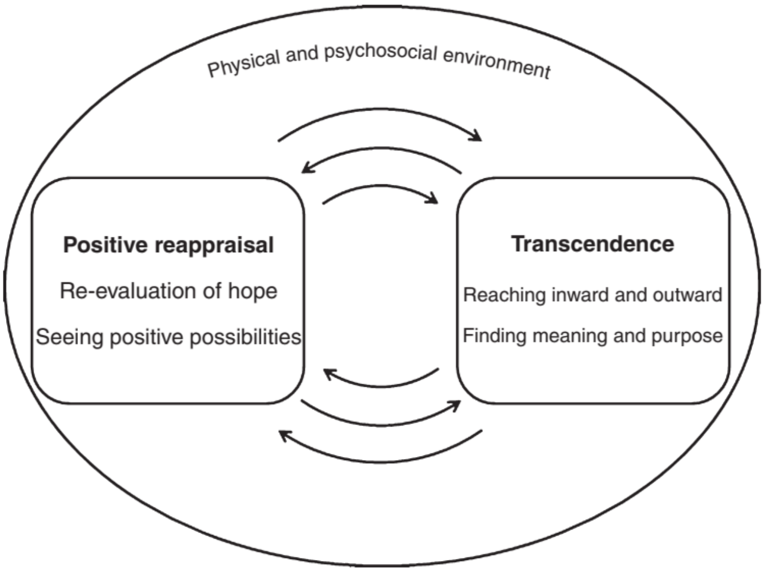
Herth and Duggleby, from the US and Canada respectively, have contributed to most of the research of hope in the palliative care setting over the past 22 years. A grounded theory analysis of the pain experience of patients with advanced cancer by Duggleby in 2000 revealed that enduring through suffering involved two processes: maintaining hope and adjusting to a new normal.(49) Duggleby's analysis found that hope was maintained through finding meaning, caring relationships and religious faith.(49) In 2005, Duggleby further described a process of transforming hope, particularly as a patient's underlying disease advances, and the focus of hope adjusts accordingly.(25) The hope experience was described as being transformative for patients via three sub-processes: accepting life the way it is, searching for meaning, and positive reappraisal (see Figure 7).(25) Duggleby suggested that transforming hope extends beyond goal-setting and problem-solving as proposed by Snyder's Hope Theory(21), and that, even towards the end-of-life, hope can be maintained by positive reappraisal when reviewing one's life, by finding purpose and meaning in leaving a legacy, and by preparing practically and emotionally for death.(25)



Ref: Duggleby et al(25)

Figure 7. Schematic representation of Duggleby's Transforming Hope theory

Duggleby et al performed a metasynthesis of hope studies over the preceding 30 years and developed this theory further in 2012.(16) The major finding of the metasynthesis study was that hope, as the ability to "transcend possibilities", primarily involved two integrated processes of transcendence and positive reappraisal.(16) Transcendence involved the sub-processes of reaching inwardly and outwardly, and finding meaning and purpose. Positive reappraisal included the sub-processes of re-evaluating hope in the context of illness and finding positive realistic possibilities to focus one's hope on (see Figure 8).(16)



Ref: Duggleby et al(16)

Figure 8. Schematic representation of transcendence and positive reappraisal as two integrated processes of hope

Kylma, Duggleby et al suggested two overarching themes of the hope experience in the palliative setting, that of hope being an existential dynamic life force ("living in/with hope") and of hope having an active focus ("hoping for something").(15) Living with hope was described as a transformative process important for maintaining relationships with others and achieving peace and comfort at the end-of-life, and strongly linked with spirituality.(15) Hoping for something was described as having a sense of the future and aiming for and experiencing important events or goals. Patients in palliative care settings typically expressed elements of both.(15)

1.5.3 The work of hope

Nierop-van Baalen et al refer to "the work of hope".(18, 33) Although hope gives energy, it can also take energy.(33) According to Nierop-van Baalen's research, patients typically look to their doctor to confirm their hope. If this hope is not forthcoming, patients turn to internal or external resources to bolster their hope, which takes effort.(33) This analysis illuminates the trust patients place in their doctors to be given truthful information, and also the responsibility doctors have towards their patients regarding the importance of truth-telling. Offering patients "false hope" by giving overly optimistic diagnostic and/or prognostic information is to be discouraged, as this not only betrays trust, but also expends a patient's valuable yet diminishing energy resources in the pursuit of futile interventions.(33)

1.5.4 The attributes of hope

According to the Hope Process Framework, as cited by Herth(14, 74), hope has four main attributes, namely experiential, relational, spiritual or transcendent, and rational thought. The experiential aspect ("the pain of hope"(80)) involves acknowledging the pain created by loss and suffering, and searching for hope in the experience.(14) The relational aspect ("the heart of hope"(80)) involves connections with other people, such as family and friends, while the spiritual or transcendent aspect ("the soul of hope"(80)) involves a connection with something or Someone higher than oneself, as well as finding purpose and meaning.(14) The rational thought aspect ("the mind of hope"(80)) involves cognitive development, e.g. goal defining and cognitive reframing processes.(14)

1.5.5 The relationship between hope and hopelessness

Regarding the experience of hope for patients and caregivers, hope and hopelessness possibly exist along a continuum, although there is debate whether these are opposite constructs entirely.(36, 81) Certainly within the literature, hope and hopelessness are viewed differently. Hope has been associated with goals, outcomes and philosophical, existential and spiritual concerns, whereas hopelessness is viewed by many authors as a form of spiritual distress, associated with depression, self-blame, suicidality and requests to hasten death.(81-84) Hope as a multidimensional construct however represents more than the absence of depression and other symptoms associated with hopelessness.(77) It is currently unknown whether interventions aimed at increasing hope also assist in decreasing the depression, self-blame and depression associated with hopelessness, and further research is needed.(81)

1.5.6 The influence of physical, psychological, social and spiritual factors on the experience of hope

Supporting the spectrum of the hope experience along a continuum between hopefulness and hopelessness, studies confirm that hope is highly individualised(77), dynamic(16, 17) and evolves with time and circumstantial change(81). A person's perception of hope is influenced by his history, present circumstance, language and culture.(51) Socio-cultural background characteristics such as age, gender, sexual orientation, immigration history, disability status and spirituality influence life goals and the perception of loss and adversity.(85) These socio-spiritual factors therefore impact hope meaning and experience.(85) Hope is influenced by physical and psychological well-being, and distress such as pain, fatigue, depression and anxiety negatively affect the hope experience.(18, 20, 77) According to research by Duggleby, patients report that uncontrolled pain, social isolation and abandonment, and devaluation of personhood negatively impact their experience of hope.(23)

1.5.7 The experience of hope for family caregivers

A metasynthesis by Duggleby et al, of the hope experience of family caregivers caring for patients with chronic illness such as cancer, describes the experience of focusing on possible positive future outcomes within uncertainty.(67) Hope is a dynamic experience for family caregivers, where multiple co-existing hopes emerge and shift in intensity and focus on possibilities rather than expectations.(67) Family caregivers describe the hope experience in terms of relational support including spiritual connections, comfort for their loved one, finding meaning in the situation and coming to acceptance.(68) Studies by Herth and Duggleby suggest that healthcare professionals can assist the family caregiver's hope experience through offering support, comfort, reassurance, information and encouragement.(67, 68)

1.6 Summary and identification of gaps in hope research within the South African context

This chapter defines and introduces the subject of hope and how hope relates to palliative care, specifically within the context of patients with advanced cancer and their family caregivers. While maintaining hope is considered universally important in holistic patient care(15-17, 48, 85), there is considerable variation in the meaning and experiences of hope for patients, depending on factors such as their clinical, socio-economic, religious and cultural backgrounds(77, 85).

Most of the research on hope in palliative care, particularly the pioneering research, as demonstrated in this chapter, has been undertaken in first-world populations such as in Canada, the US and Europe. No such grounded theory research on hope is readily identifiable from developing countries such as in Africa. As the socio-economic and cultural dynamics of developing nations differ substantially from those of more developed countries, it would be expected that the meaning and experiences of hope would differ between patients living in developed and developing countries. The relevance of westernised research on hope for patients from developing countries such as South Africa (SA) is largely unknown. Indeed, hope-fostering interventions researched internationally might not offer value, or might even be detrimental, in the South African healthcare setting.

To better characterise this perceived gap in hope research, a literature review was undertaken to evaluate the constructs of hope as researched within the South African palliative care setting. These findings were considered in light of publications from elsewhere in Africa and internationally, and addressed in the following chapter.

CHAPTER 2

LITERATURE REVIEW

2.1 Overview

This review aims to evaluate constructs of hope as evidenced in the literature relating to the importance, meaning and experience of hope in South African palliative care settings. The review relates this research to publications on hope in other African and international settings. The review analyses the research findings and identifies gaps in the literature where further research would be valuable in the South African setting. Published hope-fostering interventions will also be evaluated with regards to potential relevance within the South African setting. Gaps identified in the literature will then lead to the rationale, aims and objectives for the study.

2.2 Literature search methodology

A literature search was undertaken using the following databases: MEDLINE and other life science journals via PubMed; Africa-Wide Information, Atla Religion Database with AtlaSerials, CINAHL, APA PsycArticles, APA PsycInfo and APA PsycTests via EBSCO host. The following key words were used as search items: (‘meaning’ OR ‘experience’ OR ‘importance’) AND (‘hope*’ OR ‘hoping’) AND (‘palliat*’ OR ‘dying’ OR ‘terminal’ OR ‘cancer’) AND ‘Africa’; (‘meta-analysis’ OR ‘systematic review’ OR ‘intervention’ OR ‘program’) AND ‘hope’ AND ‘cancer’. Google Scholar was used to determine the citing frequency of articles, and to search for further articles cited as references from articles found in the initial search, assessed as being relevant to the research topic, particularly where the research had been undertaken in Africa. The chapter on “Hope” from the Oxford Textbook of Spirituality in Healthcare was also used as a reference for articles. Chapters from the Oxford Handbook of Hope relevant to palliative healthcare were also consulted. Published articles referenced through an online course “Essentials in Palliative Care Chaplaincy”, attended by the researcher in July and August 2021, through Californian State

University's Shiley Institute for Palliative Care, were also evaluated for relevance to this research. Grey literature in the form of articles and a yet unpublished textbook chapter were received via personal correspondence from Dr Eve Namisango, research manager at the African Palliative Care Association. Dr Namisango's research interest is Spirituality in Africa, and this literature was used to identify other articles relevant to the research topic, and searched via Google Scholar.

2.3 Research findings relating to the importance, meaning and experience of hope in sub-Saharan Africa

2.3.1 The importance of hope in sub-Saharan African palliative care

Evidence relating to the importance of hope in African patients receiving palliative care was provided by a recent mixed-methods systematic review by Afolabi et al, describing the palliative care needs of people with serious illness in Africa.(86) This comprehensive review used the internationally-validated Mixed Method Appraisal Tool to screen six global literature databases and three Africa-specific databases for publications on the palliative care needs of people with serious illness in Africa. The study objectives to map and critically appraise the needs of African people with serious illness and their families, based on the WHO's definition of palliative care, were met. Most patients in the studies reviewed had advanced cancer and/or HIV. Significant distress, including hopelessness and helplessness, was reported by patients and their families. Hope was identified as an important psychological and spiritual need for patients and their caregivers. The importance of spirituality and religion was highlighted in many studies as assisting with coping, finding hope, and relieving fears and anxiety.(86) The authors reiterated that palliative care needs must be considered within local cultural contexts to render person-centred, family-focused care.(86)

Only two relevant studies were found which addressed the importance of hope in South African palliative care settings. De Villiers et al(87) and Bingo et al(88) investigated the experiences of nine patients receiving palliative care and 18 patients with head and neck cancer respectively in Gauteng, SA. De Villiers et al explored how chronic pain influences the daily lives of underprivileged South

Africans via a qualitative descriptive phenomenological design.(87) Bingo et al likewise conducted in-depth patient interviews, gathering information-rich data from patients with advanced cancer in the state sector via a qualitative descriptive research design.(88) Patients described their need for psychosocial support and hope. Despite significant pain and suffering, patients in both studies described the importance of upholding their spirituality. Although some religious activities, such as attending church, were curtailed, faith in God remained strong; prayer provided hope for the future and lessened pain.(87, 88) These South African studies had small sample sizes, but nevertheless highlight the importance of hope for patients living in resource-poor communities with palliative care needs, particularly those with a high symptom burden. The strong association between spirituality and hope in SA was also accentuated.

Very few studies evaluate the experience of family caregivers of adult patients with cancer in sub-Saharan Africa, and none were found that evaluate hope specifically. A descriptive cross-sectional research study by Muliira et al reported on anxiety and depression scores and the physical impact of caregiving of 284 caregivers of adult patients with cancer in Uganda.(89) The researchers found very high levels of anxiety (35.2%), severe anxiety (20%), depression (48.2%) and severe depression (27.5%) among caregivers.(89) Most (55.6%) reported that caregiving caused deterioration in their physical health, which increased their anxiety.(89) The authors note that these levels of anxiety and depression are greater than reported for caregivers in developed countries.(89) The role of hope was however not evaluated.

2.3.2 The meaning of hope in sub-Saharan African palliative care

Relating to the meaning of hope for South African patients receiving palliative care, Maree and Potgieter published two articles describing the decision-making process around pursuing palliative chemotherapy for patients, family caregivers and nurses at a single private oncology unit in the Eastern Cape.(90, 91) Both studies met their stated objectives to describe the experiences and motivation for patients choosing to undergo palliative chemotherapy. Hope was found to inform treatment decision-making in both studies.(90, 91) Despite knowing the intent of chemotherapy was palliative, not curative, many patients hoped for life prolongation, or that added survival time would allow for the development of a new treatment offering cure. Others expressed hope for more time to get their affairs in order. Caregivers shared these hopes, supporting the treatment decision of their family member. Faith in God and encouragement from family members, healthcare workers and fellow patients helped patients to maintain hope.(90, 91) Nurses however expressed concern for patients continuing on chemotherapy under pressure from their families to continue or in pursuit of unrealistic cure or "false hope".(90)

In another cross-sectional descriptive study, Combrink et al described the experiences of nine adult patients with cancer and their family caregivers in a private oncology unit in the Western Cape, when anticancer treatment was withdrawn due to disease progression.(92) Although the study findings were limited to a small sample in a single private oncology centre, the in-depth interviews nevertheless provided valuable insights into patient and family responses when told that chemotherapy was no longer a viable option. Initial reactions included shock, disbelief and fear for the future.(92) Patients expressed their hope for a good death, and not suffering at the end-of-life. Despite physical deterioration however, some caregivers, as did patients, expressed their hope for miraculous healing.(92)

No further studies from SA or elsewhere in Africa were identified describing the meaning of hope for patients or their family caregivers in African palliative care settings. The findings from these few studies in the South African private oncology sector, similar to research in international studies, nevertheless describe the tension that exists for patients between hoping for miraculous cure and hoping for comfort in dying. The role of spirituality and encouragement from others in maintaining hope in the South African setting was emphasised.

2.3.3 The experience of hope in sub-Saharan African palliative care

Relating to the experience of hope in African palliative care settings, there is reasonable evidence to suggest that hope is associated with resilience and enhanced coping in the face of adversity, and is strongly associated with spirituality.

An original research article by Akinsola from Botswana describes the hope experience of people living with AIDS (PLWA).(93) At the time of publication in 2001, antiretroviral therapy was not yet widely available in Africa(94), and Akinsola describes how PLWA lived in fear of dying.(93) Although not describing the experiences of patients with advanced cancer specifically, one could perhaps extrapolate the hope experience of African patients living with advanced cancer from this research. Cancer and HIV are known to be closely associated; about 36% of cancers in Africa are related to infectious disease such as HIV.(95) Similarities exist between people living with incurable AIDS and incurable cancer in Africa. Illness may be seen as caused by witchcraft, the enemy, spirits of ancestors or other supernatural powers, and viewed as punishment for previous wrongdoing.(93, 96) Other similarities include societal prejudice towards people disabled by illness, similar disease trajectories associated with declining physical health and increasing psychological burden, causing economic, functional and role loss.(93)

Akinsola relates how Africans typically live with the harsh realities of poverty, disease, hunger and war, how caregivers describe losing hope when caring for family members with life-threatening illness and how the disease experience is influenced by traditional and spiritual views and beliefs.(93) He describes how having hope is associated with better QoL, better coping and resilience in the face of suffering, and can lead to healing and growth of the human spirit despite adversity.(93)

Relevant to the rural KwaZulu-Natal (KZN) context, through a series of related studies, Campbell et al explored the role of traditional healers in providing palliative care.(97-99) Traditional healers, who engage in indigenous medical practice, are recognised as an important healthcare resource in SA.(100) Traditional healers are considered the primary, and sometimes the only, healthcare providers for most of the rural population of SA, and healing includes a significant supernatural or spiritual element.(97, 100) Through a process of photo-elicitation, whereby participants discussed photographs they had taken relevant to their daily work, Campbell et al held interviews with four nurses and 17 home-based care workers providing palliative care to patients in rural KZN.(97) The patients under the participants' care engaged deeply in traditional rituals relating to disease, dying, death and bereavement.(97) Traditional healers, who uphold the concept of "whole self", were recognised as augmenting the cultural, psychological and spiritual well-being of patients.(97) The researchers suggest that traditional healers could be integral in providing culturally-appropriate palliative care to patients in rural SA.(97) An identified risk of traditional healer involvement is however the creation of false hopes regarding cure and longevity, leading to significant delays in disease diagnosis and medical treatment.(97)

Studies reveal that the people of SA are by and large deeply spiritual beings. De la Porte, a researcher for the project "Spirituality and Health" conducted at the Faculty of Theology, University of Pretoria, eloquently summarises the interaction between spirituality and healthcare in SA.(101) His research indicates that greater than 70% of South Africans belong to a faith-based community, and much of their suffering, including health-related, is shaped by their spirituality. De la Porte's research finds that belonging to a faith-based community typically improves a patient's experience of compassionate care and hope while seeking care for their illness.(101) Sadly however, despite the evident value of spiritual care, there is no accredited role for spiritual or pastoral workers in the current South African healthcare system.(101)

Combrink's study, describing the experience of nine Western Cape patients with advanced cancer and their family caregivers experiencing anticancer treatment withdrawal following disease progression, found increasing acceptance of poor prognoses, and better coping, with time.(92) This was also described by Ayane et al in their research on truth-telling regarding terminal illness prognosis in Africa(102), further discussed in 2.4.3 below. Although a small study, a strong theme in Combrink's research was the role played by spirituality and religion for patients and caregivers in coping with adversity and their acceptance of death.(92) Faith in God was described by both patients and caregivers as important in giving hope. Caregivers stated also that support, from carers, family members, church members, CANSA and hospice, gave them hope.(92)

The meaning and experience of hope are significantly influenced by one's spirituality such as religion and worldview.(15, 18, 20) Namisango, research manager for the African Palliative Care Association and based in Uganda, emphasises the importance of spiritual support for patients living in Africa.(103) She describes the potential for spiritual growth and renewed hope occurring in the face of death, particularly for those patients who believe in life after death.(103) In her research with African adult patients with cancer, patients who accept the reality of their mortality, and yet live in the "present moment", can experience spiritual healing and peace. She stresses that spiritual needs and well-being of patients receiving palliative care must be evaluated within their cultural context.(103)

Ishimwe et al, in a reliability study testing the adaption of a hope measurement tool in the Rwandan setting, relate hope experience to socio-economic status.(77) In addition to improving health outcomes, hope is also relevant to poverty alleviation.(77) The authors report that interventions which instil hope can improve education outcomes, leading to socio-economic as well as health improvement.(77) However the authors state that instituting measures to instil hope without the improvement of resources is unlikely to improve health outcomes in poorer communities. Where significant economic disparities exist, hope-instilling interventions associated with poverty-alleviation and educational programs are more likely to improve health-related outcomes.(77)

2.4 The influence of diagnostic and prognostic disclosure on hope

2.4.1 The influence of cancer stage on hope

Research by Bovero et al involving Italian patients with cancer indicates that the role played by hope appears to be unrelated to cancer stage, and that hope is relevant to all patients regardless of their staging.(20) This was a cross-sectional mixed-methods study where 350 patients with cancer and an estimated life expectancy of four months or less were interviewed and assessed for clinical and psychosocial measures, including hope, via six validated rating scales.(20) Hope represented a core need and correlated strongly with subscales measuring meaning and personal religious practice, highlighting the importance of spiritual well-being in fostering hope, regardless of cancer stage.(20)

These findings are consistent with Nierop-van Baalen et al’s research of hope in patients with cancer.(18, 33) Nierop-van Baalen’s qualitative study, involving secondary data analysis of interviews with 76 patients with cancer and a life expectancy between three and 12 months, found that hope is important to patients in all illness phases.(33) Likewise, a systematic review by Nierop-van Baalen et al, of 33 studies on hope in patients receiving oncology treatment, found hope primarily a process of a person’s inner being and unrelated to cancer stage.(18) With disease progression, hope can be sustained and maintained, even when approaching death.(18, 20, 33) Bovero et al however state that, although the role and the intensity of hope do not necessarily change with advancing disease, the qualitative nature of hope changes, and typically evolves from believing in the possibility of healing to enjoying the present moment.(20) Hope interventions should therefore be fluid and adapt as the patient’s illness progresses towards achieving realistic goals.

2.4.2 The influence of advance care planning on hope

Cohen et al from the US performed a cross-sectional analysis of 672 patients with advanced solid cancers.(104) Data were collected using validated questionnaires to assess the components of advance care planning previously undertaken (namely end-of-life planning, the election of a surrogate decision-maker, and completion of an advance directive). Hope was scored using a validated measuring tool. No association, and in particular no reduction in hope, was detected in relation to any of the advance care planning components, leading the authors to conclude that fear of causing a patient to lose hope should not be a reason for clinicians not discussing advance care planning with their patients.(104)

2.4.3 Truth-telling regarding terminal illness prognosis in the African context

Ayane and Kadimo from Botswana undertook a systematic review of the African literature describing truth-telling regarding terminal illness prognosis.(102) Thirteen peer-reviewed journal articles met their review criteria and were further analysed. Their review determined that preferences for prognostic disclosure of patients, families and medical practitioners differ and are influenced by cultural and religious beliefs. Most doctors gave bad news to family members first and were guided by the family regarding how much information to disclose to the patient. Concern was raised by both doctors and family members that informing patients of their poor prognosis would result in hopelessness, despair and premature death. This was not however borne out by their review. While some patients became depressed and lost hope after receiving bad news, most patients responded positively. With time many patients were able to process the information, regain hope, achieve a level of acceptance and attain life closure. The authors suggest that prognostic truth-telling in the African context is part of good patient care and supports the maturation of realistic hope.(102)

A descriptive study by Grant et al involving 32 patients with advanced cancer and/or AIDS in rural Kenya likewise reported that patients' understanding of their illness and prognosis was important, avoided false hope and the pursuit of "false cures", and allowed them the opportunity to prepare for death.(96) Thirty-one of 32 patients reflected that their spiritual beliefs were important, gave them hope and enabled them to cope with their advancing illness.(96)

An important study about breaking bad news in a cross-language context was undertaken by Walker et al in a state oncology centre in KZN, SA.(105) Via four semi-structured focus groups, 29 isiZulu-speaking patients receiving radiotherapy for cancer were interviewed regarding their experience of receiving bad news. The discussions were held in isiZulu, transcribed and then translated into English for further analysis.(105) Patients valued receiving bad news in their home language, via a language translator where necessary. All but one participant preferred disclosure of bad news; the remaining participant preferred instead that the family be told. Patients viewed doctors as a key source of hope, which was an important theme. Hope was upheld when truth was delivered with empathy, by doctors’ assurances of non-abandonment and the possibility of treatment. Faith in God, belief in fate or destiny, and community support further helped patients to cope and maintain hope when receiving bad news.(105)

2.5 Hope-fostering interventions in palliative care

2.5.1 The role of the palliative care practitioner in fostering hope

The role of the clinician as an instrument of hope for patients and their family caregivers has been supported since the early 2000’s by researchers such as Duggleby(23, 25, 69, 106, 107), Herth and Cutcliffe(14, 37, 48, 108) and McIntyre and Chaplain(109). A need for validation of such hope strategies or interventions has however been suggested by Herth and Cutcliffe.(48) Also, as evidenced by the influence of socio-cultural, socio-economic and other factors on hope, clinicians, when deciding on potentially effective hope-nurturing interventions for patients and their family caregivers, should be cognisant of their particular backgrounds and clinical contexts.

Twycross suggests that hope forms the framework of a palliative care consultation and affirms that palliative care practitioners play an important role in fostering hope for patients.(110) Twycross states that goal-setting is essential for maintaining hope and emphasises the need to formulate *realistic* goals for optimal patient care.(110) Indeed, the literature supports a goal-oriented approach in palliative medicine.(110) A structured and comprehensive review of 16 studies from multiple medical databases by Boa et al upholds the importance of outcome-driven patient-centred care, and proposes hope theory and theories of adaptation as a basis for goal-setting in palliative care.(111)

2.5.2 Hope-fostering interventions for patients in palliative care settings

2.5.2.1 Hope-fostering interventions based on comfort, attachment and worth

McIntyre and Chaplain suggested that hope-nurturing interventions in palliative care should focus on enhancing comfort (improving physical and psychological well-being), attachment (facilitating caring and supportive relationships) and worth (confirming a patient’s value to self and to others by respecting beliefs and promoting autonomy).(109) This supports Duggleby's research that patients describe uncontrolled pain, abandonment, isolation and devaluation of personhood as hope-diminishing.(23) Duggleby proposed hope-fostering strategies similar to those described by McIntyre and Chaplain, including good symptom control, honest communication regarding illness, encouraging supportive relationships, upholding spirituality/faith and affirming patients' worth.(23)

2.5.2.2 Hope-fostering interventions based on Snyder's Hope Theory

Numerous hope interventions have focused on the three core features of Snyder's Hope Theory, namely goal setting ("goals"), problem solving ("pathways") and motivational self-talk ("agency").(21) Typically, a Hope Theory intervention involves eight sessions based on cognitive-behavioural therapy and improves well-being by augmenting personal strengths and promoting positive change and purposeful living.(112) The length of the program would however be impractical for the majority of patients receiving palliative care. A program consisting of multiple sessions would also be highly impractical for patients living in countries such as SA where transportation issues present a significant barrier to multi-session in-person attendance.

Staats from the US first published a hope intervention in 1991, which consisted of five cognitive training sessions focused on goal setting, time management skills and happiness. In a study in older persons, this hope intervention was found to be effective in increasing hope and significantly improved QoL.(14, 24, 113)

Shah et al published a feasibility study evaluating a 4-hour hope-enhancement workshop for patients with stage IV breast cancer in Baltimore, US.(114) Ten patients participated in this pilot study based on Snyder's Hope Theory. Hope scores significantly improved from pre-workshop to post-workshop, however this improvement was not maintained at 3-month follow-up.(114)

McLouth et al, in another US study, similarly evaluated the feasibility of a hope-enhancing intervention for patients with cancer based on Snyder's Hope Theory.(115) Twelve patients undergoing infusional therapy for metastatic lung cancer enrolled in a 5-part hope intervention, via two face-to-face and three telephonic sessions.(115) Patients were assisted to identify values and goals, and to develop pathways towards their desired goal. All study patients deemed the intervention relevant and acceptable, but specific outcomes relating to hope enhancement were not measured.(115)

Another US study by Steffen et al researched the specific components of Snyder's hope model.(116) Fifty patients with advanced lung cancer undergoing oncologic treatment completed daily diary entries for 21 days, scoring their fatigue, pain, depression and functional well-being. Two components of the State Hope Scale, namely hope agency and hope pathway sub-scales, were also measured. Statistical methods were used to relate these variables. Patients reporting higher pathways sub-scores (problem-solving) also reported less fatigue and pain that day and the next day.(116) Patients reporting higher agency scores (motivation) reported greater functional well-being that day and, to a lesser extent, the following day.(116) The authors suggested that hope interventions should focus on the pathways (problem-solving) component when pursuing goals in the face of high symptom burden, while those patients with particular functional concerns (e.g. losing independence, self-perceived burden) should be assisted with agency (motivation).(116)

Chan from China published a study in 2019 on the Brief Hope Intervention (BHI), a modified, shortened version of Snyder's Hope Theory intervention.(112) This consisted of two face-to-face and two telephonic sessions. The BHI was found to be feasible and acceptable in the target population of Chinese patients living with cancer.(112) Although there was significant improvement in all aspects of the Memorial Symptom Assessment Scale, particularly physical and psychological symptoms, hope scores were only marginally increased.(112)

Interventions such as Snyder's model and Chan's BHI, although hope-fostering in some respects, have been criticised as inadequate to sufficiently address hope in patients with advanced illness. These cognitive-behavioural-based interventions neglect other important elements of hope such as attachment, worth and spiritual beliefs.(117) Hope is also not necessarily dependent on self-motivation, but is often related to a relationship with others and with a Higher Power beyond oneself.(117)

2.5.2.3 Hope-fostering interventions based on the four attributes of hope

Herth from the US has been publishing on hope and hope interventions for several decades, including the development and validation of her hope measurement tool, the Herth Hope Index.(14, 48, 68, 74, 75, 118) Herth's Hope Intervention Program (HIP), first published in 2000, involved a series of eight weekly two-hour small-group meetings focusing on various aspects of hope-enhancement.(14, 74) Herth based her HIP on the four attributes of hope identified in the Hope Process Framework, namely experiential, relational, spiritual or transcendent, and rational thought.(14, 74) Herth evaluated the effectiveness of her HIP in improving hope and QoL via a quasi-experimental study involving 115 US patients on treatment for cancer recurrence.(14) Patients represented various ethnic groups and varied in age from 21 to 80 years.(14) Statistical analysis of the scores obtained from validated hope and QoL scales confirmed that the HIP significantly improved hope levels and QoL for these patients with recurrent cancer, immediately after the intervention as well as at three subsequent time points (3, 6 and 9 months).(14)

A recent integrative review by Laranjeira et al summarised effective hope-based interventions for patients with chronic disease published between 2009 and 2019.(80) Studies reviewed originated mainly from Asia and the US and were typically multi-sessional over a period of three to eight weeks. The authors categorised elements of the hope-fostering interventions according to the four hope attributes of the Hope Process Framework and noted how many elements resembled other aspects of good holistic patient care.(80) More specifically-designed hope interventions were also identified, such as sharing positive inspirational stories of hope, searching for meaning in the present situation, and assisting in identifying and obtaining objectives.(80)

2.5.2.4 Hope-fostering interventions based on Duggleby's theory of transforming hope

Duggleby from Canada has also published widely on hope and hope interventions for patients with advanced illness and their caregivers.(15, 16, 23-25, 69, 72, 106, 107, 119) Duggleby's hope interventions are based on her published theory of transforming hope with advancing illness.(16, 25) A patient's hope transformation can be supported by maintaining good symptom control, particularly regarding pain, by supporting the patient's caring relationships and spirituality, and by acknowledging "life the way it is".(25) Positive reappraisal, one of the processes involved in transforming hope, has been associated with reduced stress and depression, and better QoL.(16) This involves re-evaluating hope in light of present illness and circumstances, seeing new possibilities and finding new goals to focus one's hope on.(16) To facilitate hope transformation, Duggleby suggests that patients be encouraged to accept their life situation, have a positive outlook, be light-hearted where appropriate, optimise control over their current circumstances, set short-term attainable goals, perform a life review and remember uplifting memories.(23)

Duggleby et al published an article in 2007 describing the evaluation of a formalised psychosocial supportive intervention for patients with advanced cancer entitled the "Living with Hope Program" (LWHP).(24) The LWHP involved first viewing a video on hope, followed by the initiation of one of three hope activities to work on during the following week.(24) The authors evaluated the LWHP in a randomised controlled trial (RCT) of 60 patients with advanced cancer, using a mixed-methods design.(24) Hope and QoL scores from two validated scales were found to be significantly increased in the cohort of patients participating in the LWHP.(24) The LWHP was found to be simple, cost-effective, and had a high rate of completion, reflecting wide acceptance and ease of implementation.(24)

2.5.2.5 Hope-fostering interventions based on psychotherapy

Dignity therapy (DT), originally developed from empirical studies on dignity in the terminally ill by Chochinov et al from Canada in 2002(120), is a brief, individualised psychotherapy intervention aimed to enhance dignity, hopefulness, meaning and QoL for patients at end-of-life.(121, 122) DT involves assisting patients with life review, life closure tasks and preparing a written legacy document for loved ones.(122) An RCT conducted by Rahimi et al evaluated hope and QoL as outcomes of DT for patients with recurrent cancer in Iran.(123) Seventy-six patients were randomised between receiving DT or no intervention. Hope and QoL were each scored using validated measures prior to the intervention or control, and four weeks thereafter. Compared to the control group, those patients who had received DT showed statistically significant improvements in both hope and QoL scores four weeks following DT.(123)

A psychological intervention developed for patients with advanced cancer entitled “Managing Cancer and Living Meaningfully” (CALM) was first introduced in Canada in 2014.(124) CALM is a semi-structured individualised psychotherapy program for patients and caregivers, scheduled over three to six sessions, and focusing on four domains: symptom management and healthcare team communication; changes in self and relationships with others; spiritual well-being and sense of meaning and purpose; and mortality and future-orientated concerns.(125) Tailored to patient and caregiver needs, CALM therapy supports both practical and existential concerns, and is based on relational, attachment and existential theories.(126) A phase 2 trial by Lo et al, involving 50 Canadian patients with advanced cancer, gave encouraging results, with patients receiving CALM therapy reporting less depressive symptoms, less death anxiety, and greater spiritual well-being over time.(124) There was a high attrition rate, only 58% of patients completed at least three sessions of CALM, but the results for evaluable patients were statistically significant.(124)

Rodin et al performed an RCT of 305 patients with advanced cancer, with life expectancy of 12 to 18 months, to further evaluate patient outcomes of the CALM intervention. Ten validated measures were utilised to assess QoL and psychosocial and spiritual well-being at baseline, and three and six months thereafter.(125) Those patients randomised to CALM therapy reported significantly less severe depressive symptoms at 3 and 6 months, and significantly greater end-of-life preparation.(125)

CALM participants also experienced less death-related distress, anxiety and demoralisation, and greater social support and spiritual well-being at six months.(125) Just over half (54.3%) of patients randomised to the CALM group had completed at least three sessions at three months, with 77.5% completing at least three sessions by six months(125), suggesting that CALM sessions are best scheduled over a number of months for better adherence. The authors do not comment on which aspects of the intervention were most beneficial for patients.

The Lancet Oncology Commission on Integration of Oncology and Palliative Care by Kaasa et al promotes CALM therapy for the psycho-spiritual well-being of patients with advanced cancer, stating that international training programs on CALM therapy are underway.(8) Rodin et al have trained more than a thousand clinicians in CALM therapy from more than 20 countries in North and South America, Europe, Australia and Asia.(127) In addition, via personal correspondence with Dr Rodin, CALM therapy has been introduced to clinicians in Africa via a workshop in August 2022; this data is currently unpublished.

Although not specifically described as a hope intervention, CALM therapy's four domains are remarkably like the four attributes of the Hope Process Framework, namely experiential, relational, spiritual or transcendent, and rational thought. The researcher was unable to identify any trials where hope was specifically evaluated in patients receiving CALM therapy. Considering, however, the similarities between CALM therapy and the hope interventions described above, particularly those developed independently by Herth and Duggleby, CALM therapy would most likely be hope-fostering, but further research may be warranted.

The McGill Cancer Nutrition and Rehabilitation (CNR) program, developed in Canada in 2003, enhances person-centred care for patients with cancer.(128) The aim of the program is to improve the physical, psychological, social and occupational well-being of patients undergoing or recovering from cancer treatment, and to optimise disease-related outcomes. Patients are empowered to harness control over their health, with the goal of improving function, independence and QoL. The CNR program is provided by a multi-disciplinary team consisting of eight healthcare professionals. An individualised treatment plan is provided for each patient and family, who are then regularly reviewed and supported through the eight-week program.(128)

Numerous publications describe the outcomes associated with the McGill CNR Program and similar oncology rehabilitation programs in Canada.(129-135) A study by Gagnon et al reviewed the outcomes of 188 patients with stages 3 and 4 cancer enrolled in the McGill CNR Program, 70% of whom completed the program.(129) Patients reported improved physical and psychological well-being with significant reduction in scores measuring depression, anxiety and overall distress.(129) A study by Chasen et al reported on the outcomes of patients participating in a similar eight-week Palliative Rehabilitation Program (PRP) in Ontario, Canada.(130) Of 116 patients analysed who commenced the PRP, 56% ultimately completed the eight-week program and provided comparative data.(130) Significant improvements were detected in multiple physical and psychological measures, including reduced anxiety and depression and enhanced overall well-being.(130)

The CNR program and PRP support patient empowerment.(128, 131, 133) The PRP team utilises a general self-efficacy (GSE) approach towards self-empowerment, which is a concept derived from Bandura’s Social Cognitive Theory: this is the perception that one can generally positively influence the events in one’s life, which then impacts one’s motivation, behaviour and ultimate affect.(131) GSE has been associated with positive health behaviours and several health benefits such as subjective well-being, and correlates negatively with depression and anxiety in patients with chronic disease such as cancer.(133) Although the studies published on CNR and PRP did not measure hope specifically, the GSE approach, with elements reminiscent of Snyder’s Hope Theory involving goals, pathways and agency, would be expected to foster hope for patients with advanced cancer. Further research on the influence of such programs on maintaining hope in patients with cancer may be warranted.

2.5.2.6 Hope-fostering interventions based on the provision of social and spiritual support

Tao et al from China performed a cross-sectional study evaluating 442 patients with advanced cancer, aiming to determine the relationship between hope, social support, spiritual coping and depression.(136) This was a quantitative study using validated rating scales to measure each of the four variables. Depression was found to be inversely related to hope. Hope correlated positively with social support and positive spiritual coping. This led to the study conclusion that social and spiritual support should be important components of interventions aiming to foster hope and alleviate depression.(136) This was the outcome analysis also of a systematic review by Salimi et al, of twenty empirical quantitative studies on hope and QoL in patients with cancer published between 2010 and 2020.(137) This review of studies from Asia, the US and Europe, chosen after meeting STROBE criteria for quality, concluded that healthcare professionals should include social and existential support in maintaining hope for their patients.(137)

An RCT evaluating the impact of a spiritual intervention on hope and the spiritual well-being of patients with cancer was conducted by Afrasiabifar et al from Iran.(138) Seventy-four patients hospitalised for chemotherapy were randomised to an interventional or a control group. The intervention consisted of five sessions of a spiritual protocol based on the four principal spiritual needs of patients with chronic illness proposed by Bussing et al(139), namely connection, peace and hope, meaning and purpose, and transcendence.(138) Each session lasted 30 to 50 minutes. The control group received standard care but no spiritual intervention. A Paired Samples t-test, comparing spiritual well-being and hope scores before and one week after the intervention or control, revealed statistically significant improvement in both spiritual well-being and hope scores in the group receiving the intervention.(138)

2.5.2.7 Other hope-fostering interventions under study

Other hope-fostering interventions have been studied in patients with cancer. An RCT by Chen et al, involving 84 patients undergoing chemotherapy in China, found statistically significantly improved hope scores following a mind map-based life review program.(140) This intervention involved four interactive sessions utilising mind maps, creative albums, video recordings and discussions up to an hour each over two weeks.(140)

A systematic review and meta-analysis of hope and hopelessness in palliative care was published in 2021 by Salamanca-Balen et al, summarising the effectiveness of hope-fostering interventions to date.(81) This meta-analysis reviewed 35 studies, 24 of which were RCTs, of interventions intending to increase hope or decrease hopelessness for adult patients receiving palliative care. The importance of hope as a relevant outcome in palliative care was confirmed. The analysis described several hope-fostering interventions, such as psychotherapy, DT and exercise, which significantly increased hope and spiritual well-being. Although depression was significantly reduced, interventions studied did not however significantly reduce hopelessness. The authors propose that further research is needed to clarify the relationship between hope and hopelessness, and to develop high-quality interventions with components specific to the patient context.(81)

2.5.3 Hope-fostering interventions for family caregivers

Hope-fostering interventions have been found beneficial for family caregivers of patients with advanced illness. A phenomenological study evaluating the lived experience of six US family caregivers via in-depth interviews by Revier, Herth et al described how caregivers find hope and strength to cope through practical and informational support, caring relationships, spiritual connections, reassurance and reflecting on memories.(68) Four main themes characterising the lived experience of these caregivers were: strengthening and maintaining connections, easing of self, finding meaning in the situation, and acceptance.(68)

Kennedy et al, in reviewing the role played by hope in palliative care, support the important role played by health professionals in maintaining hope for family caregivers, and that this in turn improves the sense of hope for the person being cared for.(17) The authors suggest that healthcare workers be aware of caregivers’ potential distress and social isolation, and that hope-enhancing interventions include strategies to facilitate coping and to address their feelings of anticipatory grief.(17) Elements of hope-fostering interventions for caregivers identified by Kennedy et al's research include supporting caring relationships, cognitive reframing, time management strategies, setting attainable goals, supporting spiritual beliefs and optimising energy levels.(17)

2.5.4 Hope-fostering interventions for patients and family caregivers in sub-Saharan Africa with palliative care needs

2.5.4.1 African primary healthcare workers as enablers of hope

Akinsola from Botswana states that doctors and nurses are often regarded as sources of hope for African community members, whether well or unwell, and for people of all ages and stages of disease.(93) Akinsola's research revolves around the important role played by primary healthcare (PHC) workers as enablers of hope. Akinsola defines PHC workers as "professional and non-professional healthcare providers, including doctors, nurses, family welfare educators and voluntary community-based health workers working in the primary healthcare facilities, as well as the communities, in both urban and rural settings" (93). About two-thirds of African people live in rural communities, where health needs are met primarily by PHC workers, who are then ideally positioned to facilitate hope.(93) He suggests that interventions to enable hope should be individualised for each patient and family unit, but should involve identifying and mobilising potential internal and external resources of hope, and a process of focusing the person's hope by setting realistic goals. PHC workers should allow patients and caregivers to voice their fears and expectations, and to encourage patients and their family members that there is indeed hope to be found beyond the present difficult circumstances. Threats to hope, for example uncontrolled symptoms and social isolation, should be recognised and addressed. Need for support (e.g. physical, psychological, social, spiritual, economic) should be identified and met where possible. Religious leaders should be actively encouraged to provide spiritual and psychological support where this is relevant to the person and family.(93) Akinsola suggests that false hope may act as a buffer in the short term, allowing time for patients and families to strengthen their reserves and to facilitate coping with difficult diagnoses. However PHC workers should help patients and family caregivers to distinguish between realistic and false hopes, and to rather encourage realistic hopefulness.(93)

2.5.4.2 Hope-fostering interventions for patients in sub-Saharan Africa with palliative care needs

There are limited data regarding the outcome of palliative care interventions in patients with cancer in sub-Saharan Africa(141-143), and no data regarding any intervention focused specifically on hope. Most publications on sub-Saharan African palliative care have focused on HIV/AIDS palliative care development, or opioid availability, or are related to palliative care policy advancement, education and training.(142-144) Local evidence-based research in palliative care in Africa is as yet sadly lacking.(144) The increasing role of international collaboration in supporting research in palliative care in Africa is however acknowledged.(144) As an example of such research collaboration, Mah et al compared the quality of dying and death of patients in Kenya and Canada.(145) The caregivers of 127 deceased patients who had received palliative care from three Kenyan hospices and the caregivers of 602 Canadian patients who had died from advanced cancer completed The Quality of Dying and Death Questionnaire (QODD), a comprehensive 31-item internationally-validated measure of the end-of-life experience.(145) Although Kenyan caregivers gave worse ratings for 14 items and overall quality of dying and death, they gave higher scores than Canadian caregivers gave for five items including family time, spiritual/religious support and dignity/self-respect.(145) The completion rate of almost half of the QODD items by the Kenyan caregivers was however very poor, questioning the validity of QODD for African participants and the accuracy of the comparative findings of the two study populations. Nevertheless, the study does support the importance of upholding family, spirituality and dignity for African patients at end-of-life.

Likewise, studies of South African patients receiving palliative care provide evidence to support the importance of integrating spirituality into their care. Selman et al described QoL for patients with incurable, progressive disease receiving palliative care in SA and Uganda.(146) A cross-sectional survey of 285 patients primarily with HIV and/or cancer was undertaken using the Missoula Vitas

QoL Index tool, a 26-item questionnaire which assesses holistic well-being.(146) Remarkably, spirituality concerns, such as having a sense of meaning and purpose in life, and being at peace, were considered more important for patients than being active or experiencing physical comfort.(146) Compared with other domains, spiritual well-being correlated most highly with overall QoL, and the study supported the importance of identifying and meeting the spiritual care needs of African patients.(146)

Similarly, a prospective cohort study of 233 patients with advanced cancer in Soweto, SA by Ratshikana-Moloko et al, highlighted the importance of upholding spirituality in patient care, particularly at the end-of-life.(147) Almost all patients studied had unmet spiritual needs, and the authors concluded that QoL would be enhanced by performing spiritual assessments and incorporating spiritual care in patient management.(147) As hope experience is strongly associated with upholding spiritual beliefs, the integration of spiritual care would be expected to improve the hope experience of patients in the palliative care setting in SA, but further research is needed.

2.5.4.3 Hope-fostering interventions for family caregivers in sub-Saharan Africa

Streid et al(148) and Potgieter et al(91) reported on the stressors and resources of caregivers of patients with life-threatening illness in rural and urban areas of SA. Streid et al interviewed ten caregivers from Uganda and 28 caregivers from rural and urban areas in SA to investigate caregiver burden.(148) Stressors identified by caregivers included physical exhaustion, witnessing suffering, financial difficulties, social isolation and balancing responsibilities.(148) Identified external resources included family and community support; internal resources involved spiritual beliefs and caregiver self-confidence.(91, 148) The quality of the patient-caregiver relationship and religious faith played a significant role in coping and gave hope.(91, 148) Interventions focusing on improving practical and community support, and supporting spiritual beliefs and caregiver confidence would be expected to enhance hope for family caregivers, but more research is needed in the South African setting.

2.6 Conclusions drawn regarding hope as relevant to the South African palliative care setting

The literature review supports hope as an important determinant and outcome of well-being in the South African palliative care setting, for both patients and their family caregivers. There is evidence to suggest that hope plays an important role in patient and caregiver decisions regarding palliative chemotherapy, where hope is expressed for life prolongation and the potential for new treatment developments. With treatment withdrawal following disease progression, studies in South African oncology settings, although small, describe increasing acceptance of poor prognoses, and better coping, by patients with time. Hope, particularly expressed through spirituality, such as religious faith, assists patients and their caregivers in coping with adversity and acceptance of approaching death.

The meaning of hope for South African patients in the palliative care setting is typically described in terms of upholding their religious faith, having time to put their affairs in order, hope for a good death, and not suffering at the end-of-life. Some patients and caregivers however continue to hope for miraculous cure. The review suggests however that further research be undertaken around the meaning of hope for patients and caregivers, such that hope-fostering interventions can be aligned with expressed needs.

Research from countries elsewhere in Africa suggests that prognostic truth-telling is part of good patient care in Africa and supports the maturation of realistic hope for patients. Although concern is raised by doctors and family members that informing patients of their poor prognosis would result in hopelessness and despair, most patients respond positively and with time are able to process the information, regain hope, achieve a level of acceptance and attain life closure. Research about prognostic disclosure however is limited in the South African setting.

Although evidence to inform the hope experience of patients and their caregivers in SA is limited, spirituality appears to play a significant role. The African literature suggests that spiritual needs and well-being, including hope, should be evaluated within the cultural context of the patient and caregiver. In areas of SA such as KZN, where much of the population lives in rural areas and seeks treatment including spiritual support from traditional healers, further research is needed to better understand the hope experience and the potential role played by traditional healers.

Except for small studies supporting the role of spiritual care and social support for patients with advanced illness and their caregivers, there is limited evidence from South African settings to validate any hope-fostering interventions in the palliative care setting. Further research is needed to develop hope-fostering interventions relevant to the South African palliative setting.

2.7 Rationale for the study

The literature review established the importance of hope for patients and their family caregivers in various stages of health and illness, including the end-of-life phase. Hope ameliorates suffering, improves QoL and facilitates coping and resilience in the face of life-threatening illness. Patients and their family members look to healthcare professionals to give them hope, and the literature supports the role of healthcare workers as instruments of hope. However, the meaning and experience of hope can vary significantly between individuals. These constructs of hope are often dependent on the clinical context and other factors such as socio-economic and cultural factors.

Patients in South African palliative care settings describe their need for psychosocial support and hope. There is however currently not a clear understanding of what hope means in the South African healthcare setting, particularly around issues such as “hope for a cure” and “false hope”. Also, while several hope-fostering interventions have been validated internationally, the benefits of such interventions are currently unknown in SA.

The study intended to clarify the importance of hope for adult patients living with a life-threatening illness, namely advanced cancer, and their family caregivers in KZN. It sought also to demonstrate the meaning and experience of hope in this population of patients and family caregivers. It was rationalised that exploring these aspects of hope would be valuable in determining the suitability of established internationally based hope-fostering interventions in South African palliative oncology settings. Exploring hope constructs in SA would also assist in identifying potential components of hope-fostering interventions suitable for future research in our local palliative care settings.

2.8 Study aim

The study aimed to describe the importance, meaning and experience of hope in the context of adult patients with advanced cancer and their family caregivers in KZN.

2.9 Study objectives

The study objectives were:

a. To explore the importance, meaning and experience of hope for adult patients with advanced cancer in KZN

b. To explore the importance, meaning and experience of hope for family caregivers of adult patients with advanced cancer in KZN

c. To further evaluate the data within the clinical, socio-economic and cultural contexts of the patients and family caregivers

2.10 Conclusion

This chapter summarises the available literature relating to the importance, meaning and experience of hope in South African palliative care settings. An attempt has been made to relate this research to publications on hope in other African and international settings. Internationally published hope-fostering interventions have been described regarding potential relevance in SA. Gaps in the literature have been identified where further research would be valuable for patients in the South African palliative care setting. In particular, no publications from SA have been identified where hope-fostering interventions have been explored or evaluated. The rationale for the study has been given, and the study aim and objectives stated. The following chapter gives the methodology used for the study.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter describes the research methodology relevant to the study.

3.2 Study design

A qualitative descriptive design was chosen for this study to research the subjective in-depth experience of people living with advanced cancer in KZN, SA. Qualitative descriptive research aims to provide a comprehensive summary of lived experience "in the everyday terms of those events".(149) Phenomenological and grounded theory research studying hope has been undertaken elsewhere as described in chapter one, and the current study aimed to provide descriptions of the South African experience. This descriptive cross-sectional study involved the recording and analysis of semi-structured interviews with patients with advanced cancer and their family caregivers. Each patient and associated family caregiver were managed as a dyad. Questions around the meaning, importance and experience of hope were explored. The study intended to collect and analyse hope experience and perspectives from patients and family caregivers from different clinical, socio-economic and cultural backgrounds, allowing deeper contextualisation of data.

3.3 Study sites

An objective of the study was to describe the constructs of hope within the cultural and socio-economic contexts of patients and their family caregivers in KZN. The study sites, a state referral hospital and a hospice site, were selected as representative of KZN's general population.

3.3.1 KZN's population demographics

KZN, with a population of 11.7 million people, is the second most densely populated province in SA.(150) Although representing only 7.7% of SA's land area, KZN is home to 19.3% of SA's total population.(150) According to national census data, 87% of KZN's population is Black African, 8% are Indian/Asian, 4% are White and 1% is Coloured.(151) This reflects a higher relative proportion of both Black African and Indian/Asian populations in KZN compared to national South African figures (81% for Black African and 2.6% for Indian/Asian populations respectively).(152) Fifty-two percent of KZN's population is female, 48% are male, in keeping with national percentages.(151) IsiZulu is the most common home language in KZN, spoken primarily by 81% of KZN's population.(151) Twelve percent of KZN's population speaks mostly English, 3% speak mostly isiXhosa while 1% speak mostly Afrikaans.(151) Of KZN's population, 99.2% were born in SA, with 96% having been born in KZN.(151)

According to the latest data on religious affiliation available from Stats SA, 86.0% of South Africans identify as Christian, 5.4% as African Ancestral, 1.9% as Muslim, 0.9% as Hindu, 0.2% as Jewish and 0.4% as belonging to an "other religion".(153) Only 5.2% of South Africans do not see themselves as religious.(153) In KZN, where Black African and Indian/Asian percentage populations are distinctly higher than the national average(152), 12.3% identify as African Ancestral, 2.0% as Muslim and 3.3% as Hindu.(153) Less than the national average (78.5%) identify as Christian or as Jewish (0.1%). A low percentage (3.3%) of KZN's population see themselves as areligious, while 0.5% belong to an "other religion".(153)

Although over two-thirds (72.4%) of KZN's population over the age of 20 years have achieved at least a grade nine level of education, less than half (45.9%) have completed matric or a higher education level.(151) The employment rate in KZN is low (31.5%), with 24% of employees working in the informal sector.(151) The average South African household size is 3.49.(154) According to 2016 data, the average annual household income in KZN is R 29 400; however 16% of KZN households report zero income, while 21% have a household income of less than R 4 800 a year.(151) Statistics from South African census data from 2011 reveal that Gauteng and KZN have the highest provincial distribution of households in the no-income (R 0) and low-income (less than R 19 200 annual household income) categories.(154)

Non-monetary indicators of socio-economic status include education (years of schooling), economic activity/employment, health and living standards (relating to lighting, heating, cooking, water, sanitation, dwelling and assets).(154) Formal dwellings in SA are associated with a higher household income level, while traditional and informal dwellings are associated with a lower income level.(154) Of KZN's total population, 69.1% live in a formal dwelling, 18.1% live in a traditional dwelling (hut or structure made from traditional materials) while 8.5% live in an informal dwelling or shack.(151) Poverty in South African households has been associated with lack of service delivery such as piped water, electricity, flushed toilets and refuse collection.(154) In KZN, 60.5% of the population have no access to flushed toilets, 56.7% have no household refuse removal, 24.6% have no access to piped water and 10.6% have no access to electricity.(151) These statistics point to a high incidence of poverty in KZN. Indeed 37.4% of households in KZN live below the food poverty line and almost a quarter of the most deprived households in SA are found in KZN.(154)

3.3.2 Study sites chosen

3.3.2.1 State hospital site: Inkosi Albert Luthuli Central Hospital (IALCH), oncology unit

IALCH is an 846-bedded centralised state hospital in Durban, receiving patient referrals from in and around Durban (eThekwini district) and from all the surrounding KZN municipal districts, including the rural areas of KZN. Most patients seen at IALCH speak isiZulu as their primary language. Many patients are unemployed and come from low-income households, however all income level groups are represented. The oncology unit at IALCH is the largest and busiest of three public health facilities providing oncology services in KZN(155) and over 2000 new patient referrals are seen per year(156).

3.3.2.2 Hospice site: Chatsworth Hospice (CH)

CH is situated in Chatsworth, a large suburb in the south of Durban. CH is a registered NGO affiliated with the Hospice Palliative Care Association of SA (HPCA). Since 1991, CH has provided palliative support to patients with advanced illness from Chatsworth and the surrounding

Durban suburbs.(157) Services include home-based care and an eight-bedded in-patient unit for patients requiring respite care, symptom management and/or end-of-life care. Patients referred to CH come from varying cultural, educational and socio-economic backgrounds.

3.4 Study population

The study population included adult patients with incurable cancer (locally advanced and/or metastatic cancer not amenable to or not responsive to curative treatment) registered at either of the two study sites in Durban, KZN. Each patient nominated a family caregiver to also participate in the study.

3.5 Selection criteria

Patient inclusion criteria included adult patients, aged 18 years or older, with locally advanced and/or metastatic cancer not amenable to or not responsive to curative treatment, a Palliative Performance Scale (PPS) of 30% or above (see Appendix A), the ability to understand English and/or isiZulu, able to understand and meet the requirements of the study, and signing informed consent. Exclusion criteria for patients included drowsiness or confusion limiting their ability to be interviewed (see PPS definitions of drowsiness and confusion, Appendix A).

Family caregivers were defined as a relative, partner or close friend of the patient, either living with the patient, or having in-person contact with the patient at least twice a week. Inclusion criteria for family caregivers included age 18 years or older, the ability to understand English and/or isiZulu, able to understand and meet the requirements of the study, and signing informed consent. There were no exclusion criteria for family caregivers meeting the inclusion criteria.

3.6 Sampling method

The study followed the purposive (non-random) method of data sampling, which is the preferred sampling method in qualitative descriptive research.(149) Maximum variation sampling is particularly useful in obtaining information-rich data regarding lived experience in a target population.(149) At each of the two identified study sites, patients with locally advanced and/or metastatic cancer not amenable to or not responsive to curative treatment were screened for eligibility for the study. The researcher intended to explore experience and perceptions of hope from patients and family caregivers from different socio-economic, educational and cultural backgrounds. Heterogeneous purposive sampling was therefore chosen as the sampling method to obtain a study sample representing the socio-demographics of KZN’s general population.

The following demographic and clinical variables were considered in the heterogeneous sampling of the patients: age, gender, first language, marital status, education level, employment status, annual household income, location of home and household access, household size, social support, religion as applicable, primary cancer site, time since diagnosis of advanced disease, treatment plan, time under palliative care, involuntary weight loss, need for assistance with self-care and PPS (for details and cut-offs of the variables, see Appendix A Data collection tools: Questionnaires for the study, and also 3.8.2). Eligibility for the study was based primarily on patient characteristics. Each patient nominated a family caregiver to also participate in the study. Demographic data were captured for the family caregivers, similar to the demographic variables captured for patients (see Appendix A), with the intention of obtaining a heterogenous sample also of family caregivers. Relationship of the family caregiver to the patient was also considered as part of the purposive sampling process.

3.7 Sample size

Each patient and their nominated family caregiver were regarded as a dyad. Enrolment of dyads continued until a representative sample was obtained and until data adequacy was reached with no significantly new data forthcoming. Qualitative research is shaped by the simultaneous collection and content analysis of data, and sampling is modified as new data and insights are accumulated.(149) This interactive process resulted in a sample size of eleven patient/caregiver dyads. Twenty-two separate interviews were therefore conducted. Of the eleven patients, six were registered at IALCH, three at CH, while two patients were registered at both study sites.

3.8 Data collection tools

Please refer to Appendix A for the data collection tools used for the study.

3.8.1 The Palliative Performance Scale

The Palliative Performance Scale (PPS) was used to select suitable patients for the study. The PPS scores of patients obtained in the study were also correlated with their hope experience. Reliability and validity studies of the PPS, published by Ho et al in 2008(158), confirm that the PPS is a reliable and valuable clinical assessment tool used to measure the performance status of patients in clinical and research settings.(158) The PPS is also widely used as a prognostic tool for patients in palliative care settings.(158)

3.8.2 Data-capturing questionnaires

The researcher designed two questionnaires to capture data from patients and family caregivers respectively. Data were collected by the researcher at the time of each separate interview. The data collected included clinical, socio-economic and cultural information. The income categories chosen were from the latest South African census data(154). Annual household incomes were classified in the latest census as follows:

Annual household income(154)
No income: R 0
Low-income: R 1 – R 19 200
Middle-income: R 19 201 – R 307 200
Upper-income: R 307 201 and above

Non-monetary indicators of socio-economic status include education (years of schooling), economic activity/employment, health and living standards (relating to lighting, heating, cooking, water, sanitation, dwelling and assets).(154) Data were therefore captured relating to these factors.

Data regarding religion and its importance to each study participant were also collected to allow an analysis of the hope experience within different clinical, socio-economic and cultural, including spiritual, contexts.

3.8.3 Semi-structured interview questionnaires

The interviews for patients and caregivers followed a semi-structured format. The researcher collated questions as a framework for the interviews. Further questions and discussion arose from this framework of questions. The framework aimed to be a guide only such that the broad aspects relating to the interpretation of importance, meaning and experience of hope would be discussed in the interviews. Open-ended questions were preferentially chosen to encourage participants' narratives in their own words and to portray their lived experiences more accurately.

The semi-structured interview questions were also translated into isiZulu, to assist the interviewer for interviews conducted in isiZulu, and for optimal understanding of the questions posed to isiZulu-speaking patients and their caregivers (see Appendix B for process of translation).

3.9 Data collection procedure and research team

3.9.1 Data collection procedure

The researcher identified research assistants at each study site to assist in screening patients. The research assistants were trained by the researcher on the study protocol and research ethics. Particular emphasis was placed on study participant selection criteria, the information and consent forms, the COVID-19 SOP, confidentiality issues and sensitivity and non-coercion relating to vulnerable populations.

Once the appropriate study permissions were in place, the researcher requested the healthcare teams at the study sites to start identifying potentially suitable patients. The staff were given a brief synopsis of the study and were alerted specifically to the inclusion and exclusion criteria for patients and family caregivers and to the patient and family caregiver information and consent forms (see Appendix C and D for Information sheets and Consent forms for patients and family caregivers respectively). Potential study patients were discussed with a research assistant, who confirmed potential eligibility with the researcher. When found to be potentially eligible, the research assistant contacted the patient to further discuss the study and to answer any preliminary questions. The patient was asked to identify a suitable family caregiver. When seen in-person by the research assistant and interest was expressed, the patient and family caregiver were given the Information sheet and informed consent documents to consider further. When conducted telephonically these documents were discussed verbally and sent to the patients via electronic means where feasible.

Where continued interest in the study was expressed, the research assistant made an appointment for the researcher to see the patient and family caregiver together in person. COVID-19 regulations and precautions were followed according to the study's COVID-19 SOP (see Appendix E). The informed consent visits took place at CH, IALCH oncology unit or in the patient's home, depending on the preferences of each particular patient. Where necessary, the research assistant was present to assist in the informed consent-taking process as a language translator.

During the informed consent visit, study eligibility was confirmed. The researcher went through the aims, requirements, risks and benefits of the study, and answered any questions around the study raised by the patient and family caregiver. The researcher explained how all study data would remain confidential and the identity of each study participant would be protected. The researcher ensured that consent at all times was freely and voluntarily given. The patient and family caregiver were reassured that they might withdraw their consent and participation at any time, with no negative repercussions regarding their ongoing care or cancer management. Consent, as given separately by each patient and family caregiver, was individually signed, dated and witnessed. A copy of the Information sheet and signed consent was given to each study participant, and the original signed document was placed in the patient's medical record. The researcher then enrolled the patient and caregiver onto the study and assigned each with a unique identifying code.

A suitable time for the study interviews was arranged, separately for patients and caregivers, either on the same day, or within a few days thereafter. COVID-19 regulations and precautions were followed according to the study's COVID-19 SOP (See Appendix E). Interviews took place face-to-face where possible. Telephonic interviews were an alternate option, particularly when more convenient for the study participant or when the risk of SARS-CoV-2 transmission was deemed to be great.

During each interview, the researcher collected data according to the appropriate data-capturing questionnaire (see Appendix A), followed by the semi-structured interview. For those study participants preferring to be interviewed in isiZulu, the research assistant served as language translator, and the isiZulu translation of the interview questions was used.

Each interview was audio-recorded by the researcher on two separate devices. The second recording, a backup version in case of primary device failure, also enhanced the accuracy of transcription where a participant's voice was less distinct. Following each interview, the researcher made field notes summarising the main points of the interview and any additional points relevant to analysis and interpretation of the data. The researcher carefully transcribed verbatim the data from each interview conducted in English. An isiZulu-speaking research assistant transcribed verbatim the sections of interviews conducted in isiZulu, which were then translated by another isiZulu-speaking research assistant into English. All data were therefore ultimately written in English.

3.9.2 Research team and reflexivity

The researcher identified and trained two research assistants at IALCH. NM is a registered social worker, speaks isiZulu as a primary language, and has assisted in counselling patients with advanced cancer and their family members in the oncology unit and palliative clinic at IALCH since January 2022. BA is a qualified doctor, speaks isiZulu as a secondary language, and has worked as a medical officer in the oncology clinics at IALCH for nine years, and in the palliative clinic since January 2022.

At CH, the researcher identified and trained VN as a research assistant. VN is a registered nurse, with prior nursing experience in cardiology and ICU. She holds an HPCA-accredited nursing palliative care qualification, and for the past eight years has worked in home-based palliative care and the in-patient unit at CH.

A further isiZulu-speaking research assistant, TR, assisted in translating the transcribed isiZulu sections from the interviews into English. TR is a registered social worker, proficient in speaking both isiZulu and English, and has assisted previously in research.

Selection criteria for the research assistants included having an appropriate healthcare qualification, clinical experience in palliative care, and being suitably positioned at the study sites to assist in screening potential patients for the research and to act as language translators where necessary. The research assistants were all female, which was incidental and in the researcher's opinion did not negatively impact the research process. Research assistants were requested to identify patients via maximum variation purposive sampling, but to avoid selection bias, for example by not intentionally choosing only highly opinionated or overly hopeful patients. While the research assistants had professional relationships with several study participants, some long-standing, there was no coercion for any patient or caregiver to participate in the study. The research assistants also did not influence the study findings, as data were collected and analysed by the researcher.

The researcher, a clinical and radiation oncologist with a post-graduate diploma in palliative medicine, is suitably qualified to consult with patients with advanced cancer and their families, and to conduct clinical research. Her 22 years' experience as an oncologist, and more specifically six years as a palliative oncologist, and her involvement in numerous clinical oncology trials as a principal or sub-investigator, contribute to her vocational and technical competence in conducting clinical oncology research. Having a compassionate, empathic, ethical approach to consulting patients, and her many years of experience in palliative care interactions, particularly involving communication skills, enhance her humanistic competence.

The screening was performed by the research assistants, such that any perceived coercion by the researcher for patients to be enrolled in the study would be eliminated. It was also made clear to all patients and caregivers that their decision to enrol, or not to enrol, in the study would not influence their ongoing care or cancer management.

The researcher had no ongoing relationship with any of the study participants. Although the researcher sees patients referred for palliative care at IALCH for a single consultation, one of the purposes of the palliative clinic is to refer patients to hospices or other community-based palliative care facilities for their ongoing care and management. Being enrolled in the study would not influence such referral or ongoing patient care. There was therefore no risk of therapeutic misconception for patients at IALCH to enrol in the study.

Circumventing personal bias when performing qualitative research is a challenge, as the research process inevitably requires the researcher to engage closely with study participants and with the data.(159) The researcher aimed to avoid such bias from affecting the research and to provide research findings that were dependable and credible.

The researcher's worldview and location of her research can be defined within the constructivist philosophical paradigm. This seeks to understand and interpret individual subjective (rather than universal) human experience, believing that there are multiple realities which co-exist, and which are socially constructed and context-dependent.(160) Research in the constructivist paradigm occurs via qualitative such as descriptive studies, and data are processed and analysed to construct new theories.(160) During the interviews, the researcher approached the topic of hope with sensitivity and curiosity, asking questions in a neutral tone, and not pressurising any participant to give a particular, or indeed any, response, thereby avoiding interviewer and response bias. The researcher attempted to conduct each interview without any pre-conceived ideas and strove not to be prejudiced or judgemental, seeking rather to understand participants' subjective experiences, and to be open to learning new perspectives and new theories. The researcher was aware of potential cognitive bias and endeavoured to minimise this where possible.

The researcher listened empathically and told the truth compassionately when called upon to do so. Although the researcher's cultural, religious and socio-economic background differed from many of the study participants, she was careful to not in any way impose her own cultural or religious beliefs on any study participant, and respected the dignity, and cultural and religious views of all study participants. Aware of potential confirmation bias in interpreting the data, the researcher looked for evidence of themes both expected and unexpected, and aimed to restrict outcome reporting bias by presenting the results comprehensively, accurately and transparently.

3.10 Data storage and confidentiality

The researcher used a confidential subject identification coding system to protect the privacy and identity of the study participants. All study data and recordings were kept securely in a password-protected folder on an access-restricted computer, with a backup on a personal hard drive kept in a locked drawer. All written collected data from study participants were kept securely in an access-controlled locked drawer in the researcher's practice. A COVID-19 register of information, as described in the COVID-19 SOP, was also kept in this locked drawer location.

3.11 Data analysis

The data, as described in 3.9.1, were transcribed and, where necessary, translated from isiZulu into English. Data therefore consisted of 22 data-capturing questionnaires and 22 interviews transcribed verbatim. Data were further analysed in four overlapping processes as detailed below.

3.11.1 Incremental analysis of data-capturing questionnaires

Data from the data-capturing questionnaires were categorised and analysed incrementally by the researcher. The aim of the research was to explore hope in a variety of patient and family caregiver contexts in KZN. Ongoing analysis of study participant data as captured via the data-capturing questionnaires facilitated purposive sampling and interviews of patients and caregivers from differing clinical and demographic backgrounds.

3.11.2 Analysis of interview data within patient and family caregiver groups

The interview data were separated into a patient group (n=11) and a family caregiver group (n=11) for further analysis. The process of data analysis in each of the two groups was similar. The researcher found the Qualitative Analysis Guide of Leuven (QUAGOL) proposed by de Casterlé et al(161) useful to facilitate transforming the volumes of raw data generated by the interviews into a more structured format allowing thematic data analysis. This guide describes stages to follow, firstly in preparation of coding, followed by stages for the actual coding process.(161) Coding in qualitative research is the process of assembling, labelling and organising data into different themes to facilitate the construction of meaningful research.(162)

In the pre-coding stage, through the processes of transcribing, thorough reading and rereading of each interview, the researcher gained holistic understanding of each participant's preferences and experience and identified key phrases and reflections.(161) Field notes were reread and additional notes taken. Key concepts from the interviews were highlighted, using different colours to distinguish words and sentences relating to the importance, meaning and experience of hope. Concepts were linked and subthemes identified. The process of inductive reasoning was followed to generate ideas from the data (hypothesis generating).(163) Interviews were then reread and reanalysed in light of the emerging subthemes ("forward-backward movement") as part of a constant data comparison process.(161)

To assist the coding process, the researcher used a computer software program called NVivo which facilitated the creation and classification of codes for each subtheme (called "nodes"). The researcher methodically linked the data from the first six interviews to the appropriate nodes. However, the researcher found it difficult to engage fully with the data on a computer interface and ultimately found the old-fashioned coloured pen-and-paper coding technique more practical. The researcher also found it helpful to draw up a conceptual framework of research questions based on the major themes, namely importance, meaning and experience of hope. Using deductive reasoning (hypothesis testing)(163), the researcher then reread the interviews and allocated appropriate fragments of participants' data to the developing thematic tables. The final steps included re-evaluation of the conceptual frameworks with redefining of subthemes where appropriate to create increasingly organised thematic results. The coding was primarily performed by the researcher, supported by regular meetings and discussions with the two supervisors of the study, who were provided with the comprehensive tabulated data and developing thematic tables.

3.11.3 Analysis of interview data within patient/caregiver dyads

A data correlation analysis was performed within the patient/caregiver dyads to identify similarities and discrepancies between the data sets.

3.11.4 Analysis of interview data in context of data captured on the data-capturing questionnaires

The data were further evaluated in the context of the clinical, socio-economic and cultural determinants captured on the data-capturing questionnaires.

3.12 Ethical considerations

3.12.1 Ethics approvals and permissions from study sites

No study-related procedure or recruitment of study participants was conducted prior to ethics approval and study site permissions being in place (see Appendix F for ethics approval and study site permissions).

3.12.2 Vulnerable populations

Vulnerable participants are those potential subjects who might feel unduly influenced to participate in research either for perceived benefit (whether justified or not), or due to the fear of retaliation or malmanagement should they refuse to participate.(164) The researcher was clear when taking consent that participation in the study was voluntary and non-participation would not influence a patient's ongoing treatment and care in any way.

Vulnerable participants also include those persons unable to give their own informed consent.(164) This was an exclusion criterion for the study. No patients or caregivers were enrolled in the study without first giving their voluntary written consent. The researcher did not include minors in the study; all participants were older than 18 years of age. No participant was entered onto the study if drowsy or confused and all participants had a reasonable performance status (PPS ≥ 30%). The researcher was ethically bound to stop or delay the interview process and, if need be, to withdraw the patient from the study if, during the interview, their physical and/or mental capacity became significantly compromised. No study participant was withdrawn from the study for any such reason.

Patients with advanced cancer and their family caregivers, who might have physical, psychological or spiritual distress regarding their illness and situation, would be expected to have considerable vulnerability. The study aimed to explore their experience and perception of hope, which for most study participants would be expected to create feelings of hopefulness, but for certain patients having such discussions might create anxiety and distress. The holistic well-being of all study participants was specifically addressed and protected throughout the study. Research was undertaken according to the South African GCP (SA-GCP) guidelines(164), which are primarily based on the ethical principles of autonomy, beneficence, non-maleficence and justice, as well as respect for the dignity of persons. It is critical that the SA-GCP guidelines are followed when conducting clinical trials involving human subjects in SA, and particularly in vulnerable populations.

3.12.3 Minimising risks and maximising benefits

Research should be conducted only when the well-being and holistic integrity of each trial participant can be protected.(164) The study intended to benefit patients and their family caregivers by exploring aspects of hope and by fostering experiences of hope. The researcher believed that the anticipated benefit to study participants justified the potential risks. Possible benefits to the patients and family caregivers involved in the research might have included the opportunity to express their feelings, experiences and their hopes, the affirmation of having their voice heard, and improved relations with others. Potential benefits of the study might also extend to improving the hope experience for future patients with advanced cancer and their caregivers in similar contexts.

Discussions around hope and hopelessness may however be difficult for patients and in some instances might cause psychological and/or spiritual distress. The researcher, with considerable clinical experience in caring for patients with advanced cancer and their family members, was aware of the possible precipitation of emotions such as sadness, anxiety or anger. The researcher intended to bring comfort and to avoid any distress resulting from the study. Patients and caregivers were informed that they need not answer any questions which might make them feel uncomfortable and could withdraw from the study at any time. In the event of patient or family distress however, the researcher was experienced in distress management and had a distress protocol in place (see Appendix G).

Measures were in place to protect the identity and privacy of study participants and to ensure strict confidentiality of all data supplied. A COVID-19 SOP was in place to best protect all study participants from the transmission of SARS-CoV-2 (see Appendix E).

3.12.4 Distress protocol

A distress protocol was in place for the study (see Appendix G), whereby any participant who appeared distressed at any time during the discussion would be offered the opportunity to stop the interview and either abandon the interview, or restart the interview when they felt more at ease and comfortable to do so. Each study site had an experienced social worker who was available to provide appropriate additional support and counselling for patients and family caregivers where needed. No study participant exhibited significant distress at any time during the study. The researcher provided a compassionate presence and listened empathically, allowing for pauses or longer silences where necessary. No interviews were prematurely discontinued, and no study participant was withdrawn because of distress. No further counselling was required for any study participant.

3.13 Conclusion

This study followed a qualitative descriptive cross-sectional research design with purposive sampling of study participants. Information has been given in this chapter regarding the methodology used in patient and caregiver selection, the research team, and data sampling, storage and analysis. Considering the vulnerability of patients with advanced cancer and their family caregivers, the study was conducted in alignment with ethical considerations, a distress protocol and a COVID-19 SOP. The following chapter outlines the results of the study.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents the study findings. Information relevant to participant screening and interviews will be described. The demographic and clinical characteristics of the patients and demographics of the family caregivers will be presented. Results will then be given relating to the importance, meaning and experience of hope as voiced by the patients and family caregivers (see Figure 9).

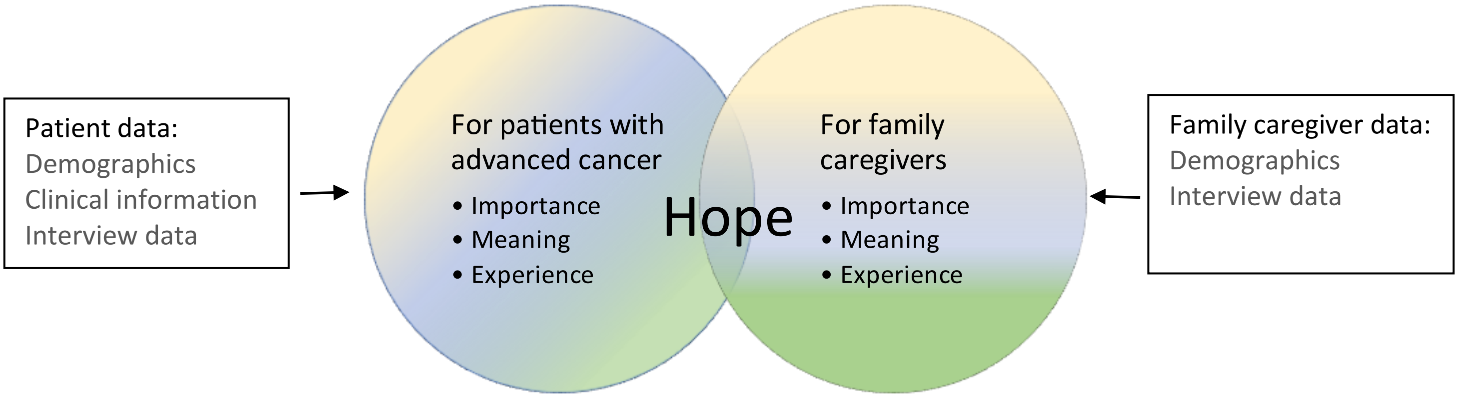
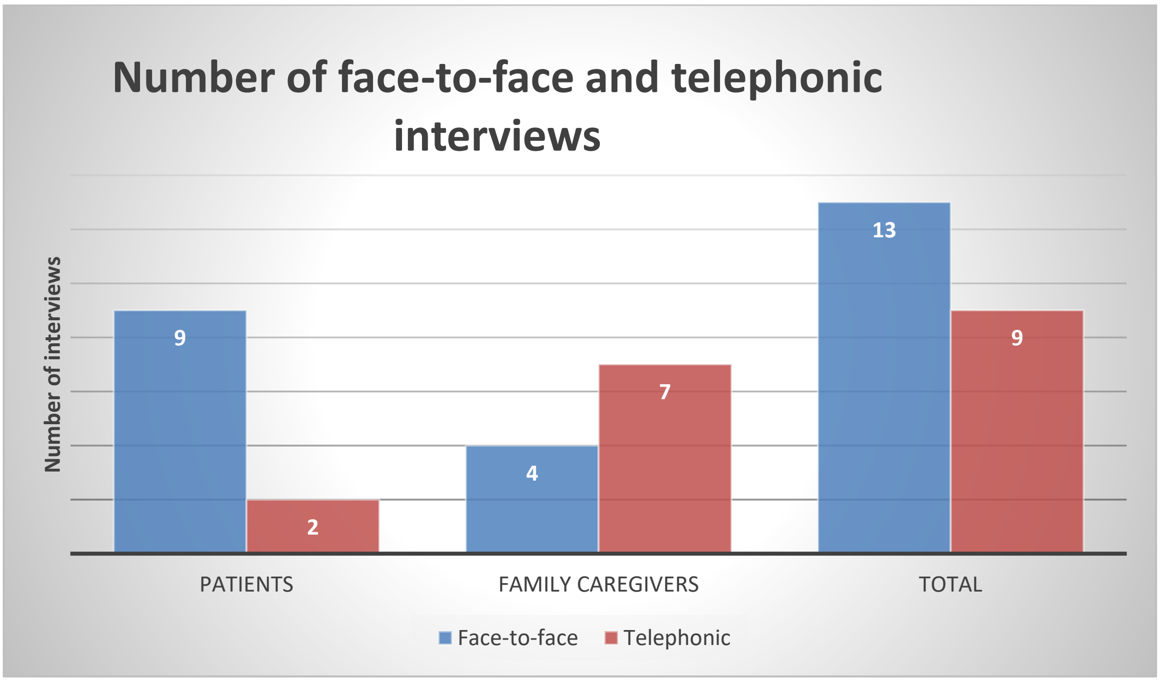


Figure 9. Summary of study data aiming to explore the importance, meaning and experience of hope for patients with advanced cancer and their family caregivers

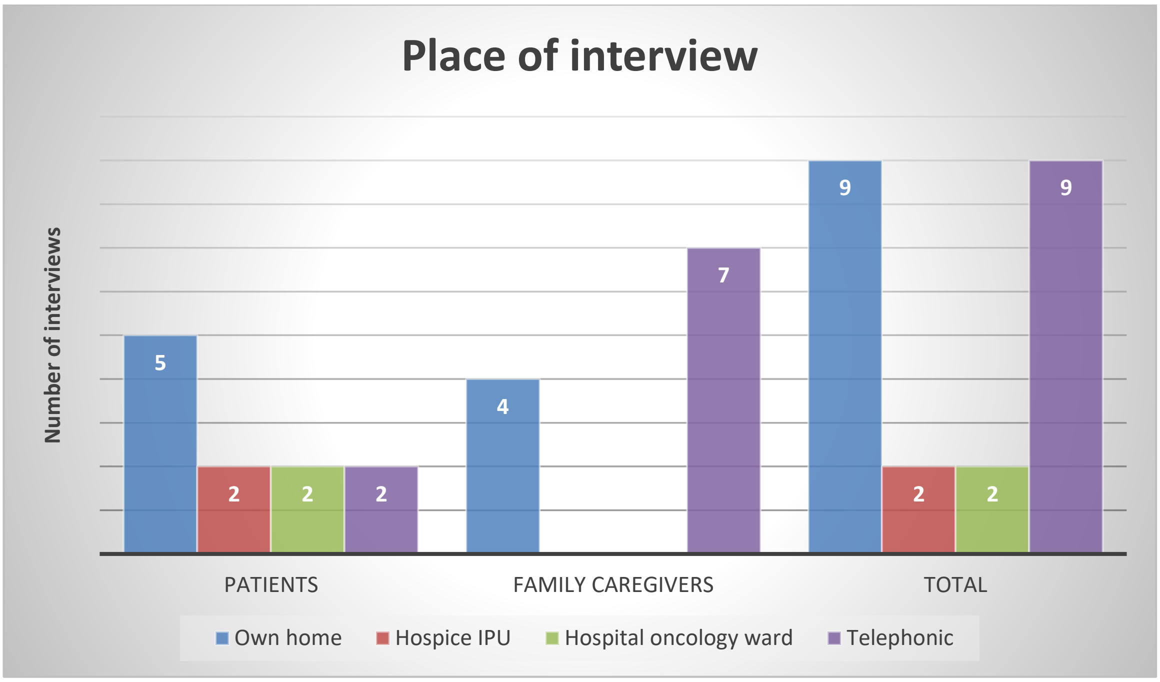
4.2 Outcome of screening and interview process

Over a five-month period, from March until July 2022, 14 patients with advanced cancer were identified by the research assistants for the study, seven patients from each study site. These patients were discussed with the researcher and deemed potentially eligible for the study. However, on final screening, three potential participants did not meet the study admission criteria; two presented with acute confusion limiting their ability to be interviewed, while one potential participant had an unanticipated admission to an outlying hospital and was therefore unable to be interviewed.

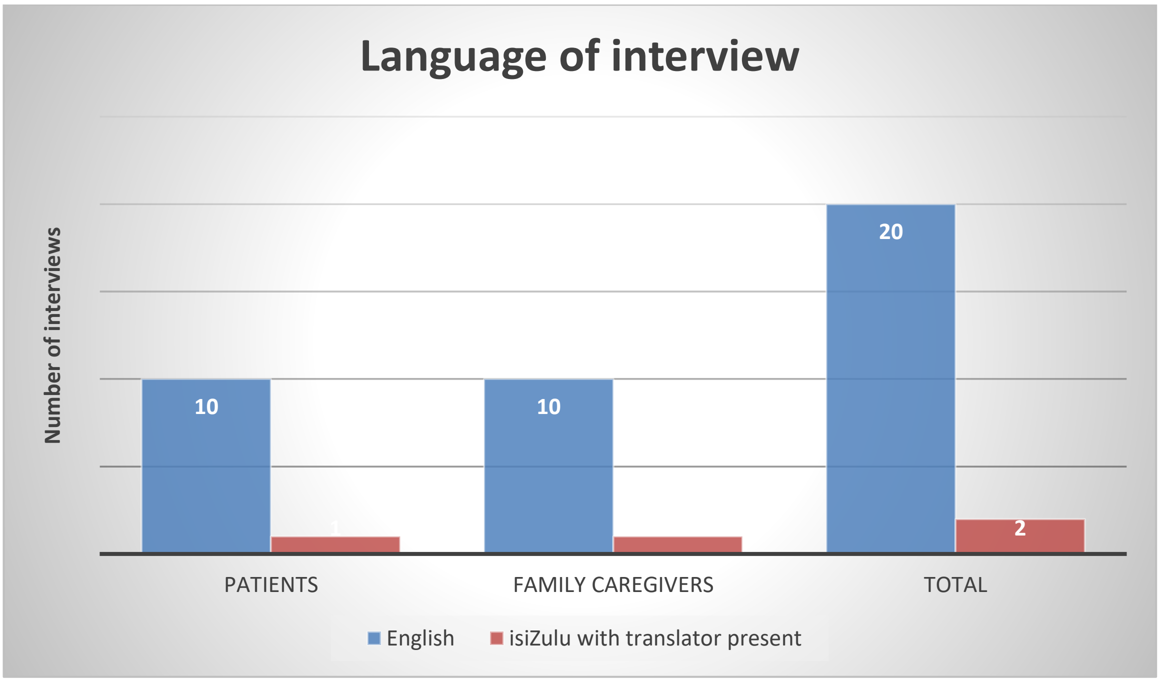
Eleven patients who met the study criteria consented for the study and were interviewed. Nine of the 11 patient interviews took place face-to-face with the researcher, while two interviews were undertaken telephonically (see Graph 1). Of the nine face-to-face interviews, five took place in the patient's own home, two in Chatsworth Hospice's in-patient unit and two in IALCH's oncology ward (see Graph 2). Ten of the 11 interviews were conducted in English, while one interview was conducted in isiZulu with the research assistant acting as translator (see Graph 3). The mean length of the patient study visits was 1 hour 14 mins (range 36 minutes to 2 hours 30 minutes); this time included introductions and explanation of the study, consent-taking, capturing of demographic and clinical information, the recorded study interview and general discussion around issues raised by the patient. The recorded section of the interview, where issues specifically relating to hope were discussed and recorded with patient consent, averaged 29 minutes in length (range 11 to 57 minutes).



Graph 1. Number of face-to-face and telephonic interviews

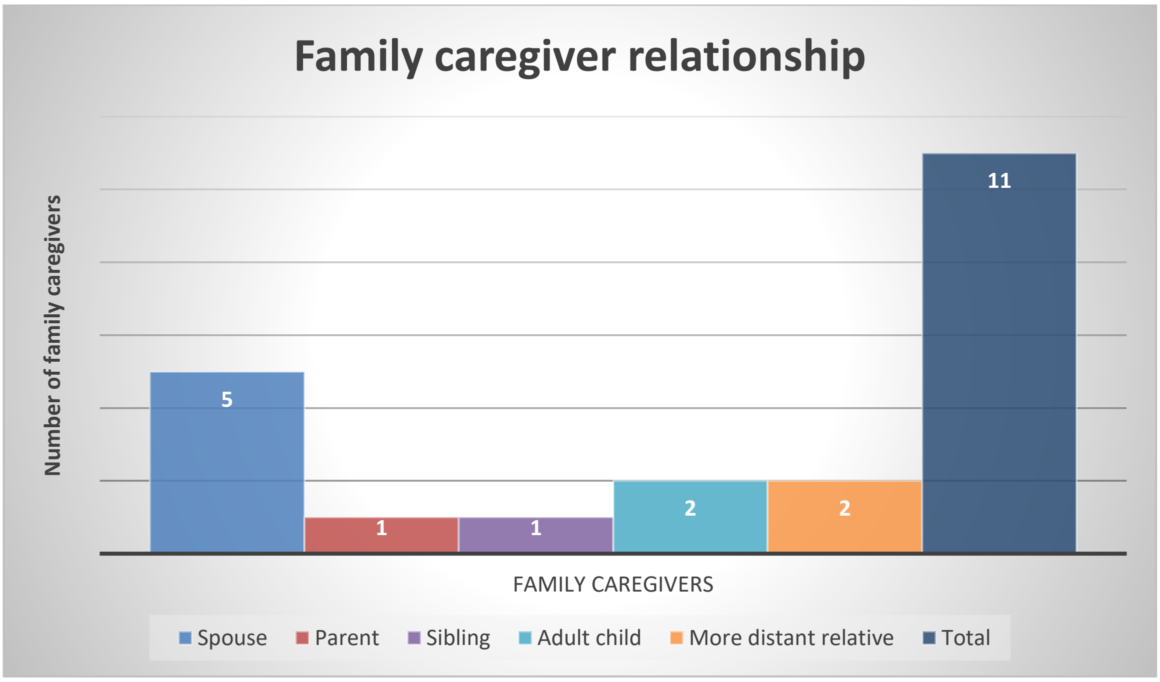


Graph 2. Place of interview for patients and family caregivers



Graph 3. Language of interview for patients and family caregivers

Each patient nominated a family caregiver. All 11 nominated caregivers consented to the study and were interviewed. Of the 11 family caregivers, five were the patient’s spouse, one was a parent, one a sibling, two were an adult child of the patient, while two family caregivers were more distant relatives (see Graph 4). Seven family caregivers lived with the patient, while four lived in close proximity to the patient. Four family caregiver interviews took place face-to-face in their own home, on the same day as the related patient interview. Seven family caregiver interviews were conducted telephonically (see Graphs 1 and 2). The seven telephonic interviews took place on average 8 days following the related patient interview (range 4 to 17 days). Ten interviews were conducted in English, while one family caregiver interview was conducted in isiZulu with a translator present (see Graph 3). The family caregiver interview guide was followed. The mean length of the family caregiver study visits was 38 mins (range 12 minutes to 1 hour 20 minutes); this time included introductions and explanation of the study, consent-taking, capturing demographic information, the recorded study interview and a further general discussion with the family caregiver. The recorded section of the interview, where hope was specifically discussed and recorded with family caregiver consent, averaged 20 minutes in length (range 7 to 36 minutes).



Graph 4. Family caregiver relationship to patient

Twenty-two interviews, involving 11 patient/caregiver dyads, were therefore conducted. The researcher’s analysis revealed that data adequacy was reached at this point in that the insights and experiences of study participants were being repeated and no significant new themes were emerging from the data. The study's COVID-19 protocol (see Appendix E) was followed for all face-to-face study interactions, including consent-taking and participant interviews. No participant was excluded or withdrawn from the study relating to COVID-19. The study's distress protocol (see Appendix G) was adhered to for all participant interviews. No study participant exhibited significant emotional distress during the interview, and no withdrawal from the study for this reason was required. The data from all 22 study participants were therefore available for analysis.

4.3 Demographics and clinical characteristics of study participants

4.3.1 Demographics and clinical characteristics of patients

Of the 11 study patients, three were registered with Chatsworth Hospice, six were registered at IALCH, while two patients were registered at both facilities. Most patients (n=7) were female, while approximately a third (n=4) were male. Ages ranged from 35 to 84 years, with a mean age of 59 years. Most patients (n=6) spoke English as their first language; other first languages were isiZulu (n=3), Afrikaans (n=1) and Tamil (n=1), which is a classical language originating in India. Approximately half the patients (n=5) were married, the remainder were single (n=2), separated/ divorced (n=3) or widowed (n=1). All patients stated they belonged to a specific religion: five were Christian, five Hindu, and one Muslim. The majority reported that their religion was very important to them (n=9).

Regarding the highest level of education attained, three patients had a tertiary qualification, five others had completed matric, two patients left secondary school prior to matric, while one patient left school after grade 1. No patients were formally employed; six were pensioners, while five were unemployed and supported financially via disability grant alone (n=3), disability and child grants (n=1) or family contribution (n=1). Most patients were in the middle-income group (n=9), while two patients were in the low-income group.

Ten patients lived in a formal dwelling, either suburban (n=8) or periurban (n=2), while one patient lived in a traditional home in a rural setting. Most patients had access to all household amenities (n=8), while one household did not have flushed toilets, one did not have refuse collection, and the rural home had access only to electricity. Two patients lived alone, four patients lived with other adults, while the remaining five patients lived together with adults and children. Household sizes ranged from one to six people, with a mean household size of 3.64. All patients spoke about significant social support available to them.

Patients had primary cancers originating from the breast (n=2), cervix (n=2), colorectum (n=3), kidney (n=1), lung (n=2) or ovary (n=1). Four had stage 3 while seven had stage 4 cancers. Most of the patients had been diagnosed with advanced cancer within the previous year (n=8), two of these patients within the past three months, while one patient had lived with the diagnosis of advanced cancer for longer than five years. Patients had a PPS ranging from 30% to 80%, with a mean PPS score of 60%. Involuntary weight loss over the preceding six months ranged from 0 to 20kg, with five patients experiencing more than 5kg unintentional weight loss. Current or planned oncology treatments included palliative radiotherapy and/or chemotherapy for five patients, hormonal therapy for one and debulking surgery for another patient. No further oncology treatment was planned for approximately a third of the patients (n=4). Most patients had been referred to palliative care (n=8), although only three patients had been receiving palliative care for greater than three months.

Please refer to Tables 1 and 2 below for more comprehensive detailing of the demographics and clinical characteristics of the study participants.

Demographics of study participants	**Patients** (=11) **Number (n) and %**	**Family caregivers** (=11) **Number (n) and %**
Registered at each study site		
Chatsworth Hospice	3 (27.3%)	
IALCH	6 (54.5%)	
Registered at both study sites	2 (18.2%)	
Gender		
Female	7 (63.6%)	9 (81.8%)
Male	4 (36.4%)	2 (18.2%)
Age		
20-29 years	0 (0%)	1 (9.1%)
30-39 years	1 (9.1%)	0 (0%)
40-49 years	2 (18.2%)	2 (18.2%)
50-59 years	2 (18.2%)	4 (36.4%)

60-69 years	4 (36.4%)	2 (18.2%)
70-79 years	1 (9.1%)	1 (9.1%)
80-89 years	1 (9.1%)	1 (9.1%)
First language		
Afrikaans	1 (9.1%)	0 (0%)
English	6 (54.5%)	7 (63.6%)
isiZulu	3 (27.3%)	3 (27.3%)
Tamil	1 (9.1%)	1 (9.1%)
Marital status		
Married	5 (45.5%)	5 (45.5%)
Separated/ divorced	3 (27.3%)	2 (18.2%)
Single	2 (18.2%)	2 (18.2%)
Widowed	1 (9.1%)	2 (18.2%)
Religion		
African Ancestral and Roman Catholic, very important	0 (0%)	1 (9.1%)
Christian, somewhat important	1 (9.1%)	1 (9.1%)
Christian, very important	4 (36.4%)	3 (27.3%)
Hindu, somewhat important	1 (9.1%)	0 (0%)
Hindu, very important	4 (36.4%)	5 (45.5%)
Muslim, somewhat important	0 (0%)	0 (0%)
Muslim, very important	1 (9.1%)	1 (9.1%)
No particular religion	0 (0%)	0 (0%)
Highest level of education achieved		
Primary school: G1	1 (9.1%)	1 (9.1%)
Primary school: G2-7	0 (0%)	2 (18.2%)
Secondary school: G8-11	2 (18.2%)	6 (54.5%)
Secondary school: G12 (matric)	5 (45.5%)	1 (9.1%)
Tertiary education	3 (27.3%)	1 (9.1%)
Employment status		
Employed	0 (0%)	2 (18.2%)
Pensioner	6 (54.5%)	4 (36.4%)
Unemployed	5 (45.5%)	5 (45.5%)
Main source of income		
Caregiver grant	0 (0%)	1 (9.1%)
Disability grant	3 (27.3%)	0 (0%)
Disability grant and child grant	1 (9.1%)	0 (0%)
Employment income	0 (0%)	2 (18.2%)
Family support	1 (9.1%)	3 (27.3%)
Pension	6 (54.5%)	4 (36.4%)
UIF and child grant	0 (0%)	1 (9.1%)
Annual household income		
Low-income: R 1 – R 19 200	2 (18.2%)	2 (18.2%)
Middle-income: R 19 201 – R 307 200	9 (81.8%)	8 (72.7%)
Upper-income: R 307 201 and above	0 (0%)	1 (9.1%)
Location of home		
Suburban	8 (72.7%)	8 (72.7%)
Periurban	2 (18.2%)	2 (18.2%)
Rural	1 (9.1%)	1 (9.1%)
Dwelling type		
Formal home	10 (90.9%)	10 (90.9%)
Informal settlement home	0 (0%)	0 (0%)

Traditional home	1 (9.1%)	1 (9.1%)
Access to household amenities		
All	8 (72.7%)	8 (72.7%)
All except flush toilets	1 (9.1%)	1 (9.1%)
All except refuse collection	1 (9.1%)	1 (9.1%)
Only electricity	1 (9.1%)	1 (9.1%)
Household arrangement		
Living alone	2 (18.2%)	1 (9.1%)
Living with other adults	4 (36.4%)	4 (36.4%)
Living with other adults and children	5 (45.5%)	6 (54.5%)
Household size		
1 person	2 (18.2%)	1 (9.1%)
2 or 3 people	4 (36.4%)	3 (27.3%)
4 or 5 people	2 (18.2%)	2 (18.2%)
6 or 7 people	3 (27.3%)	3 (27.3%)
8 or 9 people	0 (0%)	1 (9.1%)
10 people	0 (0%)	1 (9.1%)
Number of dependents on fam caregiver		
1 or 2 dependents		4 (36.4%)
3 or 4 dependents		4 (36.4%)
5 or 6 dependents		2 (18.2%)
7 or 8 dependents		0 (0%)
9 dependents		1 (9.1%)
Social support		
Minimal	0 (0%)	0 (0%)
Significant	11 (100%)	11 (100%)

Table 1. Demographics of study participants

Clinical characteristics of study patients	**Patients** (=11) **Number (n) and %**
Primary cancer site	
Breast	2 (18.2%)
Cervix	2 (18.2%)
Colon	1 (9.1%)
Kidney	1 (9.1%)
Lung	2 (18.2%)
Ovary	1 (9.1%)
Rectum	2 (18.2%)
Stage of cancer	
Stage 3	4 (36.4%)
Stage 4	7 (63.6%)
Time since diagnosis of advanced cancer	
3 months or less	2 (18.2%)
> 3 to 6 months	1 (9.1%)
> 6 months to 1 year	5 (45.5%)
> 1 to 2 years	0 (0%)
> 2 to 3 years	2 (18.2%)
> 3 to 4 years	0 (0%)
> 4 to 5 years	0 (0%)

> 5 years	1 (9.1%)
PPS	
80%	3 (27.3%)
70%	1 (9.1%)
60%	3 (27.3%)
50%	1 (9.1%)
40%	2 (18.2%)
30%	1 (9.1%)
Current/ planned oncology treatment	
None	4 (36.4%)
Debulking surgery	1 (9.1%)
Palliative chemotherapy	2 (18.2%)
Palliative radiotherapy	2 (18.2%)
Palliative radiotherapy then chemo	1 (9.1%)
Palliative hormonal therapy	1 (9.1%)
Involuntary weight loss past 6 months	
0 kg	1 (9.1%)
> 0 to 5 kg	5 (45.5%)
> 5 to 10 kg	2 (18.2%)
> 10 to 15 kg	2 (18.2%)
> 15 to 20 kg	1 (9.1%)
> 20 kg	0 (0%)
Time under hospice/ palliative care	
Not referred	3 (27.3%)
Only just referred, awaiting first visit	2 (18.2%)
3 months or less	3 (27.3%)
> 3 to 6 months	1 (9.1%)
> 6 months to 1 year	1 (9.1%)
> 1 year	1 (9.1%)

Table 2. Clinical characteristics of study patients

4.3.2 Demographics of family caregivers

The family caregivers had an age range from 28 years to 82 years, with a mean age of 56 years. Nine caregivers were female, while two were male. The majority (n=7) spoke English primarily, three spoke isiZulu as their primary language, and one patient’s first language was Tamil. Five family caregivers were married, two were single, two separated/divorced and two widowed. All belonged to a specific religion: four were Christian, five Hindu, one Muslim, while one caregiver stated she was both Roman Catholic and part of the African Ancestral religion. Ten caregivers stated that their religion was very important to them, while one regarded their religion as somewhat important.

Only one caregiver reached matric as their highest level of education, and only one had a tertiary education. The majority left secondary school prior to matric (n=6), three had a primary school education, one of whom left school after completing grade 1. Only two caregivers were formally employed, four were pensioners, while the remaining five were unemployed and financially supported via a care grant (n=1), UIF and care grant combined (n=1) or by family support (n=3). Eight caregivers were in the middle-income group, two fell into the low-income group, while one was in the upper-income category.

Ten caregivers lived in a formal home in a suburban (n=8) or periurban area (n=2), while one caregiver came from a rural area and lived in a traditional home. Eight households had access to all amenities, one household had no flush toilets, one no refuse collection, and one home had access only to electricity. While one caregiver lived alone, the majority lived with other adults (n=4) or with other adults and children (n=6). Caregiver households included one to ten people, with a mean household size of 5.09. The number of dependents on each caregiver ranged from one to nine, with a mean of 3.55 people dependent on each caregiver. Each caregiver expressed that they had significant social support.

Please refer to Table 1 above for more comprehensive detailing of the demographics of the family caregivers.

4.4 Data from interviews relating to the importance of hope

4.4.1 Importance of hope for patients

The question “How important is hope to you, as a person living with cancer?”, or variations thereof, was posed to the patient participants. Each of the 11 patients asserted that hope was important to them. Many patients gave substantiating comments, affirming how important hope was for them (see Table 3).

Importance of hope for patients
That’s what carries you through life (Pt 2) Right now it’s very important (Pt 4) Yes, it’s important. It’s *very* important to me, whether I have cancer, or I don’t have it, I always have hope that one day something new will happen (Pt 7) Ja, hope is very very important, it’s the *first* thing you must have, before you do anything. Even if you go to sleep you must have hope that I know God is there, I will wake up in the morning (Pt 7) Yes definitely, definitely… You *want* hope… you’ll have your good days and your bad days but you must always live with hope, yes, that’s what I would say (Pt 9) Well, with us, with us cancer patients, we *need* hope, we need hope… and we need to feel *good* about ourselves and although we sometimes be in pain, or discomfort, you know… but we must overcome that with hope (Pt 9) I think everybody should have hope… not only a cancer patient, I think the entire world, *everybody* should have hope… If you hope, if you hope and believe, you go a *long* way in life. If you don’t hope and believe, you can go nowhere… You gotta hope and believe… that’s how it is (Pt 10) Ja, it is, definitely, definitely… Ja, you’ve gotta have hope, yes definitely. You can’t say, you know what, oh I’ve got cancer, you know what, close the book, it’s the end of everything – no, you’ve gotta have hope, you know… (Pt 11)

Table 3. Statements from patients relating to the importance of hope

4.4.2 Importance of hope for family caregivers

All 11 family caregivers stated that hope was important to them. Many caregivers emphasised the importance of hope in caregiving (see Table 4).

Importance of hope for family caregivers
It [hope] means a *lot* (FC 1) Yes, it’s very important to have a hope… yes, hope is the key (FC 3) I’m saying that I *do* have hope, so it’s nice when you’re looking after someone you must have hope, so they can feel much better (FC 3) Yes, very important. I mean if one person can have some,… I mean the rest of us can have hope, you can’t just neglect hope or just forget about hope… it’s hope that is something that’s within you that… you need to believe in yourself, yes (FC 4)

I *believe* in hope (FC 4)

Very, definitely important, yes it is (FC 5)

Hope is what makes us live. You must stick to hope because it makes you live my child (FC 7)

Yes, it's very important… because you can't do anything without hope (FC8)

Ah hope,… I don't know what to say doctor, but hope… the only thing, hope… *first* I must have hope (FC 8)

And hope plays a big role, because you know, I mean we always hoping for some outcome, for the *best* outcome (FC 10)

Definitely, definitely… very important, you've got to believe, you've got to hope for the best… if not for the best, I think to fulfil your life… Yes… you've *got* to hope (FC 10)

Very important, very important (FC 11)

Table 4. Statements from family caregivers relating to the importance of hope

4.5 Data from interviews relating to the meaning of hope

4.5.1 Meaning of hope for patients

Patients were asked to describe what hope means to them, or what it means to be hopeful. The meaning of hope expressed by patients in the study related to their spirituality, having a goal and purpose, psychological fortitude, living well yet being ready to die, and human connection (see Figure 10). Table 5 gives examples of statements relating to these subthemes.

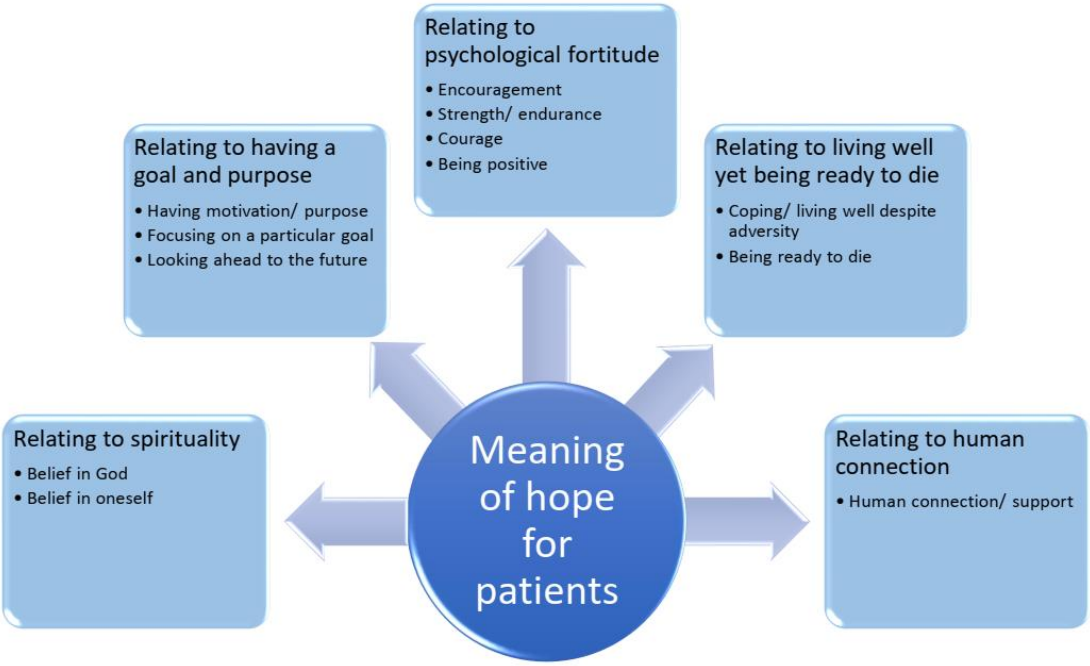


Figure 10. Subthemes relating to the meaning of hope for patients

Subthemes	Meaning of hope for patients
Relating to spirituality	
Belief in God	Hope, in myself is… it's just my belief in God. That's my hope, that's where I'm going. He said He's prepared a mansion for me, that's where I'm going. So that's where my hope is (Pt 2) Ja, having hope, having trust in the Almighty… Ja, all I did say is I've got to leave it in His hands (Pt 11)
Belief in oneself	A little bit of hope - that enlightens him to say "well, let me go further from there" (Pt 1)
Relating to having a goal and purpose	
Having motivation/ purpose	I say to myself, I need to do it for *them*, no matter what, even if I need to take the medication so I… I have to survive for *them*… my family (Pt 4) I'm a person that always *likes* to have hope, because why… if I feel that you don't have hope, then you will like ah… you don't want to do anything in life, it becomes like a, you know like a couch cabbage… ja… Ja, like a cabbage – you know like a person who just sits on that couch and just… eat, eat and drink, eat… eat and drink and just get more and more fat! (Pt 10)
Focusing on a particular goal	My son says "Daddy, now that I've got a car - the places where you wanted to go, where your heart wants to go, I'll take you, the day that you're feeling alright, we'll take you… When I'm free, Sundays are free, the weather is nice, and you are feeling ok, we'll go some place, you tell us where you want to go" (Pt 1)

	One should never give up, always should have a focus (Pt 4)
Looking ahead to the future	It makes me happy to have faith, it [hope] gives me faith that I will still continue to live on this earth (Pt 3) Hope is for the future, to be with your child, to play with him, to see him growing up, to see him study and become something (Pt 4)
Relating to psychological fortitude	
Encouragement	And then, you know whoever comes here, they offer help, they don't show pity on their faces, that's what I like… It gives you that encouragement to survive (Pt 1) Hope… well hope is um… it's like an *encouragement…* Yes, yes… and it encourages you, like it gives you hope and you know – to go on… To go on in life, especially if you are sick… yes… to go forward (Pt 9)
Strength/ endurance	I think that's [hope is] what is giving me the strength to… engage it and you know… because you know the psychologist, she told me in no uncertain terms… and then she told me it was a very advanced stage… so I must plan to… to spend what quality time that I have… you know, there are no guarantees (Pt 6) So… I do have hope… it makes me become strong… Ja, it makes me feel strong… yes…. hope has given me a hope… ja, it makes me to become stronger (Pt 8)
Courage	When I went there for the biopsy I didn't know what to expect… but luckily there was one of the nurses from B4 ward, what a lovely person. She took me down there… So now she gets hold of my hand, now I can't decide whether I want to do this, and I said to her, what do you think, no she says, she thinks… and she gave me the courage… so I said between you and the Lord… (Pt 2) You know you do say that… fear can stop the whole thing, but you hope… (Pt 5)
Being positive	The thing is, you got to… you got to have the positive attitude. If I could beat *that*, then what I'm suffering now, I can beat it (Pt 1) But just carry on, you know what I mean, and just be positive and you know what to do… (Pt 6)
Relating to living well yet being ready to die	
Coping/living well despite adversity	Ja, hope is to me, it is that I mustn't just expect that I'm dying, because I've got this disease that I'm gonna die now… Hope for me, to me it says that even young children, I saw them at [hospitals' name], that they've got this disease… and they don't know what this disease is, you find them laughing, playing, without knowledge that they are sick…so let me be like a child too, let me live as if I don't have this disease… That I'm still like a child, let me say so (Pt 7) And live one day at a time… don't take it too far ahead. Yes once you've lived

	that day, then you know you've finished that day, then when you go to bed, and you wake up the next day, be grateful (Pt 9)
Being ready to die	Ja… and if I have to go, it's fine, I'm more than prepared… I'm not like gonna say no, I don't want… no… when the time comes, if God wants you, God wants you; if God doesn't want you, you battle here in this world, that's how it is… Ja, if God wants you, God will take you; if God doesn't want you, you carry on… We're all here on a holiday, we know that, but it's a *long* holiday… Ja – when your holiday is finished then you must go now, when it's your ticket to go, you must go (Pt 10)
Relating to human connection	
Human connection/ support	Well, my hope is love… love and the support that I get, you see? (Pt 9)

Table 5. Statements from patients relating to the meaning of hope

4.5.2 What patients are hoping for

Patients' hopes related to their spirituality, to reaching goals and a better future, to cure and improved survival, to better QoL and to human connection (see Figure 11). Table 6 gives examples of statements relating to these subthemes.

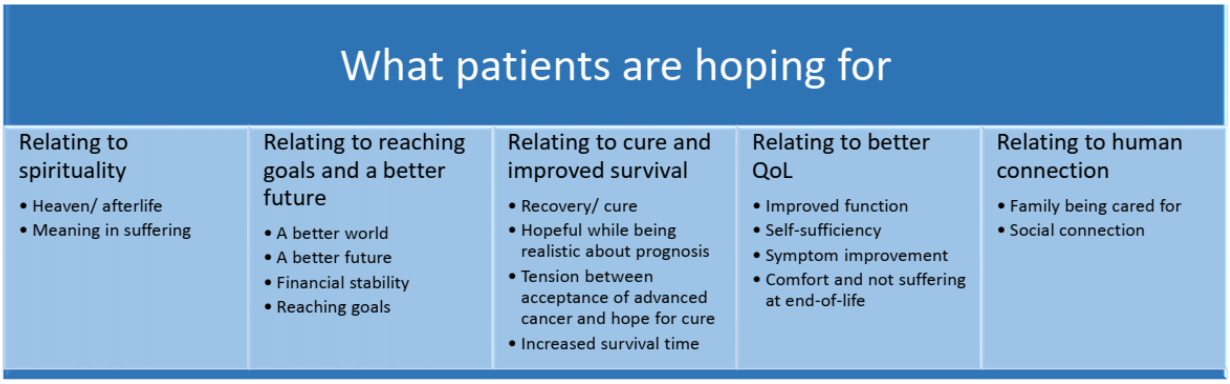


Figure 11. Subthemes relating to what patients are hoping for

Subthemes	**What patients are hoping for**
Relating to spirituality	
Heaven/ afterlife	So, in… making sure me and myself, with all my goods and bads, that I'm acceptable for the Lord to come and fetch me and *put* me in the mansion up there with Him – that's my hope. That's what I'm looking forward to (Pt 2) No like everything I do I put Him first, you know what I mean, so, I'm not a

	fanatic or something but I do pray every day, in a Higher Power, you know what I mean… So… yes I believe there would be an afterlife yes (Pt 6)
Meaning in suffering	I'm hopeful that something could come of this whole thing [having cancer] (Pt 2)
Relating to reaching goals and a better future	
A better world	You hope for the world, in fact the country to be better (Pt 1) I like to have hope to move around, hope to feel better, hope for a better world, hope for people to be better, to talk better, hope for *everything* to be nice, that's what I hope for, I hope for this whole world to change, everything to be nice, hope for *all* the people to be good… If all the people are good, we'll have no problems, we'll have the least amount of problem (Pt 10)
A better future	[I] hope for a better future (Pt 4) It's there, ja, just hope, everything's gonna be better, everything will come right (Pt 11)
Financial stability	Then, then you look at financial – you say look I just hope that the day comes that I'm financially well off that I can go (Pt 1)
Reaching goals	Yes, you always hope for something that one day you could achieve this, or one day our time will come when we get to get like… you know we haven't been there… *one* day we hope to visit the temple or certain places (Pt 1) No it's just my grandson you know – just with him, with his sporting side, if I can just – you know what I mean- if I can see him play soccer… golf, or cricket or whatever – because he's always wanting to be *doing* (Pt 6)
Relating to cure and improved survival	
Recovery/cure	My hope, I look at it, probably as a miracle for me, for my cancer to go away… Ja… that's my hope… hopefully get a miracle and it's *gone*, you know what I mean… completely (Pt 6) The only thing I – just hope is is that this cancer must just go away from me, that's the only thing, because that's the only problem, that I've got cancer (Pt 11)
Hopeful while being realistic about prognosis	Prepare, yes… Yes, yes… you gotta be realistic, that's the *main* thing (Pt 6) We have to be realistic, yes yes… Because it *is* a terminal disease, so we have to be realistic (Pt 9) You carry on… this is the point, you've just got to *accept* it, most importantly you must accept it… You can't fight it and say no, it's not right, I don't have cancer… the doctor is wrong, no (Pt 11)
Tension between	I hope I get healed… but I know it's not possible because a lot of people do lose their lives from the type of cancer that I have… (Pt 4)

acceptance of advanced cancer and hope for cure	[I hope] that this disease, this cancer, it must be away from me, from my body… Mmm, yes sometimes it's impossible to take it away, but hopefully it can go slowly slowly, up until it's finished, yes (Pt 8)
Increased survival time	That is my hope, that is my only hope… It's just to go away, just to give me a couple years more, to sort a few things out that I need to sort out, you know what I mean? (Pt 6) Well, all I hope for is the hope that the Almighty gives me a little longer life, you know? My family becomes more strong, more stabilised (Pt 11)
Relating to better QoL	
Improved function	I… although I have the cancer, I just want to start walking again… and be there for my family, and doing things while I'm alive (Pt 4)
Self-sufficiency	[I hope] to get better, to get better and to look after myself (Pt 8) What hope means to me is to be better… To be better, to be able to do things on my own (Pt 10)
Symptom improvement	I think sometimes it's paining, and I battle to walk, [my hope is] so that I can feel less pain to walk (Pt 5) Without any aches and pains, ja that's my hope… my hope is to get better… Ja, it is better not to have pains, you know that. Ok, naturally even a normal person got pains. We know that. That's fine, I can live with *that*. But I'm not talking about extreme pains. Like *we* now, because we got cancer and all this thing, we got extreme pains… You know the pain is intense… So if it's less and less pain then it's fine, no problem (Pt 10)
Comfort and not suffering at end-of-life	My hope at the moment is, not so… I'd be happy if the Lord fetches me and I don't know how else to say it, if I could just "wake up dead" because I don't want to lie there and suffer. That's the only thing that puts me off the whole thing. Other than that, I've got peace with the whole story (Pt 2) So basically I'm just looking for a nice quiet time and that's it… no suffering, no pain or anything… If you go, you go, you know what I mean… Not suffering, you know what I mean (Pt 6)
Relating to human connection	
Family being cared for	But I just hope the Lord will look after my kids, that's the most important – because that's what I'm leaving behind (Pt 2) I still have hope, I haven't lost it. I have hope because, if I can make a scenario, if my arm that the doctor told me can't work again still doesn't work like he said, I won't lose hope because all I want is to live, raise my kids and be there for them (Pt 3) … and maybe to have a job so that I can support my son (Pt 8)

Social connection	[I'm hoping for] nothing else… just my children will all be together… and they will be happy… I want *all* of you to live happy, I want *all* of you to live in peace (Pt 5) I always hope for the better, I always hope my children do well, my wife is well, my dog is right… I want hope for my family, for *everybody*, I just hope everybody is well… and good (Pt 10)

Table 6. Statements from patients relating to what they are hoping for

4.5.3 Meaning of hope for family caregivers

Family caregivers were asked to describe what hope means to them, or what it means to be hopeful. The meaning of hope expressed by caregivers in the study related to their spirituality, having a goal and purpose, psychological fortitude, living well yet being ready for their family member being cared for to die, and human connection (see Figure 12). Table 7 gives examples of statements relating to these subthemes.

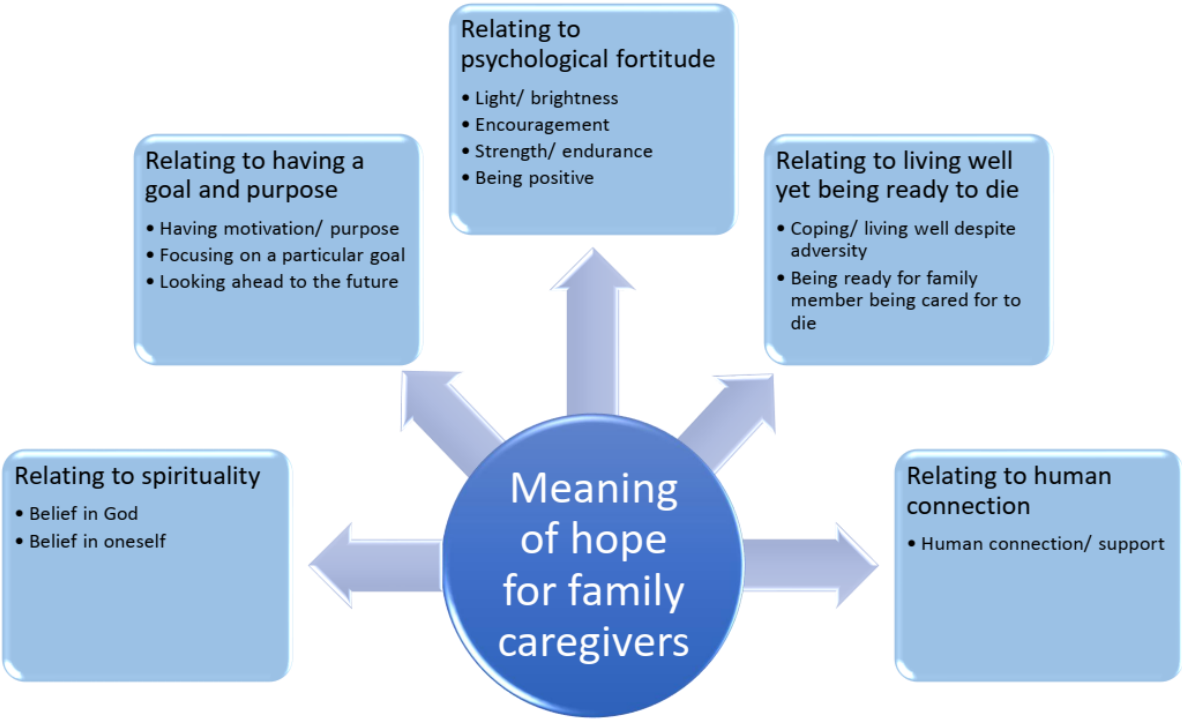


Figure 12. Subthemes relating to the meaning of hope for family caregivers

Subthemes	Meaning of hope for family caregivers
Relating to spirituality	
Belief in God	I have hope throughout my life. From where I come from to the stage when I grew up and became an adult I always lived with hope and faith that things will be better and they will work out for me, but only with God (FC 7) Because of our belief [in God], we hope for the best (FC 10)
Belief in oneself	Then I see how a miracle happened yesterday [patient mobilised in a wheelchair] and I told her, see, believe in yourself, have faith, have that hope in yourself. You always got hope in you (FC 4)
Relating to having a goal and purpose	
Having motivation/ purpose	Sometimes I sit and talk to her too and tell her not to lose hope, you've got a life to live, you've got a small child to see to, be happy, things will work out (FC 4) Yes, you know, you can't lose hope, you have us Dad, you have to live (FC 11)
Focusing on a particular goal	Two weeks back she insisted on cooking… She insisted, and we got everything together… and my nephew helped her to prepare the fish and she was cooking, she became a little tired… then we helped her to do everything and then we brought her again inside (FC 5) So you've got to always hope to fulfil whatever your dreams and your wishes are, you've got to hope that you do that (FC 10)
Looking ahead to the future	My outlook is… with… trying to be hopeful that you know the future is… you know ja… tomorrow needs to be better than today so… from a hope perspective, yes (FC 2) And even when it comes to my children, I've always encouraged them, I give them hope, you can't lose hope, whether it's your job, or whatever aspect, you don't lose hope, there's always something better… When the time is right, it's gonna come to you, don't lose hope (FC 11)
Relating to psychological fortitude	
Light/ brightness	It is hope that is giving us like a *light* for us, it's brightening up our life, that's where my wife has actually gone from the bed to the wheelchair and she's got hope in her… It's shining a light on us, and giving us hope, it's like that (FC 4) When it came to my brother as well, there were certain things that… I was always there, giving him that hope, that light, you know? (FC 11)
Encouragement	And they also give him that hope – they always say [patient's name] don't worry, you are gonna be fine, you're a fighter and you are gonna be fine (FC 1) We always give her that hope that she'll get better, we don't discuss it but we encourage her (FC 5)

Strength/ endurance	[Hope means] to hang on… to hold on (FC 6) I've been through a lot of challenges, and with their blessings was my hope, it sailed me through stormy waters (FC 11)
Being positive	I told her no, not to worry, keep positive, and everything will work out (FC 4) If you're positive, I'm sure if you're positive, then it will eventually pan out that way… So we've been taking that positiveness from the negative, you take it and you put it into a positive… And you take your battle as it comes, that's what we've been doing (FC 10)
Relating to living well yet being ready to die	
Coping/living well despite adversity	Yes, hope it means – to have a hope for everything, to have a hope for living, hope for doing things, hope for standing up… from my understanding (FC 8) Yes… you can live a good quality of life, *depending* on how you accept your illness (FC 11)
Being ready for family member being cared for to die	I believe there is a light… that we can accomplish that, we can… I mean even though, I'm not saying anything bad, but even if I lose my wife, I know in myself, we prayed, we hoped… (FC 4)
Relating to human connection	
Human connection/ support	Tomorrow I will finish work early and I'll take him [his son] to see his mother… And we can all be together as a family and we can all chat and talk and whatever yes (FC 4) So that anyone who is sick can have hope… I mustn't turn around… turn my back on people who is very ill, or who is very sick, and you must always talk to her. If you talk to that person, she is… she is already hopeful because she sees that someone is caring for her… Yes, yes… to talk to her, give her what she needs, what she wants, where… maybe ask questions, so she mustn't think, think too much about her sickness, and she must not think that she is dying (FC 8)

Table 7. Statements from family caregivers relating to the meaning of hope

4.5.4 What family caregivers are hoping for

Family caregivers' hopes related to their spirituality, to reaching goals and a better future, to cure and improved survival, to better QoL and to human connection (see Figure 13). Table 8 gives examples of statements relating to these subthemes.

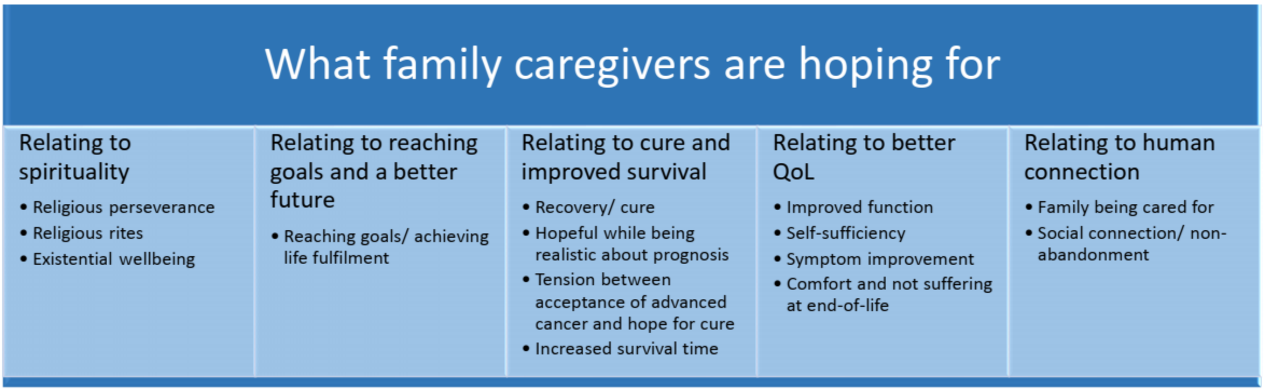


Figure 13. Subthemes relating to what family caregivers are hoping for

Subthemes	**What family caregivers are hoping for**
	Relating to spirituality
Religious perseverance	[My other hopes for him are] to hold onto God (FC 6)
Religious rites	But my hope currently is, and I always tell my children this, I told my brother, is that *one* day the Almighty takes me on the pilgrimage… The greatest blessing ever… So my aim was to work, my hope was to save, and one day as we say the Almighty takes me there… So that's my biggest hope (FC 11)
Existential well-being	I know, or maybe I don't know, but I'm asking for their forgiveness and I want God to open the way, that's my only hope (FC 5) At least God should give her a little, just a little bit of peace and freedom… she needed that me time (FC 5)
	Relating to reaching goals and a better future
Reaching goals/achieving life fulfilment	You've got to hope for the best… if not for the best, I think to fulfil your life (FC 10)
	Relating to cure and improved survival
Recovery/cure	I don't know what to say, but I do have hope that some time she will be alright, as much as it's difficult, we can see it's difficult for her, and painful, but I think one day she'll be alright, it will be over… after chemo (FC 3) Ah, I hope that some day, all people will be cured… that's the hope that I have… Especially for people who have cancer (FC 8) Mmm, I want she must get better… That she must live, she must live… for her children… Ja, she must get better… she must get better (FC 9)
Hopeful while being realistic about prognosis	Ja, ja, it doesn't… you know I think it's… what it does boil down to… it just your… your expectations… sort of… you know you get better alignment in terms of your hope and your expectation… that sort of just starts pulling together more… to say ok well, you know what – the hope for the cure is

	definitely not there, but now… what is the, what is the next step. You know, the hope is not to be in pain, the hope is to be at peace… the hope is to be… you know… to be comfortable… (FC 2) Well I hope for it to be controlled, maybe it's not going to be cured (FC 10)
Tension between acceptance of advanced cancer and hope for cure	I think right in the beginning stages it was… before the tests and before the diagnosis and the results came through, I think the hope at that point in time, from both my side and from my mom's side was different… but in the back of your mind you've always got that voice that says to you, well you've got to also… keep the worst case scenario in mind and… not let that hope run… sort of become dominant that there's gonna be a cure, or you know there is going to be a treatment that is gonna take it away, type of thing (FC 2) My hope is that, like I say, I hope he recovers. If he doesn't then still we, we have God (FC 6)
Increased survival time	And then I said Ma, we always praying God must spare you for another ten years or more to at least have… for whatever she's *been* through for us to give her that *comfort*, for her to have that *peace* (FC 5) But at least he can live, maybe a longer life, in where he can… well our eldest has just got married, she's been married two years now… Yes, yes, and she says Dad you know what, you need to see your grandchildren (FC 10)
Relating to better QoL	
Improved function	I just told her, just hang on, we just started the first phase now, that is going into the wheelchair, it will take time, maybe – give it one or two weeks, maybe miracle or… something else will… maybe you'll just hold her and maybe she will walk a little… I know I've got some hope in that, even though she won't be able to walk for the rest of her life, at least she will be in bed and we can move her around with a wheelchair, some *hope* that gives (FC 4) I hoped she would stand up, she was going to stand up on her feet… Yes… we tried, we tried to walk her, in the room, a little bit, slowly… (FC 8)
Self-sufficiency	And I hope one day like [when my husband dies], I'll be able to take care of myself (FC 1)
Symptom improvement	The hope that I've got is… I can't see how for her to get better, I know she not going to be much longer with us, but I just want God to just to ease her pain… I wouldn't want to see that, because it's hard for me to see it (FC 5) Sometimes, like after I give it [morphine] to her like she's ok, to come and see her relaxed like that it makes me feel so nice (FC 5)
Comfort and not suffering at end-of-life	And I got that hope – and I've still *got* that hope, and one more thing, if anything happens, so I know that we don't want him to suffer any more longer… Now that's my hope, yes, and I pray and that things like that must not happen, he must not go into that bed and he must not get bedridden (FC 1) Related to my mom, you know, the hope is that my mom can be as comfortable

	as possible and that her wishes, or her wish of having that comfort carries on for as long as possible (FC 2)
Relating to human connection	
Family being cared for	She tells us that if she goes away that the family must have unity, we must stick together, and I said that nothing is ever going to separate us… She worries a lot about my youngest sister. My youngest sister is everything for her. I told her if the day comes that you and Dada have to go, we will be there for her, she's my sister, she's my blood. That's what she worries about mostly, like we must stay together (FC 5) But if you take care of people, you take all that illness, you take all her illness to you, so that you can… it is easy to help her… or him… Yes, but I'm interested in cancer, what I saw from [relative's name], it was very difficult, so I'd like, one day, maybe one day, to have a… to take really good care of someone who has cancer (FC 8)
Social connection/ non-abandonment	Yes like, bereavement, we know you gonna be there for us (FC 1) Ja, it [the feeling of hope] would be positive, because we just want to see them [her dying parents] as comfortable as possible and like everybody in the family must be able to cope with what we are all going through, being on the same page with everything, ja… just to keep that positive mind and all stand together, I think everything… although we know that it's like a win-win situation, but it's not a winning battle, we just have to stand together and… be together (FC 5)

Table 8. Statements from family caregivers relating to what they are hoping for

4.6 Data from interviews relating to the experience of hope

4.6.1 Source of hope for patients

Patients were asked what gives them hope. The source of hope for patients related to their spirituality, psychological fortitude, human connection and medical management (see Figure 14). Table 9 gives examples of statements relating to these subthemes.

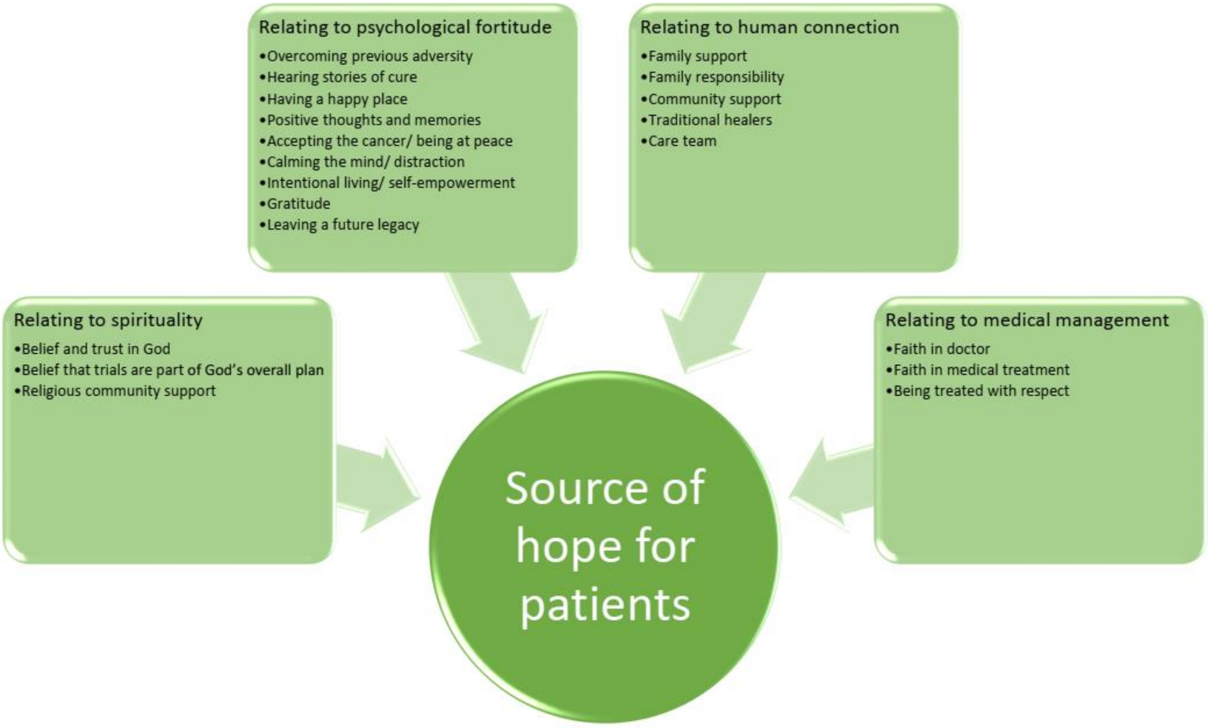


Figure 14. Subthemes relating to the source of hope for patients

Subthemes	**Source of hope for patients**
Relating to spirituality	
Belief and trust in God	You know I have… the Lord's looked after me all these years. I've been here, done that, I've been through very difficult circumstances. I've had wonderful times… The Lord has really, really blessed me… and we all have our ups and downs… so what do you want to be worried about? (Pt 2) God is playing a very big part in my life. That's my hope… that's the source. Yes, yes (Pt 9) Ja, trust in the Almighty. We turn to Him, no one else, and He's a very merciful person, because He's been there for me… It's been four years, so that is why I say that the Almighty *is* there for me, He's got mercy on me, you know? (Pt 11)
Belief that trials are part of God's overall plan	Yes I always was saying I helped people, how come it happened to me? And I took care of people with cancer as well, but how come it happened to me? But then I feel that maybe it is a test from God, to see how well I'm gonna fight for this condition (Pt 4) Because… because sometimes you gotta think like that, that it's the Almighty who has put this in you… to *test* you… so He only gives you things that you can handle, He doesn't give you things that you can't handle… Yes, He doesn't do that, so He *tests* you, He says I give you this now, let's see what do you do. How you're going to accept this in your life, how are you gonna go on, what are you going to do… to cope with this illness, you see (Pt 11)

Religious community support	Like with my first operation, I had another priest that time, who used to do all my prayers and things like that. Then I told him, look this is what I'm going through, then he's been with me all the way through, the praying, he used to come to the hospital… He used to come home and pray, and over the phone, we used to discuss any problem (Pt 1) Even my pastor told me, he told me, you know what, you know even Paul in the Bible, he asked God to take the thorn in his side away, and I said no, you know what, "My Grace is sufficient for you" (Pt 6) They [the church people] support me, they phone and do everything, they come… they do come (Pt 7)
Relating to psychological fortitude	
Overcoming previous adversity	Because I think, I've been through so many experiences, good and bad and difficult and… it has taught me to… keep… you know you get knocked down, but you'll stand up at some other time… like they say for a Christian, you can fall, but the furthest you can fall is down to your knees… Some other time you're going to get up again (Pt 2) I've had *so* many obstacles, but I've overcome, I've overcome all of them. I work on it, I worked hard on everything. I worked hard, I found where it was difficult, but you overcome, you overcome. I think when you grow up with working hard, you feel nothing. Ja, your lifestyle was like that, my lifestyle was hard, I had a hard life, that's why I feel nothing about nothing, ja, and I always got hope… Ja, I keep going, I keep going over it (Pt 10)
Hearing stories of cure	My sister's also got cancer… Yes, breast cancer… Yes she's fine… It's so nice (Pt 5) Ja… I did… there *is* some people who speak about these things… I met some people who actually *went* though the mill, and it *did* happen to them as well… so I'm hoping for the best!… That's why I don't feel down and out (Pt 6)
Having a happy place	Look at my beautiful pictures… that's my favourite - so I've put them all here and made a happy wall… That's what makes your day… And they're happy you know, all happy things. Yes, it really did make my day (Pt 2) I… I look at my children, I look at everything, I look at the sun [to give me hope] (Pt 10)
Positive thoughts and memories	Yes, and positive people [give me hope] (Pt 8) Change your mindset, ja… More positive things… ja, something you *like* now, show interest in that (Pt 9)
Accepting the cancer/being at peace	[My brother said], "It's your attitude and then you lose some confidence in yourself… so you just pray and you just be confident and carry on and that helped *me*"… and I said yes that's what I accept you know, even if it has to happen… let it be… you know I had a good innings (laughs) (Pt 6) First of all you've got to accept such an illness, you've got to accept it, you've

	got to take it and say ja, this is in me, and then to trust in the Almighty, pray to Him, ask Him to help you, to guide you to the right path (Pt 11)
Calming the mind/ distraction	Well ah… I would just ah… distract myself… yes… and I'll maybe watch something, put the TV on or listen to music, listen to anything you know? Then after a while, I'll come right (Pt 9) Well I just relax, have my medication, and say to myself, it's just one of those days (Pt 11)
Intentional living/self-empowerment	Ja. That's what I always do. That way I *can*, you know, so I just… so as I say I don't dwell on it… I just, I think back – the years when I was ok, I used to do certain things, I'm not a person that will just sit and "bring me this" and "bring me that". I would help myself (Pt 1) And "enjoy your life"… "Don't stress yourself out, you've got your family, you've got your grandchildren, and your children – if you will put yourself down then you will bring all of them down" so I think of all the consequences of all that and… so I decided no, from that time, in the beginning from that despair, I had a high and turned the whole thing around ja (Pt 6) Try to do everything as if you don't have this disease, and do the things you were doing while you were well, just whatever you were doing – don't concentrate on this disease, because this disease is there, you can't take it away, just do what you were doing before… if you were going to gym, do gym, go everywhere… visit your friends, love… whatever you were doing, because this disease is there (Pt 7)
Gratitude	But because I'm enjoying each and *every* day, here at my place… no doctor… I don't feel like, no doctor, there's nothing, there's nothing like that [to take my hope away] (Pt 7) Yes, and *each* day when I wake up, I'm grateful… Yes, I'm grateful that I've woken up, I can see the sun… you know, I can see the beautiful day, I can see my family, yes, yes (Pt 9)
Leaving a future legacy	That's why they say before you go you must be good and do good. Some people remember you from the goodness, they won't remember you from anything else… Ja, they will remember you from all the good you've been doing… And being a good person you know? (Pt 10)
Relating to human connection	
Family support	Things like, um, having people next to me, supporting me, yes… Yes I do talk with my son, a lot, and um… I talk with the people who are supporting me… with aunties and family (Pt 8) So when you are right, you need to go see them [close family], talk to them, give them hope, they give you hope, you know? That's the most important thing (Pt 10) My family support, that was amazing, they stood with me, took care of me, they always comforted me, you know, made me feel like there's nothing wrong,

	there’s nothing wrong (Pt 11)
Family responsibility	Then I sometimes… when I was diagnosed I thought of ending my life too as well but then I thought of my child… (Pt 4)
Community support	I did mention that, look I have got cancer, this is the stage I am in. And he said that in his family, he has somebody also go through, through the same thing and he knows what it is like… And he says anytime that I need any help, that is available (Pt 1) I get my hope from the people who give me support… I get a lot of hope from my support system (Pt 3) It’s basically my religion and the people around me, my friends, the loving support [who give me hope] (Pt 9)
Traditional healers	Ja, they [traditional healers] give hope, they give a little bit of support (Pt 8)
Care team	I am very grateful to hospice for taking care of others… of all kind of patients in fact… They’re providing attention, by caring, I’ve got someone to talk to when I feel depressed… (Pt 4) I was so happy when they [hospice nurses] come and talk to me (Pt 5)
Relating to medical management	
Faith in doctor	Doctors will give you hope, you know why… I mean they studied hard, you know what I mean, so you’ve got to hope in them (Pt 6) They [the doctors and nurses] encouraged me, and I… I’m fine doctor. That’s why if I go to hospital, I don’t want to miss a day. If they say today is your appointment day, I wake up in the morning and go… Because I rely on them so much… without being cured by doctors, without taking this animal out of your body… no, if it’s still there, no, only doctors who were *trained* and *know* about this disease that can cure you… Yes, I’ve got too much faith… too much faith in them (Pt 7) And we gotta believe in the medical… you know the doctors… Ja, we said we gotta believe in *both* [God and the doctors] in order to survive… Ja, I got nice support, the doctors are good ja, ja (Pt 10)
Faith in medical treatment	Hope is something that I always have. Hence since I am here in hospital I have so much hope… I have hope since I have cancer and I am here in the hospital. I know life can change and everything can change (Pt 3) Well every time I take the [chemotherapy] tablets, I do say a small prayer before I take my tablets… Well, I say Lord You are gracious and I pray that this will assist me and that it works! (Pt 6)
Being treated with respect	But also in my nervousness, because I was scared, you know you had to lie on your stomach like that. So now I say I’m talking to the Lord now, but not loud, but I’m sure they all knew too… I think he [the doctor] respected that. And he

	aimed straight… I don't know what his religion was (Pt 2) And the treatment they're giving me, and you know, the way they handled my illness, I really appreciated it, because even when I didn't want chemo, the doctors… they were fine with it, they didn't get upset with me… Yes, or they didn't say – you know you're being stubborn, or you're not listening to what we want – they told me it's *your* decision (Pt 11)

Table 9. Statements from patients relating to the source of their hope

4.6.2 What diminishes hope for patients

Patients were asked whether there is anything that takes their hope away. Patients expressed diminished hope relating to spiritual, psychological, social and physical burden, or in relation to the medical team. Four patients stated that nothing can take their hope away (see Figure 15). Table 10 gives examples of statements relating to these subthemes.

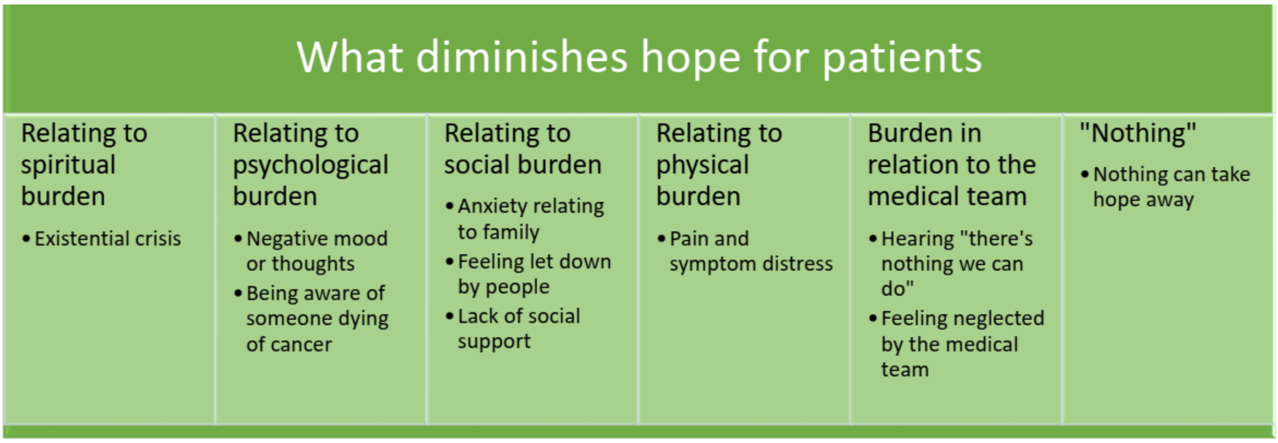


Figure 15. Subthemes relating to what diminishes hope for patients

Subthemes	**What diminishes hope for patients**
Relating to spiritual burden	
Existential crisis	I was in a state of shock… I said why me? I have done good in the world, why me? (Pt 4)
Relating to psychological burden	
Negative mood or thoughts	Some days I have hope, some days I don't have hope. It depends on how my mood and the day goes. If there is something that doesn't sit well with me, I lose all the hope I have (Pt 3) Ah not really… it's just that when I come across somebody who is negative –

	yes, then that person or the conversation like takes away my hope, yes – but otherwise no, I'm a very positive person, yes yes (Pt 9)
Being aware of someone dying of cancer	Yes sometimes when I… sometimes I see or when I read about some people… like recently a friend of mine was also diagnosed with cancer and died… and then I think what if it happens to me? What's gonna happen to my baby? What's gonna happen to my husband? (Pt 4)
Relating to social burden	
Anxiety relating to family	There's nothing I can do really to help in that [difficult family] situation. That's what makes you feel a bit on the helpless side (Pt 2) But as I say, it's sad, it's sad, because I feel, if something happens to me then I'm going to miss my grandchild, my family, you know? (Pt 11)
Feeling let down by people	What takes away my hope… sometimes people can disappoint you, they do stupid things. But that's life, you can't control that (Pt 2) Ja… things like relationships [take away my hope]… Yes, so then it's not working out for me, those things (Pt 8)
Lack of social support	If I can say perhaps that my children don't love me, or neighbours don't like me, I can say hey! let me die, you see like that (Pt 7) It's something that's very sad, it's very sad… especially when you're alone, it *gets* to you (Pt 11)
Relating to physical burden	
Pain and symptom distress	So that's how I lost all my hope when I found that my arm will never work again (Pt 3) Ja, sometimes, like when I felt very sick the other time, it was bad, bad, bad, I just couldn't handle it, couldn't handle it – because you couldn't do nothing, whether you were sitting or lying down… And I just didn't know what to do, you know what I mean? It was terrible, terrible (Pt 6)
Burden in relation to the medical team	
Hearing "there's nothing we can do"	Yes and I wouldn't like someone to let me down. If I feel there's a hope in a person and then someone else, a third person says, there's nothing you can do – no, you gotta be aware (Pt 1) If the doctors say something that makes me lose hope, I lose the hope I have in that way (Pt 3)
Feeling neglected by the medical team	My problem that doesn't sit well with me is that they burnt [irradiated] me one side. That's when I started losing hope because I ask myself why they didn't burn the other side because they saw it had the cancer too and they know these things. Why they only burnt me on the one side?… Maybe I wouldn't be like this if they gave me radiotherapy on both sides (Pt 3) Yes, yes, yes… there were some doctors in [hospital's name], they didn't know

	what they were talking about… I was lacking the plan of action (Pt 6)
	“Nothing”
Nothing can take hope away	There’s nothing [that can take my hope away] (Pt 5) Hey nothing can take my hope away, nothing… *Nothing* can take my hope away, *seriously…* Ai, I doubt anything can take my hope away (Pt 10)

Table 10. Statements from patients relating to what diminishes their hope

4.6.3 Patients’ experience of hope while having cancer

Patients were asked about their experience of hope while having cancer. Patients expressed that hope changes over time, that hope changes how they live, cope, accept their illness, view their mortality, think and connect with others (see Figure 16). Table 11 gives examples of statements relating to these subthemes.

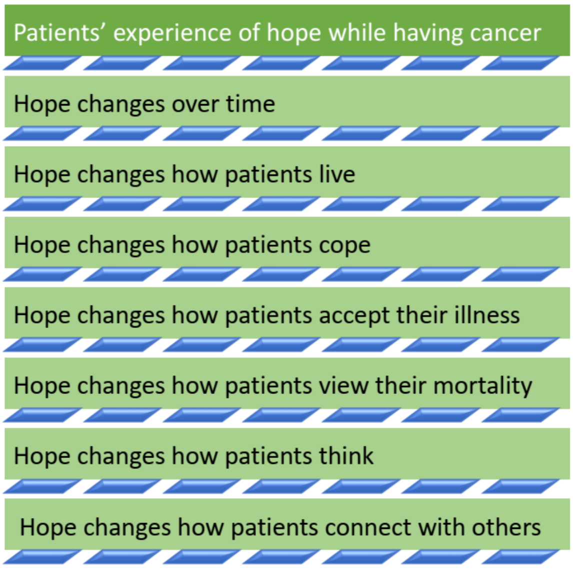


Figure 16. Subthemes relating to patients’ experience of hope while having cancer

Subthemes	**Patients’ experience of hope while having cancer**
Hope changes over time	It [hope] has changed a lot, yes, but I’m living with it, and I’ve adjusted to this illness, yes (Pt 9) I’ve had an experience, because in the situation I *was* in in the beginning of my cancer, and now – there’s a *difference…* Sometimes when I look at myself, I say to myself no, I can’t be having cancer… Because I have different days, like today you see me, ok I’m fine… Sometimes I just sleep the whole day because

	I'm sick, you see, that's how it is. I have a good day, I have a bad day (Pt 11)
Hope changes how patients live	No it's… I still hope for… like I still carry on like you know, my health, like what I had a few years back, is not the same. But then I still carry on, I don't let that be my setback. Like I still try to carry on with a normal life (Pt 1) No, not really… I don't really worry about the cancer anymore… I used to, at one time in the beginning, and then I overcome it… I overcame it and I don't really worry with the cancer… I think if you worry too much, you see when you're sick, ok like cancer, if you've got cancer, you keep on saying "no I've got cancer, I've got cancer", you're bringing down yourself… You know, you're not giving yourself the hope – because you keep on telling me… "cancer, you taking away", no no man, you tell the cancer – "ok it's fine, you're there, you fine… you *stay* where you are, I'll have the treatment, to sort you out, and I'll carry on with my life" (Pt 10)
Hope changes how patients cope	They [doctors] are here to help us eliminate this disease, but if it doesn't, if it is there forever, you won't… you can do nothing, you have to wait for your day, but don't tell yourself that oh! I'll die today or oh! I'm sick, because I see my stomach is… oh I've got a stomach ache, it's this disease… I've got a headache, it's this disease, no! Take it as if it's not there, it's not there at *all*, just be friendly to people, talk with people, be nice to everyone… Tell them, even those who are sick, tell them no, this is a killer disease, no but you're not going to die now. Look at me, I was… in 2019 I was diagnosed with this, but I'm still alive (Pt 7) No one can say that they *always* have a good day… You can still live with the hope, *yes* (Pt 9)
Hope changes how patients accept their illness	So with both prayer and medical… we put together and put it forward and forgot about the cancer, and went forward in life… Ja, that's what we done (Pt 10) It took me time, to get myself together, and I… I said to myself you know what, I can't go on crying about this, this is something now that I've got to *accept*, that this is what I've got in me, and I've got to go and get help, and do whatever I need to do to… to see what happens after that (Pt 11)
Hope changes how patients view their mortality	No, I don't think that… my… if I die from cancer or I die from somebody running me over in the road or something, it's immaterial to me… My hope is in… the Lord (Pt 2) Yes, my hope if the Lord comes to fetch me it's fine… If you think of what life's gonna be like here another ten years from now. With the way things are now. You know, then I think hey Lord, I'm glad you're fetching me earlier (Pt 2)
Hope changes how patients think	Then, the way that the doctors spoke… so they came to see me the next day when I'd recovered... the doctor had that kind of… that character, that personality that you take to him and you won't be scared (Pt 1) Ja, you see, in the beginning, you've got no hope, you don't know nothing

	about the disease and… everyone is telling you this story and that story and you are more negative than anything else… and then I turned the situation around… and I said you know what, I had a good innings… last year what I was 63, 64 and I said to myself, I said you know what hey, let it happen if it has to happen, so I used to just keep turning everything around positively (Pt 6)
Hope changes how patients connect with others	Like for instance, when my sister was suffering, she had cancer… We used to encourage her then… I used to hold her hand and bring her… I never had it in my mind, I didn't want to accept that, the fact that's she's going to … but I always given her the hope. That is why I encouraged her to come (Pt 1) It changed, the hope, ja… It changed the hope, about other people… Yes, I've been able to talk to them about cancer… because now I'm having cancer… Yes… To support, ja, and talk about it, ja, and counsel… Ja, I give them the hope… I give them the hope and um… I will talk to them about it, so that they can have the hope too… Yes, I will encourage them (Pt 8)

Table 11. Statements from patients relating to their experience of hope while having cancer

4.6.4 Patients' experience and preference regarding receiving prognostic information and bad news

Patients' experience and preference regarding receiving diagnostic and prognostic information was discussed, particularly in the setting of deteriorating illness. Ten patients expressed a preference for honest discussion about their diagnosis and prognosis, while one patient (Pt 5) preferred her family to be told on her behalf (see Figure 17). Table 12 gives examples of statements relating to these subthemes.

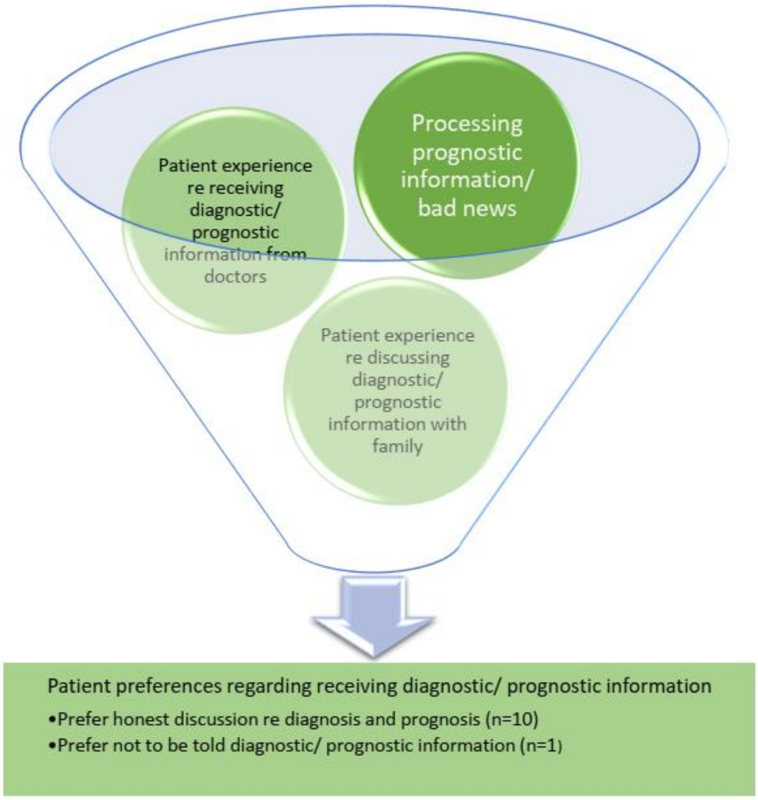


Figure 17. Subthemes relating to patients' experience and preference regarding receiving prognostic information or bad news

Subthemes	**Patients' experience and preference regarding receiving prognostic information/ bad news**
Experience regarding receiving and discussing diagnostic/ prognostic information	
Experience re receiving diagnostic/ prognostic information from doctors	I was telling [son's name] that you said I must dance a little bit sooner with [grandson's name] and not wait for when I'm 80… And I could see he didn't really want to talk about that so I just left it, but I'm glad you told me because… to me, I know, ok, I've got X amount of time, whatever that's gonna be, and maybe it's good for him too, although it's more difficult for them, whether he's told [grandchildren's names] about it I don't know… And it doesn't have to suddenly fall on them sort of thing (Pt 2) You know the doctors will be trying to assist you and there's no guarantee, because cancer is… and with my case it was… *very* advanced… then she spoke to me and… and then she explained… because she was honest with me… she told me… and she did mention it, "You seem to be taking it ok" (Pt 6) I cried a little bit, ja I cried… I did cry… I did cry because I was very depressed, you know the shock and everything… And then eventually I overcame everything (Pt 10)
Experience re discussing diagnostic/	Then afterwards, a couple of other times I did have a… this thing… like in the situation with my wife, but I didn't want to tell her it all… or about the stage… you know I just wanted to water it down a bit, you know what I mean? Then

prognostic information with family	slowly as time went on, and she was hearing from other people… (Pt 6) Ja, tell me, and she's [his wife is] there to support me, because she needs to ask any questions, and she'll ask them, she don't be afraid, to clear our mind before we walk out of the doctor's rooms, so we know where we stand and what is happening and what is needed to be done (Pt 11)
Preference regarding receiving diagnostic/ prognostic information	
Prefer honest discussion re diagnosis and prognosis (n=10)	I want to be told as to what my position is, and I'd like the family to know where I stand. So that they can know how to support me (Pt 1) Eish I would like them [the doctors] to let me know so that I can know what is going on in my life although it will cause me stress, because I will have so much stress (Pt 3) No I want the truth doctor, truth cures. I want the truth doctor, they [the doctors] mustn't hide what is happening with me. As I said doctor, I know that I've not come to grow as a *tree* or what, or I'm not going to remain as a what… I don't know what I can call it, I am a *human being*, I will pass as my parents died, as my ancestors died, so *they* must tell me the truth, they mustn't hide it from me… yes doctor (Pt 7) Just talk to me as normal, like how *you* are talking to me, it's fine. Ja it's nothing, it's nothing, you just have to tell me "I've got good news" or "I've got bad news"… It's fine… Ja no, it's fine man, good news, bad news, but it's better to hear the bad news from the *person* that's got the bad news to tell you, than hearing it from somebody else… I like to hear it directly from the doctor that's treating me, who tells me the bad news, it's fine! (Pt 10)
Prefer not to be told diagnostic/ prognostic information (n=1)	Tell the family… I don't think nothing about that (Pt 5)

Table 12. Statements from patients relating to their experience and preference regarding receiving prognostic information or bad news

4.6.5 Patients' experience and preference regarding receiving hope from doctors and nurses

Patients were asked about the role of healthcare workers like doctors and nurses in giving hope. Patients described their experience and preference relating to receiving hope from doctors and nurses (see Figure 18). Table 13 gives examples of statements relating to these subthemes.

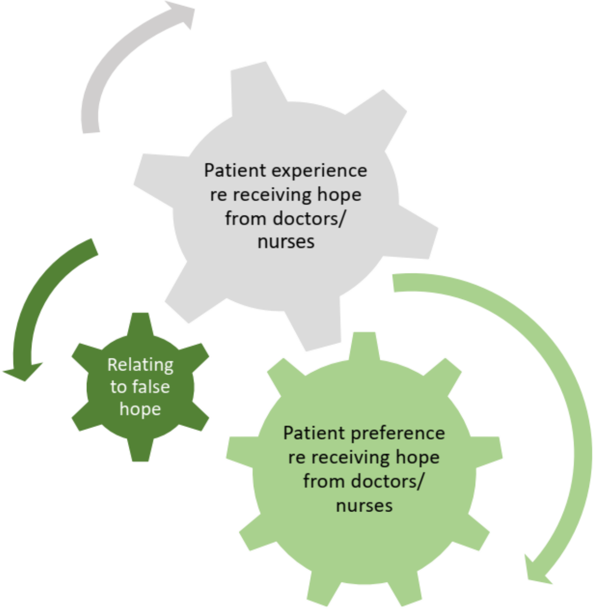


Figure 18. Subthemes relating to patients' experience and preference regarding receiving hope from doctors and nurses

Subthemes	Patients' experience and preference re receiving hope from doctors/ nurses
Experience re receiving hope from doctors/ nurses	You know without the doctors, before he treated me, you know I looked at the doctors and I said no, now I'm in the better hands. So the doctor removed the bag, he said this is your condition, this is how you're gonna be, and they were very kind, they explained everything. Then they set the ball rolling… And after the scan, they told me look this is what you've got. The doctors that I spoke to, when they examined me, I felt like I wasn't scared (Pt 1) I've grown so close to the doctors and to the nurses at [hospital's name], yes, even one nurse, she's very spiritual and she prays for me… Yes, whenever I go – yes… Yes she always say a prayer for me, she calls me aside and she says a prayer, yes… It's nice, you feel better, you know? (Pt 9) Ja, he's a doctor, a professor, he's very good, so he treated me [for pain] and gave me a lot of hope… His treatment was good, I don't know what he used, but his treatment was very good (Pt 10) No, the way they [doctors] speak to you gives you a lot of hope… Yes, yes, they did [give hope]… like when I was diagnosed the first time with cancer, in [hospital's name] it was a female, and she… she brought it out very calmly, and she even told me you know what, we're not gonna just say you've got cancer, we're gonna get a second opinion, we're gonna send you to [hospital's name], then we will really know whether this is right or whether this is wrong, you know… Yes, they didn't just throw it at you and say you've got cancer, and now you're gonna die, and this, they say, no, don't worry, we'll send you to [hospital's name], we're gonna get a second opinion… (Pt 11)
Relating to false hope	Yes I do, yes I do, yes [think doctors should give hope]… Encourage the person like, you know, to handle the sickness, to you know um… and not *false* hope,

	not false hope, yes ja (Pt 9)
Preference re receiving hope from doctors/ nurses	The doctors should give us hope. They can give us the hope we need, because they are the ones who send us for check ups and check up everything that is wrong in our bodies and they are the ones who see everything in us (Pt 3) I think, yes, you gotta give some type of hope… they [doctors] should be giving hope (Pt 6)

Table 13. Statements from patients relating to their experience and preference regarding receiving hope from doctors and nurses

4.6.6 Source of hope for family caregivers

Family caregivers were asked what gives them hope. The source of hope for caregivers related to their spirituality, psychological fortitude, human and pet connection and medical management (see Figure 19). Table 14 gives examples of statements relating to these subthemes.

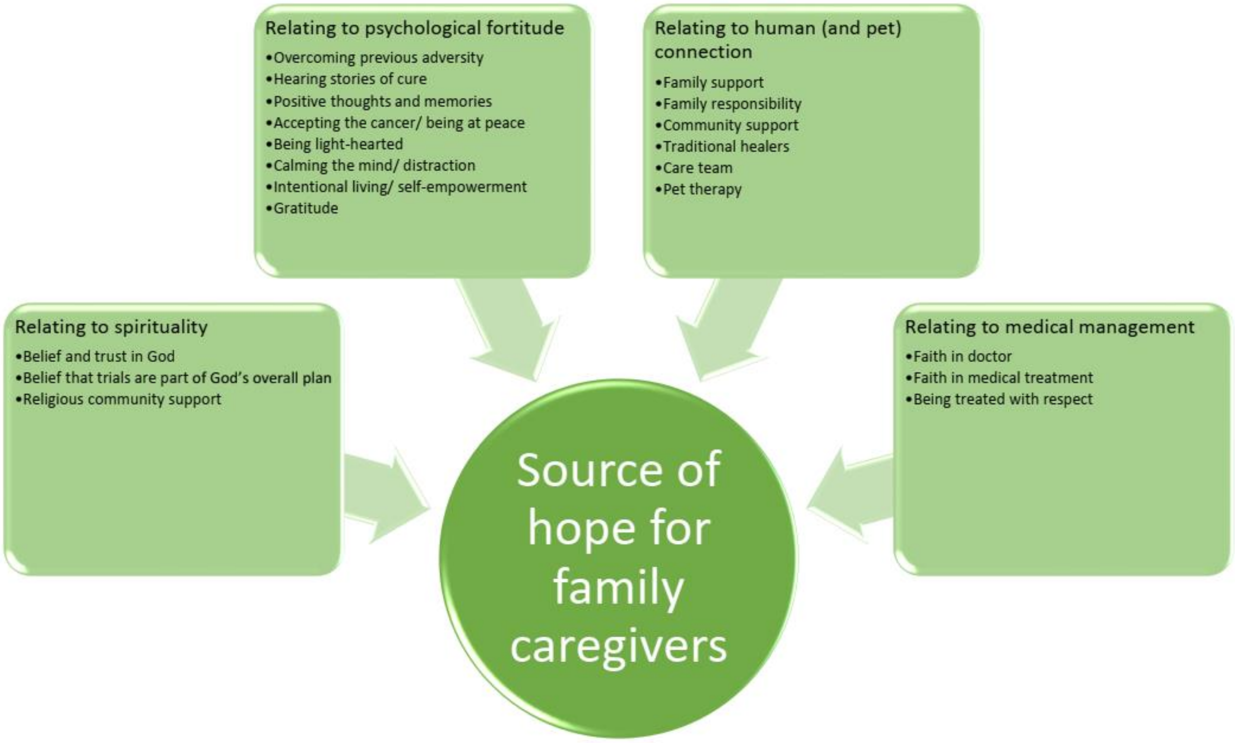


Figure 19. Subthemes relating to the source of hope for family caregivers

Subthemes	**Source of hope for family caregivers**
Relating to spirituality	
Belief and trust in God	I think it's [she has hope] because she's a believer in God. And that she has a knowledge that we have a beginning and an end in this life (FC 7) In the Almighty, like I said, I go through my stuff, I go through it on my own… Privately, in my own thoughts, you know? At the end of the day, it's just the Almighty – like my daughter is with me now for a little while, but she knows, when I go to bed, my hope is the Almighty, because… I plug my ear, and it's all religious stuff that I am hearing, so that is my source of hope, and my strength (FC 11)
Belief that trials are part of God's overall plan	I tell him God knows best… What's going to happen, ja He knows everything (FC 6) And I also tell him you know what, when you have your good days, you enjoy it; when you have your bad days, enjoy it as well, because it's all coming from the Man above… Whatever we go through, is by the will of the Almighty… It's not on our own (FC 11)
Religious community support	But she [hospice nurse] told me, you must pray (FC 1) And through prayer, through encouragement, he survived that… then the sepsis… you know we have our prayers, our bhajans and things like that, our songs… That's what we've been using and um for him to believe, although he was in a coma, that's what I've been praying and using that as a… you know stepping stone for him to get better (FC 10)
Relating to psychological fortitude	
Overcoming previous adversity	That's where my wife has actually gone from the bed to the wheelchair and she's got *hope* in her… And she *did* get better – from the bed to the wheelchair, that was a *big* difference, she *did* something ja… And she's trying to *fight* to walk as well, yes (FC 4) Yes, 2009 he had a stroke… He's recovered from that stroke as well… Well… after the stroke we sort of changed. Because with the stroke he lost his… well his mobility, so with therapy and with hope, prayer and encouragement, he came right (FC 10)
Hearing stories of cure	Because there's a lot of people who went through, in her situation, so that is why we still have hope, because there are people who are healed (FC 3) And even my son had lymphoma non-Hodgkin's – so he's also in contact with her, give her good… this thing… everybody is giving her that support, so I feel *that* is what really makes her so strong a person – hearing from others (FC 5)
Positive thoughts and memories	Yes, even my children give him hope… saying "don't worry, you'll be fine" (FC 1) It's hard for us to shed a tear, she doesn't like us to shed a tear… She is very strong… She'll tell us straight – if you want to cry, don't enter (FC 5)

	So all those memories gives me hope. There may come a time in my life when my kids will give *me* that hope, you know? (FC 11)
Accepting the cancer/being at peace	Each individual person – their mind, or their psyche, the way you process things is different to what the next person is experiencing… and like in, I use my mom's case as an example, because my mom is in such a good space… I know that she does have fear, and fear is a normal… would be absolutely normal to have… However when it comes to some… you know… other patients, as an example, you know that might be the worst fear that they can ever, ever imagine and you know they might not be in the same sort of peaceful state of mind where other people might be, and the, the effect of *that* might, you know, be manifesting itself in a totally different way to what it is with my mom for example, or with myself (FC 2)
Being light-hearted	We are taking it as a joke. She will say like "I am going to die, or I'm going to dodge a bullet and not die", and we will laugh. We don't get serious about it anymore… You see, we take it as a joke (FC 7)
Calming the mind/ distraction	Right now, there are days like that, but I just, I overcome it… I don't think about it, you see I get busy doing things, yes, I just leave him here and I go away to the kitchen… Yes I'll be active, I don't want to dwell on something (FC 1) Yes, and he mustn't stress, and if things are not working out the way you want it to work out, don't stress about it… Just sit back, relax, calm your mind down, and process it, and then see how you're gonna work it out… and eventually it will come right! (FC 10)
Intentional living/self-empowerment	Yes, yes, I was *all* the time with him, that time, I used to have a lot of hope because he used to go and come and do things (FC 1) I mean we cried for months, we cried, cried, cried. Eventually we said you know what? We're going to be in this together, and we're going to fight it, and we're gonna stick it out (FC 10)
Gratitude	It's just being thankful. I'm thankful for the patience of the doctors… I'm thankful, please pass on my gratitude (FC 7) You know, I have seen cancer patients, I've interacted with a lot of them, and… I always tell him also, there's patients out there worse off (FC 11)
Relating to human (and pet) connection	
Family support	So the kids also are there for us … They give us hope, give *him* hope, you see … And they're taking a lot of care of him at night, my big son will sit here, up and down, and they can see to him, especially in the night (FC 1) You see the support that each one of us gives to one another… You see that's the *hope* that we all got… the family support… The support of our children, yes… That's more stronger than anything else… It's all of us in it (FC 5)
Family	While [husband's name] my husband is living, I've still got hope (FC 1)

responsibility	No we do… ja no definitely, ja ja… I mean there’s times when you’re down, when you feel down about it, but then you need to pick yourself up and think about others, because now you must understand, everybody has to depend on you (FC 10)
Community support	We all check if they’re all alright, maybe they have something to eat and even though we don’t have much, but whatever we have we share… Ja… it [the community support] gives us hope (FC 3) We always want to encourage other patients as well, because we’ve been doing that, we’ve been doing that… We have to, we have to be there for each other (FC 10)
Traditional healers	It [herb] will work for cancer patients, because my ancestors told me that it will work for cancer, but they want me… yes, they want me to understand that herb, and do more studying on that herb, so that I can give the thing that I really know… that will cure people… but I… I want to go further, and to go to the laboratories… So that anyone can see that this is the herb that can cure cancer (FC 8)
Care team	That hope that they’re [hospice nurses] giving *me* to have strength to give *them* [wife and child] strength, yes (FC 4) Even when it comes to the hospice team, they’re very supportive, and they love him… and they’re forever giving him hope… I would say again the staff of the hospice have been very supportive, they’ve seen him on his worst days, and they’ve seen him on his good days (FC 11)
Pet therapy	My dog takes a lot of time [laughs], our pet… he came at a time when we really needed him. He was a stray. He was a stray, and he came the time when my husband was at his very very worst time… Yes, and he became such a big part of our life! He’s been amazing as well, oh he’s just too loving (FC 10)
Relating to medical management	
Faith in doctor	You see they [doctors] give her treatment, like everything, they look after her, that gives you hope (FC 3) I have hope for [relative’s name] since she will be seeing a doctor soon (FC 7) Yes, because I saw that [relative’s name] had, has a hope… and she said that one day maybe I will cure this cancer, with the doctors and the nurses… She had a very good hope… Because the doctors are taking good care of people (FC 8)
Faith in medical treatment	Yes… that is why we still have hope… she does chemotherapy, and now she’s in hospital, I have a lot of hope (FC 3) There’s nothing that we *can* do, there’s the medication… we’re just praying for her to be pain-free (FC 5) And my dad also didn’t give up hope… the doctors had told him, even if you

	have to go for chemo, it's too late now… but he had been persistent that he *wants* the chemo, because he had *hope*, you know? (FC 11)
Being treated with respect	And the social worker, sister - that was very nice, that Friday we came there and everybody spoke to us, that gave us the hope and courage (FC 1) Speaking from the experience that I'm going through now, and the experience that my mom's going through now… I think the added benefit that we've had… going through the relationship with [social worker's name] and the connection between… you know between all the different people that we've been dealing with, based on that relationship… has made it… has made a… a marked difference in our experience that could be very different to the experience for a person that… that doesn't or did not have that type of connection… or… or sort of structure that they can lean on or people to talk to (FC 2)

Table 14. Statements from family caregivers relating to the source of their hope

4.6.7 What diminishes hope for family caregivers

Family caregivers were asked whether there is anything that takes their hope away. Caregivers expressed diminished hope relating to spiritual, psychological, social, financial and physical burden. Three caregivers stated that nothing can take their hope away (see Figure 20). Table 15 gives examples of statements relating to these subthemes.

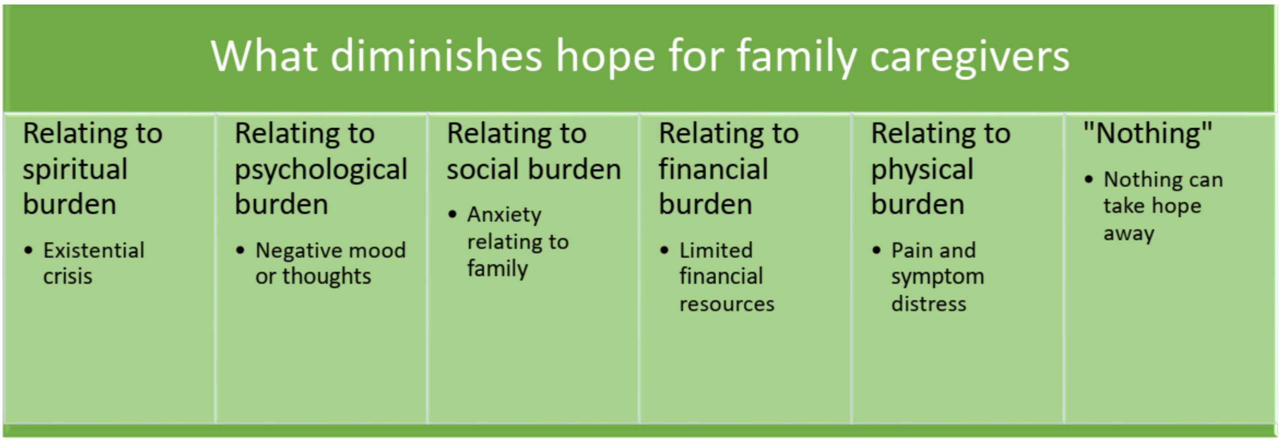


Figure 20. Subthemes relating to what diminishes hope for family caregivers

Subthemes	**What diminishes hope for family caregivers**
Relating to spiritual burden	
Existential crisis	I didn't expect God to do this to us… I didn't think I'm gonna see this… Some other way and maybe we would have been able to handle it, but don't give her a sickness where we can't even heal her! (FC 5)

Relating to psychological burden	
Negative mood or thoughts	That stress, and stress tends to… you know the mind is a very powerful thing and, you know, that could end up that the physical part of a person's well-being actually goes backwards because of… the mental, the mental side… (FC 2) Sometimes when he's being… when he's grumpy with me, when he's angry, when he shows a little bit of aggression, that's the only time [he is less hopeful], but I always say you know what I'm sorry, and let's… let him, you know… it's his pain, he knows what he's going through, so just forgive him and let him carry on… Yes it's just for a short while… that's how it is (FC 10)
Relating to social burden	
Anxiety relating to family	At that last… last week when she was here, at her home, she has hope but she was worried about her son, very worried about her son… I think the level of hope at that time goes down (FC 8)
Relating to financial burden	
Limited financial resources	Yes… she left the children and she's apologised and financially she knows she left home and it's almost like, there's no income, only grant, so that is why, I think sometimes she gets stressed because of that (FC 3)
Relating to physical burden	
Pain and symptom distress	It was the time when she was starting to attend [the hospital]. Not that we lost hope, but it was like it [the cancer] was destroying her, but eventually things got better, the time she was doing chemo (FC 7) Like many a time he would say I give up now, the pain is too much, I can't handle it. So then I tell him, you have your days, one or two days you're down, then you're up again (FC 11)
"Nothing"	
Nothing can take hope away	Not really, because we have got the support (FC 5)

Table 15. Statements from family caregivers relating to what diminishes their hope

4.6.8 Caregivers' experience of hope while caring for a family member with cancer

Caregivers were asked about their experience of hope while caring for a family member with cancer. Caregivers expressed that hope changes over time, that hope changes how they live, cope, accept illness, view mortality, think and connect with others (see Figure 21). Table 16 gives examples of statements relating to these subthemes.

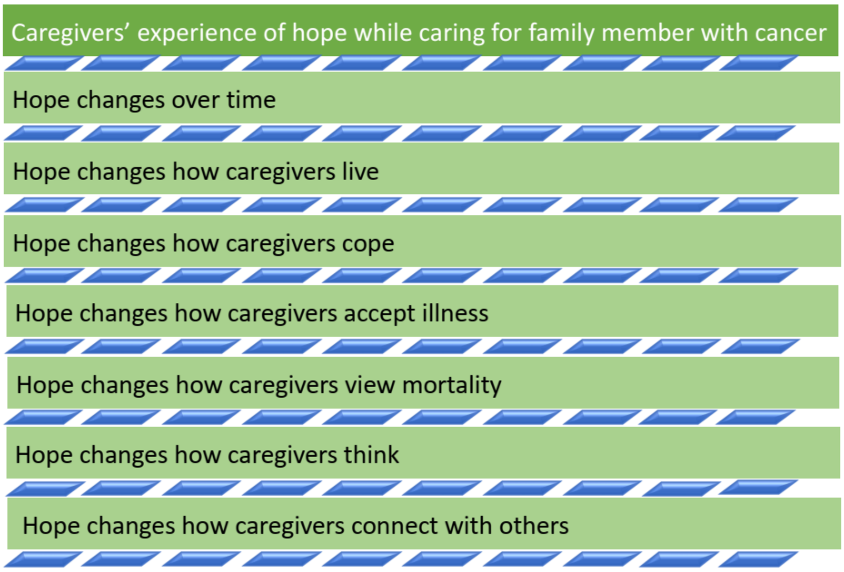


Figure 21. Subthemes relating to caregivers’ experience of hope while caring for a family member with cancer

Subthemes	**Caregivers’ experience of hope while caring for a family member with cancer**
Hope changes over time	That’s what really stuck us very badly, even if God had taken one hand or leg away from her, we would have been able to help her, but not this, this is very hard for anybody, out of anyone, it’s very sad, we never knew that it’s gonna hit us so badly… but now I’m, I’m coming to terms with it, and I understand… At least God should give her a little, just a little bit of peace and freedom… she needed that me time (FC 5) And then when things were just coming better for us, he had this incident with this cancer… for now we’re still, I mean… look, within the first two years of the cancer, he was very very bad… He was extremely bad, I’m sure you must have seen it on his reports or something… And we also thought we were gonna lose him… And through prayer, through encouragement, he survived that (FC 10)
Hope changes how caregivers live	Hope is what makes us live. You must stick to hope because it makes you live my child (FC 7)
Hope changes how caregivers cope	Mmmm, mmm… I mean, because when the doctors told him [he had cancer], he looked worse in those two years, that was depressing… But we overcome *all* that (FC 10)
Hope changes how caregivers accept illness	Yes after… like once she fell… Yes… she asked me, “I don’t know why this is happening to me” so I said, “It’s all part of life” (FC 5)
Hope changes how caregivers	Nobody can tell you how long you gonna live… Nobody… but… *but*, you gotta have ah… encouragement and the hope, that’s where the hope is… yes (FC 10)

view mortality	
Hope changes how caregivers think	I mean we cried for months, we cried, cried, cried. Eventually we said you know what? We're going to be in this together, and we're going to fight it, and we're gonna stick it out (FC 10) A person with cancer, you also don't lose hope, you learn to accept, and you look at the bigger picture… There's patients worse off out there (FC 11)
Hope changes how caregivers connect with others	Hope, my child, when she was telling me about her sickness and the way she was worried, I told her that she was better and looking healthy (FC 7)

Table 16. Statements from caregivers relating to their experience of hope while caring for a family member with cancer

4.6.9 Family caregivers' experience and preference regarding receiving prognostic information and bad news

Caregivers' experience and preference regarding receiving diagnostic and prognostic information was discussed, particularly in the setting of their family member's deteriorating illness. Ten caregivers expressed a preference for honest discussion with the patient about his/her diagnosis and prognosis, while one caregiver (FC 5) preferred the family to be told on the patient's behalf (see Figure 22). The same patient however, presented with the suggested treatment option (radiotherapy) in discussion with the family, made an autonomous decision to decline the suggested treatment (FC 5). Table 17 gives examples of statements relating to these subthemes.

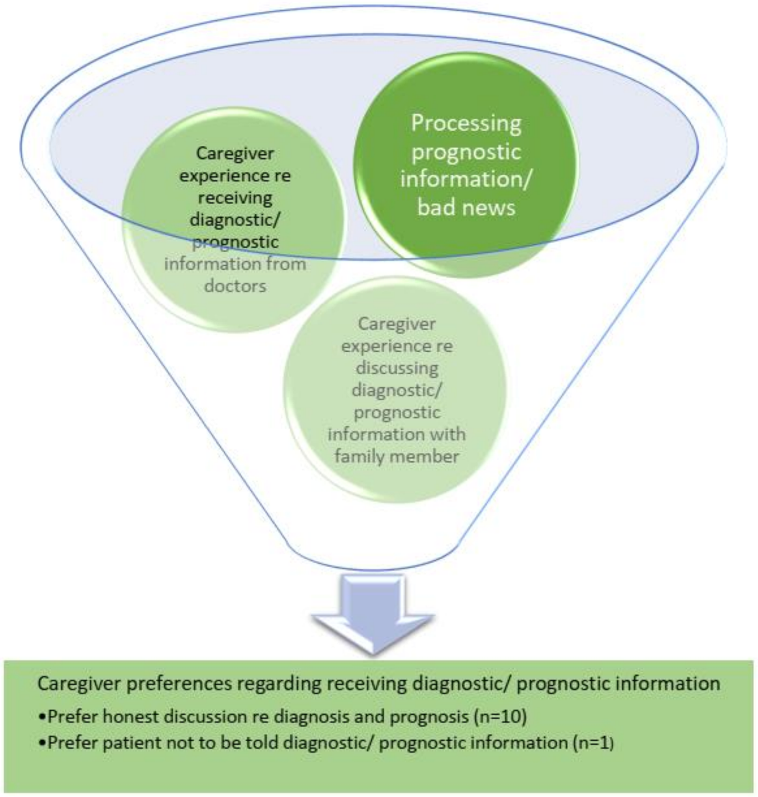


Figure 22. Subthemes relating to family caregivers' experience and preference regarding receiving prognostic information or bad news

Subthemes	**Caregivers' experience and preference regarding receiving prognostic information/ bad news**
Experience regarding receiving and discussing diagnostic/ prognostic information	
Experience re receiving diagnostic/ prognostic information from doctors	No but, I'm ok with it, I *was* a bit heartsore, when they told us now that it's spreaded throughout, and the doctor at [hospital's name] also told me. That time, I lost a bit of hope, but then they said no, let's not do this, and not let *him* get disappointed, and he mustn't feel that we are losing hope (FC 1) Yes… when we found out, it really got me… We didn't expect that… we had other family members that had cancer and thing, but we didn't expect to get that news, we just thought, you know it was going to be like a normal woman's sickness… Yes. So it was a big shock to everybody (FC 5)
Experience re discussing diagnostic/ prognostic information with family member	Every time that I've seen my mom now, the previous time, we did have a sit down and… how are you feeling? What are your wishes?… How would you like it to see it happen? Whether it's possible or not, just to talk about it and vocalise it so that, so that you know, so that everybody knows, so that you know that's what it's all about (FC 2) Yes… so, she sit down with me and tell me everything that she has a… a cancer. Then I told her that she mustn't lose hope… Because the doctors are taking good care of people (FC 8)

Preference regarding receiving diagnostic/ prognostic information	
Prefer honest discussion re diagnosis and prognosis (n=10)	Ja, I think she would [want to be given the information]. You know, because my mom has handled, you know this is my perception… because she's handled this bad news so well, you know, I think she would want to know… because at the moment she's on this high, she's experiencing… you know she's feeling a lot better, she's got a lot more comfort… But in, you know, in the scheme of things… you know I also know it's not going to last forever and because of the… because it's a progressive disease that you know at some stage, it is going to start getting worse… And I personally feel that she would want to know… And I think that would also just… you know, it would give her that peace of mind of what to expect and when to expect it, ja (FC 2) That was her decision, she refused to have it [radiotherapy]… But we explained everything and then she decided not to take the radiotherapy… It was better if she knows what it is going to be like (FC 5) Yes we do, definitely [want the information as a family]. At least to be aware of it (FC 5) Ja, ja, but so far with things like scans and that… we always wanted to know what's going on, and then they show us, they show us… so we know what's going on, we definitely like to know what's going on, I mean (FC 10)
Prefer patient not to be told diagnostic/ prognostic information (n=1)	I think when it comes to [her mother] like she'll ask us if it's ok, then maybe my brother or somebody will tell her like what to do (FC 5)

Table 17. Statements from family caregivers relating to their experience and preference regarding receiving prognostic information or bad news

4.6.10 Family caregivers' experience and preference regarding receiving hope from doctors and nurses

Family caregivers were asked about the role of healthcare workers like doctors and nurses in providing hope. Caregivers described their experience and preference relating to receiving hope from doctors and nurses (see Figure 23). Table 18 gives examples of statements relating to these subthemes.

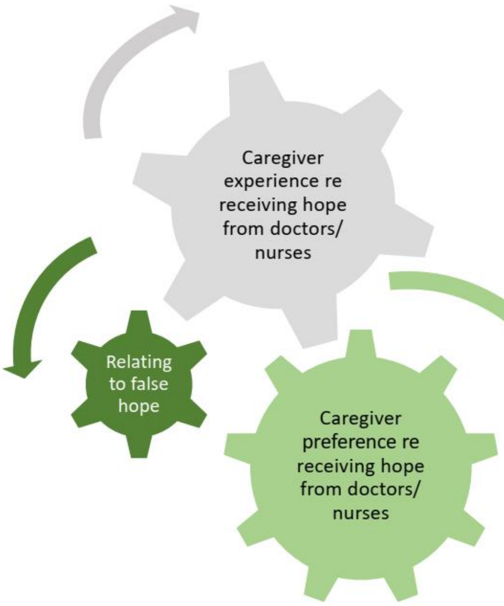


Figure 23. Subthemes relating to family caregivers' experience and preference regarding receiving hope from doctors and nurses

Subthemes	**Family caregivers' experience and preference re receiving hope from doctors/ nurses**
Experience re receiving hope from doctors/ nurses	Say for instance the nurses who came now [from hospice], when they come and talk to you and they say like you know… she feels so much better… You prefer them to do that for you and to give you hope… To give you hope, to give you motivation… Like if they talk to you now you feel so nice… She always talks about Sr [name]. When we come from work she'll say she came and spoke so nice to her. They [the hospice nurses] love her to bits… The more they talk to her the more comfortable she feels (FC 5) No, it's also for the doctors as well… No they've always been supportive, and they always have given him hope (FC 11)
Relating to false hope	No, I think… you know… everybody that, everybody that we've dealt with so far has been you know very professional and you know, there's definitely been no experience from my side specifically of any creation of false hope… It's really… it's been… factual (FC 2)
Preference re receiving hope from doctors/ nurses	Yes, I would *love* that… You can give us the hope also… We *want* your encouragement (FC 1) Yes, more like to encourage the person, motivate them, give them like a speech or a talk or something to make them feel happy inside - like you know what, "I'm always having those negative thoughts, lucky this doctor came along, and she brightened up my mind and now I can think positively" – that can motivate them then yes (FC 4) Aish, it's better to give hope… Because you can't know… you won't know if after that, after a period, you don't know when a person hearing those words,

	how will he react… It's very difficult… it's hard, to know how she's gonna take the news, how she's going to handle that thing… But the hope is the one (FC 8)

Table 18. Statements from family caregivers relating to their experience and preference regarding receiving hope from doctors and nurses

Tables 5 to 18 give examples of participant statements relating to the themes and subthemes. The researcher has compiled separate tables with the comprehensive data; these tables are available from the researcher upon request.

4.7 Conclusion

This chapter has furnished the results obtained from the study, separated into patient and family caregiver sections. Interpretation and further discussion of the results will be presented in the following chapter.

CHAPTER 5

DISCUSSION

5.1 Introduction

This chapter discusses the study findings. The results given in the previous chapter will be interpreted and related to the clinical and demographic contexts of the study participants. The findings will also be evaluated against the backdrop of previous research, and new information obtained in the current study will be highlighted. Strengths, limitations and future implications relevant to the research will be discussed.

5.2 Analysis of the data

5.2.1 The study sample as representative of KZN’s population

The study sample, determined by purposive sampling, included 11 patients and 11 family caregivers. An attempt was made to achieve diversity regarding clinical and demographic factors. Patients chosen had locally advanced and/or metastatic disease from a variety of the more commonly seen solid cancers. There was variance regarding performance status, involuntary weight loss (an indicator of cachexia in advancing illness), current or planned oncology treatment, time since diagnosis of advanced cancer and time under palliative care.

Regarding patients and their identified family caregivers, the study sample showed variance in gender, age, first language, marital status, religious affiliation, highest level of education, income and employment status, home location, access to household amenities, household arrangement and size, and number of dependents on the family caregiver. In these areas the researcher felt that KZN’s general adult population was reasonably well represented.

There are however notable exceptions regarding these variables: There were no young adults in the study sample; the youngest patient and family caregiver interviewed were of age 35 years and 28 years respectively. Most family caregivers interviewed (81.8%) were female, in keeping with the caregiving role in SA typically falling upon women rather than men. No study participant lacked social support. Each participant felt supported by family, neighbours and/or the wider community. Although two patients and one family caregiver lived alone, each confirmed good social support.

The average household size in SA is 3.49.(153) In this study, household sizes were bigger than the national average (3.64 and 5.09 for study patients and caregivers respectively). The low or middle annual household income of most study participants, particularly when considering their household arrangements and sizes, and lack of access to household amenities, reflects the financial poverty typical of households in KZN. Only one study participant, a family caregiver, fell into the upper-income group. No patients were employed at the time of interview, in keeping with their age and/or advanced illness, and those not yet qualifying for state pension received financial support from various state grants or family. The two male caregivers were both formally employed and balancing their employment and caregiving roles.

Regarding religious affiliation, all study participants identified with either the Christian, African Ancestral, Hindu or Muslim faiths. There were no atheist or agnostic participants. While religious affiliation does not necessarily mean strong adherence to religious doctrine or rituals, there is belief in God or a Higher Power. An attempt was made to differentiate religion being "not at all important", "somewhat important" and "very important". No study participant felt their religion "not at all important". The vast majority considered their religion "very important". Although the researcher had intended to interview patients from all religious faiths, and patients without a particular faith, no suitable study patients from the Jewish religion, or religions other than mentioned, or atheist or agnostic, were readily identifiable during the time allocated for data collection. These limitations to the study are discussed further below (see 5.6). Only one caregiver, a traditional healer herself, identified openly with the African Ancestral religion, and claimed that she was also Roman Catholic. Indeed a close relationship between African Ancestral religion and The Catholic Church has been identified.(165) Although only one participant stated direct affiliation with the African Ancestral religion, one patient and two caregivers were members of the Zion Christian Church, which is an African Independent Church upholding both Christianity and an African spiritual religion and culture, and which believes strongly in spiritual healing.(166)

5.2.2 The exploration of the importance of hope for adult patients with advanced cancer and their family caregivers in KZN

There was unanimous affirmation by the study patients that hope was important to them, in all contexts, through good days and bad. As Pt 9 stated, “Well, with us, with us cancer patients, we *need* hope, we need hope… and we need to feel *good* about ourselves and although we sometimes be in pain, or discomfort, you know… but we must overcome that with hope”. Family caregivers likewise unanimously agreed that hope was important, particularly in their caregiving role. As FC 3 affirmed, “Yes, it’s very important to have a hope… yes, hope is the key… I’m saying that I *do* have hope, so it’s nice when you’re looking after someone you must have hope, so they can feel much better”. There was complete concordance regarding the importance of hope within all patient/caregiver dyads.

5.2.3 The exploration of the meaning of hope for adult patients with advanced cancer and their family caregivers in KZN

5.2.3.1 The meaning of hope for patients

In SA, where most of the population identifies as religious(153), it would be expected that spirituality would play an important role in the meaning and experience of hope, and indeed this was found to be true. Within our sample, there was no association found relating the meaning of hope to clinical or socio-economic factors such as education, level of income, marital status or housing.

Regarding the meaning of hope in relation to their **spirituality**, patients asserted their belief in God and belief in oneself. Belief in God played a strong role in the meaning of hope whether patients reported their religion to be “somewhat important” or “very important”. Pt 2 for example said, “Hope, in myself is… it’s just my belief in God. That’s my hope, that’s where I’m going. He said

He’s prepared a mansion for me, that’s where I’m going. So that’s where my hope is”. Patients spoke of their hope for an afterlife/Heaven and for meaning in suffering.

Hope was also related to **having a goal and purpose**. As Pt 4 stated, “One should never give up, always should have a focus”. Patients spoke of goals they hoped to achieve. Despite several participants coming from very poor economic circumstances, surprisingly only one patient expressed hope for financial improvement, and this to reach a travel goal. Many hoped-for goals were very generalised, such as hope for a better world or a better future. A few patients had specific goals, but goals in general were unfocused in terms of time and scope. As an example, Pt 1 expressed, “Yes, you always hope for something that one day you could achieve this, or one day our time will come when we get to… *one* day we hope to visit the temple or certain places”.

Patients spent more time speaking about health-related goals, which were more focused. Here hope was related to **living well yet being ready to die**. Six of the 11 patients spoke about hope for a miraculous cure. All six patients however also spoke about being realistic about their prognosis and conveyed the tension that exists between hope for a miraculous cure and acceptance of advanced cancer. Pt 11 expressed this tension well by stating, “Miracles can happen, even if it’s not – cancer is not going to get cured, that’s what *we* know and that’s what we’ve been told, we don’t know, but it depends on the Almighty, it may just go away overnight, you know?”. These six patients hoping for a miracle represented three religions, Christian (Zion and non-Zion), Muslim and Hindu, both men and women, a range of ages (42 to 66 years), a range of performance states (PPS 40 to 80%), a range of cachectic states (0 to 15kg weight loss), all households (rural, periurban and urban) and both middle- and lower-income groups. Hoping for miraculous cure while being realistic about poor prognosis therefore was not context specific. It is perhaps noteworthy that the patient with the poorest PPS (30%) and greatest weight loss (20kg) did not express a hope for miraculous cure, but for comfort at the end-of-life.

Three patients expressed hope for improved survival, particularly to sort out personal affairs and for their families to be stabilised. This was expressed by the youngest patient (age 35 years) and two patients in their early 60's. Almost all patients (representing PPS 30 to 80% and <5 to 20kg weight loss) expressed hopes for better QoL, including improved function, self-sufficiency, symptom improvement and to not suffer at the end-of-life. Pt 6 acknowledged, "So basically, I'm just looking for a nice quiet time and that's it… no suffering, no pain or anything… If you go, you go, you know what I mean… Not suffering, you know what I mean". In summary patients hoped to live well, and many hoped to live longer. Patients largely felt prepared for death but hoped for **physical and psychological comfort** particularly at the end-of-life.

Many patients, from all contexts, equated hope to **psychological fortitude**, such as encouragement, strength or endurance, courage and being positive. Patients from all contexts also related hope to **human connection and support**. Pt 9 stated clearly, "Well, my hope is love… love and the support that I get, you see?". Many patients spoke about their families, and hoped that their families would be cared for and stay peacefully united. Pt 5 hoped for "nothing else… just my children will all be together… and they will be happy… I want *all* of you to live happy, I want *all* of you to live in peace".

5.2.3.2 The meaning of hope for family caregivers

The meaning of hope for family caregivers was thematically very similar to that for patients, although hopes appeared to be more focused and arguably were more realistic. **Spirituality** played an important role in the meaning of hope for most caregivers, both relating to belief in God and belief in self. FC 4, having witnessed his loved one mobilising in a wheelchair, enthused, "Then I see how a miracle happened yesterday and I told her, see, believe in yourself, have faith, have that hope in yourself. You always got hope in you". Caregivers hoped for religious perseverance for their loved ones "to hold onto God" (FC 6) and for existential well-being in the areas of forgiveness and peace (FC 5).

Hopes were also related to **having a goal and purpose**. FC 10 asserted, “You’ve got to hope for the best… if not for the best, I think to fulfil your life”. Caregivers encouraged their loved one by focusing on a particular goal, for example FC 11 mentioned, “And the other factor is, he’s looking forward to our son getting married, the little one”. Despite several caregivers coming from very poor financial circumstances and particularly large households, none expressed any hope relating to socio-economic improvement.

Caregivers related hope also to **living well yet being ready for their loved one to die**. FC 4 stated pensively, “I believe there is a light… that we can accomplish that, we can… I mean even though, I’m not saying anything bad, but even if I lose my wife, I know in myself, we prayed, we hoped…”. Caregivers expressed that living well was possible for patients, if they accepted their illness. FC 11 declared, “Yes… you can live a good quality of life, *depending* on how you accept your illness”.

Similar to patients, caregivers from all contexts equated hope to **psychological fortitude**, particularly encouragement, strength or endurance, and being positive, and in addition that hope meant light and brightness. Caregivers related hope to **human connection and support** and particularly that solidarity and non-abandonment were essential in maintaining hope for someone who was seriously ill. FC 8 stated kindly, “So that anyone who is sick can have hope… I mustn’t turn around… turn my back on people who is very ill, or who is very sick, and you must always talk to her. If you talk to that person, she is… she is already hopeful because she sees that someone is caring for her… Yes, yes… to talk to her, give her what she needs, what she wants, where… maybe ask questions, so she mustn’t think, think too much about her sickness, and she must not think that she is dying”. Caregivers also saw hope relating to support in the future, as FC 1 expressed by saying, “Yes like, bereavement, we know you gonna be there for us”.

5.2.3.3 The meaning of hope within patient/caregiver dyads

The meaning of hope in terms of **spirituality**, **human connection and support** and **psychological fortitude** was very similar for patients and caregivers, with good concordance within the patient/caregiver dyads. Regarding **having a goal and purpose**, patient goals were typically less focused, while caregivers described goals in more specific terms. An example of this was FC 5's description, "Two weeks back she insisted on cooking… She insisted, and we got everything together… and my nephew helped her to prepare the fish and she was cooking, she became a little tired… then we helped her to do everything and then we brought her again inside".

There was some discordance in **health-related goals**. Of the six patients who expressed a hope for miraculous cure, only four of their caregivers shared this hope, three of whom concurrently remained realistic about their poor prognosis. FC 6 gave an example of this by saying, "My hope is that, like I say, I hope he recovers. If he doesn't then still we, we have God". One caregiver, FC 9, was fiercely hopeful for her daughter's recovery and pleaded, "Mmm, I want she must get better… That she must live, she must live… for her children… Ja, she must get better… she must get better", while her daughter, Pt 9, was more pragmatic and said, "We have to be realistic, yes yes… Because it *is* a terminal disease, so we have to be realistic". Another caregiver, a traditional healer, expressed her hope of cure for *all* patients with cancer although she acknowledged her relative's cancer was incurable. FC 8 stated, "When checking [relative's name] with the cancer, I hoped that maybe one day, even if it, if it's not [relative's name], maybe one day for [relative's name]'s sake, maybe a cure for the cancer will come out… But I don't know doctor, maybe some herb, or traditional herbs, maybe one day it will cure the cancer". Most caregivers, like patients, expressed their hope for improved QoL and **physical and psychological comfort** for their loved one, including not suffering at the end-of-life.

5.2.4 The exploration of the experience of hope for adult patients with advanced cancer and their family caregivers in KZN

5.2.4.1 The experience of hope for patients

Regarding the experience of hope, in keeping with the largely religious cohort of patients in the study sample, **spirituality** once again played a very important role for both hope-enhancing and hope-diminishing factors. Indeed, spirituality was expressed as a significant source of hope by almost every patient in the study. Spirituality includes how a person views and seeks meaning and purpose in life, and also incorporates the relationships that a person has with him- or herself, with family, the community, with nature, with pets and other animals, and also with the significant or sacred.(54) Patients derived hope from trusting God and believing that trials are part of God's overall plan for their lives. This aspect, particularly the belief that they were being tested by God, assisted with meaning-making in their dire situation. As Pt 4 said wistfully, "Yes, I always was saying I helped people, how come it happened to me? And I took care of people with cancer as well, but how come it happened to me? But then I feel that maybe it is a test from God, to see how well I'm gonna fight for this condition." Religious community support was also an important source of hope for most patients, such as praying and visits from religious clergy.

Regarding **psychological fortitude** as a source of hope for patients, **overcoming previous adversity** was mentioned by almost all patients, regardless of context. This was an unexpected finding of the study, and not readily apparent in the international hope literature. The experience of overcoming previous hardship was something all patients could relate to. Remembering the strength and resources that had helped them to overcome previous hardship assisted patients to cope with the present challenges of having cancer. As Pt 10 said "I've had *so* many obstacles, but I've overcome, I've overcome all of them. I work on it, I worked hard on everything. I worked hard, I found where it was difficult, but you overcome, you overcome. I think when you grow up with working hard, you feel nothing. Ja, your lifestyle was like that, my lifestyle was hard, I had a hard life, that's why I feel nothing about nothing, ja, and I always got hope… Ja, I keep going, I keep going over it". Similarly, **intentionally living well or self-empowerment** was also mentioned by most patients. Patients also derived hope from hearing stories of cure, having a happy place, positive thoughts and memories, accepting the cancer and being at peace, calming the mind and distraction, gratitude, and leaving a future legacy.

Every single patient spoke about the importance of **human connection and support** such as family and community support. Pt 2 for example reflected, “My two brothers here, they often phone me… or… and especially now that I’ve been ill, somebody phones me at least once or twice a week you know… Yes, I’m hearing more from them than I ever had before … You know, with your family around you, it gives you hope”. Those patients already referred for palliative care praised the hospice staff and the support given to them. Pt 4 said, “I am very grateful to hospice for taking care of others… of all kind of patients in fact… They’re providing attention, by caring, I’ve got someone to talk to when I feel depressed…”, while Pt 5 remarked, “I was so happy when they come and talk to me”. Traditional healers were also seen to support hope, as voiced by Pt 8, “Ja, they give hope, they give a little bit of support”.

Relating to their medical management, most patients spoke about deriving hope from their doctor and the treatment prescribed. Patients felt more hopeful when they were given **physical and psychological comfort.** Some patients had an almost child-like faith in their doctor, for example Pt 1 who said, “And like, I just had complete… faith in the doctor, that I’m putting my life in your hands”, while Pt 6 explained, “Doctors will give you hope, you know why… I mean they studied hard, you know what I mean, so you’ve got to hope in them”. Patients also found hope in being hospitalised, receiving chemotherapy or radiotherapy, and having analgesics prescribed for their pain. Two patients described the value they placed on being treated with respect by the medical team.

Hope-diminishing factors for patients related to physical, psychological, social or spiritual distress. Feeling neglected by the medical team or being told there was nothing more that could be done, took away patients’ hope. Pt 1 remarked, “Yes and I wouldn’t like someone to let me down. If I feel there’s a hope in a person and then someone else, a third person says, there’s nothing you can do – no, you gotta be aware”, and Pt 3 echoed, “If the doctors say something that makes me lose hope, I lose the hope I have in that way”. Four patients however expressed that, despite their challenges, nothing could take their hope away. On further analysis, these four patients had each described their trust in God, and the support received from family and the medical team, as the main sources of their hope.

Regarding the **experience of hope in their cancer journey**, patients expressed how hope changed over time, and assisted them in adjusting to their cancer diagnosis. As Pt 9 reflected, “It {hope} has changed a lot, yes, but I’m living with it, and I’ve adjusted to this illness, yes”. Hope was found to be valuable for patients in all contexts in changing the way they lived, thought, coped, accepted their illness, viewed their mortality and connected with others.

5.2.4.2 The experience of hope for caregivers and concordance within patient/caregiver dyads

The thematic analysis of the hope experience for patients and caregivers was very similar, with good overall concordance within the patient/caregiver dyads. Caregivers, like patients, described their source of hope relating strongly to their **spirituality**, **overcoming previous adversity**, **human connection and support** and finding **physical and psychological comfort** for their loved one. One caregiver (FC 10) mentioned the importance of pet therapy. Caregivers likewise derived hope from palliative care support, their faith in doctors and in treatment such as chemotherapy. Two caregivers described the importance of being treated with respect.

Hope-diminishing factors for caregivers related to their or their loved one’s physical, psychological, social or spiritual distress. In addition, one caregiver (FC 3) remarked on financial burden causing stress. Three caregivers stated that nothing could take their hope away. These three caregivers had all described a strong religious faith and family support as the main sources of their hope. There was some overlap of this finding within the dyads, with two of the three family caregivers aligning with a patient who had also affirmed that nothing could take their hope away.

Regarding their **experience of hope while caring for a family member with cancer**, caregivers in all contexts described how their hope changed over time. Hope was reported as valuable in assisting caregivers to live, cope, accept illness, view mortality and connect with others.

5.2.4.3 Patients and family caregivers' experience and preference regarding receiving diagnostic and prognostic information

Ten of the 11 patients preferred to be given truthful information about their diagnosis and prognosis, whereas Pt 5, an elderly patient, preferred the doctors to "tell the family… I don't think nothing about that." There was concordance here within the patient/caregiver dyads, with only FC 5 preferring the patient not to be given the information directly from the doctor, but indirectly from the family: "I think when it comes to {her parent, the patient} like she'll ask us if it's ok, then maybe my brother or somebody will tell her like what to do". Interestingly this same patient, although stating her preference for her family to be told her diagnosis, did herself decide not to have oncological treatment: "That was her decision, she refused to have it {radiotherapy}… But we explained everything and then she decided not to take the radiotherapy… It was better if she knows what it is going to be like" (FC 5).

Patients spoke of their experience when receiving diagnostic and prognostic information. Some were "in a state of shock" (Pt 4), or "depressed" (Pt 4); some "got emotional and all that" (Pt 6), or "it really broke me down… it really, really brought me down" (Pt 11); while some stated, "it didn't really impact on the time when I was told" (Pt 1). Some expressed gratitude for the truth. Pt 2 for example stated, "but I'm glad you told me because… to me, I know, ok, I've got X amount of time, whatever that's gonna be". Regarding truth-telling, Pt 7 stated firmly, "They {doctors} must tell us the truth, they mustn't hide it… hiding it is the thing that will kill us, but if you know the truth – you can tell your family, please pray for me, you can tell your church please pray for me, this thing is not going to go out, it's here to stay, ja, ja". Despite initial emotional responses, patients eventually came to terms with their diagnosis, as Pt 10 said, "I cried a little bit, ja I cried… I did cry… I did cry because I was very depressed, you know the shock and everything… And then eventually I overcame everything". Patients preferred their family to be likewise informed "so that they can know how to support me" (Pt 1).

All caregivers preferred to be given truthful diagnostic and prognostic information about their family member’s condition. Remembering previous experience, caregivers described initially being “disappointed” (FC 1), “heartsore” (FC 1), “it really got me” (FC 5), “it was a big shock” (FC 5) and “it becomes such a scary thing” (FC 10). Like patients, however, there was increasing acceptance of such information over time. FC 1 stated, “I’m ok with it” while FC 10 voiced that, with time, “we just took it in our stride”.

5.2.4.4 Patients and family caregivers’ experience and preference regarding receiving hope from doctors and nurses

Patients and caregivers remarked that doctors and nurses should, and do, play a role in giving them hope. FC 1 declared, “Yes, I would *love* that… You can give us the hope also… We *want* your encouragement”. Pt 9 mentioned that doctors should encourage patients without giving them “false hope”, but no patient or caregiver recalled any experience of having been given false hope. Patients and caregivers described receiving hope from doctors and nurses who “were very **kind**, they explained everything. Then they set the ball rolling” (Pt 1). Pt 11 explained that “**the way they** {doctors} **speak to you** gives you a lot of hope… so calm, they make you feel, you know, relaxed”. FC 4 suggested, “Yes, more like to **encourage** the person, motivate them, give them like a speech or a talk or something to make them feel happy inside - like you know what, ‘I’m always having those negative thoughts, lucky this doctor came along, and she brightened up my mind and now I can think positively’ – that can motivate them then yes”.

Doctors give hope to patients through appropriate **symptom management** and **advice**. Pt 10 recounted, “He’s very good, so he treated me {for pain} and gave me a lot of hope” and “They {doctors} do {give hope}. They always tell us, they always… the doctors always tell you… they give you the best advice”.

Hope was enhanced through **physical touch**, such as Pt 2 described, “So now she {the nurse} gets hold of my hand… and she gave me the courage…”. Hope was also enhanced by “**the love and the care**” (Pt 4), **physical presence** [“I was so happy when they {hospice nurses} come and talk to me”

(Pt 5)], through **spiritual accompaniment** by nurses “who can talk to you… about God, who can tell you no don’t be afraid” (Pt 7), and through **prayer**. Pt 9 explained, “Even one nurse, she’s very spiritual and she prays for me… Yes, whenever I go – yes… Yes she always say a prayer for me, she calls me aside and she says a prayer, yes… It’s nice, you feel better, you know?”.

5.3 The study findings relative to the study aims

The study aimed to describe the importance, meaning and experience of hope in the context of adult patients with advanced cancer and their family caregivers in KZN. The researcher determined that these research aims were met, considering the limitations of the study. The study objectives to evaluate the data within the clinical, socio-economic and cultural contexts of the study participants were met.

5.4 New knowledge gained in the South African setting

The importance of hope in the oncology palliative care setting in SA was confirmed. Two distinct themes were strongly evident in the analysis of both the meaning and the experience of hope. These themes were **spirituality** and **human connection and support**. Spirituality involved trust in God, belief in self and religious support. Belief that suffering was part of God’s plan assisted in meaning-making. The importance of receiving support from family, community and the healthcare team was clearly described.

Participants also associated hope with **psychological fortitude** and **having a goal and purpose**. Regarding psychological fortitude, **overcoming previous adversity** was a notable and unexpected finding of this study. Almost all study participants remarked on overcoming prior hardship in relation to hope. Comparatively, this was a stronger finding than in international hope literature. Regarding health-related goals, just over half the patients and a third of the caregivers hoped for miraculous cure, while being realistic about their poor prognosis. Almost all patients and caregivers however spoke about hope relating to **physical and psychological comfort**, particularly nearing and at end-of-life. Hope played a significant role in assisting patients and caregivers to **live well**

while preparing for death and changed the way they lived and coped with the cancer diagnosis. Except for health-related goals however, patients' **goals** were generally unfocused and non-specific. Caregiver goals tended to be more well-defined and were often focused on motivating their loved one. Almost all participants in this South African setting expressed a **preference for truthful communication, spoken with empathy**, regarding their diagnosis and prognosis, and described how hope assisted them to cope with bad news and to reach acceptance. Participants described how doctors and nurses can be instruments of hope.

5.5 Integration of new knowledge gained into what is previously known about hope

5.5.1 Integration of the study findings

The two major themes of this study, **spirituality** and **human connection and support**, align with what has been previously published about hope, internationally but more specifically in Africa, such as described by African researchers Akinsola(93), Afolabi(86) and Namisango(103), and in SA by de Villiers(87), Bingo(88), Walker(105) and others(90-92, 101, 148). As reported by these researchers, the present study highlighted the importance of spirituality and religious support in assisting patients and their caregivers to cope with their fears and anxiety, to focus on living well, and to find hope. In her research on African adult patients with cancer, Namisango had found that patients who accept the reality of their mortality, and yet live in the "present moment", can experience spiritual healing and peace.(103) The present study supported this finding. As Akinsola has suggested, religious leaders should be actively encouraged to provide spiritual and psychological support where this is relevant to the person and family.(93) Also relating to spirituality, **meaning-making**, described as hope-enhancing in international studies(14, 68), was associated in the present study with the religious belief that suffering was part of God's plan, and would lead to personal growth.

The findings of this study correlate well with Duggleby's early research on hope, which found that **good symptom control**, **truthful communication**, **supportive relationships**, **upholding spirituality** and **affirming patients' worth** enhanced hope(23, 25). The present study findings also align with Duggleby's Transforming Hope theory, which described two integrated subprocesses of hope, namely **transcendence** (reaching inwardly and outwardly, finding meaning and purpose) and **positive reappraisal** (finding positive realistic possibilities as a focus for hope)(16).

Overcoming previous adversity was a particular finding of this study. This could reasonably fall within the positive reappraisal subprocess described, although Duggleby's research pertains more to reframing the situation looking ahead, while overcoming previous adversity involves a process of reflection while looking towards the past, and then intentionally moving forward through present and future difficulty.

The present study also correlates well with The Hope Process Framework, as cited by Herth(14, 74). Themes identified in this study relate to the relational aspect of hope (**human connection and support**), the spiritual or transcendent aspect (**spirituality**), the rational thought aspect (**overcoming previous adversity**) and the experiential aspect (**finding meaning in suffering**, **living well**).

As the patients in this study did not focus on making and meeting **specific goals**, the role of goal-based interventions, such as based on Snyder's Hope Model, would perhaps have less relevance in the South African setting. Goal-directed interventions may however assist in fostering hope for caregivers, who generally had more focused goals.

Living well while preparing for death was evident in a number of the afore-mentioned studies and referred to specifically by Namisango, who describes spiritual growth, healing, peace and renewed hope for African patients in the face of death(103). The study findings aligned also with Kübler-Ross' research(50), in that participants described how hope persisted through all the stages of denial, anger, bargaining, depression and acceptance. Indeed, as Kübler-Ross reported, hope in this study was an important aspect of reshaping the dread of dying and of living well.

The research findings also confirmed in the South African setting the **importance of truth-telling** and the **role of hope in coping with bad news**, as described by international researchers such as Kübler-Ross(50) and Nierop-van Baalen(33), by African researchers Grant and Ayane(96, 102) and by Walker, who reported that patients in SA derive hope from compassionate truth-telling, reassurances of non-abandonment and the possibility of treatment(105). All these elements were confirmed in this study. The present study echoed previous findings that patients view doctors and nurses as key sources of hope(14, 23, 25, 33, 37, 105, 109). Nierop-van Baalen discussed the harm in giving patients "false hope".(33) Receiving "false hope" was however not part of the recalled experience of the present study participants.

5.5.2 Balancing the positive and the negative

What was strongly evident, while listening to the stories of patients and their caregivers, was the way they oscillated between seemingly contradictory states of being. This **tension of hope** was also demonstrated clearly by Nierop-van Baalen(33) and Buckley(75), as well as South African researchers Combrink(92), Maree(90) and Potgieter(91), who all found that outcomes hoped-for were sometimes mutually exclusive. The subtheme hoping for a cure while being realistic about poor prognosis is one such example. At times such apparent contradictions occur even in the same sentence. Pt 4 alternated, "I hope I get healed… but I know it's not possible because a lot of people do lose their lives from the type of cancer that I have…", while Pt 8 hoped "that this disease, this cancer, it must be away from me, from my body… Mmm, yes sometimes it's impossible to take it away, but hopefully it can go slowly slowly, up until it's finished, yes". Many patients spoke very distinctly about balancing the positive with the negative. This balance reflects the to-and-fro process involved in gradually coming to accept the reality of one's dire situation and suggests how patients oscillate yet cope in the face of ongoing adversity.

Other examples of such balancing demonstrated by the study participants included living well while accepting the body's decline in dying, seeking meaning while acknowledging suffering, being grateful for the present while grieving change and loss, seeking respect for autonomy while being reliant on assistance and support, and looking forward to future good while overcoming the adversities of the past. In short, participants demonstrated well how hope assists in balancing the two realities of **hoping for the "best" while preparing for the worst** (see Figure 24). It is worth noting here that "best" varies between people and over time. "Best" may change from cure to prolonged survival to comfort to a peaceful death.

The researcher would suggest that, in addition to hope, there are two other facets of the fulcrum necessary for balancing the positive and the negative, as voiced repeatedly by patients and caregivers in this study. These are **trust or belief** (in God, in the healthcare team, in family and community, in self) and **compassionate truth-telling and support** (see Figure 24). The researcher would also suggest that the healthcare team influences all three inter-related facets of the fulcrum, and plays a significant role in supporting this balance for patients and caregivers.

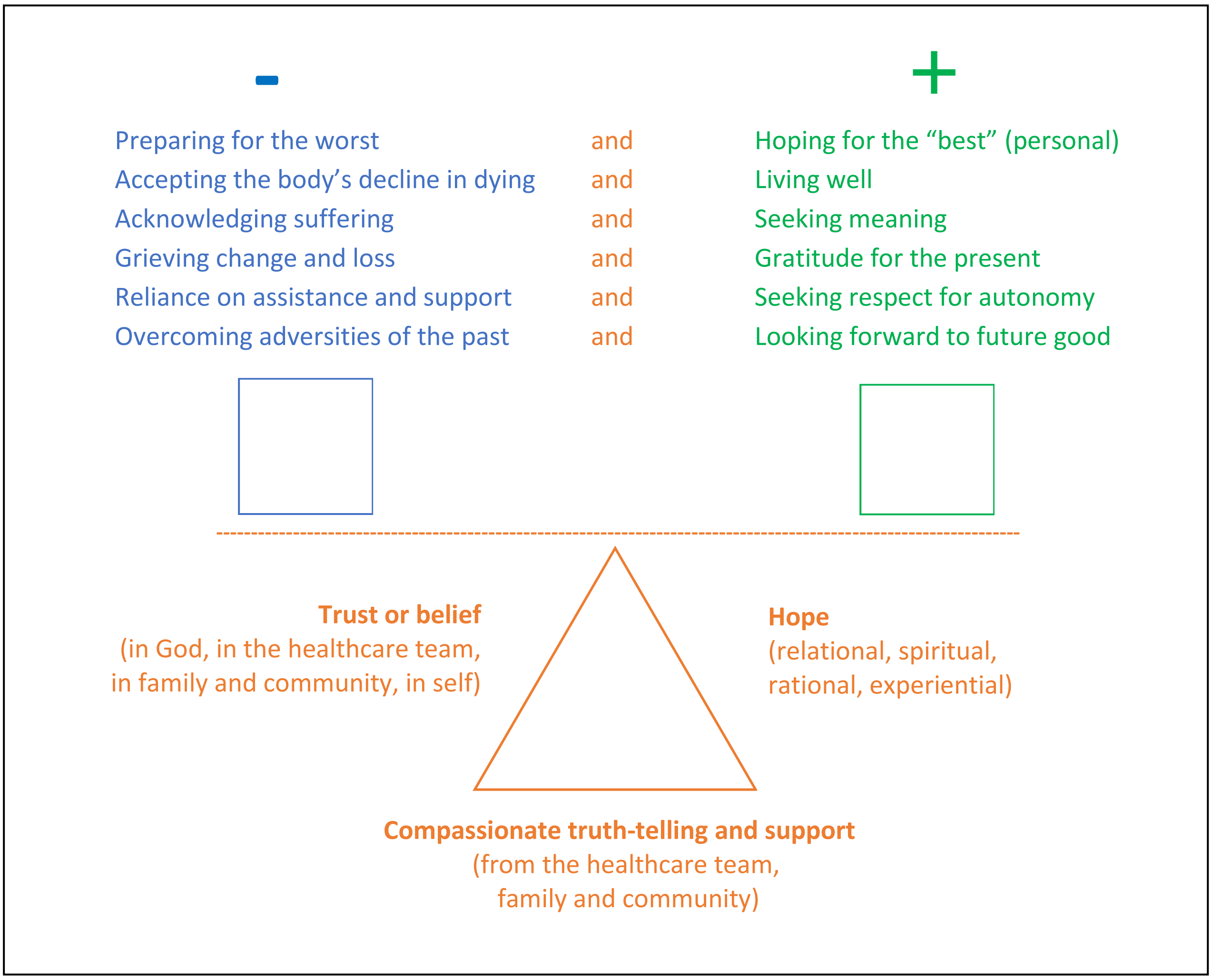


Figure 24. Balancing the positive and the negative on the fulcrum of trust or belief, compassionate truth-telling and support, and hope

5.5.3 Application of the study findings to known hope-fostering interventions

Based on the study findings, the following interventions would likely be beneficial in fostering hope, with good adherence in the South African setting, although further research and validation would be recommended:

- Interventions based on comfort, attachment and worth(23, 109)
- Interventions based on the four attributes of hope, such as Herth’s HIP(14, 74)
- Interventions based on Duggleby’s hope theories such as LWHP(24)
- Interventions based on psychotherapy such as DT(121, 122), CALM therapy(124), CNR program(128) and PRP(130)
- Interventions based on social and spiritual support(138)

The above interventions may perhaps be more suitable for patients receiving **specialist palliative care**, with access to facilities offering specific interventions. Most South Africans, however, have limited access to specialised health services, and **generalist palliative care** would therefore be more appropriate for most South African patients with palliative care needs. Here Akinsola's research within African communities, on the important role potentially played by **PHC workers as enablers of hope**(93), bears merit and deserves further study in SA.

Hope-fostering interventions based on Snyder's Hope Theory(112, 114, 115) would arguably be less valuable in the South African setting, as patient goals appeared non-specific and unfocused, but may however be appropriate for caregivers, whose goals were more specific.

5.6 Strengths and limitations of the study

5.6.1 Study strengths

This exploratory qualitative research, involving individualised, in-depth interviews with patients and caregivers from a variety of backgrounds, provided rich and detailed information on the lived experiences and perceptions regarding hope in the South African context. Open-ended questions encouraged participant narratives in their own words, providing more accurate and dependable data, with less potential for interpretation bias. The semi-structured interview framework gave an overall structure for data collection, yet retained flexibility for the researcher to pursue new topics which arose. The research yielded results with a number of practical applications, both in the immediate context, and for future research (see 5.7).

5.6.2 Study limitations

5.6.2.1 Small study sample

Due to time and resource constraints, this was a small study involving only 11 patients and 11 caregivers. Although purposive sampling aimed for maximum variation, certain populations, such as young adults and patients from rural KZN, were under-represented. There were also no patients with head and neck cancer, which can be particularly disfiguring, and often associated with a high symptom burden and/or substance abuse. The study findings may therefore not be generalisable to all populations of patients with cancer and caregivers in KZN.

5.6.2.2 Lack of non-religious participants

Although the researcher attempted to enrol patients from the major religions in KZN, as well as atheist or agnostic patients, only participants from the Christian, Hindu, Muslim and African Ancestral religions were represented. The role of spirituality in hope, although a strong finding in this study of religious participants, cannot be extrapolated for atheist or agnostic persons.

5.6.2.3 Social support

Every study participant, even those living alone, reported significant social support. The study findings may be different for patients and caregivers lacking social support.

5.6.2.4 Traditional healers

The researcher attempted to study the role of traditional healers regarding hope for patients and caregivers. Most likely due to the urban setting of the study, and under-representation of participants from rural KZN, there was little data forthcoming regarding traditional healers. One caregiver was herself a traditional healer, and provided excellent data, but the role of traditional healers in fostering hope would be best studied in a rural South African setting.

5.7 Implications for practice

5.7.1 Implications for clinical practice

The research has validated the importance patients and caregivers place on hope in coping and living well when faced with a cancer diagnosis. The research also confirms that doctors and nurses are viewed as instruments of hope. Doctors and nurses can enhance hope by providing physical and psychological comfort, facilitating human connection and support, and addressing spiritual care. These aspects of person-centred care are well described in the biopsychosocial-spiritual model of palliative care. Those less familiar with incorporating spiritual care in patient care are advised to utilise a recommended tool, e.g. FICA spiritual assessment tool.(54) Further, assisting patients and caregivers to identify inner and outer sources of strength and support, such as reflecting on overcoming previous adversity, may be beneficial in fostering hope. Patients and caregivers, who place great trust in their doctors, value truth-telling regarding diagnostic and prognostic information, but told with empathy. Compassionate truth-telling enhances hope, which assists in the non-linear stages of despair, anger, bargaining, depression and acceptance. Doctors and nurses should strive to foster trusting and trustworthy relationships with their patients and their families.

5.7.2 Implications for palliative care research, training, education and guidelines

This study aligns with international and wider African research regarding the importance of hope for patients with advanced illness and their caregivers. Educating under-graduate and post-graduate medical and nursing students about hope as an aspect of patient-centred care is suggested. Several measures can be taken at the education level to assist healthcare workers with balancing truth-telling and maintaining hope for their patients, such as incorporating patient-centred communication skills training, working with spiritual care providers and accentuating evidence-based practice. This research proposes components of hope-fostering interventions which may prove beneficial in the South African setting. Further research is needed regarding the validation of hope-fostering interventions in SA (see 6.4). Adding such interventions to South African palliative care guidelines and training modules may be a future consideration.

5.7.3 Implications for public awareness

Cancer, known as a “dread disease” in SA, is a word associated with significant fear and dread. Many people associate a cancer diagnosis with hopelessness, depression and a desire for hastened death. This study, alongside other research in hope, proves that a person can indeed live well, without dread, and maintaining realistic hope, in the face of life-threatening illness such as cancer. Furthermore, at a time when arguments for euthanasia are gaining traction in SA, the counterargument of evidence-based palliative care interventions promoting realistic hope is opportune and necessary.

5.8 Personal reflections

The researcher experienced significant professional and personal growth throughout the study. The privilege of being invited into people's homes, to hear stories of their cancer journeys and experiences of hope, was truly an enriching experience. The researcher was heartened to verify in her local setting how hope helped patients and caregivers to cope while facing a cancer diagnosis, to accept their advancing illness and to continue to live well, even knowing that the cancer was incurable.

Each study participant willingly shared details of their lives and cancer journeys. Indeed, for many participants, the opportunity to tell their story appeared to be therapeutic. Hearing how patients and caregivers balanced the two realities of hoping for the best while preparing for the worst, and supporting one another despite great personal hardship, was truly inspirational. The researcher is indeed grateful for this valuable learning experience.

It was an unexpected study finding that, although the research originally focused on the exploration of hope, study participants reflected on the importance not only of hope, but also of faith (in God, in the healthcare team, in family and community, in self) and of love (human connection and support, compassionate truth-telling). The researcher finds synergy and validation for her research within her own personal spiritual journey. Faith, hope and love, known as the three theological virtues, are Biblical scriptural foundations, and mentioned together in several Biblical passages such as Hebrews 10:22-25 and 1 Corinthians 13:12-13. This finding aligns also with the WHO's statement in 1998 that "patients and physicians have begun to realise the value of elements such as faith, hope and compassion in the healing process"(35).

The research also correlates well with the African philosophy “Ubuntu” which is an isiZulu word translated as “I am because we are”. Ubuntu describes the African philosophy that “a person is a person through other people”.(167) Archbishop Desmond Tutu, as cited by Chowdhury et al, stated that “we are made for community, for togetherness, for family, to exist in a delicate network of interdependence…. no one can be human alone”.(167) The research, with its strong theme of human connection and support, particularly within caring communities, resonates with the African philosophy of Ubuntu.

5.9 Conclusion

This chapter has discussed the study findings in relation to the study aims. New knowledge gained in the South African setting has been presented and integrated into what was previously known about hope. Strengths and limitations of the study, implications for practice and personal reflections have also been described. The following chapter concludes the dissertation and gives future recommendations.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

When the researcher started her research, it was with a particular question in mind. What could she say to the patients that she saw with advanced cancer, many of whom faced particularly harsh challenges including significant socio-economic hardship, to maintain, or possibly even increase, their hope? Without resorting to glib statements or false promises, what could she possibly say to patients who were experiencing significant burden and facing death, that would meaningfully lift their spirits and instil a sense of realistic hope for their future? The researcher, who had been interested in the constructs of hope for some years, understood from the international literature the importance of hope for patients with life-threatening illness such as cancer, but did not know which elements of hope would be relevant in her own context in SA. Seeking to better understand hope in the South African palliative oncology context formed the basis of the present research.

6.2 Findings in relation to study objectives

The study met its objectives in that the importance, meaning and experience of hope, for adult patients with advanced cancer in KZN and their family caregivers, were explored and evaluated within the clinical and demographic contexts of the study participants.

There was unanimous affirmation from all patients and caregivers that hope was important to them, particularly in the face of a cancer diagnosis or in caregiving. Ascribing importance to hope justifies further research regarding hope in this setting. Thematic analysis of both the meaning and experience of hope revealed a strong correlation with spirituality, human connection and support, and physical and psychological comfort. Hope was also associated with psychological fortitude, having a goal and purpose, and living well while being ready to die. The role of overcoming previous adversity as a source of hope for most participants was an unexpected finding.

6.3 In remembrance

The researcher was invited as the guest speaker at a Remembrance Day event held at Chatsworth Hospice, one of the study sites, in November 2022. Family members of patients who had died while under the care of the hospice team in the previous year were invited to attend the memorial event. Some of the family members present would have been participants of the present study. The researcher, to give back to the community, and in memory and honour of the patients who had died while on the study, presented some of the study fundings at a level appropriate for the grieving family members. The researcher reflected on her study findings within four main themes H-O-P-E, and suggested that this thematic framework might be helpful for someone facing the challenge of a cancer diagnosis, or during caregiving, but also might provide support for the grieving family members present:

H: The importance of **Human connection** and (where applicable) **hospice support** – journeying with a person, walking alongside them, not abandoning them gives a person hope

O: **Overcoming previous adversity** – South Africans are resilient and resourceful people. Many people in SA have overcome great hardship. If a person is reminded of the strength and resources they had at their command in times of previous adversity, this gives them hope when facing new challenges

P: **Physical and psychological comfort** – there is *always* something more that can be done. Easing a person's symptoms physically and psychologically, and bringing them comfort even at the end-of-life, gives them hope

E: **Existential or spiritual support** – this aspect of care, relating to meaning, purpose in life and spirituality, is very important to people in SA. These are some suggestions for spiritual care: By providing a "compassionate presence", spending time with a person facing difficulty, being fully present in the moment; Supporting them in what they enjoy doing, whether it is enjoying art or music, spending time in nature, being with loved ones, or special pets, or simply sitting quietly; Listening to their stories, people love to tell their stories; Affirming that fear, anxiety, loss and sadness are part of the normal range of human experience, and assuring them that they are not alone; Establishing trusting relationships in which the person feels safe to explore difficult questions relating to their mortality, their life's meaning and purpose; Helping a person to re-discover realistic hope, resilience and an inner strength to cope in times of illness and loss; Upholding their own religious faith, beliefs and rituals, encouraging visitation and support from their own religious leaders or clergy and the performance of their own religious rites.

6.4 Recommendations for the future

6.4.1 Future research in hope in the South African palliative care setting

Many who were present at the Remembrance Day event maintained they were personally encouraged by the researcher's study findings as described under the four themes above. The researcher has also applied her H-O-P-E framework to the patients with advanced cancer and their family caregivers seen in her palliative oncology clinic, with favourable initial acceptance and response thus far (see Figure 25). The researcher believes that her research in the exploration of hope has been valuable in the search to find appropriate ways to uphold realistic hope for patients and family caregivers within her own setting. This research on hope may prove beneficial in other palliative care settings in SA, and such research is recommended. Further research in validating hope-fostering interventions appropriate to the South African setting, such as the H-O-P-E framework proposed by this study, and the hope-fostering interventions determined by international study as discussed in 5.5.3, are further recommendations.

6.4.2 Future dissemination of the study findings

Researchers have an ethical and scientific responsibility to disseminate their research findings, even when the outcome measures are unfavourable or less favourable than expected. This adds to the body of scientific knowledge and enhances evidence-based clinical practice. The researcher intends to provide the two study sites with a copy of her final thesis document and to offer to present her study findings to the clinical staff at the study sites via a formal presentation. The researcher aims to publish her study findings in a peer-reviewed medical journal where the readership is likely to include South African oncologists and palliative care practitioners, subject to acceptance. The researcher intends also to present her study findings at a conference organised by the South African palliative care organisation PALPRAC, to be held in Cape Town in April 2023.

6.5 In closing

As the researcher was writing up her dissertation, she met a young woman in one of her palliative oncology clinics. She was a 26-year-old university student, with a young child, on third-line chemotherapy for stage 4 triple-negative breast cancer, a particularly aggressive form of breast cancer. When the young woman entered the consultation room, she looked dejected and asked to lie down on the examination couch. She was not in any significant physical pain. Not long into the consultation, she said sadly, “I have lost all of my hope”.

As part of her biopsychosocial-spiritual approach to patient care, the researcher spoke to the young mother about the four elements of the H-O-P-E framework. She acknowledged that she had overcome great hardships in the pursuit of her studies despite poor socio-economic conditions and raising her child as a single mother. She was then encouraged to reflect on the inner and outer sources of strength and support available to her then, and still available to her now. She acknowledged the availability of good family, community and church support. The palliative team advised her regarding symptom control and counselling services available for her and her family, and organised a referral to her local hospice for home-based visits. She was reassured that she would not be abandoned but would be supported by the medical team.

At the end of the consultation, the young woman sat up, set her shoulders back with an air of determination, and left the room for her chemotherapy session with her head held high.

Figure 25. Closing vignette

“Hope is a powerful weapon and no one power on earth can deprive you of (this)”

Nelson Mandela (1918-2013)
From a letter to his wife Winnie Mandela during his imprisonment on Robben Island, 1969

“Our human compassion binds us the one to the other – not in pity or patronizingly, but as human beings who have learnt how to turn our common suffering into hope for the future”

Nelson Mandela (1918-2013)

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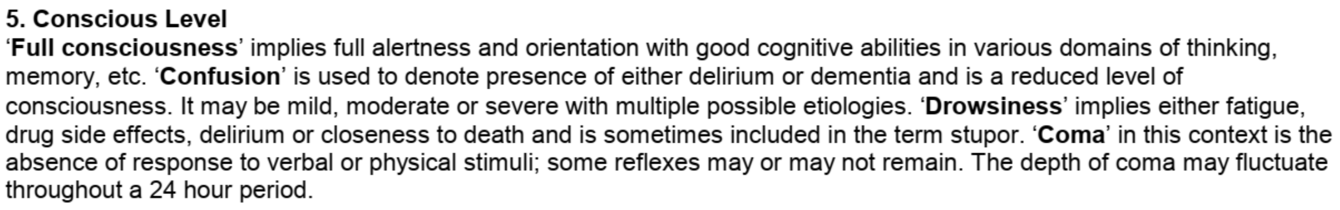
APPENDICES

Appendix A - Data collection tools

A. Palliative Performance Scale

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Definitions given for Conscious Level:



5. Conscious Level

'**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Reference for Palliative Performance Scale

Victoria Hospice Society. Palliative Performance Scale version 2 (PPSv2). 2001. [Accessed 27/11/2021]. Available from: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwjktI7f0vn9AhUUSkEAHeuFDPYQFnoECAoQAQ&url=http%3A%2F%2Fwww.npcrc.org%2Ffiles%2Fnews%2Fpalliative_performance_scale_PPSv2.pdf&usg=AOvVaw073F-pxZkmOjUN6C-GACzN

B. Questionnaires for the study 1. For patients

1. **Study-related:**
    a. Patient identification number for study purposes: __________________
    b. Functional status (Palliative PS): _______ %
    c. Date of signed consent (DD/MM/YYYY): ____/____/________
    d. Date of interview (DD/MM/YYYY): ____/____/________
    e. Language of interview: _______________________
    f. Language translator required: Y/ N

2. **Patient-related:**
    a. Age: ________________________
    b. Gender: __________________________
    c. First language: isiZulu/ English/ isiXhosa/ Afrikaans/ Other: ___________
    d. Marital status: Single/ Married/ Common-law marriage/ Separated/ Divorced/ Widow(er)
    e. Education level: None/ Primary school/ Secondary school: grade ____/ Tertiary/ Higher education: __________________________
    f. Employment status: Unemployed/ Student/ Housewife/ Employed/ Retired
    g. Income: None/ Informal employment/ Self-employed/ Salary/ Wages/ Social grant/ Disability grant/ Pension/ Other: ________________
    h. Annual household income: R0/ R1- R 19 200/ R 19 201 – R 307 200/ R 307 201 and above/ prefer not to divulge
    i. Location of home: Inner city/ Suburban/ Peri-urban/ Rural
    j. Dwelling type: Formal/ Traditional/ Informal (shack)
    k. Household access (circle all which apply): Mains electricity/ Piped water/ Flush toilet/ Household refuse removal
    l. Household arrangement: Alone/ With partner/ With partner and children/ With children/ With relatives/ With friends
    m. Household size: _______ adults, _______ children
    n. Social support (circle all which apply): Spouse/ Partner/ Parent(s)/ Sibling(s)/ Child(ren)/ Other relative(s)/ Friend(s)/ None/ Other: ________
    o. Religion/ spirituality important: Yes very much/ Somewhat/ Not at all
    p. Religion: African ancestral/ Christian/ Hindu/ Jewish/ Muslim/ None/ Other (state): ___________________

3. **Illness-related:**
    a. Primary cancer site and stage: ______________________________________
    b. Time since diagnosis: ____
    c. Time since diagnosis of advanced disease if different: __________________
    d. Current/ planned oncology treatment: ________________________ or none
    e. Time under hospice care/ palliative care if applicable: __________ or N/A
    f. Other illnesses or chronic conditions: ______________________________
    g. Involuntary weight loss over past 6 months: _________________________
    h. Need for assistance with self-care? Y/N
        i. If yes, primary caregiver relationship to patient: _______________

2. For family caregivers

1. **Study-related:**
   a. Family caregiver identification number for study: ___________________
   b. Relationship to patient: _______________________
   c. Length of time caring for patient: _________________
   d. Date of signed consent (DD/MM/YYYY): ____/____/________
   e. Date of interview (DD/MM/YYYY): ____/____/________
   f. Language of interview: ______________________
   g. Language translator required: Y/ N

2. **Family caregiver-related:**
   a. Age: ________________________
   b. Gender: __________________________
   c. First language: isiZulu/ English/ isiXhosa/ Afrikaans/ Other: ___________
   d. Marital status: Single/ Married/ Common-law marriage/ Separated/ Divorced/ Widow(er)
   e. Education level: None/ Primary school/ Secondary school: grade ____/ Tertiary/ Higher education: __________________________
   f. Employment status: Unemployed/ Student/ Housewife/ Employed/ Retired
   g. Income: None/ Informal employment/ Self-employed/ Salary/ Wages/ Social grant/ Disability grant/ Pension/ Other: _______________
   h. Annual household income: R0/ R1- R 19 200/ R 19 201 – R 307 200/ R 307 201 and above/ prefer not to divulge
   i. Location of home: Inner city/ Suburban/ Peri-urban/ Rural
   j. Dwelling type: Formal/ Traditional/ Informal (shack)
   k. Household access (circle all which apply): Mains electricity/ Piped water/ Flush toilet/ Household refuse removal
   l. Household arrangement: Alone/ With partner/ With partner and children/ With children/ With relatives/ With friends
   m. Household size: _______ adults, _______ children
   n. Number of dependents (incl elderly, children) responsible for: __________
   o. Social support (circle all which apply): Spouse/ Partner/ Parent(s)/ Sibling(s)/ Child(ren)/ Other relative(s)/ Friend(s)/ None/ Other: ________
   p. Religion/ spirituality important: Yes very much/ Somewhat/ Not at all
   q. Religion: African ancestral/ Christian/ Hindu/ Jewish/ Muslim/ None/ Other (state): ___________________

C. Questions for the semi-structured interviews

1.1 For patients - English

Please answer these questions if you feel comfortable to do so. If any questions make you uncomfortable, please say so and you do not need to answer if you feel uncomfortable.

1. What does hope mean to you? (OR What does it mean to you to be hopeful?)
2. When is the last time you felt hopeful?
3. Can you describe how hope makes you feel?
4. How important is hope to you?
5. Is there anything that takes your hope away?
6. Is there anything that gives you more hope?
7. What effect does your cancer have on the way you experience hope?
8. Do you think that healthcare workers like doctors and nurses increase or decrease your hope? Can you explain your answer?
9. Do you think your doctors and nurses *should* play a role to increase your hope? If yes, how?
10. Have you consulted a traditional healer?
11. If yes, do you think that your traditional healer increases or decreases your hope? Can you explain your answer?
12. Do you think your traditional healer *should* play a role to increase your hope? If yes, how?
13. If your cancer was spreading or getting worse, do you want your doctors to give you all this information?
14. Do you think that having all this information about your cancer changes your experience of hope? If yes, how?
15. Have you discussed your hopes with anyone in your family?
16. Is there anything more you wish to say about your experience of hope while having cancer?

Thank you for answering my questions. This information is very valuable so that we can understand more about what hope means for cancer patients.

1.2 For patients – isiZulu translation

Sicela uphendule lemibuzo uma uzizwa ukhululekile ukuyiphendula. Uma kunemibuzo ongakhululekile ukuyiphendula, sicela usho ngoba awuphoqelekile ukuyiphendula.

1. Lichaza ukuthini ithemba kuwe? (Noma kuchaza ukuthini ukuba ne themba kuwe?)
2. Ugcine nini ukuzizwa unethemba?
3. Ungachaza ukuthi ithemba likwenza uzizwe unjani?
4. Libaluleke ngani ithemba kuwe?
5. Ikhona yini into esusa ithemba kuwena?
6. Ikhona yini into ekunikeza ithemba elikhulu?
7. Umdlavuza ubenamthelela muni ekubeni uqhubeke ubenethemba?
8. Ucabanga ukuthi abezempilo njengo Dokotela, noNesi bayalinyusa noma bayalehlisa yini ithemba lakho? Uma uvuma chaza ukuthi kanjani?
9. Ucabanga ukuthi odokotela noNesi bakho kufanele bayidlale indima yokukhuphula ithemba lakho? Uma uvuma chaza ukuthi kanjani?
10. Ukewaxhumana nabalaphi bendabuko?
11. Uma uvuma, ucabanga ukuthi abalaphi bendabuko bayayidlala indima yokulikhuphula noma ukulehlisa ithemba? Chaza impendulo yakho?
12. Ucabanga ukuthi abalaphi bendabuko bangayidlala indima yokwe nyusa amathemba akho? Uma uvuma, chaza ukuthi kanjani?
13. Uma ngabe umdlavuza wakho usabalala umzimba wonke, uyadinga yini ukuthi odokotela bakwazise noma bakuchazele ngakho?
14. Ucabanga ukuthi uma usunalolonke ulwazi ngo mdlavuza wakho kuzoshintsha ithemba lakho? Uma uvuma, chaza ukuthi kanjani?
15. Uke waxoxisana nomunye womundeni wakho mayelana namathemba akho?
16. Kukhona yini okunye ofisa ukukusho mayelana namathemba onawo ngaleskhathi usanomdlavuza?

Ngiyabonga ngokuphendula imibuzo yami. Lemininingwase ibalulekile kakhulu ukuze siqondisise mayelana nokuthi lichaza ukuthini ithemba kwi-ziguli ezizomdlavuza.

2.1 For family caregivers – English

Please answer these questions in relation to your caregiving role for X [where X = patient’s name]. If any questions make you uncomfortable, please say so and you do not need to answer if you feel uncomfortable.

1. What does hope mean to you in relation to your caregiving role for X?
2. When is the last time you felt hopeful?
3. Can you describe how hope makes you feel?
4. How important is hope to you?
5. Is there anything that takes your hope away?
6. Is there anything that gives you more hope?
7. What effect does X’s cancer have on the way you experience hope?
8. Do you think that healthcare workers like doctors and nurses increase or decrease your hope? Can you explain your answer?
9. Do you think that doctors and nurses *should* play a role to increase your hope or X’s hope? If yes, how?
10. Has X consulted a traditional healer?
11. If yes, do you think that the traditional healer increases or decreases hope? Can you explain your answer?
12. Do you think the traditional healer *should* play a role to increase your hope or X’s hope? If yes, how?
13. If X’s cancer was spreading or getting worse, do you want the doctors to give you all this information?
14. Do you think the doctors should give X all this information about his/her cancer?
15. Do you think that having all this information about X’s cancer changes your experience of hope? If yes, how?
16. Do you think that having all this information about X’s cancer changes his/her experience of hope? If yes, how?
17. Have you discussed your hopes with X?
18. Is there anything more you wish to say about your experience of hope while caring for X?

Thank you for answering my questions. This information is very valuable so that we can understand more about what hope means for the caregivers of cancer patients.

2.2 For family caregivers – isiZulu translation

Sicela uphendule lemibuzo mayelana nendima oyidlala ngokunakekela uX [uX umele igama le-sguli]. Sicela uphendule lemibuzo uma uzizwa ukhululekile ukuyiphendula. Uma kunemibuzo ongakhululekile ukuyiphendula, sicela usho ngoba awuphoqelekile ukuyiphendula.

1. Lichaza ukuthini ithemba kuwena mayelana neqhaza olibambile lokunakekela uX?
2. Ugcine nini ukuzizwa unethemba?
3. Ungachaza kabanzi ukuthi likwenza uzizwe kanjani ithemba?
4. Libaluleka kangakanani ithemba kuwe?
5. Ikhona yini into esusa ithemba kuwena?
6. Ikhona yini into ekunika elinye ithemba?
7. Kube namthelela muni kumdlavuza kwa X ngendlela othemba ngakhona?
8. Ucabanga ukuthi abasebenzi bezempilo njengo Dokotela noNesi bayalinyusa noma bayalehlisa ithemba lakho? Uma uvuma chaza ukuthi kanjani?
9. Ucabanga ukuthi odokotela noNesi bangadlala indima ukukhuphula amathemba akho noma amathemba ka X? Uma uvuma chaza ukuthi kanjani?
10. uX uke waya kubalaphi bendabuko?
11. Uma uvuma, ucabanga ukuthi abalaphi bendabuko bayayidlala indima yokulikhuphula noma ukulehlisa ithemba? Chaza impendulo yakho.
12. Ucabanga ukuthi abalaphi bendabuko bangayidlala indima yokwenyusa amathemba akho noma amathemba ka X? Uma uvuma chaza ukuthi kanjani?
13. Uma umdlavuza ka X usabalala noma uyangoku nyuka kungabingcono, uyadinga yini ukuthi odokotela bakunikeze leyomniningwane?
14. Ucabanga ukuthi odokotela bamnike uX yonke lemniningwane mayelana nomdlavuza wakhe?
15. Ucabanga ukuthi yonke lemniningwane mayelana nomdlavuza ka X ishintsha amathemba akho onawo? Uma uvuma chaza ukuthi kanjani?
16. Ucabanga ukuthi ukuba nayoyonke lemniningwane mayelana nomdlavuza ka X kushintsha amathemba akhe? Uma uvuma chaza ukuthi kanjani?
17. Usuke waludingida udaba lamathemba akho no X?
18. Kukhona yini ofisa ukukusho mayelana ne themba onalo ngaleskhathi usamnakekela uX?

Ngiyabonga ngokuphendula imibuzo yami. Lemininingwase ibalulekile kakhulu ukuze siqondisise mayelana nokuthi lichaza ukuthini ithemba kwi-ziguli ezizomdlavuza.

Appendix B – Translation process from English to isiZulu for semi-structured interview questions

1. Translators

XS

XS is a palliative care caregiver working with one of the hospices in Durban, KZN. She has a certificate in Palliative Caregiving and works looking after patients with advanced disease, mainly advanced cancer, and their family caregivers in the home-based setting.

XS's home language is isiZulu. She is also proficient in the English language.

ZS

ZS is a registered nurse with a master's degree in nursing and several other advanced nursing qualifications, including in community health care and palliative care. She has worked in the South African health care sector in various disciples including general nursing, midwifery, community health care, palliative care and nursing education. She is a strong advocate for the integration of palliative care in various sectors, including the South African prisons, and was involved in developing the palliative care curricula for nurses and for traditional healers.

ZS's home language is isiZulu. She is also proficient in the English language.

XS and ZS were chosen to assist with the translation of the semi-structured interview questions as they have significant experience in and an understanding of the context of isiZulu-speaking patients with advanced cancer and their family caregivers, and knowledge of the terminology used as pertinent to this study. Their command of both the isiZulu and English languages is excellent.

2. Process followed for translation from English into isiZulu:

a. Questions for the semi-structured interviews for patients and family caregivers were written in English by the researcher
b. Questions in English were given to XS for forward translation into isiZulu
c. Questions translated into isiZulu were given to ZS for backward translation into English. Only minor discrepancies in wording were detected.
d. Further discussions were held between the researcher, XS and ZS regarding changes to the isiZulu wording which best conveyed the meaning of the English questions, and further changes to the isiZulu wording were made accordingly
e. ZS evaluated the completed document and made further minor changes to give the final version of the questions in isiZulu.

Appendix C - Information sheet regarding the study:

Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal

Information for potential patients for the study

My name is Dr Colleen Cox, I am a palliative oncologist practising in Durban. I am conducting research towards my Masters in Palliative Medicine for which I am currently registered through the University of Cape Town.

What is the purpose of the study?

In international research studies, having hope has been found to be important for patients living with serious illness, as well as for their family caregivers. There is however limited research from South Africa regarding the importance and experience of hope in patients living with serious illness and their family members.

My study will be exploring the importance, meaning and experience of hope in patients in KZN living with cancer and their family caregivers. I am hoping that this research will improve our understanding of how hope is experienced in South Africa by patients living with a serious such as cancer and their family caregivers. This information would be useful to determine whether and how healthcare professionals can assist in supporting the hope experience of patients living with cancer and their family caregivers.

What does participation in the study mean?

You are being invited to participate in this research as a person living with cancer. Your participation is entirely voluntary, and your future health care and your cancer management will not be influenced by your decision to take part in this study. The study is self-funded. No additional costs are expected to be incurred to you, and you will not be reimbursed for the study.

Please take your time to consider this study. Please ask any questions you might have about the study and discuss this with your family where necessary, before deciding whether to take part. Should you wish to take part, you will be asked to sign the consent form on the last page of this document. You will be free to withdraw from the study at any time without giving a reason; your continued care will not be influenced by your decision to take part in this study.

What is involved in the study?

The study has been ethically reviewed and approved by the UCT Human Research Ethics Committee. No study procedure will take place without ethics approval.

The study will involve a single consultation with you, myself as the researcher and, if necessary, a language translator present. The consultation will last approximately 30 to 40 minutes. During the consultation, there will be a short questionnaire requesting some background information relating to you and to your cancer. Your name, address and other identifying details will not be captured. You will be identified by a unique identifying number and all identifying details will be kept confidential.

During the consultation I will ask you a series of questions relating to how you view and experience hope. There are no correct or incorrect answers. I rather wish to understand how hope is experienced from your point of view. The answers that you give will not affect or influence the care or the cancer management you receive from your doctors and nurses.

It is a requirement of the study that the interview be recorded. This is to ensure that your answers are captured correctly and exactly as you have described your experience. The recording will be kept for purposes of the study only and will be kept confidential at all times. The recording will be destroyed once this is no longer required for the study purposes.

Your participation in this study is entirely voluntary. Your health care and cancer management will not be affected in any way by your decision to be involved in the study. You will be free to withdraw from the study at any time, without giving a reason, and without your current or future care or cancer management being affected.

What are the benefits of taking part in the study?

The study is aimed at giving you an opportunity to express how you experience hope. Many people do find the opportunity to discuss such experiences helpful and meaningful. There may however be no direct benefit to you from participating in the study.

Hearing your experience with hope may however assist healthcare workers in understanding how other patients experience hope, and may lead to a better understanding how healthcare workers might assist you and other patients with a serious illness such as cancer in supporting your experience of hope.

Will there be payment for participants in the study?

There will be no payment made to you for taking part in the study. However there is a travel allowance to assist with paying for your travel expenses which will be offered to you should you take part in the study.

Are there any risks to taking part in the study?

Answering some questions about your health and experience of hope might be difficult, and sometimes may cause an emotional response. You do not need to answer any question that makes you uncomfortable. You may decide to stop the interview at any time, and further support will be made available to you. Should you decide to withdraw from the study for any reason, this will not affect your continued health care or the management of your cancer.

What precautions will be taken regarding COVID-19?

Any exposure to a person carrying the COVID-19 virus (SARS-CoV-2) carries the risk of being infected with the virus. This can happen in any setting including hospitals and clinics. For the duration of the study, all appropriate precautions will be taken to prevent transmission of the virus between you and the research staff while taking part in the study visits. This will include answering a number of screening questions and having your temperature measured. At all times, face masks will be worn, there will be access to alcohol-containing hand sanitisers and social distancing precautions will be taken. The study has a standard operating procedure (SOP) to follow regarding COVID-19 precautions to be taken.

If there is any concern that you or a member of the research team might have COVID-19 or carry the virus, no face-to-face study procedures or interviews will take place. Should you develop COVID-19 while involved in the study, this will be reported in the study follow-up report and you will be advised about self-isolation and management of your symptoms according to the COVID-19 guidelines at your local clinic or hospital.

What about confidentiality issues?

Your questionnaires and information regarding this study will be kept in a secure place, and will not include your name, ID number, address or any other identifying details. Each questionnaire will be labelled with a unique number and your information will be kept private. All your responses given during the interview will likewise be kept strictly confidential.

The results of the study may be published in a medical journal. No publication will use your name or identify you personally.

Who to contact regarding the study?

In the event of any problems or concerns you may have regarding the study, you may contact the researcher Dr Colleen Cox (please email colleen.cox@teamcare.support; alternatively phone number 031 240 1915/6). Should you have any concerns about the way in which the study is conducted, please contact:

Human Research Ethics Committee, UCT
G50, Old Main Building
Groote Schuur Hospital
Observatory, 7925
Tel: 021 650 1236
email: hrec-enquiries@uct.ac.za

Thank you

Thank you for considering to take part in this study. Your involvement in the study would be valuable and would contribute to our understanding of the role played by hope in patients with serious illness and their family caregivers.

Yours sincerely

Dr Colleen Cox

Consent form regarding participation in the study:

Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal

Consent form for patients

1. I confirm that I have read and understand the information sheet and have had my questions regarding the study answered to my satisfaction.

2. I give my consent for the interview to be recorded. I understand that the recording will be kept confidential and will be destroyed once this is no longer needed for the study purposes.

3. I understand that my participation in this study is voluntary. My health care and cancer management will not be affected in any way by my decision to be involved in the study. I am free to withdraw from the study at any time, without giving a reason, and without my care or further cancer management being affected.

4. I agree to take part in the above study.

Patient: Full name: ____

Signature: ______________________ Date: ____________________

Researcher: Full name: ____

Signature: ______________________ Date: ____________________

Witness: Full name: ____

Signature: ______________________ Date: ____________________

Appendix D - Information sheet regarding the study:

Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal

Information for potential family caregivers for the study

My name is Dr Colleen Cox, I am a palliative oncologist practising in Durban. I am conducting research towards my Masters in Palliative Medicine for which I am currently registered through the University of Cape Town.

What is the purpose of the study?

In international research studies, having hope has been found to be important for patients living with serious illness, as well as for their family caregivers. There is however limited research from South Africa regarding the importance and experience of hope in patients living with serious illness and their family members.

My study will be exploring the importance, meaning and experience of hope in patients in KZN living with cancer and their family caregivers. I am hoping that this research will improve our understanding of how hope is experienced in South Africa by patients living with a serious such as cancer and their family caregivers. This information would be useful to determine whether and how healthcare professionals can assist in supporting the hope experience of patients living with cancer and their family caregivers.

What does participation in the study mean?

You are being invited to participate in this research as a person supporting a family member or close friend living with cancer. Your participation is entirely voluntary, and the future health care and management of you and your family member will not be influenced by your decision to take part in this study. The study is self-funded. No additional costs are expected to be incurred to you, and you will not be reimbursed for the study.

Please take your time to consider this study. Please ask any questions you might have about the study and discuss this with your family members where necessary, before deciding whether to take part. Should you wish to take part, you will be asked to sign the consent form on the last page of this document. You will be free to withdraw from the study at any time without giving a reason; the continued care of you and your family member will not be influenced by your decision to take part in this study.

What is involved in the study?

The study has been ethically reviewed and approved by the UCT Human Research Ethics Committee. No study procedure will take place without ethics approval.

The study will involve a single consultation with you, myself as the researcher and, if necessary, a language translator present. The consultation will last approximately 30 to 40 minutes. During the consultation, there will be a short questionnaire requesting some background information relating to you and to your caregiving experience. Your name, address and other identifying details will not be captured. You will be identified by a unique identifying number and all identifying details will be kept confidential.

During the consultation I will ask you a series of questions relating to how you view and experience hope. There are no correct or incorrect answers. I rather wish to understand how hope is experienced from your point of view. The answers that you give will not affect or influence the care or the management you and your family member receive from the doctors and nurses.

It is a requirement of the study that the interview be recorded. This is to ensure that your answers are captured correctly and exactly as you have described your experience. The recording will be kept for purposes of the study only and will be kept confidential at all times. The recording will be destroyed once this is no longer required for the study purposes.

Your participation in this study is entirely voluntary. The health care and management of you and your family member will not be affected in any way by your decision to be involved in the study. You will be free to withdraw from the study at any time, without giving a reason, and without you or your family member's current or future care being affected.

What are the benefits of taking part in the study?

The study is aimed at giving you an opportunity to express how you experience hope. Many people do find the opportunity to discuss such experiences helpful and meaningful. There may however be no direct benefit to you from participating in the study.

Hearing your experience with hope may however assist healthcare workers in understanding how other family caregivers experience hope. This may lead to a better understanding how healthcare workers might assist you and other family members looking after a person with a serious illness such as cancer, in supporting your experience of hope.

Will there be payment for participants in the study?

There will be no payment made to you for taking part in the study. However there is a travel allowance to assist with paying for your travel expenses which will be offered to you should you take part in the study.

Are there any risks to taking part in the study?

Answering some questions about your health and experience of hope might be difficult, and sometimes may cause an emotional response. You do not need to answer any question that makes you uncomfortable. You may decide to stop the interview at any time, and further support will be made available to you. Should you decide to withdraw from the study for any reason, this will not affect you or your family member's continued care or management.

What precautions will be taken regarding COVID-19?

Any exposure to a person carrying the COVID-19 virus (SARS-CoV-2) carries the risk of being infected with the virus. This can happen in any setting including hospitals and clinics. For the duration of the study, all appropriate precautions will be taken to prevent transmission of the virus between you and the research staff while taking part in the study visits. This will include answering a number of screening questions and having your temperature measured. At all times, face masks will be worn, there will be access to alcohol-containing hand sanitisers and social distancing precautions will be taken. The study has a standard operating procedure (SOP) to follow regarding COVID-19 precautions to be taken.

If there is any concern that you or a member of the research team might have COVID-19 or carry the virus, no face-to-face study procedures or interviews will take place. Should you develop COVID-19 while involved in the study, this will be reported in the study follow-up report and you will be advised about self-isolation and management of your symptoms according to the COVID-19 guidelines at your local clinic or hospital.

What about confidentiality issues?

Your questionnaires and information regarding this study will be kept in a secure place, and will not include your name, ID number, address or any other identifying details. Each questionnaire will be labelled with a unique number and your information will be kept private. All your responses given during the interview will likewise be kept strictly confidential.

The results of the study may be published in a medical journal. No publication will use your name or identify you personally.

Who to contact regarding the study?

In the event of any problems or concerns you may have regarding the study, you may contact the researcher Dr Colleen Cox (please email colleen.cox@teamcare.support; alternatively phone number 031 240 1915/6). Should you have any concerns about the way in which the study is conducted, please contact:

Human Research Ethics Committee, UCT
G50, Old Main Building
Groote Schuur Hospital
Observatory, 7925
Tel: 021 650 1236
email: hrec-enquiries@uct.ac.za

Thank you

Thank you for considering to take part in this study. Your involvement in the study would be valuable and would contribute to our understanding of the role played by hope in patients with serious illness and their family caregivers.

Yours sincerely

Dr Colleen Cox

Consent form regarding participation in the study:

Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal

Consent form for family caregivers

1. I confirm that I have read and understand the information sheet and have had my questions regarding the study answered to my satisfaction.

2. I give my consent for the interview to be recorded. I understand that the recording will be kept confidential and will be destroyed once this is no longer needed for the study purposes.

3. I understand that my participation in this study is voluntary. My and my family member's health care and cancer management will not be affected in any way by my decision to be involved in the study. I am free to withdraw from the study at any time, without giving a reason, and without my or my family member's care or cancer management being affected.

4. I agree to take part in the above study.

Family caregiver: Full name: ____

Signature: _____________________ Date: _____________________

Researcher: Full name: ____

Signature: ______________________ Date: _____________________

Witness: Full name: ____

Signature: _____________________ Date: _____________________

Appendix E – COVID-19 standard operating procedure

1. Background

The COVID-19 pandemic has had a considerable impact on the management of patients at all healthcare levels. The pandemic has also affected the management of patients undergoing clinical trials, where multiple challenges and safety concerns regarding potential virus transmission in study patients may arise. In all situations any risks taken regarding potential SARS-CoV-2 exposure to study participants and staff must be minimised. The welfare and safety of study participants is paramount and potential benefit to study patients must justify the risks taken as a result of participating in the study.

The health and wellbeing of study patients and research staff is a primary concern of this study. Patients and healthcare staff should be managed according to their COVID-19 status, where this is known, in keeping with best practice guidelines and to optimise the best possible health outcomes for all. Study enrolment must not compromise or delay appropriate clinical management of patients in any way.

Safety, namely preventing cross-infection of SARS-CoV-2 between patients, family members and healthcare staff, is also a primary consideration of this study. The most effective infection control measure to prevent the spread of SARS-CoV-2 is avoidance of persons carrying the virus. Where such avoidance is not possible, or where SARS-CoV-2 status is unknown, the appropriate use of PPE, hand washing, hand sanitising and social distancing measures have been shown to reduce the spread of the virus.

This standard operating procedure (SOP) has been put in place to curtail the spread of SARS-CoV-2 between patients and their caregivers and the research staff involved in this study, to protect the wellbeing and safety of study participants and research staff, to minimise potential risks associated with the study and to comply with good clinical practice (GCP).

2. Purpose

The purpose of this SOP is to describe the process to follow when managing the study patients and their family caregivers for the above study during the time of the COVID-19 pandemic.

3. Scope

This SOP applies to the researcher, research assistants, translators and all other healthcare staff relevant to the above study during the process of managing the patients and family caregivers screened and enrolled in the study.

4. Responsibilities

It is the responsibility of the researcher, research assistants, translators and all other healthcare staff relevant to the above study to read, understand and adhere to the procedures described in this SOP.

5. Procedure

5.1 All rules and regulations pertaining to the level of COVID-19 national lockdown at the time of the study must be adhered to. If necessary, the period of data collection (patient and caregiver interviews) must be delayed until a lower and more suitable level of national lockdown is reached.

5.2 The most updated rules and regulations given by UCT/ HREC regarding studies undertaken during the COVID-19 pandemic must be adhered to.

5.3 Face-to-face visits and interviews must only be undertaken where safety for study participants can be reasonably assured and where potential benefit to study participants justifies the possible risks of the study.

5.4 No face-to-face study procedure is to take place if any party (patient, family caregiver or study-related healthcare worker) has any symptoms suggestive of COVID-19, or within 10 days of a positive test, or is a primary contact of a person testing positive for SARS-CoV-2.

5.5 Where possible, patients and family caregivers are to be phoned by the researcher or research assistant a day before the scheduled visit to confirm that the patient/ caregiver is well enough to attend the interview.

5.6 Patients and family caregivers are to be screened for signs and symptoms of COVID-19 by asking the following questions:

Have you had any of the following symptoms within the past 10 days:

- High temperature ≥ 38ºC
- Mild to severe respiratory illness with a cough
- Sore throat
- Shortness of breath or difficulty breathing (unrelated to underlying condition)
- Loss of taste or smell
- Contact with a person with COVID-19 or a positive SARS-CoV-2 test

If the answer to any of these questions is yes, the interview is to be delayed until at least 10 days following the last symptom or the last positive contact.

5.7 Patients and family caregivers must have their temperature measured prior to any face-to-face study procedure. If temperature ≥ 38ºC, or if patient or caregiver is looking unwell (unrelated to the underlying condition), in-person interviews must be delayed for at least 10 days.

5.8 A study-related COVID-19 register must be kept, recording the responses to the screening questions and the temperature measurements, along with patient/ caregiver identifiers, household contacts, date, time and place of the contact or interview.

5.9 In-person interviews must not continue, and the site protocol for SARS-CoV-2 testing and ongoing clinical management must be followed should the patient or caregiver have symptoms suspicious for COVID-19.

5.10 A patient and family caregiver is considered a dyad for the study purposes, although each is to be interviewed separately. If a patient and/or family caregiver cannot be interviewed following positive COVID-19 screening, the interviews for both patient and family caregiver should he delayed.

5.11 Should the in-person interviews with the patient and family caregiver proceed, suitable face masks must be worn by all participants at all times. Hands should be washed with soap and water, or sanitised with an alcohol-based hand sanitiser, at the beginning of the interview and after any physical contact with the patient/ caregiver. All surfaces and stationery should be disinfected with an alcohol-based cleaning liquid where appropriate. Cough etiquette should be explained to all participants: cover the mouth and nose with a tissue when coughing or sneezing; throw the used tissue into a rubbish bin or medical waste bin; if no tissue is available, cough or sneeze into the inner elbow; wash hands or sanitise thoroughly after any coughing, sneezing or adjustment of the mask.

5.12 Venues for the interviews should be chosen with safety of all participants in mind. Where possible, interviews should take place in a ventilated room with an open window. Persons not living in the same household should sit at least 1.5m apart. Patient examination is not a requirement for the study, and physical contact with patients and family caregivers should be kept to a minimum.

5.13 Following the interview, should it be determined that the patient, family caregiver or healthcare worker tests positive for SARS-CoV-2 within a period of two days, all positive contacts should be notified via contact tracing, and site-specific protocols for SARS-CoV-2 testing, isolation and clinical management must be followed as appropriate to the situation. The positive test results and final outcomes of all involved parties must be recorded as part of safety monitoring of the study.

5.14 Should the risk of SARS-CoV-2 transmission via face-to-face interviewing be determined by the researcher to be too great (e.g. high prevalence of SARS-CoV-2 positivity in the patient's community at the time of data collection), consideration should be given to delay face-to-face data collection until a more suitable time. Telephonic interviewing may also be considered as an option for the patient and/or family caregiver to minimise overall risk of viral transmission. Another option might be to consider face-to-face interviewing for patients and telephonic interviewing for family caregivers.

6. Updates

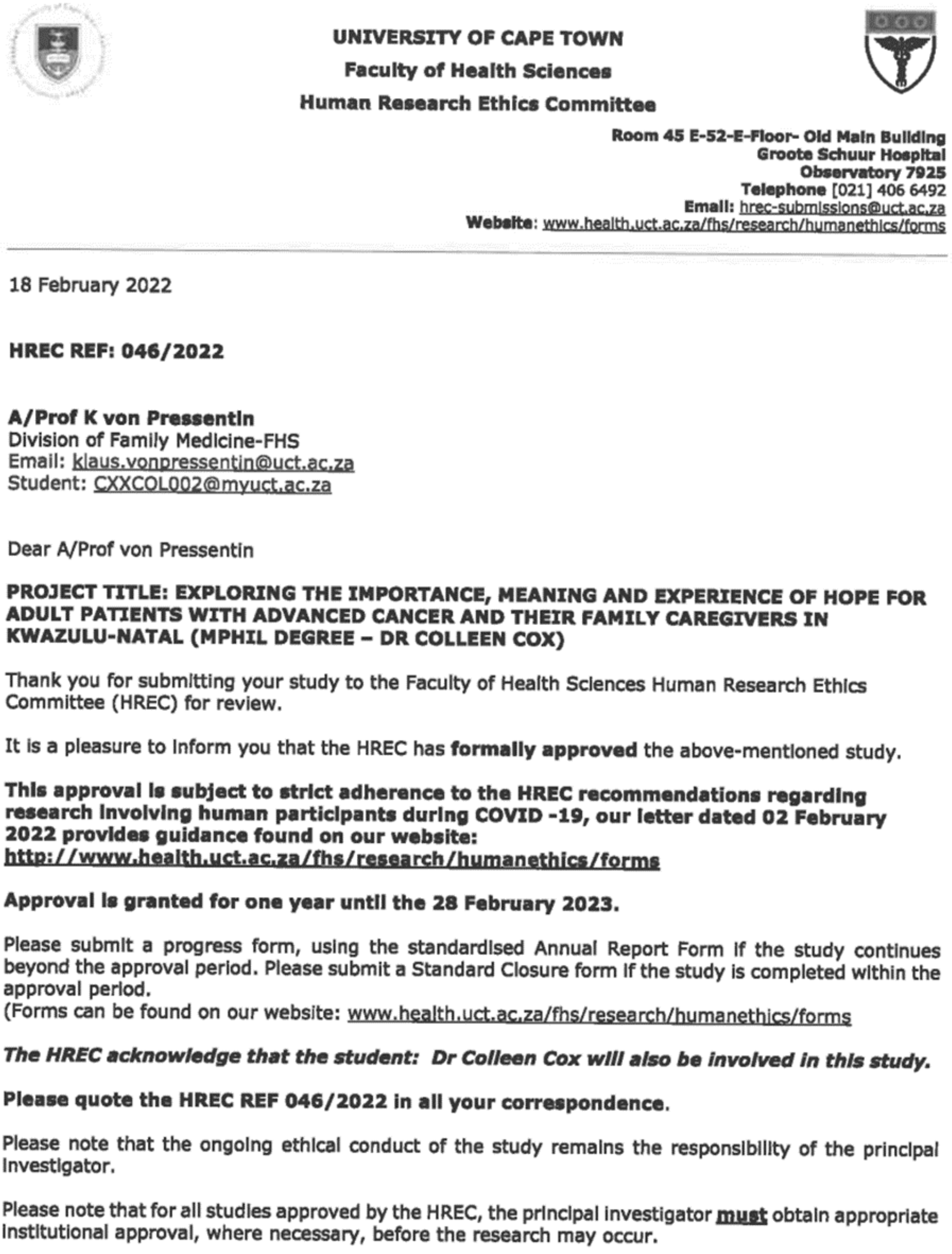
This SOP should be updated should scientific information become available regarding SARS-CoV-2 transmission and/or COVID-19 which changes the way study participants should be managed within the research setting.

References for COVID-19 standard operating procedure

1. NIHR King's Clinical Research Facility. Managing clinical trial visit during Covid19 pandemic in King's Clinical Research Facility. 31 Dec 2020. [Accessed 27/11/2021]. Available from: https://www.maudsleybrc.nihr.ac.uk/media/crf-qa-sop-14-managing-clinical-trial-visit-during-covid-19-pandemic-in-the-king-s-crf-v20.pdf

2. The United States Food and Drug Administration. Conduct of clinical trials of medical products during the COVID-19 public health emergency: Guidance for industry, investigators, and institutional review boards. 30 Aug 2021. [Accessed 27/11/2021]. Available from: https://www.fda.gov/media/136238/download

Appendix F - Letters regarding ethics approval for the study and study site permissions



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

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18 February 2022

HREC REF: 046/2022

A/Prof K von Pressentin
Division of Family Medicine-FHS
Email: klaus.vonpressentin@uct.ac.za
Student: CXXCOL002@myuct.ac.za

Dear A/Prof von Pressentin

PROJECT TITLE: EXPLORING THE IMPORTANCE, MEANING AND EXPERIENCE OF HOPE FOR ADULT PATIENTS WITH ADVANCED CANCER AND THEIR FAMILY CAREGIVERS IN KWAZULU-NATAL (MPHIL DEGREE – DR COLLEEN COX)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, our letter dated 02 February 2022 provides guidance found on our website: http://www.health.uct.ac.za/fhs/research/humanethics/forms

Approval is granted for one year until the 28 February 2023.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms

The HREC acknowledge that the student: Dr Colleen Cox will also be involved in this study.

Please quote the HREC REF 046/2022 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number:
IRB00001938 NHREC-registration number: REC-210208-007
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

[redacted]
colleen.cox@teamcare.support

25 November 2021

The Board of Management
Chatsworth Regional Hospice Association
15 Strelitzia Road
Silverglen, Chatsworth
4092
manager@chatshospice.co.za

Dear Mrs Enoch and the Board of Management, Chatsworth Hospice

Re: Request for Chatsworth Regional Hospice to be a study site for my Masters research study: "Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal"

I hereby request permission for Chatsworth Regional Hospice to be a study site for my research study. My research is being undertaken as part of the requirements necessary for my Masters degree in Palliative Medicine, for which I am currently registered at the University of Cape Town. My study is to be self-funded; I will not derive any financial benefit from my research.

As a palliative oncologist, I am interested in improving quality of life for patients and their family caregivers particularly when they are facing a life-threatening illness such as advanced cancer. For some time now, I have been interested in the concept of hope, what this means to patients and family members, and how we as healthcare workers can maintain hope and thereby optimise quality of life for our patients and their families.

In the international literature, hope is described as an essential component of coping and adapting to the changes experienced when faced with a life-threatening illness such as cancer, and is associated with better quality of life. There is rich data describing the meaning and experience of hope for palliative care patients in countries in USA, Canada and Europe. In South Africa, while research indicates that hope is important for patients facing life-threatening illness, there is limited evidence regarding the meaning and experience of hope in our local context. Also concepts such as hoping for a cure, and having false hope, have not been well explored in our South African context.

My study aims to explore the importance, meaning and experience of hope for patients with advanced cancer and their family caregivers in KwaZulu-Natal. This will be a qualitative study, whereby patients and an identified family caregiver will be interviewed separately via a semi-structured interview methodology. The data will be coded and analysed to determine these constructs of hope in our local context. The study will take place at two study sites, namely the oncology unit at Inkosi Albert Luthuli Central Hospital, and a hospice site, and for this I am requesting your permission to utilise your site for patients to include in my study. The study will aim to include a total of 12 to 15 patient/ family caregiver pairs, 6 to 8 patients from each study site, with each patient identifying a family caregiver to interview separately.

I will not commence the study until I have been given ethics approval by the UCT Human Research Ethics Committee. Once approved by the ethics committee, expected in the first half of 2022, I will commence screening and meeting with patients. I will ensure that all COVID-19 protocols are in place and followed as necessary. It would be most appreciated if a research assistant, namely one of the Chatsworth Hospice nursing staff, could assist me in identifying and screening potential patients who meet the study criteria.

Once patients are identified, I will arrange to meet with them at Chatsworth Hospice or in their home, by mutual agreement, to discuss the study further. No study procedures will take place before a patient and caregiver has been given the information sheet regarding the study, has had a chance to ask questions, and has signed informed consent. I will conduct all the interviews myself, with the help of an isiZulu translator as necessary for isiZulu-speaking patients who cannot understand English. I will ensure that training and remuneration for research assistants and translators are in place as appropriate.

Professor Klaus von Pressentin, head of the Division of Family Medicine at UCT, and Professor Martin Chasen, Medical Director of Palliative Care at William Osler Health System in Brampton, Canada, are the two supervisors allocated to supervise my research. The study will take place according to SA GCP guidelines, and all data collected from patients will be kept confidential. Once my study data has been analysed, and the study is completed, I will share the findings of my study with the staff at Chatsworth Hospice, and I am hoping that this research will benefit your patients and their family caregivers, as well as the staff at Chatsworth Hospice.

Please contact me should you have any concerns or questions with regard to the above request. If need be, any ethical concerns can be addressed to the UCT Human Research Ethics Committee, contact details of which are:

Human Research Ethics Committee, UCT
G50, Old Main Building
Groote Schuur Hospital
Observatory, 7925
Tel: 021 650 1236
email: hrec-enquiries@uct.ac.za

I thank you most sincerely for considering my request. I trust that my research will prove beneficial for your patients, their caregivers and your staff.

Yours faithfully

Dr Colleen Cox

CHATSWORTH REGIONAL HOSPICE ASSOCIATION

Registered in terms or the Non-profit Organisations Act 1997 Reg. No.: 004-008NPO
Approved as a Public Benefit Organisation in terms of section 30 of the Income Tax Act
Income Tax Exemption Reference No.: 18/11/13/2890, Section 18A of the Income Tax Act, 1962

15 Strelitzia Road, Silverglen
4092, Durban
PO Box 56198 , Chatsworth
4030, Durban
Tel: 031 403 2273
Fax: 031 403 2417
www.chatshospice.co.za
info@chatshospice.co.za

9th December 2021

Dr Colleen Cox
[redacted]

Dear Dr. Cox

Re: Letter requesting permission for Chatsworth Hospice to be a study site for my research

Chatsworth Hospice Board of Management want to pass on their congratulations to you for being accepted to pursue your Master's degree in Palliative Medicine.

We have the greatest pleasure in allowing you to use Chatsworth Regional Hospice as your study site. This we believe will benefit our patients greatly.

The Board has requested that once your study has been completed, you will provide Chatsworth Regional Hospice a copy of your thesis for our records. Also, would you be providing consent forms for the patients to fill out before you meet with them? Please let us know.

We wish you all the best with your study and please know that we will be more than willing to assist you in any way needed.

Sincerely

Shanno Enoch
Manager

CHATSWORTH REGIONAL
HOSPICE ASSOCIATION
FUND RAISING No. 066009550007
P.O. BOX 56198
CHATSWORTH 4030
TEL: 031 403 2273
FAX: 031 403 2417

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL
Private Bag X03, Mayville, 4058
800 Vusi Mzimela (Bellair) Road, Mayville,4091
Tel: **Fax:** Emai: Shona.Bhadree@ialch.co.za

ONCOLOGY DEPARTMENT

Dear Medical Management (IALCH)

Re: Approval for research – Dr Cox

I would hereby like to acknowledge my approval for Dr Cox to do her Masters research, titled: 'Exploring the importance, meaning and experience of of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal.'
Dr Cox is currently a sessional palliative oncologist in our department who provides exceptional services from which our patients and their families derive significant benefit. Her proposed research will be useful to us as we build on our palliative services. I am happy to provide my support in this regard.

Thank you

Yours Sincerely

02/03/2022

health
Department:
Health
PROVINCE OF KWAZULU-NATAL
FIGHTING DISEASE, FIGHTING POVERTY, GIVING HOPE

Shona Bhadree
Head of Clinical Unit - Oncology
Inkosi Albert Luthuli Hospital
☎ 031 240 1906/1920
086 521 5190
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www.kznhealth.gov.za

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL
Private Bag X03, Mayville, 4058
800 Vusi Mzimela (Bellair) Road, Mayville,4091
Tel: 031 240 1059 **Fax:** 031 240 1005 Email: Ursula.john@ialch.co.za

OFFICE OF THE MEDICAL MANAGER

Reference: BREC/00003779/2022
Enquiries: Medical Management

4 March 2022

A/Prof K von Pressentin
Division of Family Medicine-FHS

Dear A/Prof K von Pressentin

RE: PERMISSION TO CONDUCT RESEARCH AT IALCH

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **Exploring the importance, meaning and experience of Hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal (MPHIL DEGREE – DR Colleen Cox).**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully

…………………………
Dr A Harrichandparsad
Clinical Care Manager

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

INKOSI ALBERT LUTHULI CENTRAL HOSPITAL
Private Bag X03, Mayville, 4058
800 Vusi Mzimela (Bellair) Road, Mayville,4091
Tel: 031 240 1059 **Fax:** 031 240 1005 Email: Ursula.john@ialch.co.za

OFFICE OF THE MEDICAL MANAGER

4 March 2022

A/Prof K von Pressentin
Division of Family Medicine-FHS

Dear A/Prof von Pressentin

Re: Approved Research: Ref No: HREC REF: 046/2022: Exploring the importance, meaning and experience of Hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal (MPHIL DEGREE – DR Colleen Cox).

As per the policy of the Provincial Health Research Committee (PHRC), you are hereby granted permission to conduct the above mentioned research once all relevant documentation has been submitted to PHRC inclusive of Full Ethical Approval.

Kindly note the following.

1. The research should adhere to all policies, procedures, protocols and guidelines of the KwaZulu-Natal Department of Health.
2. Research will only commence once the PHRC has granted approval to the researcher.
3. The researcher must ensure that the Medical Manager is informed before the commencement of the research by means of the approval letter by the chairperson of the PHRC.
4. The Medical Manager expects to be provided feedback on the findings of the research.
5. Kindly submit your research to:

The Secretariat
Health Research & Knowledge Management
330 Langaliballe Street, Pietermaritzburg, 3200
Private Bag X9501, Pietermaritzburg, 3201
Tel: 033395-3123, Fax 033394-3782
Email: hrkm@kznhealth.gov.za

Yours faithfully

……………………..
Dr A Harrichandparsad
Clinical Care Manager

GROWING KWAZULU-NATAL TOGETHER

[redacted]
CXXCOL002@myuct.ac.za
[redacted]

14 March 2022

The Secretariat
Health Research and Knowledge Management
Private Bag X9501
Pietermaritzburg, 3201
Tel: 033 395 3123
hrkm@kznhealth.gov.za

Dear Secretariat

Re: Application for PHRC research approval: HREC REF: 046/2022: Exploring the importance, meaning and experience of Hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal (MPhil degree – Dr Colleen Cox)

I hereby wish to apply for Provincial Health Research Committee (PHRC) approval regarding my research study towards the degree Masters (MPhil) in Palliative Medicine. My study is entitled “Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal”. Attached please find the following documents in support of my application for PHRC approval:

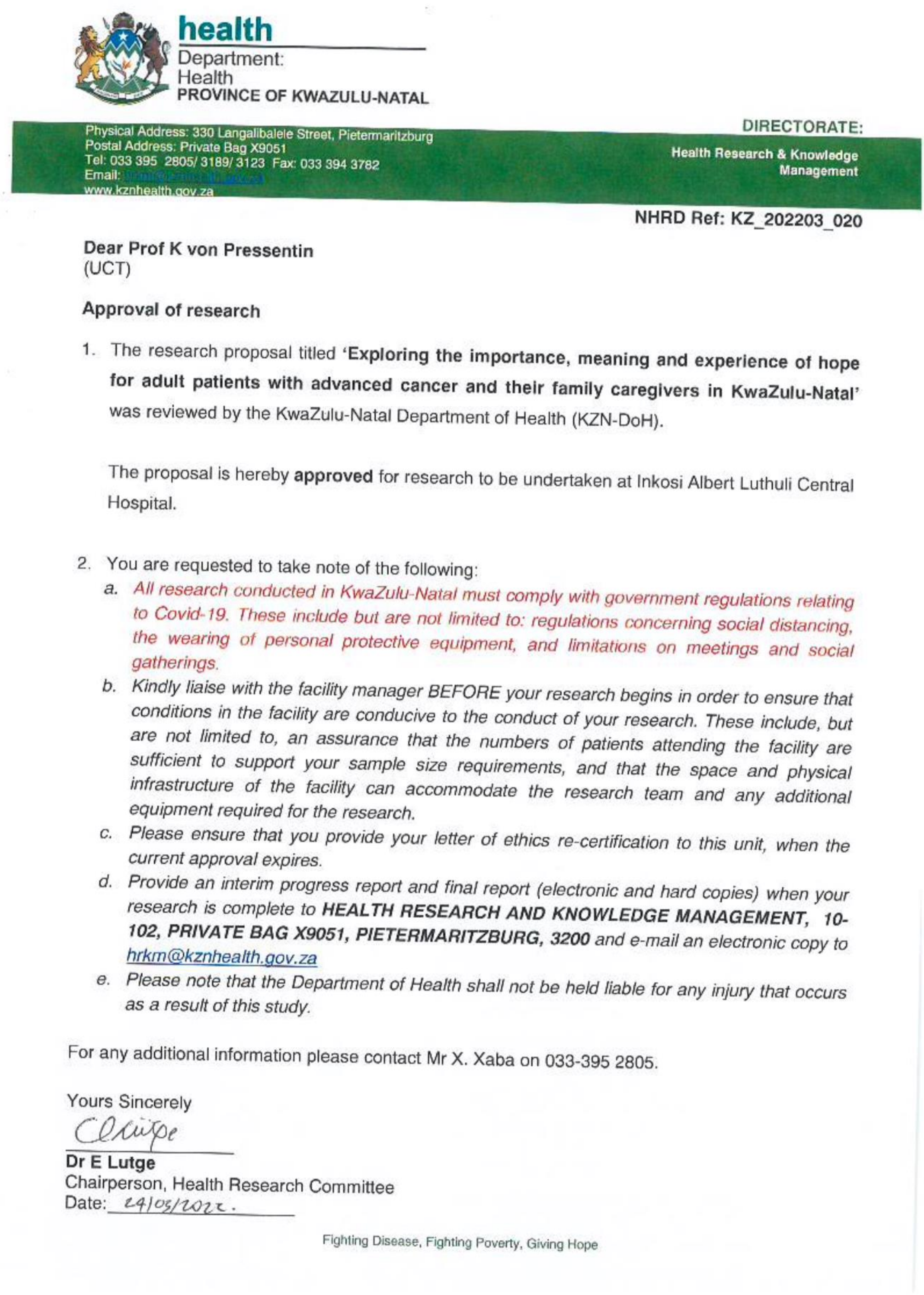
1. University of Cape Town (UCT) Faculty of Health Sciences Human Research Ethics Committee (HREC) approval (Ref no: 046/2022)
2. UCT HREC document relating to research undertaken during COVID-19 lockdown
3. Approval letters from Dr A Harrichandparsad, Clinical Care Manager, Inkosi Albert Luthuli Central Hospital (IALCH), KZN
4. Approval letter from Dr S Bhadree, Head of Clinical Unit – Oncology, IALCH, KZN
5. Research proposal
6. Research proposal – appendices
7. Research proposal – synopsis

I thank you most sincerely for reviewing my research proposal and application for my research to be conducted at Inkosi Albert Luthuli Central Hospital (IALCH) in KZN.

Yours faithfully

Dr Colleen Cox

Cc: A/Prof Klaus von Pressentin (main supervisor)



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
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DIRECTORATE:
Health Research & Knowledge Management

NHRD Ref: KZ_202203_020

Dear Prof K von Pressentin
(UCT)

Approval of research

1. The research proposal titled **'Exploring the importance, meaning and experience of hope for adult patients with advanced cancer and their family caregivers in KwaZulu-Natal'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central Hospital.

2. You are requested to take note of the following:
   a. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   b. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to* ***HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200*** *and e-mail an electronic copy to* *hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 24/03/2022.

Fighting Disease, Fighting Poverty, Giving Hope

Appendix G – Distress protocol

1. Prior to the study-related interview:

- As part of the discussion about the study when taking informed consent, the researcher will inform each patient and their family caregiver about the issues to be discussed in the interview, pertaining to their experience of hope
- Only patients and family caregivers willing to have such discussions will be included in the study

2. During the study interview, if any participant appears upset or expresses distress, the researcher will follow these steps:

- Pause the study-related line of questioning
- Assess the reason for the distress, apologise where the study-related line of questioning has caused the distress
- Provide a compassionate presence, empathic listening
- Address the cause of the distress where this is possible
- Provide appropriate support and counselling as needed
- Offer the participant the opportunity to stop the interview and either to abandon the interview, or to restart the interview when they feel more at ease and comfortable to do so
- Reassure the participant that discontinuing the interview and withdrawal from the study will not compromise ongoing care or management by the healthcare team
- Continue with study-related questioning only when the participant is comfortable to do so
- Refer for further support or counselling (to social worker or psychologist) should this be appropriate; treat all information with confidentiality within the best interests of the study participant
- Document that the distress protocol was required, and record the final outcome of the interview

3. After the interview, the researcher will:

- Contact the study participant to ascertain whether the distress has been resolved and appropriate support and counselling received
- Refer for further support or counselling as indicated
- Thank the patient or family caregiver for their time spent participating in the study