CANCER STORYTELLING
Revealing prayer and well-being

By

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CANCER STORYTELLING:
revealing prayer and well-being

Abstract

It is a truth, frequently disclosed in this research, that the storytelling of cancer patients was prayer, which contributed to their well-being. Spirituality was found to provide the context within which storytelling, prayer and well-being were strongly correlated. A corollary followed, that improvement in well-being was mediated by oncology professionals who practiced active listening and who provided a fully patient-centered presence.

The sources used in this research were the stories published by 160 cancer patients, selected because they were equally distributed between females and males and represented the spectrum of cancers.

The aim was to probe this published oncology literature qualitatively, to determine exactly what the patients were saying about their prayer and well-being, making no pre-conceptions. The method involved a blending of interpretative phenomenology and grounded theory, the latter as expounded by
Use of the qualitative data analysis tools of NVivo 10® enabled the performance of coding, clustering, and analysis of the sources, forming the basis for reflection.

Reflection on the analytical results involved making comparisons with the published findings of oncology researchers and the millennia of prayer experience found in the spiritual classics. Christian trinitarian and incarnational theology emerged as providing the most wholistic paradigm for the nexus found between prayer and well-being. Further, a pastorally significant benefit for active listening was realised.

Four future suggestions emerged: (i) that a wider and deeper theological study of the faith-prayer link in oncology is needed; (ii) that study of the metaphors that cancer patients and the professionals treating them deploy, would enhance their mutual well-being; (iii) it identified a need for improved communication, so that the findings of medical, psychological and theological researchers could be shared to their mutual benefit and to that of their patients; (iv) that the paradigm of “training” be changed to one of “education” for undergraduate oncological professional induction; also that continuing professional development should provide for critical reflection that was both patient and practitioner centered.
Title

CANCER STORYTELLING: revealing prayer and well-being

Gregory Brown

Declaration

I declare that the word length of this thesis is approximately 95,000 words. This does not exceed the maximum length specified in the regulations.

I declare that the bibliography format is consistent and conforms to the requirements of the Turabian Style (Turabian, Kate L. A Manual for Writers of Research Papers, Theses and Dissertations: Chicago Style for Students and Researchers. 8th ed. Revised by Wayne C. Booth, Gregory G. Colomb, and the University of Chicago Press Editorial Staff. Chicago: University of Chicago Press, 2013.)

INSTITUTIONAL REVIEW PROCESS

Human Research Ethics Committee approval was received on 20 March 2012. Approval was refreshed on 20 March 2013 and 20 March 2014. (University of Divinity Regulation 22.19).

All requirements for the requirements of “Examination of Theses” were met under regulation 26 (Higher Degree by Research Handbook, Rev. July 2014).

Statement of Originality

I hereby certify that this thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other institution, and affirm that to the best of my knowledge, the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Signed: ..............................................

Date: ..............................................
Acknowledgements

Many people have encouraged and assisted me in the completion of this thesis. I am indebted to them and make special thanks.

Firstly I thank Karen, my wife, and my family without whose constant enthusiasm, encouragement and help, I could not have completed this work.

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   For support of family
   For purpose and the chance of a new life
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   Just thanks
   To God for being Saviour
   For God listening and people reading the patient’s story
   For professional support
   For present and past gifts including laughter
   For survival

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<th>MEANING</th>
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<td>CAQDAS</td>
<td>Computer Assisted Qualitative Data Analysis Software</td>
<td></td>
</tr>
<tr>
<td>CT</td>
<td>Computed Tomography</td>
<td>A medical diagnostic technique that combines X-rays and radiofrequency radiation to produce a three dimensional image of the body.</td>
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<td>EORTC QLQ-SWB36</td>
<td>European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Spiritual Well-being 36 items.</td>
<td>Proposed in 2012 as a stand-alone measure of spiritual well-being proposed for clinical and psychometric use by the EORTC Quality of Life Group.</td>
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<td>FACIT-Sp</td>
<td>Functional Assessment of Chronic Illness Therapy – Spirituality.</td>
<td>Part of the larger FACIT measurement system for multi-dimensional health related quality of life (HRQOL) FACIT-Sp is used to determine biopsychosocial –spiritual well-being.1</td>
</tr>
<tr>
<td>GT</td>
<td>Grounded Theory</td>
<td>Used in the form described by Anselm Strauss &amp; Juliet Corbin in 1997.</td>
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<tr>
<td>IP</td>
<td>Interpretative Phenomenology</td>
<td>IP seeks to understand lived experience that has already been the subject of reflection by the experiencing person.2</td>
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| **MRI** | Magnetic Resonant Imaging | A medical diagnostic technique that uses strong magnetic fields and radiofrequency radiation to produce a three dimensional image of the body. |
| **MBSR** | Mindfulness Based Stress Reduction. | Jon Kabat-Zinn developed MBSR as a technique (detached from religious and cultural forms) to help people to self-regulate chronic pain. Used to reduce ruminative thinking, anxiety, or depression. ³ |
| **OP** | Oncology Practitioners | Used to refer collegially to the group who practice in oncology. For this research, this group includes Doctors, Nurses, Radiation Therapists, Radiographers, Psychologists, Pastoral workers and Clergy. If the context relates to one or two only of these professionals, their cohort is named. |
| **Pr** | Pearson Correlation Coefficient or Pearson’s r. | The words contained in selected sources or nodes were compared and their similarity (correlation) expressed using the Pearson coefficient (Pr). Values of Pr range from +1 through 0 to -1. A value of +1 denotes total positive correlation. Value 0 means no correlation and -1 total negative correlation. |
| **QDA** | Qualitative Data Analysis | |
| **QLACS** | Quality of Life in Adult Cancer Survivors | A quantitative measuring scale used to evaluate the quality of life of long-term adult cancer survivors.⁴ |
| **SF-12** | Short form, 12 questions | Questionnaire (measure) widely used in medicine to determine the association of well-being with spirituality. The longer version SF-36 was developed by the Medical Outcomes Study.⁵ |

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Note on Style

The thesis style required by the University of Divinity is that of Kate Turabian, which has been followed throughout.\(^6\)

When reference is made to the cancer patient, the practice in the published literature, in which the stories are sourced, is to use the "form of name individuals were most commonly known by or known to prefer". This is recommended in the *Oxford Style Manual*.\(^7\) For example, in the earlier part of the first chapter, Lynn Eib was first introduced as the author “Lynn Eib”; but will be called “Lynn” when the reference is to her as a patient.

To avoid confusion, it should be noted that my research is generally referred to as “this study” to separate it out from the many citations and comparisons of the research findings of others that are found throughout this thesis.

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\(^6\) Kate L. Turabian, *A Manual for Writers of Research Papers, Theses, and Dissertations* (Chicago, USA: The University of Chicago Press, 2010).

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Word Frequency Cloud for this Thesis

A word frequency cloud presents the most frequently occurring words through the medium of lettering whose size is directly proportional to the number of times that each word occurred within the document. In this case the cloud shows the most frequent fifty words found in this thesis of some ninety five thousand words. The words in the title of this research are prominent in the cloud, namely cancer, prayer and well-being. The sources of this research are stories of oncology patients which are also prominent. The emergent paradigm is seen in the words spirituality, god, one, meditation, metaphor, self, others and listening.

Word frequency cloud for this thesis.

Amongst the top 50 words that occurred most frequently were: cancer (700), prayer (436), well-being (416), patients (343), god (258), stories (232), life (208), spirituality (175), meditation (156), one (150), people (129) and story (121).

This cloud map indicates the presence of a consistency between the themes of this research and the purpose of qualitatively analysing the content of 160 cancer patients’ stories.
Chapter One: Sourcing stories told by cancer patients

1 Introduction

In one hundred and sixty stories, told by patients about their cancer experience, what did the storytellers say? What was found by qualitative data analysis based on this pool of experience? How did the findings of this research relate to those found in the published domains of oncology, psychology, theology and pastoral care? These questions indicate the path taken by this research. It will be shown that cancer, prayer and well-being were the most frequently occurring words in the dataset comprising the patients’ stories. Further that the storytelling of the cancer patient is prayer that arises from the person’s spirituality and contributes to her or his well-being. A hypothesis emerged from the storytelling that prayer was linked to the well-being of the cancer patients studied.

This thesis presents my study conducted to determine if and how prayer impacted on the well-being of people receiving a diagnosis of cancer: it presents the evidence in support of the hypothesis that emerged; further, it presents the findings of my critical reflection from viewpoints which are both theological and pragmatic. It favours a “bottom up” approach as described
by John Polkinghorne. It is better characterised as *a posteriori* than *a priori*, in that evidence emerging from the actual experience of cancer patients is given preference over seeking validation of a pre-existing theory. This research found that cancer patients acted out of a spirituality that was mostly prayerful; yet few described “prayers” or presented a scheme of spirituality. However twenty three patients quoted some seventy seven passages from Christian scripture. Early psycho-oncology research found difficulty with linking spirituality, prayer and well-being. But this research found consistency with the publications of many contemporary psycho-therapists. Although it must be said that opinion varies amongst the cohort of psychologists as evidenced by those who would see meditation as a technology void of any context of spirituality. Most people experience cancer: whether as patients; or as a closely involved person; or as professionals involved in pastoral care; or the medical management of patients. The experience always changes

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lives, affecting the well-being of patients and oncology professionals alike.\(^5\)

This research focused particularly on the cancer patients’ experience as they revealed it through their published stories. Such storytelling was shown to contain a real wealth of lived experience that provided the opportunity for this research. The approach taken here is novel: novel because such a collection of stories had never been subjected to critical analysis, aimed at determining the fact and extent of any correlation between spirituality, prayer and well-being; novel too, because the patient’s experience was not fitted into any pre-conceived model or conceptual framework, arising from a discipline driven research methodology as is common in oncology and psychology.\(^6\) The focus and grounding of this research was primarily on comprehending what the patient said. Thus it can be truly characterised as qualitative data analysis rather than quantitative data analysis.

Grounding the research in such a data rich repository of stories provided both strength and limitation. The structure and content of the narratives were determined entirely by the narrator; and the conclusions were limited to the narrated context. Further, I have a lifelong interest in cancer that arose both from receiving a cancer diagnosis and from some forty years of extensive professional oncological experience as a medical scientist and


an academic. These provided me with qualification to conduct this research but contained a potential to introduce bias. My story was only one amongst some one hundred and fifty nine others and was not afforded the status of an exemplar.

The stories of this study were published to be sources of hope for others with cancer. And at this level, they succeed; people are generally interested to hear credible stories that relate to their present experience, particularly if it is one of cancer; and particularly if it offers hope. But can the stories offer more? Can there be hidden messages? To what extent do the metaphors that people use, when talking about cancer, influence prayer and well-being? Does well-being depend on spirituality? Do all cancer patients have a spirituality? These and similar questions were addressed in this research.

7 NOTE: In 1963 I received a provisional diagnosis of “Malignant Melanoma”, which subsequent biopsy proved to be a benign growth. I found the waiting period between the biopsy and communication of the diagnosis to be traumatic beyond belief. And then came the coping with the knowledge that the surgery was now proven unnecessary because the provisional diagnosis was histologically proven wrong. For forty years I worked to provide radiation treatment, educate radiation therapists, radiation oncologists, and medical physicists in both local and overseas cancer treatment centres. My professional experience led me to believe that meditation, especially contemplative prayer, was the best way for people living with cancer to maintain their contact with God in spite of the traumatic events arising from their diagnosis, their treatment and their subsequent altered life. Such life experience led me to the desire to share, with others my belief that the Christian paradigm may help them too, as it has enriched my life.
2 Sourcing stories of cancer, prayer, and well-being

Where could one find the first-hand accounts of cancer patients needed for this research? How could my personal and professional experience of cancer be incorporated, respecting its integrity whilst avoiding bias? Literature searching had revealed that some stories were located in books but the majority were published via the internet. Sourcing enough representative first-hand accounts of peoples’ experience with cancer and of its effect on their prayer and well-being was a condition sine qua non for this research. This is because its credibility derives from remaining faithful to real cancer experiences as told by the patients themselves. Brad Zelbrack noted that such writings comprised but “a small yet burgeoning survivorship literature”. The one hundred and sixty stories studied were chosen to represent the spread of cancer incidence and to achieve an equal representation of gender. Few of the authors wrote about death as imminent. They were concerned primarily with achieving the best quality of life for themselves and all believed that they published to help others; and in that sense all were considered to be survivors, striving to find meaning in the reality of their cancer.

A proportion of the stories studied were found published in the printed literature as books, sections in books, or newspaper accounts. The internet

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provided the biggest number through accounts from public websites and some internet blogs. Sources for discussion, comparison and critical reflection were derived from professional refereed journals and spiritual classics.

3 Sourcing in the spiritual classics

The published references found before the post-modern era, represent the experience of generations of people whose well-being was influenced by illness and prayer. The literature comprising the spiritual classics contains the developed wisdom arising from all forms of prayer practised over more than a thousand years: the writings of the desert fathers, made systematic by John Cassian, remain typical of such spiritual classics; Hildegard of Bingen, and St Francis, were early medieval writers; Thomas à Kempis, Richard Rolle, and Julian of Norwich, later medieval writers; John Baptiste de La Salle, Teilhard de Chardin, and Thomas Merton were more contemporary writers.⁹ This present study would be incomplete and bereft of the wisdom

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of more than a thousand years if it chose to ignore sources from the spiritual classics. Such literature is a most valuable record of human experience that has been validated by the acceptance of people over a significant period; and this especially when considered in relation to the contemporary accounts that, lack the proof of their wisdom, arising from continuous practice over centuries. Also by including references published before 1990 in the data collection and analysis, this research stands to benefit serendipitously from forgotten practices with relevance to contemporary people living with cancer. Meditation is an example of an ancient practice that fell out of use amongst lay people but is now exceedingly popular. More generally too are the accounts of the ancient practices of prayer that are being “re-discovered”. In its process, this research found five hundred and twenty two references to meditation in its various forms within the one hundred and sixty stories.

Paradoxically, within the secular publications, the minority of such references were found throughout the longest period, extending from biblical times (c. 2,500 years BCE) until the post-modern (c. 1900). Early modern psychology in the 1900’s did show an interest in prayer but tapered off for almost a hundred years. The majority of the data of contemporary research was found to be derived from literature published since c.1966 when electronic access to publications through search-engines such as PubMed

and ProQuest, became possible and very popular.\textsuperscript{11} These databases include both books and serials amongst their resources. A PubMed query performed now would reveal at least the following numbers of publications since 1990: for \textit{Cancer} (81,863); for \textit{Prayer} (1,360); and for \textit{Well-being} (117,431).\textsuperscript{12} Combining the two terms in a search, \textit{Cancer AND Prayer} would reveal at least 2,000 publications since 1990 and only 449 prior to 1990. Combining the three terms \textit{Cancer AND Prayer AND Stories} since 1990 would yield just 17 publications which are either books or journal articles. Some of the stories used for this research were published in the printed literature (n= 53, 33%), whilst others were published via the internet (n= 107, 67%).

\textsuperscript{11} NOTE: PubMed: The US National Centre for Biotechnology Information (NCBI) and US National Library of Medicine's freely available online database and search facility. It contains more than 11 million references to the many indexed biomedical journal articles that are in MEDLINE, PreMEDLINE and other related databases. MEDLINE is the US National Library of Medicine's database that contains more than 11 million references to journal articles in the health sciences http://www.cirem.co.uk/definitions.html#p [Accessed April, 17, 2014]


NOTE: PubMed comprises over 21 million citations for biomedical literature from MEDLINE, life science journals, and online books. PubMed citations and abstracts include the fields of biomedicine and health, covering portions of the life sciences, behavioral sciences, chemical sciences, and bioengineering. PubMed also provides access to additional relevant web sites and links to the other NCBI molecular biology resources. PubMed is a free resource that is developed and maintained by the National Center for Biotechnology Information (NCBI), at the U.S. National Library of Medicine (NLM), located at the National Institutes of Health (NIH).
4 Print published sources used

The majority of the stories of cancer experience found published in the form of printed literature were written by established authors. Frequently these authors were journalists, who were in remission from cancer. Some of these authors produced an anthology by including the stories of others with a similar experience. They often wrote that their intention was to provide witness to hope for their readers who may be recently diagnosed or seeking guidance in the period after treatment. Lynn Eib said it best, when in her introduction she wrote “If you already have enough hope and healing in your life, don’t bother to read this book. But if you’ve got questions and would like to find the light in cancer’s shadow, then unlock the car door, let me hop in, and keep reading.”

This is a very compelling statement. Equally compelling, and for the same reason, were the other autobiographical stories, that were found in the literature, in which individuals wrote about their personal cancer experience. Lynn’s writing typified the books recounting cancer stories, of others, by people who have survived cancer themselves such as those of Susan Sorensen and Laura Geist which reveal as much about the author’s

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14 Lynn Eib, *Finding the Light in Cancer’s Shadow*, xvii.
spirituality as of the people whose stories they tell. Lynn again provides a typical example of the well-being of an author being realised through helping others. She wrote: “I loved her (Alice) and she would be my forever friend. Do you, like Alice even feel you weren’t good enough and that’s why you got cancer. In the first couple of days after my cancer diagnosis, the devil brought to my mind all kinds of sins I had committed and good deeds I had omitted. I felt alone. Worthless. Condemned. Defeated. Not good enough.” Lynn’s personal spirituality of the love of God had been upset by the feelings associated with her diagnosis of cancer and now she was telling Alice what a friend (Sheila) had told her in the midst of her “fiery arrows”:

Sheila prayed with me and reminded me what I knew in my head but could not feel in my heart: God’s love and presence in our life are not based on whether we’re “good enough” – they are gifts, unconditional and with no strings attached. Slowly but surely, I began to feel God’s love again and to understand that my prayer for healing would not be answered as a reward for good behaviour. So I remind you today, you don’t have cancer because you weren’t good enough. And you don’t need to do something special to earn or deserve healing from God.

Lynn’s personal well-being had improved at the time of diagnosis through her friend Sheila’s spirituality and it was being reinforced by sharing

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15 Susan Sorensen and Laura Geist, Praying through Cancer: Set Your Heart Free from Fear (Nashville: Thomas Nelson, 2006).

16 Lynn Eib, When God and Cancer Meet (Wheaton, Illinois: Tyndale House Pub, 2002), 80; Susan Sorensen and Laura Geist, Praying through Cancer: Set Your Heart Free from Fear.

17 Lynn Eib, Finding the Light in Cancer’s Shadow, 81.
it with Alice at the time of her diagnosis. It was clear that Lynn had dissociated her cancer from punishment for past sins. Reaching such a realisation is difficult for religious people. Further she realised that spiritual healing was not associated with personal merit but was a freely given gift from God. Lynn was led to a deeper understanding of her Christian belief in grace through her cancer experience.

The near universal theme in the autobiographical accounts was the conveyance of a message of hope for the reader, who in all likelihood would be a person experiencing a recent diagnosis of cancer. They can be paraphrased as: “I have been where you are and I am doing well now!”

Another common characteristic of the published stories was that the form of prayer was frequently recorded: all sorts of prayer; angry prayer, prayer of petition, thanksgiving, and meditation. Sometimes it was categorised as: colloquial prayer (talking to God), petitionary prayer (asking God), ritual prayer (formal) and meditative prayer (open to God).

The published literature contained a collection of stories covering the whole oncology spectrum, validating it as a repository of lived experience for use as a data source for this research. Their consistency, and the depth of their grounding in the experience of people living with cancer made them a

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source of choice for this research. To the patients’ stories were added the stories published by chaplains who published to pass on their oncology experience.

Melvyn Thompson was the Anglican Chaplain at the Royal Marsden Hospital in London, one of the world’s leading cancer treatment centres.¹⁹ He wrote as a compassionate person who has reflected and prayed about his vast experience of working with cancer patients. His *Cancer and the God of Love* provided a comprehensive introduction to cancer, its treatment and his experience as a chaplain. He knows the questions of patients and their relatives such as “What have I done to deserve this?”, “I’m sure it will all come right in the end”, “Why did God let him die?” and “All these things are sent to try us”. All common questions. But Thompson offered little that would assist a pastor or patients; his interest remained philosophical.

Other chaplains who had published their experience took a similar philosophical approach to the problems of cancer, prayer and well-being. Disappointingly their works offered little for this study: some because the text was too far abstracted from the individual case sources; frequently the presentation was made in a manner that supported the individual chaplain’s thesis rather than revealing the thoughts and feelings of the individual patient;

a practice shared with their oncology practitioner researchers. Valid sources for this research must include individual details of the cancer patient’s experience and must contain no third party interpretation. The writings of John Main and Ernest Larkin combined their extensive pastoral experience along with their personal experience of cancer. Their stories were told directly and so became sources for this research. John Paver was another example of a chaplain who experienced cancer and whose writings told his own story directly. Paver offered the fruit of his experience and reflection in what he called a “theology of the Cross”, which will be shown, later in this study, to be a very complete Christian paradigm.\(^{20}\)

Medical doctors, especially oncologists, are a group of writers who have a vast experience of cancer, so their publications could be expected to contain the stories of their patients. Regretably their publications were generally done in the medical model and characterised by a pseudo-science that frequently set spirituality at nought. Typically they offered empirical evidence based information that was planned to assist physicians, nurses and health professionals and only indirectly did it offer benefit to patients’ well-being.\(^{21}\)


However, some exceptions were found amongst the publications of medical practitioners. Amongst these were Larry Dossey, Daniel Hurley, Joan Borysenko and Herbert Benson who described their oncology experience in ways that offered practical help for cancer patients; and thus became sources for this research. Of particular interest, was the assertion that the prayer of patients in oncology changed in response to the diagnosis and the pain that they often experience. Joan Borysenko wrote “When we are absolutely miserable, prayer is no longer a dry rote repetition. It becomes a living and vibrant cry for help. It becomes authentic. In pain we forget the "thee's" and "thous" that keep us separated from God, and reach a new state of intimacy that comes from talking to God in our own way, saying what's in our heart.”

Herbert Benson of Harvard University Medical School worked with a physiologist Robert Keith Wallace to conduct experiments that demonstrated the health benefits arising from “transcendental meditation”. Over time,

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Benson worked with Jared Kass, a psychologist as a research partner and the group studied was expanded to include pastors. Benson made four conclusions from his research. Firstly, that the health benefits of meditation were lower blood pressure, slower heart rate and lower metabolic rate. Secondly, that a mantra need have no meaning for effectiveness; although those meditators using a mantra with a spiritual significance, persevered longer in meditation than those deploying a meaningless mantra, such as repeating the word "one". Thirdly, *aerobic prayer*, comprising short phrases uttered in phase with the walking meditator's steps, produced equal benefits to those meditating in a comfortable position indoors. Fourthly, that there was no method of prayer that was common to all participants in his studies.

These were typical of the many studies that doctors and medical scientists have performed into well-being, taken in the context of the parameters of this research. About 80% of such studies found that prayer, amongst the extrinsic and intrinsic religious practices, improved well-being. Further, this paper by Matthews and colleagues said “the available data suggest that practitioners who make several small changes in how patients’

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24 NOTE: Aerobic prayer is a quasi-medical term for what spiritual writers would identify as *aspirative prayer*, the *prayer of ejaculations* or even simply as *walking meditation*.


religious commitments are broached in clinical practice may enhance health care outcomes".27 This indicates the usefulness of the study of this thesis with its emphasis on spirituality giving rise to prayer and well-being for cancer patients.

Other researchers had established links between spirituality and well-being. William Gabler’s study showed that “stronger religious beliefs were positively correlated with less fear of death (Pr= 0.77)”.28 Such strong Pearson correlation indicates the strength of association between two variables but does not establish causality.

Margaret Poloma and colleague Brian Pendleton showed that prayer, and both intrinsic and extrinsic religious factors correlated with well-being. The “Spiritual Well-Being Scale” was used by William Gabler and Bufford and colleagues, who also confirmed that there was a relation between spirituality and positive feelings about life.29

27 Matthews, “Religious Commitment and Health: A Review of the Research and Implications for Family Medicine,” 118.

28 Gabler, "The Relationship of Prayer and Internal Religiosity to Mental and Spiritual Wellbeing," 17. NOTE: The symbol Pr is used throughout this thesis because it is the conventional symbol for Pearson correlation coefficient which is a measure of similarity; Thorleif Petterson, "Welfare Policies, Religious Commitment, and Happiness," in Religion, Personality, and Mental Health, ed. Laurence B. Brown (New York: Springer-Verlag, 1994), 174-92.

Some medical studies showed an interest in the spontaneous remission of cancers thought to be incurable. In 1976 Dr. B. J. Kennedy and his co-workers at the University of Minnesota Medical School studied twenty-two patients with supposedly incurable cancers who had recovered and lived for at least five years. They had similar attitudes. After they recovered from their initial shock, they were determined to fight and win. They firmly believed in recovery. Many cited the importance of knowing that even one other person had survived with their type of cancer. If someone else could survive, why couldn't they? Patients cited their belief in their doctors, in medical science, and in God. The key factor was that they had strong faith in something that prevented them from feeling helpless. There were other examples of the mind's power over the body. Science is only beginning to understand the importance of the patient feeling hopeful and in control. This theme will be shown repeated in many of the patients' stories that follow.

Research into the power of spirituality (mind) over the body is becoming seen as constituting a valid domain of increasing interest to psychological and psychiatric researchers. Laurence Brown saw this increasing interest and perceived legitimacy amongst the scientific researchers in interpreting the religiousness of cancer patients from a

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standpoint of depression; this was in marked contrast to making their interpretation of the stories from a preconceived Freudian psychoneurosis model. Increasingly the reactions of patients to their cancer diagnosis were being seen as normal mental health issues rather than as evidence of psychiatric mental health conditions. Thus leading to an increase in research activity that in time offers much for a more objective understanding of cancer, prayer, and well-being.

Most studies of cancer survival remained immersed in the negative experiences associated with the diagnosis and so failed to identify the positive aspects of posttraumatic growth. By way of contrast, in more recent studies, improved well-being was reported by Erin Costanzo, Carol Ryff and Burton Singer amongst the longer term survivors of a cancer diagnosis. Costanzo and colleagues conducted a longitudinal survey deriving their statistically significant sample from the “National Survey of Midlife Development of the United States”. Their research contained a comparison group, without a diagnosis of cancer, which was statistically matched on age, sex and education; they tracked the groups over 9 years and made corrections for people in the comparison group who received a cancer diagnosis during the time of the study. The areas of well-being researched were psychological,

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**social, and spiritual.** Costanzo and colleagues had produced evidence of well-being beyond what might be commonly expected.

Rare and hence valuable stories written by non-medical scientific academics were found in the professional literature. They were told by people who survived a cancer diagnosis, describing their personal experience in the fully referenced manner of academic papers. Martha Stoddard Holmes typified this small group.

Our task, after Sontag, is to rethink metaphor as a site of self-direction rather than one of interpellation by medical discourse. When I was diagnosed with cancer in 2003, six weeks into a Literature and Medicine class — and barely two weeks after teaching Illness as Metaphor and AIDS and its Metaphors — I told my students the news and exhorted them to “Remember Sontag!” I privately cringed at the kind, concerned e-mails from students, family, and friends that began, “I heard that you’re battling cancer.” Truly, I did not feel that this metaphor helped my apprehension of my illness. Battling? It felt inauthentic. I was crawling. Or rather: sometimes I was trundled from hospital to home in a stunned state; sometimes feeling well enough to be curious about and fascinated by the unfamiliar experiences; sometimes flushed with grateful relief in a moment of comfort; sometimes feeling wildly uncomfortable with pain or frantic with awkwardness — the shame of asking for pain meds, the embarrassment of looking awful when visitors came, or the combined shame and awkwardness of being too preoccupied with bone pain or GI misery to pass as my usual self. And sometimes, wonderfully, I was just asleep. It’s not that battling was distasteful or reprehensible to me (as it seems to have been to Sontag); it just didn’t fit. But without a fitting metaphor, I had no story. During those times in which I was blessed with the mental and physical liberty to even begin conceptualizing my disease, I would have welcomed a spur to transform it, and myself, through a change in language: the comfort of seeing cancer as a presence, an anchor, an infant, a bubble, a lover, a mosaic, a seedpod, an energy — each metaphor generating a different complement of stories. Or, if not comfort, metaphors could have
offered the gifts of distraction and curiosity: what is most like this?

Stoddard Holmes, in responding to her diagnosis of ovarian cancer, rejected Sontag and the “war metaphor” and advocated a more direct form of expression derived from real life or based on a simile. She believed that patients, carers and medical staff gained a more direct control in dealing with cancer diagnoses if they used plain language. This theme of metaphor and simile use is continued in the next chapter because of its importance in interpreting the communication between patients and between doctor and patient obviating misrepresentation.

5 Internet sources

The largest contemporary collection of cancer stories was found posted on the internet (n= 107, 67% of the stories of this study). Selecting stories from such a vast and diverse literature was a challenge in achieving a sample that was genuinely representative but not impossibly large for the analysis which required frequent iterations of the selected stories. Organisations such as the American Cancer Society and the Cancer Council


of Victoria provided a platform for hundreds of stories to be told by people who were living with cancer. The provenance of the stories published through such organisations was considered to be of the highest order because of the code of ethics to which the publishing authority subscribed. Although some evidence of bias in the organisation’s selection of stories chosen for publication was found, the integrity of the narratives themselves could not be doubted. The greatest care has been exercised to ensure the privacy and confidentiality of the internet sources used for this research and to determine and respect the storyteller’s intention. Care was taken to avoid the “Google effect” with its lack of proper referencing.

In brief, I have sourced the data for the qualitative analysis, which is the method of this research, from both traditional and contemporary printed publications. Approximately two thirds of the stories are derived from postings to the internet. Such a rich potential data set poses unique opportunities for this research. The question of how much data is enough to ensure representation and validity arises, and is dealt with in subsequent chapters, under the terms data sufficiency and theoretical saturation.

6 Place of this research

The existing literature either appeared to take a quasi-philosophical approach to the oncology experience that it reported, or it remained at the

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level of offering hope to other cancer patients on the basis of their shared experience. The credibility of this latter depends on concurrence of the reader’s experience with that being reported by the author. The research documented in this thesis was entirely derived from the lived experience of cancer patients and identified strong relationships between the three concepts of cancer, prayer, and well-being. It was found to be independent of any philosophy nor did it require a belief in any particular form of spirituality or “God talk” in its derivation. In its application, it required that a person have a spirituality. If that spirituality involved a concept of “meaning for life”, then the findings could benefit any oncology patient. In such linking of prayer with well-being, it contributes to the hermeneutic circle of oncology practice. Further, it identifies benefits for patient and oncology professional alike arising from a more complete implementation of active listening. It suggests that changing the paradigm from training to education would enable this and that the future needs in oncology would more likely be met.

7 Organisation of this thesis (Connections)

This chapter has provided an introduction to the research into cancer, prayer and well-being, whose study comprises its principal goal. It introduced

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the sources of the study which are one hundred and sixty stories (frequently referred to as “patient dataset” or “stories studied”). This chapter is concluded by providing the following overview to outline the content and path to be followed in the subsequent chapters. Each chapter’s connections section contains a word frequency cloud for that chapter. It follows for this chapter as figure 1.1. In such a word frequency cloud, the size of the lettering is directly proportional to the number of times that every word in the chapter occurred. The depiction is of the 50 most frequent words. The cloud is included because it is an objective indication of the chapter's themes: thus providing a context for the summary that follows in the connections section.

**Figure 1.1: Word frequency cloud for Chapter 1.**

The size of the lettering is directly proportional to the number of times that each of the words in this chapter occurred for the 50 most frequently occurring words. The most frequent were cancer (76), stories (44), research (42), prayer (40), and well-being (32). In this introductory chapter, the cloud gave the idea that the text was concerned with research on cancer stories involving prayer and well-being. This indicates that the themes in the chapter related to the topic of the research and served to introduce it.
Chapter two establishes a context for the analytical chapters that follow by defining the key terms found in the literature of oncology and spirituality. It extends the understanding of metaphor use in oncology, which affects the interpretation of what is written. Finally it introduces three exemplars whose cancer narrative was found to typify their cohort. The exemplars are Ernest Larkin and Lynn Eib, both of whom professed a belief in God and Christopher Hitchins who was an articulate atheist. Chapter two concludes with a section titled “Connections”. Each chapter concludes in this way to address the quality issue of rigour (trustworthiness). The quality measures used for quantitative research are inappropriate for this research because it is essentially qualitative. The measure of trustworthiness for qualitative research arises if the reader is able to audit the events and see the decision trail. Connections is intended: to make the evolving concepts explicit; to identify the thread of reflection in all of its domains, including theological; to summarise the current chapter and fit the next chapter into the evolving context.

Chapter three presents the methodology which is a blend of Grounded Theory, as interpreted by Strauss and Corbin, and Interpretative

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**Phenomenology.** It outlines the logical phases that were used in performing the qualitative analysis of the oncology story data using the computer assisted qualitative data analysis software (CAQDAS) package NVivo. The “Connections” paragraph continues the open signage to assist the reader to identify the progress in this and in every following chapter.

Chapters, four, five and six describe the results that arose directly from the systematic study of the cancer stories in relation to well-being, spirituality, and prayer respectively. The emphasis in these chapters is to represent the findings accurately whilst remaining fully grounded in the content of the stories told. They identify the facts that have emerged from within the patients’ stories and form the material for the reflection that follows.

Chapter seven, titled “Coherence through reflection on the findings made from the patients’ stories”, presents the critical discussion of the results of this research. Further, it concentrates on making comparison with and reflections on the findings in the published literature of the relevant domains particularly theology, oncology, psycho-oncology, and pastoral care.

The final chapter, eight, contains the statement of the outcomes of this research project. It identifies the emergent paradigm about the link between prayer and well-being and a corollary on active listening. It proceeds to

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38 NVivo and QSR words and logos are trademarks or registered trademarks of QSR International Pty Ltd. Copyright © 2011 QSR International Pty Ltd. ABN 47 006 357 213. All rights reserved.
discuss the strengths and weaknesses of this research. It concludes by describing the place established by this research in the oncology domain.
Chapter Two: Understanding cancer stories

1 Introduction

Before proceeding to analysing the patients’ stories, a context is needed. To this end, definition of the key terms, found in the literature of oncology and spirituality, follows. The chapter extends the understanding of metaphor use in oncology because its frequent use affects the interpretation of what is written. Later three writers are introduced as exemplars; because the detail and completeness of their storytelling elucidates the cancer experience of other patients in their cohort, in a ways that enrich the accounts.

The stories that people tell about their cancer are very personal. They are often told emotionally. The authors lack expertise in the specialised vocabulary deployed by experts in fields as diverse as those contained in this study; the fields of cancer, spirituality, prayer and well-being do not constitute a single discipline. Even the experts become constrained when they use the lexicon germane to their profession, potentially locking out comprehension by a professional in another discipline and certainly creating opportunities for misunderstanding amongst professionals and by patients alike.¹

Poor communication is further exacerbated because of the specialised requirements of publication by writing or by posting to the internet. Such difficulties affected this research because it depended on cancer stories as the principal data source. Further, the lack of precise terminology in the narratives complicated comparison with professional oncological literature and added complexity to theological reflection. Firstly, this chapter provides definitions of the fundamental key words to address these issues. The first paragraphs are devoted to providing definitions of spirituality, prayer, well-being, and cancer to unlock the door to mutual understanding. Other terms with a more local significance will be defined in a note on the page where they first occur. Secondly, a brief study of the war metaphor and some of the alternatives found in the published stories follows. This is done to identify the issues affecting communication that arise because of mismatches in the metaphors that people use and those used by oncology professionals. Thirdly, it provides a justification for many of the coding allocations made in performing the qualitative data analysis (QDA). And finally, this chapter introduces three very articulate and well published characters, whose stories typify many of their group. Collectively, they are taken as representing the cancer experience of the full gamut of people expressing their spirituality. This trio are designated exemplars. Lynn Eib has already been encountered and she has more to reveal. The other two exemplars are a Carmelite priest, Ernest Larkin and Christopher Hitchins, an atheist.
Chapter 2: Understanding cancer stories

2 Spirituality Defined

The word *spirituality* is like the word *God*. It takes different meanings for many people even amongst those raised in the same culture. The “indefinable oneness that underlies all that exists” of Yin De Shakya was taken as defining “God” for this study because can be inclusive of theists and atheists alike. The literature was found to contain numerous definitions of spirituality as authors strove to fully understand cancer experience. Many of the more modern definitions however disappointed, because they lacked any reference to literature pre-dating the coming of computer aided library search engines for serials in the mid-1960’s; and further because they were solely self-referencing. They were written as if no previous literature existed. Consequently they failed to identify or confused the parameters of spirituality. David Aldridge typified these in that he made no reference to definitions of spirituality earlier than 1986. He made no reference to God in the subject index and only seven references to God (six to *God* and one to *god*) in the thirty three page long chapter on prayer and healing.

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NOTE: Yin DeShakya defines her atheist *god*: I “can assure you that "God" to me doesn't bear any resemblance to the commonly held Christian, Judaic, or Muslim concept. Neither does it bear any resemblance to the ancient Greek or Norse Gods. Still, I have to use the label God because that label most closely fits my understanding of the indefinable oneness that underlies all that exists; my concept of God”; Yin De Shakya, “The Prayer of a Zen Buddhist Atheist,” http://www.hsuyun.org/chan/en/essays/essays-from-clergy/byyinde/730-the-prayer-of-a-zen-buddhist-atheist.html. [Accessed April 23, 2014].

3 NOTE: The electronic databases most used in this project were PubMed and ProQuest 5000 which only started indexing relevant material in the mid 1960’s.

4 NOTE: Such authors either confuse or omit reference to other spirituality parameters than those that they have defined. Many failed even to define spirituality.

Further, as James Nelson noted, misrepresentation is compounded because much contemporary literature lacked sophistication in its presentation of theology or made attempts to operationalise it. This confusion tests credibility when contemporary researchers proceed into the topic after failing to provide working definitions.

By contrast, David Ranson provided a modern paradigm that placed its roots in much older tradition and could include people claiming to be spiritual but not religious; thus his model easily includes atheists and theists alike. The cyclical nature of his model is consistent with the idea that spirituality changes in response to a person’s experience. This is important for this research because a patient’s responses to cancer will be shown to change along an existential trajectory. Ranson wrote: “Spirituality is a certain attentiveness to life which contains within itself a certain desire, a certain hopefulness, a certain anticipation. Spirituality is attention combined with intention.”

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NOTE: The findings of this research provide evidence of frequent changes made as patients accommodate the realities of their cancer.

Ranson’s approach is cyclical in concept, requiring that genuinely spiritual activities be identified with one of the four categories of attention, inquiry, interpretation, or action. He derived these from Bernard Lonergan. These are similar to and congruent with the cyclic categories of encounter, experience, interpretative reflection or prolongation postulated by Gustavo Gutierrez. Ranson’s cycle of spirituality with both the Lonergan and Gutierrez descriptors is shown in figure 2.1 above.

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Ranson’s concept of locating spirituality within a set of categories, whether using the Lonergan or Gutierrez sets of descriptors, readily accommodates human behaviour, considered in a cognitive developmental sense, and the person’s religious belief, whether creedal or not. It can accommodate the disturbance caused by a person receiving a diagnosis of cancer.

Ranson’s definition of spirituality provides a platform for prayer to be identified as conversation to or listening to God or alternatively with a non-creedal person’s self-talk. Ranson’s “attention combined with intention” is reminiscent of a phrase first used by the Cistercian monks and now made popular as a description of centering prayer by Thomas Keating and Basil Pennington.11

The Ranson concept of spirituality is evident in the self-talk of Christopher Hitchins when he wrote:

In Tumortown you sometimes feel that you may expire from sheer advice ... Analyzing the blues that I developed during that lousy seven days, I discovered that I felt cheated as well as disappointed. ‘Until you have done something for humanity’ wrote the great American educator Horace Mann, ‘you should be ashamed to die’. I would have happily offered myself as an experimental subject for new drugs or new surgeries, partly of course in the hope that they might salvage me, but also on the Mann principle. And I didn’t even qualify for the adventure.12

In Hitchin’s text the words analysing, discovered and adventure occur. These are similar to the terms above that are indicative of spirituality in the

11 David Ranson, Across the Great Divide: Bridging Spirituality and Religion Today, 80.

Ranson model. Hitchins’ writings and life indicate that he was empowered by a spirituality that was constantly searching for understanding; constantly critically questioning and acting out his belief; being given expression through his journalism. His spirituality never found a place for a God in the Christian sense, but nevertheless fits comfortably within Ranson’s model.

Spirituality is very individual, creating the challenge associated with settling on just one model. There is no “one size fits all” approach to spirituality as is commonly seen in many contemporary definitions that can be characterised as “thin”.¹³ A useful definition of spirituality must combine reference to being and experience and doing. It involves searching for meaning and inner freedom. References made in this research, relate dominantly to the concept of spirituality as defined by the Ranson cycle of the four sequential activities. The activities provide a platform for understanding prayer in all of its senses and permits discussion of the practice of prayer by atheists and the whole spectrum of people who pray. Further, the cycling and the possibility of splitting¹⁴ allowed in the Ranson model of spirituality also provides a context for subsequent investigation into well-being.

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¹⁴ NOTE: In the Ranson paradigm, *splitting* is stalling in the phases of attending and inquiring or in the phases of interpreting and acting. This allows a separation of spirituality from religion, *ie.* it legitimises a person claiming to be spiritual but not religious or creedal.
3 Prayer Defined

Prayer encompasses different meanings and takes many forms for people in the twenty-first century.\textsuperscript{15} And what people would call prayer has become increasingly diverse and sophisticated.\textsuperscript{16} This chapter presupposes that all people act in response to their personal spirituality and that therefore there can be a sense in which all can be said to pray. Spirituality is deeply rooted in human anthropology and people have practiced meditation and other forms of prayer for very long periods in history; many modern forms are very similar to long established practices of people responding to their innate spirituality.\textsuperscript{17}

In oncology, all people diagnosed with cancer share a similar experience as they move along the trajectory of diagnosis, treatment and remission or death. Many will have rejected the timeless notions of God and prayer. Or if theist, many will follow individual spiritual paths. But, however it is understood or named, the existential reality of God and prayer remains. Any denial fails to alter the underlying reality. So it is not surprising that an expanding group of people profess to be spiritual but not religious, but would deny God in any conception.\textsuperscript{18} Many would focus on the “deeper layers of the self” or source their spirituality in various levels of nihilism.\textsuperscript{19} Consequently, a wide variation in the terms used in

\textsuperscript{15} Hedley Beare, \textit{God in the Present Moment: Prayer in the 21st Century} (Mulgrave Victoria: John Garratt publishing, 2009), 67.


the individual stories, was found and required a process to discern what the
author was intending. Satisfactory definitions for this research, of necessity,
should be grounded in the real world of experience.

Towards reaching a patient centered understanding of prayer, three
accounts were selected, as representative of the spiritualties found in the story
database for this research, to define prayer. Elements from this set of stories,
once identified, were used quasi-parametrically in performing the analysis.

In the first account, Yin De Shakya, a popular Zen Buddhist atheist, says
when speaking about prayer:

I gave a talk recently at the request of a church group that was
interested in my perspective on prayer and worship as a Zen Buddhist
and an Atheist. I told them that even though I am a Zen Buddhist and
an Atheist (in the conventional sense of the term), I do consider myself
a spiritual person, and I do indeed pray; albeit maybe not in exactly
the same way that this group might understand prayer. How can
someone be an Atheist and a Zen Buddhist and still consider himself
a spiritual person and claim to “pray”? That's what I set out to convey
to the gathered congregation … For me prayer has elements of wish,
hope, and intention; plus elements of actualization, engagement, and
execution. For me prayer is the generation of the intent to engage with
the world in a way that is beneficial and not harmful. Prayer for me is
not a petition to an outside agency for favours, but rather a dialogue
that begins with an undefined subtle hope for things to be better in
some way and progresses to a commitment and an action plan that
can be executed to make those things better …
For me, prayer should be an internal process that leads to the
development of intention and commitment and not a request for
external intervention or a signal of resignation. 20

buddhist-atheist.html. [Accessed April 22, 2014].
Prayer for De Shakya looked to the betterment of the world as its effect and required change on the part of the person making the prayer. Prayer was not solely a subjective activity. She identified wish, hope, and intention as the essential internal elements of a person’s prayer so that the person praying may reach actualization, engagement, and execution. She implied that the attainment of well-being for the world is a goal of prayer. Although, her prayer was not directed to any “outside agency”, De Shakya respected those whose prayer is. For her the effects of prayer, both internal and external, seemed more important than specifying or addressing the agency.

Our second account of prayer was told by Larry Dossey, a physician who worked with terminally ill patients, and who had published his experiences. He recalled the following conversation:

A patient of mine was dying from lung cancer. The day before his death, I sat at his bedside with his wife and children. He knew he had little time left and he chose his words carefully, speaking in a hoarse whisper. Although not a religious person, he revealed to us that recently he had begun to pray frequently. "What do you pray for?" I asked.
"I don't pray for anything," he responded. "How would I know what to ask for?" This was surprising. Surely this dying man could think of some request.
"If prayer is not for asking, what is it for?" I pushed him.
"It isn't 'for' anything," he said thoughtfully. "It mainly reminds me that I am not alone."21

Dossey has recognised that the self-talk of his patient has moved beyond words and has yielded to a resting in a presence that is fully immersive and transcendental. Despite the pain and morbidity frequently associated with

cancer, like Dossey’s patient, very few people lack such a sense of presence although not expressing it exactly in “God” terms.\textsuperscript{22}

The third account of prayer was taken from the writings of Laurence Freeman who described the meditative prayer of John Main (1926-1982) a Benedictine monk who died of cancer.

In his death he lived his teaching to the full. He lived life to the full. When he spoke of death he spoke about it with vitality. He didn’t want to get off the train until he had gone as far as his ticket was meant to take him. But when he realized that death was coming up in the near future, he prepared himself fully for it. He threw himself into the process of dying with self-abandon; as fully as he committed himself to the process, the journey of meditation; as fully as he was committed to God. His dying was a wondrous manifestation of the spiritual dimension of humankind. It was as if he was being filled with life to a point the body could not contain. He became powerfully silent. It was not the silence of being withdrawn from human contact, or regression of consciousness. It was the silence of an intensifying presence: the new person. …

Now in meditation we accept the gift of our being in its wholeness. Silence is the context for that acceptance. In meditation we are not living from the mind or from the body alone but from the centre or what tradition calls the heart. …

But what John Main said and what he showed by the way he lived and died, and by the way he lived his death, is of great importance to us all. What he said six years ago I would repeat to you with the same conviction.” We must prepare for death. Just as we prepare for life by education, so we must prepare for death”.\textsuperscript{23}

Clearly, for John Main, the practice of meditation was the best form of prayer for all the stages in life. He believed that all people could learn to practice

\textsuperscript{22} NOTE: The issue of names for God such as Supreme Being, Absolute, Allah, Krishna and other like names along with the dilemma posed by simply changing the gender specific names for God do not represents a wide field of study and do not form part of this research.

\textsuperscript{23} Laurence Freeman, \textit{A Short Span of Days} (London: Medio Media, 2010), 15-17.
meditation as a constant form of prayer contributing to well-being throughout life from childhood to maturity, including terminal illness (cancer).24

Paradoxically, these three accounts, indicated both the diversity and similarity of what people today understand as prayer and indicated that it has roots extending far back into antiquity. The understanding of prayer is expanding today and has resulted in newer forms of praying.25 To write a simple definition of prayer becomes difficult: because of the diversity of what people of different cultures call praying, because of the great diversity in peoples' spiritualities, and because of the probability of misinterpretation. In respect of this latter, Yin De Shakya wrote:

Another thing we must consider in analyzing how one can claim Atheism, Worship, and Prayer all at the same time is the use of labels and how labeling gets us into trouble sometimes. A famous Korean Zen Master named Seung Sahn once said; "Open mouth already a mistake". This is because anything we say misses the mark of the actual thing or phenomenon we speak of. You know how every time a thought or idea is translated, the resulting translation is always many more words than the original thought? For example, in the Quran the opening verse is only 26 words in Arabic, but when translated into English it requires between 64 and 72 words to get the meaning close... but all we ever do is come close.26


Whatever the difficulty associated with defining prayer however, silence is no option. The research interest here is not in prayer *per se* but in the acts called praying. A clue characterising this concept emerges when we consider the changes that praying makes in one’s life. Laurence Freeman, in a recent *Encounter Program on ABC Radio National* used words that can apply to people of any spirituality:

The deepest change of all, of course, is that you are becoming less self-centred and less-preoccupied with yourself. When you look into yourself, you find the mirror of your soul that reflects God, not your ego. The ultimate goal is a complete conformity of the inner and outer dimensions. … Prayer changes our life, because it unites our experience of life with our experience of God. And in this sense of prayer, you don’t need even to be a religious believer to discover prayer. You may not know what you are discovering, but you can discover it.²⁷

Freeman provided a definition of praying that is as much operational as it is essential, and was adopted for this research. The key words taken from the context above are definitive “[praying] changes our life, because it unites our experience of life with our experience of God”. Ranson’s definition of spirituality allows this meaning of prayer for all people. It is reminiscent of the ancient parable of two birds contained in the ancient *Mundaka Upanishad* in which prayer was visualised as the restless bird of action merging with the majestic bird of absolute perfection.²⁸

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The oncology narratives forming the dataset for this research contain accounts of many forms of prayer. For the process of QDA, certain concepts were identified as nodes, which can be conceived as the name of containers into which text can be located for the purposes of analysis of their content. The subsequent analysis facilitated comparison with other content of the node and became part of the critical reflection process. The nodes for prayer were derived from within the patients’ stories and not from any a priori set borrowed from the many formal theological studies in spirituality. Arising from their form, the nodes included petition, intercession, thanksgiving, meditation, liturgical (including secular liturgy), praise, and traditional prayers. Arising from their situation, the nodes included angry prayer, healing prayer, confident prayer, and accepting prayer. For non-creedal people, the nodes used for searching included atheist self-talk, agnostic self-talk, first prayer, best preparation, and can’t pray. In the following chapters, some umbrella-like groupings were made to suit the trends being observed as the QDA progressed. All categories of prayer were divided into female and male with interesting findings. A set of umbrella groupings were derived from the contemporary works of Hedley Beare, William Gabler, Ernest Larkin and Carolyn Van Dort. Such groupings for prayer are named colloquial,

\[\text{29 Beare, God in the Present Moment: Prayer in the 21st Century, 67-70.} \]
\[\text{NOTE: Beare postulates three categories for prayer, vocal, images and silence.} \]

\[\text{William M. Gabler, “The Relationship of Prayer and Internal Religiosity to Mental and Spiritual Wellbeing,” (MSc Thesis, University of Wisconsin-Stout, 2004), 21.} \]
\[\text{NOTE: Gabler’s groups for prayer are colloquial, petitionary, ritual and meditative. He reports strong correlation between prayer and well-being in all four of his groups. They are based on Gallup Poll data collected by M.M. Poloma, “The Effects of Prayer on Mental Well-Being,” Second Opinion 18 (1993): 37-51.} \]

\[\text{Ernest E. Larkin, Contemplative Prayer for Today: Christian Meditation (Singapore: MedioMedia, 2007), 150.} \]
meditative, and ritual. These groups suited the methodology by providing parent nodes (or top level nodes that aggregate the content of child nodes) in a hierarchical structure to be described in the next chapter devoted to methodology.

Colloquial prayer was generally taken as talking with the absolute or seeking meaning. It is typified by Thomas à Kempis, in The Imitation of Christ, where he describes prayer as “the great art of conversing with Jesus”.30 This research understood and coded all examples of “self-talk” as colloquial prayer in its process of coding of the patients’ stories.

Meditative prayer included forms of prayer variously described as relaxing, contemplation, being still, quiet, open to God or ultimate meaning, mysticism, mindfulness, centering, or imaging.31 William Gabler reported that meditative prayer and the frequency of its practice are correlated in a positive

NOTE: Larkin uses the following labels to categorise prayer: active, passive, centering, meditation, discursive, liturgy, cataphatic, apophatic, and mindfulness.


NOTE: More recently we find Alfons Kirchgasser writing that “All prayer is a continuation of a conversation, our reply to what God has already said.” This way of conceptualising what is happening when we are praying, easily accommodates the prayers of petition, intercession and the like; but it becomes problematic for those whose spirituality is centred around “listening” or mystical thinking such as Meister Eckhart did or around the discipline of the popular mindfulness meditation of John Main, Laurence Freeman, Thomas Keating and Basil Pennington.

sense with one’s closeness to God or to the pursuit of ultimate meaning.\textsuperscript{32} This way of conceiving meditation is very broad and was deemed necessary to include the diverse spread of spiritualities, many of which were non-Christian, that this research encountered in the stories told by people with cancer. The group of meditative prayer includes contemplation which was defined as “a joyful resting in the being of the beloved”. This type of definition was found since patristic times in writings typified by: John Climacus, the unknown author of the Cloud of Unknowing, Augustine Baker, Evelyn Underhill and Ernest Larkin.\textsuperscript{33} Such a concept of contemplation was chosen because it is applicable to all forms of spirituality and has been validated through the acceptance of countless

\begin{footnotesize}
\begin{enumerate}
\item\textsuperscript{32} Gabler, "The Relationship of Prayer and Internal Religiosity to Mental and Spiritual Wellbeing," 23.


Augustine Baker wrote in 1657 CE "Now prayer, in this general notion, may be defined as an elevation of the mind to God". Baker, \textit{Holy Wisdom: Or, Directions for the Prayer of Contemplation}, 299.

Evelyn Underhill wrote that “Mysticism is the art of union with Reality. The mystic is a person who has attained that union in greater of less degree; or who aims at and believes in such attainment.” Evelyn Underhill, \textit{Practical Mysticism} (Columbus Ohio: Ariel Press, 1986), 23.


This historical grouping of prayer was found useful in defining a concept of contemplation for use in this research. In the emerging paradigm, praying will be seen to consist in living with a constant awareness of the presence of God in response to an appreciation of God’s will, however God is understood in the person’s spirituality
\end{enumerate}
\end{footnotesize}
generations. Contemplative prayer is relevant today and can be practiced by all people.\textsuperscript{34} Meditative prayer has the greatest perceived relationship with God in reference to other types of prayer.\textsuperscript{35} In oncology, the forms of prayer are acutely influenced by the circumstances, particularly the patient’s role in the illness, and were found to be severely affected by the clinical staging of the disease.\textsuperscript{36} Many methods of contemplation require some mastery of the discipline and consequently better suit terminal patients with a longer term prognosis along with all health carers.\textsuperscript{37}

\textit{Ritual prayer} was taken to refer to the most formal types of prayer. It is characteristically performed in groups gathered to mark an occasion and follows an arranged format. Secular ritual prayer examples include flag raising and lowering ceremonies and Remembrance Day ceremonies. Religious ritual prayer is seen in the liturgy and in the administration of the Sacraments. The experience of guided imaging and music therapy is a form of ritual prayer helping cancer patients to find meaning and consolation in their current circumstances.\textsuperscript{38}

\begin{flushright}
\textsuperscript{35} Gabler, “The Relationship of Prayer and Internal Religiosity to Mental and Spiritual Wellbeing,” 22.
\textsuperscript{37} Laurence Freeman, \textit{A Short Span of Days} (London: Medio Meda, 2010), 17.
In practice, music and imagery is a highly structured process involving relaxation induction, focus image, set music, and discussion.\textsuperscript{39}

The goal has been to identify those practices of prayer that contribute to patients’ well-being when it is considered wholistically. But in oncology, the contribution of prayer to well-being is not restricted to patients alone. It will be shown in the stories that such proven prayer practices offer potential contribution to the well-being of oncology professionals also.

\section*{4 Well-being Defined}

How does one describe well-being? Krishna Mohan said that the notion of well-being required an amalgamation of both Western and Eastern viewpoints:

The western concept of well-being] revolve(s) around the ability to satisfy one's needs, avoidance of frustrations and stress, and exercising certain amounts of control on the environment such that it enhances the satisfaction of personal and social needs. In the Indian tradition control over the senses is thought to be essential to well-being. Emphasis is on the maintenance of balance between extremes of satisfaction and denial … the essence of well-being lies in not being overwhelmed by either aspect. \textsuperscript{40}

This concept is more wholistic than those appearing in present day health promotion literature: much of which leaves well-being as a vague or limited

\begin{itemize}

\item VanDoort, and Grooke, "Music, Imagery and Mindfulness with Substance Dependency, 117.

\end{itemize}
concept, that is constricted by external variables that can be easily measured; but which in fact fail to fully capture the essence of well-being.\textsuperscript{41} This Mohan definition contains two elements that can be identified in the storytelling dataset of this research. It requires the ability to satisfy personal and social needs as well as achieving a balance between satisfaction and denial. The Mohan definition is much more appropriate for use when performing the analysis of qualitative data which comprises the substance of this research. It does not channel well-being into divisions such as mental or spiritual or physical; nor does it capture only one or two of the \textit{cognitive, affective or psycho-motor} domains. These latter classifications typically derive from \textit{a priori} tests common in psychology and more recently psycho-oncology which fit patients into a pre-determined matrix by the manner in which questions are framed. Frequently with the outcome of failing to fully and sensitively realise the contribution of the patient’s spirituality to their well-being in any qualitative sense.\textsuperscript{42}

\begin{flushleft}
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\textsuperscript{42} NOTE: 1. Quantitative researchers into well-being favour performing psychometrics by questionnaire such as the \textit{European Organisation for Research and Treatment of Cancer (EORTC QLQ-SWB36 or the COPE inventory or the Quality of Life in Adult Cancer Survivors (QLACS) scale or the Functional Assessment of Chronic Illness Therapy –Spiritual well-being (FACIT-Sp) or the Functional Assessment of Cancer Therapy – General (FACIT-G)}.
\par
\end{flushleft}
In determining well-being, this research takes its grounding from the storytelling of cancer patients rather than from measurements undertaken by instruments such as the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp)\(^{43}\) or the QLACS (Quality of Life in Adult Survivors Scale).\(^{44}\)

The empirical orientation of these tests however has ensured that they are reasonably well validated and many of their search items were found to be of use to this research particularly at two stages: Firstly, during the coding stages of the computer aided qualitative data analysis (CAQDAS) to be detailed in the next chapter, which is therefore essentially a methodology chapter. Secondly, by providing comparisons against which the findings of this research could be compared and reflected upon.

Mohan required that a subjective element exist in order to satisfy his concept of well-being.\(^{45}\) Thus well-being encompasses both subjective existential elements and subjective elements of spirituality. Peter Kaldor and his co-researchers investigating this issue using the SF-12 form report the findings


\(^{45}\) NOTE: The Mohan definition requires a subjective element in well-being, which this research sees as deriving from an individual’s spirituality and consequently capable of becoming an outcome of prayer. The analysis of patients’ stories that this research performed, found significant links between spirituality, prayer and well-being.
arising from their measurements of well-being.\textsuperscript{46} And they were a complete validation of the parameters of personal and relational well-being identified in the Mohan definition of well-being that we have adopted for this work. Further the domain of research in the Kaldor paper included Australia which is lacking in the previously cited European well-being measures.

This research does not set out to investigate the notion of well-being \textit{per se} but its methodology must provide a working set of concepts that can form a meaningful criterion for the qualitative analysis that signals the attainment of the goal of well-being, in relation to prayer and cancer. In a working sense, the Mohan definition requires both the ability to satisfy needs coupled with the subjective ability to balance the senses. These become criteria to determine the existence of well-being in a given instance. As a further consequence, individual well-being can be visualised as a location along a \textit{continuum} which contains degrees but no opposite as will be seen in Chapter four. By way of analogy well-being and its \textit{continuum} is like the "gravy" that Arthur, one of the cancer patients in this study, described when he said:

\begin{quote}
Health and illness, wellness and sickness perpetually alternate as foreground and background. Each exists only because of the other and can only alternate with its other. There is no rest in either word. In "health" there can only be fear of illness, and in "illness" there is only discontent at not being healthy. In recovery I seek not health but a
\end{quote}


\textbf{NOTE:} SF-12® is a short form, single page containing 12 questions used by Kaldor et al to measure well-being to determine its association with spirituality. This form is widely used in medicine and its longer version SF-36 was developed by the Medical Outcomes Study (MOS) which is a multi-year study of patients with chronic conditions.
word that has no opposite, a word that just is, in itself. When I seek the meaning of my recovery, the opportunity of illness, I call it gravy.47

The coding nodes, that were used to analyse the patients’ stories, emerged from the literature read during the literature search (open coding). This initial set of open coded nodes was added to during subsequent early analytical stages (axial coding). Fine details of the coding are presented in next chapter on methodology. The nodes of well-being used were: feelings, best part of having cancer, worst part of having cancer, advice to others, model of cancer, expression of spirituality, and meaning of the cancer experience for life. In the method of this research each one of these nodes became a question requiring an answer or answers from each story.

5 Cancer Defined

How cancer is understood is determined by whether one is experiencing it or has a role in managing it. Scientific medical staff use a derived definition for cancer as a tumour which typically is:

A neoplasm or tumour is a disturbance of growth characterised primarily by an excessive proliferation of cells without apparent relation to the physiological demands of the organ involved.48

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This definition, although formal, is useful because it sets up the concepts of *prognosis, acute* and *palliative* which are necessary for the discussion on well-being and provides a platform to differentiate the healing potential of the different forms of prayer.

Orderly growth is a normal part of the life of cells, it is only when a cell or group of cells proliferates non-homeostatically (out of normal control) that it becomes a problem (cancer).\(^{49}\) Statistics show that the majority of cancers occur in middle-aged to older people; consequently this research adopts the viewpoint that cancer is a part of ageing.\(^ {50}\) But one must remain cognizant that whilst properly compiled statistics remain valid for the population, they give no certain knowledge about individuals. Children do get cancer and some childhood cancers carry over into adulthood. So some accounts of paediatric oncology were included in the data set. However, this analysis concentrated on the adult experience of cancer. To fully develop the separate aspects of prayer and well-being associated with children is a large topic for research requiring a very different methodology to deal with the vicarious nature of the reporting in paediatrics.

Recapitulating this chapter so far, the complexities of defining the key terms have been explored and their meanings for this project have been defined.


It is clear that spirituality strongly influences both one’s prayer and well-being: this, at the time when a diagnosis of cancer occurs in one’s own life; or when it affects the lives of others, even casual acquaintances.\textsuperscript{51}

The research journey next leads a deeper understanding of how prayer and well-being were found in the cancer patients’ stories. This is to be aided by taking a deeper look at the language with its metaphors used by people and the oncology professionals.

\section{Cancer as Metaphor}

Cancer conversation frequently involves metaphors. Patients use them as do oncology professionals; frequently the metaphors of these two groups fail to coincide; consequently poor communication results impacting on the patient’s well-being. Gaining an understanding of patient’s stories requires an understanding of the metaphors used in cancer.

You will crawl out of here. I'm going to kill you. Everyday I'm going to kill you, and then I'm going to bring you back to life. We're going to hit you with chemo, and then hit you again, and hit you again. You're not going to be able to walk. We're practically going to have to teach you how to walk again, after we're done. \textsuperscript{Anonymous Oncologist}\textsuperscript{52}


Lance Armstrong did what most would do if faced with this or similar language from their doctor. He simply walked away. Sadly, his experience in seeking help to treat his testicular cancer was not rare. Bellicose language consistent with the war metaphor is still widespread in use. Its prevalence is evidence of a near universal public reluctance to “tell it as it is”. As recently as the 1950’s a cancer survivor was prevented by the New York Times from placing an invitation to join her support group because it contained the words breast and cancer. Cultural taboos also abound that continue to serve to prevent more direct language being used.

In the war metaphor, the patient and oncology professionals fight the cancer to achieve a victory. The treatments are deployed or mobilised against the enemy which contains killer cells that must be destroyed; taking no prisoners. Treatment modalities such as radiation or chemotherapy do battle in their struggle to achieve supremacy. Patients hope for a magic bullet. Survivors are described as victorious because of the severity of their fighting back and its victory. Doctors and nurses become heroes because they become loyal and powerful allies who fire the shots that destroy the enemy.

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54 Bethune, “The 5,000-Year War on Cancer: An Oncologist’s Beautifully Written History Attempts to Grapple with the Disease” (Toronto Canada: Rogers Publishing Limited, 2010), 1.
Susan Sontag clearly identified this war metaphor and cautioned against its continued use.\textsuperscript{55} It gives rise to many often irrational fears, creating anxiety and stigma resulting in a detrimental effect to the individual’s sense of well-being. And in relation to this research, war metaphor use can conceal or confuse the genuine experience of the person with cancer. Catherine Czechmelster wrote that metaphor is like a two-edged sword. She agreed with Sontag about the adverse effects of metaphor use in cancer but saw positive effects that were absent from Sontag’s works. Czechmelster saw that people who fight back improved their well-being by gaining a sense of control which enhanced their prognosis, even amongst some patients using a war metaphor.

Ulrich Teucher conducted an empirical analysis of all cancer metaphors and whilst identifying the dominance of the war metaphor found others in use.\textsuperscript{56} He used statistical methods that placed the metaphors into clusters and located them in three dimensional space. The invasion cluster contained the terms attack, opponent, enemy, and battle; this group of metaphors Teucher located in the tangible and dynamic domains but with intrusion into both internal and external domains of the cancer patient. In other words it dominated over the other metaphor clusters. And the dominant cluster for cancer treatment was battle understood in its common use sense, but which some patients associated with historical wars such as World War II, the Vietnam War or the Gulf War.


\textsuperscript{56} Teucher Ulrich, ”The Therapeutic Psychopoetics of Cancer Metaphors: Challenges in Interdisciplinarity “. NOTE: Teucher’s statistical methods included “Hierarchical Cluster Analysis and Multidimensional Scaling”. His experimental group comprised 29 cancer patients and 120 other people to rank the clusters.
Further, Teucher’s research identified other clusters of metaphors named *intrusion, oppressive surroundings* and *growth inside* which he located in the internal domain. The *intrusion* cluster contains gentler images (but still unwanted) such as “unwelcome intruder in the body” and “thief that steals one’s time, energy and dreams”. The *oppressive surroundings* cluster contained images such as “dark overhanging cloud and dark scary cave”. The *growth inside* cluster contains images such as “being eaten from the inside out” and “parasite”. In his conclusion, Teucher offered advice that can be seen as relevant to the process here in that a given metaphor will not be understood in the same way by all patients and by all doctors. Further, he advised that patients can be ambivalent because a metaphor that was used early can be disapproved of later. My research will show that mismatches between the metaphors of the oncologist and the patient were almost always associated with poor well-being.

Outside the oncological domain, metaphors abound. The way they are used in common language aids in conveying meaning which goes far beyond the facts by involving emotions and thoughts. Receiving a diagnosis of cancer raises epistemological issues.\(^{57}\) Doctors are primarily concerned with the “nuts and bolts” of the cancer, whereas the patient must consider the cancer in the context of one’s whole life, family, job, finances and psyche.\(^{58}\) The right kind of metaphor can assist here. When a diagnosis of cancer is received it is interpreted in the light of habitual metaphors. Lance Armstrong saw his cancer as the most

\(^{57}\) Czechmeister, "Metaphor in Illness and Nursing: A Two-Edged Sword: A Discussion of the Social Use of Metaphor in Everyday Language, and Implications of Nursing and Nursing Education," 1227.

important bike race in the world; and his well-being benefitted. Doctors who are largely unaware of the patient’s habitual metaphor and communicate the diagnosis and treatment plans in terms of their personal metaphor can harm the patient’s well-being. Good cancer management is like a delicate flower whose beauty can be destroyed by insensitive or unknowing treatment. The patient’s well-being is greatly dependent on achieving a synchronisation of their spirituality (expressed through a metaphor) with that of their doctors. Good treatment also needs to achieve this mutual understanding through a common metaphor that is derived from the patient’s spirituality. Rarely would this be a war metaphor. So what other options are there?

Other metaphors for cancer found in the literature included a chess match, a marathon, a drama, Armstrong’s bike metaphor, a dance, wobbly stones and a collaborative exploration.59 The journey metaphor is universal and can easily be applied to cancer. A traveller can drop out of the cruise control of ordinary living and follow an uncertain route along which roadblocks, U-turns and the like are encountered. The journey metaphor is gentler and more subtle than the war metaphor and can have diversions, destinations and exits. Doctors and nurses

are guides like a GPS that leads us towards the destination.\textsuperscript{60} Lynn described her experience of cancer as sliding on black ice:

\begin{quote}
I consider myself an organized, well-prepared person, but … I never saw the black ice of cancer ahead of me. It took me so by surprise that I couldn’t even think how to react. I tapped the brakes and nothing happened. I still had cancer. I pressed a little harder on the brakes, and I found out the cancer had spread to my lymph nodes. I slammed on the brakes only to learn that the odds I would survive were less than the odds I wouldn’t. I was sliding sideways out of control, and it was the scariest time of my life. Thankfully I didn’t crash, but I did find something bigger than me to stop my slide. Actually, Someone. I slid right into the big, open arms of a loving God, and He assured me that He had seen the black ice coming and was waiting all along to stop my slide. … One of the strange things about a cancer diagnosis is that often it can be more difficult to live as a cancer survivor after treatment than during it — not the physical part of dealing with cancer, but the emotional and spiritual sides of it. … Chances are that you and I probably will never meet, but I’d like to offer to get in the car with you as you anxiously survey the shadows on the road for black ice or furtively glance in your rear view mirror to see what’s following you. Don’t worry, I’m not going to try to drive. I’ll just buckle up as we ride together, and I’ll help you hear from the One who does know how to navigate on this often treacherous journey.\textsuperscript{61}
\end{quote}

Lynn has provided a wonderful example of living a metaphor that gave meaning to her life following her diagnosis, treatment and subsequent survival from cancer. Further, it continues to provide images for her current role as a cancer patient advocate “I’ll just buckle up as we ride together, and I’ll help to hear from the One who does know …” Like other professional journalists who personally experienced cancer, she wrote and continues to publish messages of hope for others. Some of the stories of other people living with cancer that she included in her books were used in this research as sources.

\textsuperscript{60} Reisfeld, "Use of Metaphor in the Discourse on Cancer," 4026.

In summary, although the war metaphor dominates as patients and doctors and nurses strive to comprehend its meaning for their lives, the literature reveals that alternative, more positive, metaphors are emerging. In seeking to understand cancer stories, discerning the metaphor used can provide insight into the patient’s well-being. The methodology of this research includes codes under the node well-being to identify them and to uncover their structure and potential for contemporary use in relation to prayer, especially where the metaphor offers a basis for hope.\textsuperscript{62} Hope has synonyms like expectation, longing, desire, confidence, trust and faith. One word contains all of its antonyms “hopelessness”.\textsuperscript{63}

7 Three Exemplars

Three writers typified their class of people experiencing cancer and provided this research with an individual account of their experience that was full, deep and intimate. They were designated exemplars for this research and are given a weighting to the extent that their testimony correlates with that of their peers. They were Lynn Eib, Ernest Larkin and Christopher Hitchins.

Lynn was thirty-six when she wrote:

The picture of perfect health. Dressed in soft yellow, with my waist-length brown hair glistening in the summer sun and my smile radiated the deep happiness I felt. …

\textsuperscript{62} NOTE: The terms codes and nodes are defined in the next chapter on methodology. But they can be conceived as tags or labels that a computer can recognise and use for data analysis.

\textsuperscript{63} Lynn Eib, \textit{50 Days of Hope} (USA: Tyndale House Publishers Inc., 2012).
I could tell from their body language that the news wasn’t good. They stood against the wall at the end of my hospital bed, as far away from me as they could get and still be in the same room. “Cancer was found in five of twenty-four lymph nodes”, the surgeon explained matter-of-factly. “You will need chemotherapy and radiation.” Again I cried, but no one moved toward me to comfort me. … Lying in that bed, I had lots of time to talk with God. … You are making a really big mistake here, I fumed. There’s absolutely nothing You can ever do to make up for this because it is too awful. And don’t think You are going to pull me through this somehow and I’m going to go and minister to cancer patients, because I won’t do it!

Lynn felt extremely lonely and abandoned. She was very angry with her doctors, upset with God too. A God who, she ranted, had wrecked her life; and she had placed herself beyond bargaining. In time, she became a cancer patient advocate in her doctor’s practice helping hundreds of patients find hope in their lives beyond cancer. She maintains several cancer support groups. She has published four books and maintains a web site to help others experiencing cancer. Her personal experience and the simplicity with which she wrote the stories, make her witness credible and, herself, an exemplar for this research.

Ernest Larkin (1922-2006) was a Carmelite priest who lived continuously conscious of God’s presence. His cancer proved to be too extensive to be contained. He died as he had lived, fully prepared for his death. His final book Contemplative Prayer for Today: Christian Meditation was published posthumously and traces the development of his spirituality and beautifully describes the contemplative union with God that he practiced and manifestly


experienced during his life. Larkin’s prolific publications allow the reader to follow the development of his prayer life and thus to understand the many methods of praying that led to what is now called “Christian Meditation”. These writings were heavily influenced by his doctoral thesis on Mary Magdalen de’Pazzi and his research on the teachings of St Teresa of Avilla and St John of the Cross. Near the end of his life Larkin established the “Cornerstone Centre for Christian Meditation” in Phoenix which is a major resource for thousands of people practising Christian Meditation, who keep death before ones’ eyes. The great detail about contemplation provided in Larkin’s writing and its validation through scholarship and the great numbers of lay people practicing Christian Meditation today made him an exemplar for this research.

The third exemplar was Christopher Hitchins (1949-2011) who wrote on living with cancer:

It’s a malady like any other and it will yield to reason and science. (Battling cancer) is a subversion of the pathetic fallacy. I rather think it’s battling me, it’s much more what it feels like. I have to sit passively every few weeks and have a huge dose of kill-or-cure venom put straight into my veins … It doesn’t feel like fighting at all, possibly resisting. You feel as if you’re drowning in passivity… I prefer resistance to battling.

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A very self-centered view of an obviously unwelcomed situation, expressed in terms of a war metaphor; offering not much for his well-being. The following is a more positive reflection:

My chief consolation in this year of living dyingly has been the presence of friends. I can’t eat or drink for pleasure anymore, so when they offer to come it’s only for the blessed chance to talk. … What do I hope for? If not a cure, then a remission. And what do I want back”? In the most beautiful apposition of two of the simplest words in our language: the freedom of speech.70

Hitchins was a self-professed atheist who achieved and maintained a very large media presence during his life. His thoughts about cancer are common with many in his cohort and so he is treated in my research as an exemplar.

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8 Connections

The research journey thus far, has progressed through the domain of understanding the published stories of cancer and prayer. The method required that the research be grounded in such stories. The grounding was also required for the definitions of spirituality, prayer, well-being and cancer. These were derived from experience rather than from the a priori lexicon of any discipline. Understanding cancer patients’ stories raised the issue of metaphor use in oncology. Alternatives were found that could contribute more to patients’ well-being than the dominant war metaphor. Finally, the chapter introduced three well-known people who had cancer and who were very popular because their publications represented the spectrum of spirituality: Lynn Eib, a lay-woman,
Christopher Hitchins, a self-professed atheist, and Ernest Larkin, a Carmelite Friar. They were taken as exemplars for this work.

In the next chapter the research journey advances into the territory of methodology: which must be traversed in order to find the way to obtaining findings from within the patients’ stories; making discussion and reflection; making comparisons with the published findings of other oncology, psychology or theological researchers; and making consequent consistent interpretations.
Chapter 3: A systematic study of cancer stories

1 Introduction

To let the stories talk was the method behind this research. Their own stories published by cancer patients were the sole source of data for this qualitative research. The analysis sought to be grounded in these stories. Only a few researchers had studied this rich repository of stories from the perspective of a person experiencing cancer, allowing the patient to control the dialogue. Most research in this domain had been conducted from an external perspective that looked at cancer patients through the lens of a professional discipline: be it be medicine, nursing, psychology, or theology. Such discipline specific, narrowly focussed research, had failed to reveal much information beyond the set parameters, and often were directed towards validating a particular measuring scheme. However in theology the approach was seen to be similar


to that of science, in that the methodology sought to affirm modify or disaffirm an already held premise. Theology differed in being much more qualitative particularly in its pastoral aspects. But of theological reflection, Gerald Downing said “there is nothing equivalent to scientific verification or falsification”.\(^5\) In the patient’s lived experience, theological reflection finds a source of wisdom in which God’s presence can be found; also, it can lead to transcendental integration of the lived experience.\(^6\) This issue of verification, as it related to this research, is presented in the section on need to identify each stage reached on the journey later in this chapter in section 6. Generally too, the research reports were seen to be limited by the jargon of the researcher’s professional discipline restricting intelligibility for professionals in other disciplines. Frequently too, but with the notable exception of theology, their methodology was focussed on the use of measuring instruments in satisfaction of the requirements of empiricism; often with the outcome of simply identifying a need for further research for validation of those instruments.\(^7\)


\(^6\) John E. Paver, Theological Reflection and Education for Ministry (Great Britain: MPD Books, 2006), 35, 79.

\(^7\) The following four citations are representative of this “deficiency” of professional discipline driven research because the researchers can be seen to “fit” patients into narrowly defined categories or because they are primarily concerned with implementing or validating a “measuring” instrument as demonstrated in their discussion and conclusions: B. Bivat et al., “Cross-Cultural Development of the EORTEC QLq-Swb36: A Stand-Alone Measure of Spiritual Wellbeing for Palliative Care Patients with Cancer.” Palliative Medicine 27, no. 5 (2012): 457-69; Nancy E. Avis, Edward Ip and Kristie L. Foley, “Evaluation of the Quality of Life in Adult Cancer Survivors (QLACS) Scale for Long-Term Cancer Survivors in a Sample of Breast Cancer Survivors,” Health and Quality of Life Outcomes 4, no. 92 (2006): 1-11; Charles S. Carver, “You Want to Measure Coping but Your Protocol's Too Long: Consider the Brief Cope,” Int. J. Behavioural Medicine 1,
By way of contrast, contemporary qualitative research, published in refereed journals, had produced more wholistic conclusions that reflected the complexity of the cancer trajectory in the lives of people. Further, qualitative research has assisted quantitative researchers by providing many of the details necessary to enable the development of the parameters used in the measuring instruments of quantitative methodologies. The methodology of this research is qualitative because of its striving to uncover the meanings that the patient storytellers intended. This research uses a roughly even mix of data sources comprising both conventionally published narratives (77, 43%) and those posted to the internet (103, 57%)⁸. Every effort has been made to understand what the narrator intended taking cognizance of the warning of Gunter Eysenbach and James Till that these narrators (the cancer patients) did not expect to become research subjects when they published their stories.⁹

However, the accounts of their personal experience, with their contained metaphors, constituted a most authentic source of data, offering potential to uncover how the diagnosis of cancer had impacted on their lives and spirituality. Grounded theory (GT) provides a valid method to respect the uniqueness of each patient’s cancer experience whilst contributing to the credibility of the

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⁸ The format (N, %) represents N the number of patient stories and % represents the percentage of the pool of stories contained within the cohort N. N is the number of sources which must be distinguished from n which denotes the number of references, when the format would be (n, %); the 100% here would be the total number of the references being discussed. Numerically the number of references can exceed the number of sources.

hermeneutic process and to the validity of any emergent hypothesis.\textsuperscript{10} My own story of a diagnosis of melanoma is one story amongst the collection. Consequently a blending of GT and interpretative phenomenology was adopted as the methodology best suited to the nature of the data and the process required.

The motivation for this research arose out of a desire to satisfy the curiosity that grew during my forty years of experience involving daily contact with cancer patients. The object of the curiosity was to determine the extent of any causality between prayer and well-being amongst those people who are or who have been diagnosed with cancer. Any correlation found could offer real benefit for the well-being of many people by indicating the best preparation for the impact of cancer when it is diagnosed, and the best meaning for life subsequently.\textsuperscript{11}

The following paragraphs provide information on how the blended methodology was applied. Firstly, they discuss why conducting a survey was considered to be an unsuitable strategy for this research. Secondly, they provide details of the approach that blended GT and phenomenology follows. Thirdly, they indicate how the practical issue of data saturation (how many stories were deemed to be enough to validly represent the population in relation to gender and the spectrum of cancer incidence). Fourthly, they provide information about


the role of NVivo in this research.\textsuperscript{12} Also they indicate the computer assisted qualitative data analysis software (CAQDAS) requirements that justify its use for this project. Fifthly, the related issues of bias, nature of evidence, decision trail, quality, and rigour, were addressed.

Stated briefly by way of introduction to this chapter, the methodology involved critical reflection on the cancer patients’ stories with their contained metaphors. In collecting and analysing the data, a method was used that blended GT with phenomenology.\textsuperscript{13} It employed dedicated computer software to apply a matrix of criteria in performance of its hermeneutics. The methodology progressively and summarily reflected critically; such reflection was both sourced in theology, in oncology and psychology research. It adopted open signage of analytical processes to summarise the argument progressively and to state any conclusions that were justified by the evidence presented in each chapter.

2 Why not deploy a survey methodology?

This project strove to identify outcomes that could be practical and realistic for individuals with cancer today. The question arose "Why not survey people with cancer to gather the data necessary to formulate and test any emerging

\textsuperscript{12} NVivo is used in this thesis to designate the CAQDAS software package produced and marketed by © QSR International Pty Ltd. The version used is NVivo Ver. 10.0.573.0 SP5.

hypotheses?” Or “could a focus group help?” Surely a survey could be designed to discover if and how such people pray, if they do, and how they think praying affects their well-being? No survey into prayer and well-being conducted to date has produced findings with significant correlations that indicate strong statistical confidence or causality or the contrary. Some surveys tend to influence the outcomes by the way that questions or interviews are formulated. The wording used and the options offered in multiple response options potentially reinforce researcher bias. Surveys tend to be testing theory that the researcher already holds. Because of limited sample size and heterogeneity of the sources, surveys have failed to produce outcomes with much relevance beyond the population level; offering little at the individual level. Surveys reported in the scientific study of prayer are better suited for the investigation of cognitive domain behaviours rather than the affective and psychomotor domains that this research considers. Here the research is to be grounded in the individual cancer patient’s experience. How people deal with cancer is very individual and influenced by many complex factors, some of which are cultural and whose expression in narrative is subject to influence by the many taboos that continue to surround cancer.

14 Krause et al., "Using Focus Groups to Explore the Nature of Prayer in Later Life," 191-212.

15 NOTE: for example the following article reports the use of a survey methodology whose purpose is to validate a preconceived model of prayer that fails to define prayer, that gives results and discussion but makes no conclusion and that contains some 60 examples of unsubstantiated conjecture. Indicating a disregard for data except for that which suits a pre-conceived hypothesis. K. L. Ladd and B. Spilka, "Inward, Outward, Upward Prayer: Scale Reliability and Validation," Journal for the Scientific Study of Religion 45, no. 2 (2006): 233-51.

Hugh MacKay describes several caveats for researchers in QDA proposing to use a survey methodology that render it less than useful.\(^\text{17}\)

MacKay’s first caveat is that the information to be supplied can be influenced by the format of the question. Usually the answers to questions are predicated by the question’s phrasing and the tone in which it is asked in oral surveys; thus, may lack congruence with the individual respondent’s experience. The second caveat is that a survey designed to yield information about a complex topic such as well-being, can fail to uncover attitudes beyond the scope of the questions. Peter Kaldor and his colleagues reported this after conducting their survey into well-being and also into the other related but complex topic of spirituality.\(^\text{18}\)

The third caveat is that surveys probing “what” and “why” questions suggest that there is a rationale: often in cancer there is none; or one that is not perceived by the respondent at the time due to faded memory of the painful experience; or may arise from a metaphor of belligerence arising from the dominant medical model for cancer.\(^\text{19}\)

The fourth caveat is that a survey conducted into cancer, prayer and well-being is largely concerned with qualitative information which cannot easily be quantified or contextualised. Elizabeth MacKinlay found that even with her modifications to the Spiritual Health Inventory for Elderly people (SHIE) instrument, she recommended the use of in-depth interviews because of

\(^{17}\) Hugh Mackay, *Reinventing Australia* (Pymble Australia: Angus & Robertson, 1993).


the inability of a Likert style of instrument to effectively trap all of the information relevant to spirituality and well-being.\textsuperscript{20} And fifthly and finally, manageable small sample sizes can produce skewed outcomes whose application is to the whole population surveyed but to no individual within that population.

In summary, the situation of the unlikelihood of a survey to result in any correlation between cancer, prayer, and well-being arising from qualitative data, required that a different methodology be found. Further, objectivity here required that any hypothesis induced from the stories of cancer patients remain fully grounded in the stories themselves and the shedding of any mantle of culture or metaphor or bias that they contain.

3 Exploring cancer using real life stories as a data source

Hundreds of cancer stories were found in the published literature or were posted on the internet, as the previous chapter indicated. Because the quality and reliability of such stories were found to be extremely variable, screening for appropriate data proceeded cautiously. Meaningful images were found within the stories as single words, metaphors, similes or intended silences, posing particular challenges for the hermeneutics.\textsuperscript{21} Two characteristics of the stories were identified as needing care: The idiosyncrasy of the stories, and the hegemony of the “war” metaphor.

\textsuperscript{20} NOTE: Elizabeth MacKinlay modified and conducted Highfield’s Spiritual Health Inventory ($\sum = 75$,) and achieved correlation factors of low significance. Elizabeth B. MacKinlay, \textit{The Spiritual Dimension of Ageing} (London; Philadelphia, PA: Jessica Kingsley Publishers, 2001), 32.

Idiosyncrasy of cancer stories

Dominantly, such cancer narratives found in the published literature are written by professional writers, who themselves experienced cancer and felt a need to publish their story. They provided authentic expression because the storyteller was not constrained to any standardised format of expression. There is a strength in this, because the experience was narrated in the way that the individual wanted and resulted in the truest expression of feelings arising from the impact of the cancer on the person’s life and well-being. However, most published narratives were compromises between what was remembered and the relevant themes deemed important by the author at the time of writing; typically this latter was the desire to offer hope to every reader.22

The majority of the cancer narratives were written by an individual writer who did not write professionally. Often they were incomplete and most likely omitted some of the more painful aspects of the storyteller’s experience. This required the exercise of care in understanding the narrative. What was stated was taken to be true, but the context required discernment. Dell Hymes compared such writing to oral performance in which everyone can tell a story but in so doing few can be entertaining.23 The methodology considered this. People who habitually maintained journals or diaries, although not professional journalists, provided direct accounts of their cancer experience that were very personal. Indeed their writing continued after the diagnosis of cancer was made,

22 Paal, Written Cancer Narratives: An Ethnomedical Study of Cancer Patients’ Thoughts, Emotions and Experiences, 56.

often continued as a form of therapy (narrative therapy) which they integrated into their medical treatment as they worked towards a reordering of their lives.24

Care was taken to maintain proper ethical standards in relation to the privacy and confidentiality of all storytellers.25

Hegemony of war metaphor

The widespread use of metaphors and simile by people narrating their cancer experience was noted in the previous chapter. Whilst being deployed to make the experience meaningful for the patient and the text understandable to others, a metaphor can conceal the full nature of the writer’s individual cancer experience from the researcher. Susan Sontag persistently warned about the poor communication that can result from the metaphor chosen by the narrator or by oncology professionals.26 Typically, the hegemony of the use of the “war” metaphor by breast cancer patients characterised their descriptions. Cancer is an invading enemy with intention to occupy and eventually kill the patient; the treatments of surgery, radiation and chemotherapy are all weapons used to destroy this enemy and the medical staff are to be the heroes. Successfully treated patients are happy to describe themselves as survivors! But what of


25 Eysenbach and Till, "Ethical Issues in Qualitative Research on Internet Communities", 1103-05.

NOTE: Ethics approval was sought and given by the University of Divinity Human Research Ethics Committee.

26 Sontag, Illness as Metaphor.
those who die? Kristen Garrison describes the poverty of such warlike imagery to help the loved ones of the “cancer victim”, who in this instance was her mother:

Writing an obituary for my mother was so much harder than I would have thought. After all, as "the English major in the family" I accepted the task as soon maybe even before, my dad asked. Describing her life was easy enough. Describing who survived her, was straightforward. But I had no words to describe her death, and I stumbled over, resisted, what dad, my sister, and my aunts finally advised: she lost a four-year battle with cancer. I had most difficulty with the verb. 27

Here Garrison revealed the inadequacy of the war metaphor to express emotion and feelings in any positive sense. To die is failure, to have lost the war and all that remains for the army that has been routed (relatives in this case) is despair and hopelessness. From the perspective of this research too, the exclusive use of metaphor in the patient’s narrative conceals the real experience. Stories that make the narrative personal were preferred in this research. The breast cancer patient who talked about fear of losing a breast, of her hair falling out with their associations of femininity were closer to revealing what the patient was experiencing. 28

The use of the war metaphor was found in many cancer stories and was not restricted to breast cancer alone. It stood dominant amongst all the metaphors. Susan Sontag was one of the earliest to publicly identify and


advocate resistance to this feature of the cancer literature in 1979.\(^{29}\) By 1990 Sontag’s thinking had become more ambivalent in that she progressed to conceding that thinking about cancer is difficult without a metaphor and that it offered a value but that many of the commonly used metaphors were better avoided\(^ {30}\).

In 2003, Ulrich Teucher reported another metaphor, viz. journey that can symbolise chaos and uncertainty much more gently than the war images. It is also a well-used metaphor for the spiritual life and indeed of the “Church” which in contemporary publications is described often as a “Pilgrim People”. Journey references are found in the Old and New Testaments of the Bible and in first and second century patristic writings.\(^ {31}\) The metaphor of the “Church as a pilgrim people” is foundational to the *Lumen Gentium* document of Vatican II and was reinforced by John Paul II in *Redemptoris Mater*.\(^ {32}\) Literary references to pilgrimage are found in Geoffrey Chaucer and in Dante’s *Paradiso*.\(^ {33}\) This

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\(^{29}\) Sontag, *Illness as Metaphor*.


metaphor has wide applicability and is much more conducive to well-being than and metaphor derived from war.

Teucher also performed an empirical analysis using standardised questionnaires and including respondents who did not habitually write. He found a cultural dependence in the use of metaphors and that the usage was constructive towards the patients’ sense of well-being. Further he noted that metaphors “can have different meanings for different people, or even different meanings for the same person at different time. For some patients, cancer may be a plague; for others, such metaphors are a plague.”

Teucher, cautioned that language can have many meanings and its use may involve misinterpretation. The reality of the occurrence of different metaphors must be acknowledged and ambiguity was be avoided through the critical selection of the stories that were included in the database for coding. Coding describes the process used to associate a searchable tag with each cancer model identified. Here the term cancer model was used when coding narratives.

4 Blending grounded theory and phenomenology as a methodology

The methodology of this research was chosen to constantly ensure a solid grounding in the whole data set of stories of their cancer experience as told by the patients. Grounded theory (GT) was therefore appropriate for how this study was to proceed; that is its methodology was chosen to be GT. However declaring

Chapter 3: A systematic study of cancer stories

the methodology locks in a philosophy that the research should follow; the consequence for this study follows in the next paragraphs. Further, understanding and interpreting the dataset of oncology patient stories required a phenomenological approach as part of its method.\textsuperscript{35} The method was also hermeneutic in that it sought to uncover latent meanings in the narratives that could have relevance for 21st century people. Kyla Yaskowich and Henderikus Stam wrote that GT in the eyes of its originators was primarily an inductive technique; however when it seeks to uncover meanings inherent in the narratives, as was the intention here, it can be considered more a hermeneutic enterprise.\textsuperscript{36}

Getting to the objective reality, to the extent that it can be found, was difficult and required complex hermeneutics because of the difficulty associated with the ontological and epistemological aspects of the analysis.\textsuperscript{37} Any quantification in a purely empirical manner was extremely difficult due to the individual nature of the cancer experience. However, the use of modern analytical CAQDAS tools did render quantification possible to some extent. Maxwell declared the legitimacy of making causality claims arising from qualitative process oriented arguments.\textsuperscript{38} The blended methodology of this


\textsuperscript{36} Yaskowich, "Cancer Narratives and the Cancer Support Group," 732. The next paragraph considers the issue of the essential nature of the GT process which may not be so simply described as being purely and solely inductive.


project successfully unlocked the content of the large volume of qualitative oncological data and enabled conclusions to be made. The research is grounded in the patients’ stories as the principal source of data.

All stories about the experience of cancer that can be found in the public domain were deemed relevant to the purpose of this research, particularly those providing evidence of peer acceptance of any recommendations that the author may have made. Thus, story provided the main source of data for this study.

This research took a phenomenological analytical approach to the storytelling of cancer patients along the lines described by Donald Polkinghorne and Theodore Sarbin. They wrote, “the method emphasises storying as a recursive constructive process” that is conducted by the researcher and is thoroughly grounded in the cancer story narrative. As the number and complexity of stories in the database grew, Polkinghorne and Sarbin would have the researcher compare the evidence emerging from each case in a systematic manner to move towards the formulation of a new theory or hypothesis or towards the validation of any *a priori* ideas. The essential requirement of this mixed method is that any emerging hypothesis must arise from and remain firmly grounded in the data of the original stories including phenomenological narrative and exhibit a high degree of consistency. Further, in addition to such grounding of the data, the method of this study made constant comparisons within the data set relative to codes (which are like key words and which were progressively

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refined as the discourse analysis progresses). Memos were used to record the entire process and the outcomes of hermeneutic analysis and assist in identifying any emerging hypothesis, with the intention of providing an indicator of trustworthiness\textsuperscript{40}. They also served to create an audit trail.

Such a method is seen in the original idea of Barney Glaser and Anselm Strauss in 1967, when they first described GT.\textsuperscript{41} By 2004, Glaser, in collaboration with Judith Holt wrote to decry what he called the “remodelling of GT” by scholars who over forty years had come to use GT analytical methods to “force” “descriptive findings” rather than to concentrate on allowing the theory or hypotheses to emerge entirely from within the data.\textsuperscript{42} This study’s research method respects the pure form of GT originally expounded by Glaser and reiterated in his 2004 article on the remodelling of GT, but also requires cognizance of the need to incorporate an \textit{a priori} idea and to include some personal ethnographic narrative without violating the integrity of the process. The knowledge must fit the data.\textsuperscript{43} This research places a priority on allowing any hypothesis to emerge from the story in contrast to forcibly extracting it.


The 1990’s saw a split between Glaser and Strauss that caused a dilemma in formulating a methodology for this study because its process required it to strive to retain a “theoretical sensitivity” compatible with “theoryladenness” to use Glaser’s terminology. In essence this method required that any theory contained in the data must emerge thence. Udo Kelle provided a commentary on the epistemological problem; he said that what Glaser proposed is rather a “hotchpotch of concepts” lacking the detail needed to process empirical data. Pragmatically, the best solution, that would provide a practical methodology, commences with the Strauss and Corbin approach to coding by adopting their paradigm of axial or skeleton coding from which to develop GT, rather than the vaguer open coding, whose nomenclature emerges literally from the narrative text that Glaser demands. The details of the Glaser/Strauss and Corbin controversy are given in the note below; a fuller exposition of the controversy comprises an ever expanding subject of debate. However, when the analysis of

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46 Anselm L. Strauss and Juliet M. Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (London: Sage Pub. Inc., 2008), P99. The term “open coding” denotes descriptions using terminology from narrative emanating from each story itself in response to questions such as “what category does this incident indicate?” Each new code is used to gather together similar data that the GT researcher uses in the quest for similarity or difference. The term was first described by Glaser in 1967. The term “axial coding” is found in Strauss and Corbin (1990) and designates code words or phrases that act like a skeleton about which the GT researcher can aggregate similar narrative moving towards the development of a paradigm or model. The terms used to designate axial codes may not be found explicitly within the data but must have relevance to the data. Constant comparison ensures this.
stories contained within the initial data set was commenced, a utility was found in using Glaser style *open coding*. In common with other contemporary researchers, it was found that personal empirical oncological experience required more precision and flexibility that was better served by using *axial coding* as described in the Strauss and Corbin paradigm. This provided a challenge, at the stage of devising the methodology and subsequently, throughout the work, of keeping the integrity of the GT process uncontaminated by personal empirical oncological experience. However, this challenge was accepted and reassurance derived from Strauss and Corbin and the other researchers, who endorsed the inclusion of researcher experience within the GT process and who saw advantage in using discipline-based knowledge. Indeed in 1992, Glaser himself conceded that “the analyst’s assumptions, experiences and knowledge are not necessarily bad in and of themselves. They are helpful in developing alertness or sensitivity to what is going on.”

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Thus interpretative phenomenological elements were accommodated as data along with personal oncological narrative as a reflexive hermeneutic tool.\textsuperscript{50}

My personal melanoma diagnosis was included in the data set as subjective lived experience and was coded in the same way as all other stories. It was imported into the NVivo analytical engine initially as \textit{open coding} as understood by Glaser, Corbin and Strauss.\textsuperscript{51} Such use in NVivo reduces the effect of bias because the coding can be selected or omitted from the hypothesis during testing and the effect of the inclusion or omission on the outcome is immediately seen. Such use of phenomenological narrative within the Strauss & Corbin model of GT gave rise to the “blended theory” nomenclature to the methodology of this study.

Glaser may see a deviation from his “pure GT” in this “blended mode” that is applied here. However, any deviation is more apparent than real. It is noted that his original paper arose from his research on dying patients in 1965; and although this present study deals with cancer, comprising a similar group of people, the circumstances are very different. His was an era characterised by less complex data sources than were used here and lacked the sophisticated computer based analytical tools that are deployed here in research that is being


NOTE: In grounded theory as expounded by Corbin and Strauss, coding is divided into the three categories of \textit{open}, \textit{axial} and \textit{selective}.
conducted nearly half a century later. Glaser’s lack of warmth towards CAQDAS tools was identified by Harris and colleagues when they showed a mapping that equated “experienced QDA hands” (Glaser would be located in this set) with “low familiarity with CAQDAS”. Udo Kelle is more typical of recent GT researchers who see advantage in using CAQDAS tools.

The manner in which the present blended methodology used CAQDAS software tools, offers the real possibility of an affinity with Glaser’s concept of the “systematic generation” of “conceptual hypotheses”. He said “I wish to remind people, yet again, that classic GT is simply a set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area.” Classic GT is a highly structured but eminently flexible methodology. Its data collection and analysis procedures are explicit: The pacing of these procedures is, at once, simultaneous, sequential, subsequent, scheduled and serendipitous, forming an integrated methodological “whole”; that


enables the emergence of conceptual theory, as distinct from the thematic analysis characteristic of QDA research.56

Reaching a “methodological whole” through blending, this study’s method, describes a necessary goal as it strives to test a hypothesis whilst simultaneously allowing it to emerge from within the cancer narratives logically, paradoxically and perhaps serendipitously.57

Three major logical phases may be identified in the way the methodology was planned and executed in this study: firstly, using cancer narratives as a data source; secondly, coding the narratives; thirdly, constant hermeneutic comparison. When considered sequentially as time progresses, the process is seen to be repetitive.58 Conclusions emerged from the application of this mixed methodology.

Grounding in cancer narratives

In the first logical phase, every cancer narrative became a data source in this study. Obviously too, extractions were made from books and publications in various printed formats and from newspapers. The Internet abounded with stories from the various cancer societies such as the Victorian Cancer Council or the American Cancer Society and various centres providing oncology


treatment such as “Mayo Clinic Stories” and self-help groups such as “Steve Dunn’s Cancer Guide”. And “YouTube” provided scores of narratives posted by individuals who told their experience directly. In the face of so much potential data, a problem was to discern when data acquisition should cease. The “Word Frequency” query tool found in NVivo was useful in determining when the quantity of data was enough to ensure valid representation (called theoretical saturation). Theoretical saturation occurred when no new principal themes were found when new stories were added. As the data accumulated, coding was commenced and was repeated over time. Such constant sorting aided the hermeneutical analytical process.

**Coding the narratives**

Coding is the second logical step in the method. Consideration was given to what the author was saying, taking into account cultural relativity and the metaphors being deployed, in order to allocate a code or tag to that text whilst entering it into the electronic database; this was the birth-process for new codes. In Glaser terminology this is open coding, which soon gave way to axial coding during this study. However the NVivo software with its function of parent and child nodes made it easy to code for the dominant and dependent distinctions within each cancer narrative. Text was often coded under several nodes. Joy

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61 Glaser, "Remodelling Grounded Theory," 7-12, 9.
Bringer also had identified this as the process that she deployed with NVivo for her doctoral research.\textsuperscript{62} The coding experience of this research was characteristic of the Strauss and Corbin model and remained consistent with Glaser.

Such a large volume of data generated a large number of codes but some core variables were seen within the data. The goal was to facilitate what Glaser called “parsimonious theory”, which began emerging during the constant comparison and sorting. It must be remembered that sorting is \textit{conceptual sorting} not just \textit{data sorting}, which occurred at an earlier stage.\textsuperscript{63}

\textbf{Constant comparison}

The third and final logical stage in the methodology was this constant comparison and axial sorting that moved the analysis from rich description towards revealing any hypotheses.\textsuperscript{64} In this, the process can be described both as inductive and deductive because of the cyclic nature of the constant comparison and the alternative process that dominated each phase of the iteration.\textsuperscript{65} The NVivo software helped by providing tools that were used to

\textsuperscript{62} Bringer, "Using Computer-Assisted Qualitative Data Analysis Software to Develop a Grounded Theory Project".

\textsuperscript{63} Glaser, "Remodelling Grounded Theory," 13.

\textsuperscript{64} Bringer, "Using Computer-Assisted Qualitative Data Analysis Software to Develop a Grounded Theory Project".

\textsuperscript{65} The process is inductive when the data stories are being coded and these codes lead to a provisional hypothesis. When the provisional hypotheses are iteratively verified or rejected by consistency or lack of it when the process compares them with the initial substantive story data, the process is described as deductive. So the complete process with all its repeated cycling is described as an “inductive-deductive” cycle in the GT method. Fernández, "Using the Glaserian Approach in Grounded Studies of Emerging Business Practices," 90.
perform queries aimed at finding correlations within the data that might indicate a strong relationship. Memos were useful to keep track of this process and to help to delimit the analysis. Glaser and Holton describe the continuous process of memo writing as the “frontier of the analyst’s thinking”. They said that memos “locate the emerging theory with other theories with potentially more or less relevance.” 66

A summary of planning and deploying the methodology that mixed phenomenology and GT centred on a process of continuously asking and answering the questions: “What is this story data saying or implying about prayer or well-being? What is the analysis just performed implying about any correlations? Do the results of this analysis add to any proposition or increase its empirical content? How does one understand instances of negative concordance with the emerging heuristic framework?”67 The use of CAQDAS computer software helped in managing all stages of the analysis and facilitating conclusions; however it must be stated that the main research tool always remained the process of critical thought and reflection by the researcher.

5 How NVivo is used in the blended process

The challenge posed by the misunderstandings and poverty of the descriptions of CAQDAS software in the current literature had been considered and a pragmatic decision was made to use a blended method facilitated by such


software. But declaring the methodology was only the beginning. A second challenge arose when considering how to implement the methodology using the tools available to perform CAQDAS. Are the tools needed for this research available? Which was the best software package to use? How much of a compromise would this selection be?

In the previous section of this chapter three logical stages that can be used to visualise this research were specified. In order to answer the above questions and to choose the best CAQDAS tool for this research, the tasks to be performed must be considered in a functional sense. The first task was to import and store hundreds of stories derived from sources as diverse as books, journals, and internet blogs. The second task was to organise and code the data into nodes, which are like search keys that can be sorted and analysed using logical software functions. The third task was to deploy sophisticated text analysis tools that can run queries based on the products of coding. And the fourth task was to determine the appropriateness of the algorithms (which are the instructions that the computer can use, for hypothesis testing such as correlation coefficients.) Additionally to assess the tools provided for visualisations arising from text search queries and how they could be exported to Microsoft Office

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69 NOTE: A node is a collection of references about a specific theme, place, person or other area of interest. One gathers the references by ‘coding’ sources such as interviews, focus groups, articles or survey results; http://help-nv9-en.qsrinternational.com/nv9_help.htm [Accessed April 13, 2012].

70 These coefficients result from calculations that enable the similarity of items to be qualitatively compared. http://help-nv9-en.qsrinternational.com/nv9_help.html. [Accessed April 13, 2012]
A full comparison of all of the computer programmes suitable for use as adjuncts to GT analysis was deemed outside the scope of this dissertation and may be found in an ever expanding literature.\textsuperscript{72}

NVivo\textsuperscript{®} was chosen for CAQDAS to aid the performance of this research because in trial it was found useful and personally recommended as suitable for handling and analysing the large data set of this research.\textsuperscript{73} NVivo made it possible to analyse data from the time its collection commenced; it was not necessary to load the full data set before commencing the analysis and hermeneutics. And early findings assisted in culling the massive source of data by making it easy to determine when one reached the theoretical data saturation point.\textsuperscript{74} Technical support and instruction for NVivo were available locally. It was found to be a valuable adjunct to this research by enhancing creativity in what Strauss and Corbin called the “interplay between researcher and data”.\textsuperscript{75} Bringer

\textsuperscript{71} Microsoft\textsuperscript{®} software


\textsuperscript{73} NVivo qualitative data analysis software; QSR International Pty Ltd. Version 10.0.573.0 SPJ, 2014.

\textsuperscript{74} Bringer, "Maximizing Transparency in a Doctoral Thesis: The Complexities of Writing About the Use of QSR Nvivo within a Grounded Theory Study," 248.

\textsuperscript{75} Strauss, Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 14.
had described her success in using NVivo to support her GT methodology.\textsuperscript{76} Whilst hoping to achieve a similar outcome, recognition was made of her warning that this program “may facilitate the user’s development of theory, this does not suggest that the program can guarantee theory development nor coherence with a particular methodology.”\textsuperscript{77} Personal previous experience in using CAQDAS in my Masters project led me to conclude in favour of its appropriateness for the success of this research. Further support for the appropriateness of NVivo for this project is evidenced by the high level of support for my electronic seminar conducted by the invitation of QSR; this attracted 716 registrants and the YouTube video made of the seminar has had 721 views up to now; the title of the eSeminar is \textit{The Storytelling Nature of Cancer Patients with Greg Brown}.\textsuperscript{78}

This research commenced with the entry of a heterogeneous set of stories derived from those published by cancer patients on the internet (57%), books (18%), newspapers (15%) and a miscellaneous collected set from internet blogs, academic journals and theses (20%). Demographically, 62% of the stories were told by patients in the United States, 34% were from Australia, and 4% were from patients in other countries. Stories were rejected only on the basis that they contained too little information or that there was bias evident in the source or that


excessive redundancy existed (as for example was the case with Breast Cancer).  

Stories were entered into NVivo progressively and then commenced a round of open coding when the early themes began emerging. Frequent use of the text search tool and the word frequency queries had assisted the identification of the open coding themes by visualising the query outputs. Further they helped answer the necessary question “When have you collected enough stories to be sure that they constitute a representative and unbiased sample of the group?” Or what determines the end of theoretical sampling or data saturation? Three measures were taken in response. Firstly, the word frequency query was run regularly during the process of entering the stories and the most frequently occurring 100 words exceeding 5 characters were compared on each run. Soon the relative value of these top words were continually recurring, indicating that any further stories would only confirm the validity of this set being taken as a representative sample of the whole population. Secondly, equal numbers of male and female stories were required to permit comparison between the genders. And thirdly, to further obviate bias from the sample each common type of tumour should be represented in the data-set in the same pattern as cancer incidence. Accordingly 34 different types of cancer pathology were included in patterns typical of new case incidence in Victoria and the United

79 The set of stories published on the Cancer Council of Victoria (CCV) website showed what seemed to be a bias away from meditation which was deemed a complementary therapy. The CCV references (R) to sources (S) ratio R/S was 2.0. This was similar to that of atheists R/S = 3.0. Whereas the average R/S ratio for all of the sources of storytelling in the database was 9.8.  

On the basis of these three criteria, saturation was deemed to be reached at 160 stories of which 80 were female and 80 male.

The analysis was progressed by using the NVivo analytical tools to respond to the following questions about well-being:

- How did the majority of cancer patients express their well-being?
- Were there gender differences?
- What did the patients say were the best and worst parts of having cancer?
- About prayer I considered the following questions:
  - Did the majority of cancer patients pray?
  - What was the commonest form of prayer?
  - What is the detail of the commonest form of prayer?

In responding to these questions many more rounds of coding (axial) were performed using NVivo. The NVivo tools helped to commence the hermeneutics of the dataset of patient stories. The answers to these questions are presented in the following three chapters and are visualised by the figures that they contain.

6 Need to identify each stage reached on the journey

But how did this research justify the integrity of relying on patients’ cancer stories as its principal data source? How does one establish the rigour of story to make it a legitimate research activity? It is often, and too easily said that the intended use is biased or too personal, especially when the researched and the researcher seem to be fused. Tina Koch addressed the issue of the complexity of establishing rigour in qualitative research. Koch wrote that, from the late

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Chapter 3: A systematic study of cancer stories

1980’s, researchers started developing evaluative criteria for qualitative research in the health care area. Deborah Cohen and Benjamin Crabtree in 2008 indicate that although general agreement was found on four elements of an eight criterion matrix, controversy existed on the last three.\(^8^3\) This research follows the Cohen and Crabtree criteria. An aim in relation to how its methodology deals with the data of patients’ stories was to make it generally compliant and place an emphasis on providing the reader with an ability to audit the processing of the stories.\(^8^4\) The “signposts” that are placed at the conclusion of each chapter aim to add credibility by leading the reader through the interpretations being made progressively and by describing such conclusions as arise along the journey. Evidence of the validity of conclusions would flow from their rigorous grounding in the data stories and from the application of reflexivity in obviating ethnographic bias. Some application of Peter Achinstein’s “Logical Constraint Model” were possible too and provide a logical reason for believing (proof) the principal conclusion of this study.\(^8^5\) Certainly the NVivo software provided some capability

\(^8^3\) Cohen and Crabtree list 7 criteria for good qualitative data research. These are: (1) Carrying out ethical research, (2) importance of the research, (3) clarity and coherence in the report, (4) vigorous use of appropriate method, (5) reduction of researcher bias through reflexivity, (6) importance of establishing validity or credibility, and (7) importance of verification or reliability; D. Cohen and B. Crabtree, "Evaluative Criteria for Qualitative Research in Health Care: Controversies and Recommendations," \textit{Annals of Family Medicine} 6, no. 4 (2008): 331-39.


\(^8^5\) Peter Achinstein, \textit{The Book of Evidence} (Oxford: Oxford University Press, 2001); S. Miller and M Fredericks, "The Nature of "Evidence" in Qualitative Research Methods," 1-27. NOTE: For qualitative research, Achinstein defines evidence (e) as a good reason to believe s hypothesis (H). Data can be transformed into hypothesis under his logical constraint model if two conditions exist. Namely that (H/e)>½ and also that a logical connection exists between H and e. The validity of the conclusions of this study are shown because they comply with the logical constraints of Achinstein’s model. Pearson correlation coefficients found in the analytical results of this study taken with the Venn Diagram for the union and intersection of storytelling, prayer and well-being as sub-events of spirituality, satisfy the two “logical constraint model”
to establish the strength of hypothesis and the truth of its emergence from within the data set. The progress of evidence to hypothesis as the analysis proceeds will be charted.

A further need to identify each stage as it is reached during this research journey, arose from Hans-Georg Gadamer’s philosophical hermeneutics. He proposed no method but sees “the entire research process as a reflexive exercise which provides answers to the question ‘What is going on in methods?’ I claim that if the research product is well sign-posted, the readers will be able to travel easily through the words of the participants and makers of the story and decide for themselves whether the story is a legitimate research endeavour” 86 This study is iteratively reflexive on empirical oncological experience. So in applying his principle here, Gadamer would require that in parallel with the progression of the data processing, the reader be enabled to visualise the line of the argument clearly. He requires that at all times, during any hermeneutic reflection, the process being used, be placed into clear relief and be identified throughout the research process.

Investigating the relationship between prayer and well-being for people with a cancer diagnosis was similar to Pat Bazeley’s dog seeking the rabbit’s scent.

I have a Welsh Springer Spaniel dog. It is fascinating to watch him cross a field: he will course back and forth in what appears to be a

conditions thus establishing the conclusions made in the final chapter of this thesis as credible.

very indirect route until he picks up a scent—his brain makes the connection with rabbit, and so then he will move rapidly and directly in line with that scent. Arrival requires that you have moved along a tortuous and possibly twisted path until you have found the scent, but having found it, you make the connections and you are then able to lead the reader directly to the goal.\textsuperscript{87}

Initially the path through the large volume of dense and complex oncology narratives was unclear and one took many wrong turns. The “scent” must be found. Deploying CAQDAS made this GT task manageable and helped reveal meaningful connections that lead towards discovering the latent theory or hypothesis. Once found, the “scent” must be followed and not lost in order to reach the goal. The message was that research activities must always be dictated by the main purpose. Bazeley was present and could observe and therefore describe the progress of her spaniel as he followed the scent. This research was complex both in relation to the oncological data and in the blended method used to perform the GT process. It was easy to become lost. So understanding the stages reached and the path taken must be identified to suggest the next destination in the research journey and to allow a reader to see the progress of the argument. Further it has the potential to identify the arrival at the destination.\textsuperscript{88}

\textsuperscript{87} Bazeley, "Analysing Qualitative Data: More Than ‘Identifying Themes,’" 22.


Lyn Richards addressed this important question “When have you arrived?” and proposes five signs of sufficiency for an analysis such as this. Stated briefly these are simplicity (like a small polished gem of a theory), elegance (arising from coherence), completeness, robustness, and that it makes sense. Other sets of criteria can be found in the literature, but the Richards set was chosen here because they were germane to this research and can produce clear outcomes when applied.

Accordingly, signposts headed connections were located, at the conclusion of each chapter of this thesis. The purpose was to highlight the unfolding argument arising from the data as the work progressed and to enhance the quality of the hermeneutic research decision trail. Each connection looks back making conclusions arising from the chapter just completed and looks forward towards the next stage of the journey. Connections will contain the results of CAQDAS analysis but will also show independent thinking as the GT process proceeds towards reflection and the goal of conclusions.

89 Lyn Richards, Handling Qualitative Data: A Practical Guide.

7 Connections

The function of this chapter was to present the blended methodology of grounded theory and interpretative phenomenology to be used in this study. The top words were: cancer (73), research (57), data (53), stories (49) and methodology (33). These indicated that cancer patient stories comprised the data for the research.

The exegetical part of the method did not appear in the top 50 words, but as the text will show, discussion and reflection on the findings of the analytical processes were a significant part of reaching conclusions.

The conclusion reached at this stage is that a methodology and method have been defined in a manner that enables the management of the collection of the stories told by people about their diagnosis of cancer and of its impact on their well-being. The methodology has been designated as “blended” because it melds the essences of interpretative phenomenology and grounded theory; the
latter particularly as described by Anselm Strauss and Juliet Corbin in 2008. The methodology deployed the CAQDAS software package NVivo as a tool to aid research and had been chosen under the influence of recently published authors, particularly Bringer et al. Three measures were used to determine theoretical saturation establishing that the 160 stories (80 female and 80 male) constitute a sample that can validly represent the patients' storytelling. NVivo tools were used to further the analysis by matrix coding queries, clustering and modelling. This process has produced results that are significant for cancer patients and those providing treatment and care. Open signage through the “connections” section of each chapter is to be deployed throughout to reveal the trail of hermeneutic analysis of the oncology patients’ storytelling.

In order to achieve the GT goal of keeping conclusions grounded in and arising from the patient stories studied, the analytical process and the findings are presented separately and prior to the discussion and conclusions. Thus the journey taken in the next three chapters passes through the territory of the results. It commences with presenting the analytical process followed and the findings on the emotions as indicators of well-being.

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Chapter Four: Well-being revealed in patients’ stories

1 Patients’ perceptions of their cancer as well-being indicators

Rosemary’s story follows to introduce this chapter by setting the scene for the presentation of what the patients’ stories said about their well-being. She revealed that she experienced a range of emotions, frequently changing, sometimes conflicting and some experienced simultaneously as her cancer progressed. Her storytelling was typical of that of most other patients. She expressed her emotions, mainly as feelings, and they were taken to be the key indicators of her well-being.¹ She experienced a diversity of emotions as she moved through the stages of diagnosis, treatment, recurrence, and preparation for her death. Initially she recorded feelings of fear, apprehension, sadness, confusion, disillusionment and comprehension, which she likened to a “roller coaster” ride. During her treatment phase she mentioned helplessness, depression, regret, loss of control. In the latter stages she described her feelings of acceptance, thanksgiving, confidence and joy; but there still remained an element of denial when she said “Now I knew I didn't have long to live, though I certainly haven't wanted an estimate of just how long that may be” ² The

¹ This research makes no distinction between the use of the words “emotions” and “feelings”. The research interest is in considering the actual terms used by the cancer patients themselves. In practice they made no distinction between emotion and feeling. In every case the trigger was an oncological reality (emotion) accompanied by internalization (feeling). This chapter concentrates on the consequential impact on well-being that the patient had chosen to express through a description of emotions.

fluctuations in her feelings signalled how she perceived her well-being during her life with ovarian cancer and her self-talk can be understood as prayer.

Ovarian cancer seldom produces any symptoms at all until the latest stages. So it was with me. I felt fine. Just before a routine physical exam in June 1994 at the age of fifty, I noticed a lump in my lower abdomen... The C word was not uttered, but that mention of chemotherapy alerted me. I was hoping for the best at my appointment with the gynecologist. What I was told was not the best; it was almost the worst ... By the time I saw the medical oncologist in his office (he had visited me in the hospital), I had all my questions written down. I brought one of my sons with me. This was one of the smartest things I did. It was impossible for me to hear and understand what I was told. Kevin would help me put it all together later...

Has cancer changed my life? I am arrogant enough to want to say no. The truth is it has. I changed occupations. I am now a substitute teacher rather than a lawyer. I guess many people rethink their careers when faced with a life threatening illness. I rode an emotional roller coaster for some time. I was depressed for periods of time. I think that's only natural. I found out that some friends can't cope with cancer and disappear, but others are worth their weight in gold.... It wasn't until July, 1998 that I truly felt like my old self, a real person, not a cancer patient. It was as though a switch had been thrown and my emotions now coincided with my intellect...

This all happened amazingly quickly. Maybe you can imagine the double blow this was to me: I thought I was cured; I had been practicing saying, "I had cancer," rather than, "I have cancer." Now I knew I didn't have long to live, though I certainly haven't wanted an estimate of just how long that may be....

I considered it a blessing to have such a clear sign of immanent liver failure. Now I would concentrate on living the rest of my life as well as possible. I chose referral to hospice home care.

I am very pleased with my hospice team (a doctor, nurse, social worker, and a chaplain and therapist should I need them.) They are not just emphasizing preparation for death. They are helping me live well. ...

I don't think I've ever been afraid of death; perhaps because I am at peace with my family and friends--no unfinished business there...

Lastly, I want to thank all who have written to me to ask questions, show concern, tell me their stories or offer prayers. It has meant a lot to me. Some have said they found my story inspirational. I meant it to be informative; I mean this update to be informative, whether or not you agree with my decisions.³

³ Grimm, "Rosemary Grimm's Experience with Ovarian Cancer,".
Rosemary’s narrative was introspective as she worked through the impact of her ovarian cancer diagnosis on her life and as she made the consequential changes; “I considered it a blessing to have such a clear sign of immanent liver failure”. However, in addition to revealing her feelings, her self-talk provided the reader with insight into the new meaning for her life. “Now I could concentrate on living the rest of my life as well as possible… This all happened amazingly quickly. Maybe you can imagine the double blow this was to me”. She thought she was cured but then learned that she had not long to live. She was working out her own future through telling her story and simultaneously intending to provide advice to others. “Some have said they found my story inspirational… I mean this update to be informative, whether or not you agree with my decisions.”

Rosemary’s story was chosen to introduce this chapter which presents the results of investigations into the things that cancer patients said contributed to their well-being.4 This study indicated the existence of other valid strong existential indicators of well-being within the cancer patient story dataset. The full set of indicators were feelings, patient self-talk, worst part, meaning for life,

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4 Chapter 1 contains the Krishna Mohan definition of well-being which includes Western and Eastern elements. Positive well-being requires some control over needs, stresses and frustrations (Western) and also an ability to achieve balance between satisfaction and denial (Eastern). Well-being can be visualised as located along a linear scale ranging from positive to negative. The lowest well-being is the total absence of control or balance and is located close to maximum negative end of the well-being scale. Mohan requires a subjective element to well-being which is taken in this research to be the existence of spirituality which renders both well-being and prayer meaningful and provides evidence of faith; Rosemary’s story, just told clearly contained all of the Mohan elements and arose from faith.
advice to others, best part, and advice from others. These seven indicators of well-being were clustered by similarity to the words used by all storytellers in the node for well-being.\(^5\) They were found to be very highly correlated providing confidence in using them as indicators of well-being.

Figure 4.1 following, shows graphically, the results of this CAQDAS made under the parent node well-being for each of the child (dependent) nodes identified above.\(^6\) The substance of this chart forms the context for the detailed results presented in this chapter and in the next. The concentration of this chapter is on the relation of feelings to well-being as found in the patients’ stories. The next chapter presents the results of the remaining well-being expressions found in the cancer stories.

\(^5\) Clustering describes the process in which the content of the parent node (well-being here) was compared for word similarity with the content of the related child nodes (here feelings, self-talk etc.). Six of the child nodes had very strong positive Pearson coefficients (Pr) relative to well-being in the range 1.000 to 0.7454. Only advice from others had a Pr outside this range.

\(^6\) In this study’s computer assisted qualitative data analysis process (CAQDAS) using NVivo®, nodes were visualised as containers into which conforming text was placed. A generic container, that enclosed other related smaller containers, was called a parent node here and the sub-containers were called child nodes. The analysis involved determining the similarity of the words in the containers (nodes) being compared. In the analysis, similar word contents were understood to indicate a similarity existing between the nodes being compared. The strength of the relationship was quantified by statistically analysing the clustering of similar words between the nodes.
One thousand nine hundred and forty six references to well-being were found in the compendium of cancer stories examined in this study. Taken collectively these exhibited a high positive Pearson correlation of 0.95 based on word similarity. The feelings sub-group was observed to be the most popular of the total of nine; it received the largest number of references. Almost equal, second were the references found in the child nodes meaning for life and advice to others. A paradox seemed to exist here in that the stories contained 350 references to giving advice to help others (female references =146, male
and yet only 12 references were made to taking advice from others (female references = 3, male = 9), as is seen in figure 4.1. If such a substantial pool of good advice existed, why was so little taken up? This led to a deeper investigation into well-being and into prayer that revealed a unique finding about the quality of listening and its link with healing prayer. Full discussion requires the results of the investigation into healing prayer that follows in the next chapter. The discussion in chapter 7 brings these elements of listening and healing together. Rosemary wrote her story both as a means of managing her cancer, but also intending to give advice to others; yet she herself preferred professional advice over that of her peers. In this she typified the greater popularity of the advice to others over advice from others seen in figure 4.1 above. The results also indicated some gender based differences that were seen within each of feelings, advice to others and self-talk found in the results.

This chapter addresses well-being by presenting the results obtained from CAQDAS performed on the patients’ stories taken as indicators or sources of well-being. Similarly chapter 5 contains the results obtained by analysis of the dataset under the term prayer as it was contained there. Chapter 6 contains the discussion, reflection and conclusions derived from these results to reveal the impact of the prayer of cancer patients on their well-being, which was the big question addressed by this research. This sequence of presenting results prior
to presenting the discussion and conclusion was used to ensure valid grounding in the dataset of stories as required by the GT methodology.\(^7\)

This introduction to well-being can be summarised by saying that the words in which the cancer patients expressed their feelings were found to be very individual as they described their personal experience of cancer. However they seemed to have much in common. The GT methodology required a complete grounding in the individual narratives that rendered a complex hermeneutic process very productive. Productive, because eighteen mutually well correlated indicators of well-being were identified. These formed the parameters for the CAQDAS of well-being whose results are presented in the following paragraphs.

### 2 Patients’ feelings about their cancer

Rosemary’s feelings that were manifest in her story just told, were key indicators of her well-being at the time. Like her, another cancer patient, Steve said “The next few days were a blur of decisions and hysteria. My emotions would change from second to second from despair, to horror, to hope, to extreme anger to moments of calm.”\(^8\) In the period immediately following his renal cancer diagnosis, his well-being fluctuated frequently. He experienced such a rapid flow of conflicting emotions moving between strong and bad to extreme good

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\(^7\) The grounded theory (GT) methodology adopted for this study was set out in chapter 3. Achieving integrity in the process, required that the analysis be confined to the story dataset and that conclusions be derived entirely from within the dataset. This was achieved here by first presenting the results of the analysis (chapters 4, 5, and 6) prior to presenting the discussion (in chapter 7) and conclusion (in chapter 8).

feelings. Similar experiences were found in the 210 references to feelings made by the women and 271 references by the men; only 14 patients in the whole dataset made none. Does well-being really fluctuate as rapidly as feelings can?

Well-being cannot be absolutely rated as “good” or “bad”. However well-being at a particular time can be visualised along a continuum ranging from highest to lowest. Lowest well-being would exist in a situation where the patient remains captive to negative emotions such as depression, is self-destructive or suicidal. Evelyn’s well-being would have been ‘lowest’ if she had remained suicidal any longer than she did, as was seen in this extract:

I dreamed of suicide and the best way to do it. I pictured myself in my vehicle with the garage door tightly sealed. I lay awake nights trying not to think of my family discovering my body. But all the fight was drained out of me… I remember the nurse had this huge needle to stick in my arm. I said, “Oh God here comes the bad stuff,” and she looked me straight in the eyes and corrected me, saying this is not the bad stuff this is the good stuff. She informed me that the last person she injected this drug into, she was going to marry 2 weeks from today. This gave me a real boost and I looked at her as if she were my guardian angel. She proceeded to tell me her story and it gave me great confidence in the procedure that was going to follow.9

This kind empathic nurse probably prevented Evelyn’s depression from leading to suicide and gave her the desire to continue living; Evelyn became able to control her urge to suicide, so averting an outcome of what might have merited the label “lowest well-being”. In the Mohan definition, well-being consists in the “ability to control” needs, stress and frustrations and to “balance” the senses

between satisfaction and denial. Spirituality produces a calming effect on fluctuating emotions. For high well-being, Mohan requires that our patient achieve an ability to control and balance their emotional responses. This process which derives from, but is less volatile than the emotions, was seen as spirituality in the studied cancer patients. So the answer to the question above appears to be that well-being fluctuations are less frequent than those of the emotions; which in effect became smoothed by the patient’s spirituality. Certainly the well-being scale has fewer gradations than the expressions of emotion found in this study. Ninety five percent of the patients studied gave evidence of possessing a spirituality and provided insight into their total well-being when they expressed their emotions.  

Figure 4.2, following, charts how both women and men manifested their feelings relative to the number of times each term occurred in the story dataset. On overall observation, the chart revealed that patients used a wide variety of words to express their feelings, sixty eight different words altogether. The majority of expressions occurred less than four times and even the most frequent occurred just fourteen times. Making groupings of similar emotions was possible but the process would destroy the GT methodology of giving preference to the words used by the patients themselves. So the actual naming term used by the patients is retained in order to preserve the grounding. Certainly the more commonly coded expressions of feelings that occur most frequently on this chart

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10 When the child nodes of well-being were clustered by word similarity, spirituality was strongly correlated with well-being and with feelings (Pr=0.75 ).
must be afforded more significance than that of individuals which occur least frequently.
Figure 4.2: Feelings expressing well-being. The chart provides an indication of the wide range of expressions of feelings made by cancer patients, their frequency and the gender differences. (The male value appears first in each pair of bars and is coloured blue; the female value is coloured red).
A consequence of retaining the terms that the patients used to name their individual emotions was that such a large collection became difficult to analyse because of the inherent subtle similarities and differences. Is the emotional response simply so individual as to prohibit meaningful generalizations? Two approaches were taken in response to this question. Firstly, a word frequency analysis was undertaken of all the words that had been coded from the stories under the parent node well-being for the child node feelings. Secondly, a cluster analysis was performed based on the similarity of all the words in the same well-being/feelings node. These analyses revealed feelings that range from mild expressions to severe, when considered on a Plutchik scale for classifying the emotions.\textsuperscript{11}

**Feelings expressing well-being: word frequency analysis**

Table 4.1 following lists the feelings in the ranked order of their popularity. The order of popularity being derived from the frequency of references found in the story dataset under the parent node well-being for the child feelings. Gender based differences were noted. So the results were presented in two pairs of columns with the first column being ranked by the popularity of the males beside the corresponding female values for comparison and in the second set of columns the ranking is for females first with corresponding male values for comparison.

Table 4.1: Top expressions of feelings in relation to well-being

Popularity of the top expressions of feelings in relation to well-being found in the dataset of cancer stories. The first pair of columns are ranked by popularity found in stories told by males (with female values for comparison). The second pair of columns are ranked by popularity in female stories (with male values for comparison).

<table>
<thead>
<tr>
<th>FEELINGS</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Acceptance</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Confident</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Overwhelmed</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Hope</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Determination</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Denial</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Comprehension</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Cheated</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Depression</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Anger</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Calm</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Gratitude</td>
<td>1</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FEELINGS</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Devastated</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Joy</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Confident</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Happy</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Comprehension</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Shock</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Acceptance</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Denial</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Apprehension</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Confusion</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Overwhelmed</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Disillusion</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

Stronger terms were found in the women's expressions of their feelings and the top two tended to be darker than those of the men. The top two for the
women were *fear* and *devastation*, whilst for men were *happy* and *acceptance*. All of the terms used by women are contained within the male dataset, as figure 4.2 showed, but, as table 4.1 showed, the frequencies were different between the genders. The two words *unwanted* and *bargaining* were only found in the male stories.

**Feelings expressing well-being: cluster analysis**

The remainder of this chapter presents the results of a fuller analysis that was based on clustering similar words that the patients themselves used.\(^{12}\) This provided a measure of similarity as determined by the Pearson correlation coefficient. Emotions expressed in words similar to well-being (as determined by values of the Pearson correlation coefficient Pr > 0.5) were understood to be better related to well-being than those with Pr < 0.5. This constituted evidence of the proximity of each emotional term relative to well-being. The more highly correlated terms (emotions) were better indicators of well-being. Clustering of emotions based on similarity of the word content to that of the well-being node found some eighteen with significant correlation.\(^{13}\) This presentation of results proceeds in two groupings suggested by the Mohan well-being definition: one as *needs more satisfied* and a second, as *needs less satisfied*.

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\(^{12}\) Cluster analysis is an NVivo® tool used to explore data by grouping sources based on similar words. Similarity is expressed in terms of a correlation coefficient and can be displayed in tables, dendrograms, a circle graph, or 2D and 3D maps.

\(^{13}\) Twelve emotions when clustered with well-being had Pearson correlation coefficients >0.5 indicating a significant relationship.
Needs more satisfied cluster of feelings

The following feelings fell into the needs more satisfied group, which when ranked by strength of correlation with well-being were: comprehension, acceptance, happy, confident, determination, joy, hope, gratitude and, pragmatic.

“Ian” was located in the needs more satisfied group. He was happy because of the success of the treatment for his sarcoma and that his writings had helped others. “It’s a great feeling to have recovered from cancer … to have been through it all and to be living a full, happy life again. I have done it. I have seen others do it and I know many more will repeat the process in the future.” 14 Paul was happy too for the regression of his tumour and for his survival: “I am very happy these days. I just had another MRI in late August. The tumor area in my brain stem is still dead and is now somewhere just over 80% reduced. I am currently not on any treatment”. 15 Some, like Brent, were happy because of their family “it was a great source of relief to my family members and that alone made me happy.” 16

Some of the men attributed their well-being to their wives as they reached comprehension of the impact of their cancer on their lives. Dan wrote “even though it’s a man’s disease [prostate cancer], it affects the couple. The macho

14 Ian Gawler, You Can Conquer Cancer (Melbourne: Hill of Content, 1984), 1.
man has to realize that his wife is there with him, and she's probably not being recognized enough as someone who has been very supportive of him. His wife Sally wrote 'we decided that we have to be close in all facets of our marriage, not just in the sexual part of it. You’re not an intimate couple anymore, so you have to have your intimacy in other ways.’”\(^\text{17}\)

Life after cancer is an altered life of which some expressed acceptance. Deborah “realizes she is a completely different person since her cancer diagnosis.”\(^\text{18}\) Cullen’s life reached acceptance through motherhood. “[She] has been able to put her cancer in the rear view mirror and embark in another big adventure: motherhood. Today, she, her husband, and her 1-and-a-half-year-old son continue to thrive.”\(^\text{19}\)

Two writers expressed acceptance of their situation in the absence of any hope of a curative treatment. Christopher wrote “new peaks of medicine are rising and new treatments beginning to be glimpsed, and they have probably come too late for me... so I have to trudge on... to lose this ability is to be


deprived of an entire range of faculty: it is assuredly to die more than a little.”

Steve: “[his] cancer diagnosis taught him the importance of making the most of the time he still does have left.”

Twenty one references were made to feelings of confidence. Ardeth was the only one to express feeling confident absolutely when she said “I feel like it would be all right too.” Others gave reasons for expressing confidence. Some had made a study of cancer, becoming confident of the treatment and in the ability of their doctor. “I never expected to be a candidate for a mastectomy …but this was the recommended treatment so I agreed to proceed”. Barbara said “my doctor was young, intelligent, and a pro in this field. He had me checked from head to foot. When I got through I knew I was in expert hands. Surgery was scheduled.” Two said that they gained their confidence through faith in God. Lynn wrote "He equipped me with everything I needed to fight physically,


mentally, emotionally, and spiritually like the shepherd boy David going up against the nine-foot-tall Goliath.”

Susan said that God is “compassionate, kind and full of love toward me. These truths are able to make my heart secure in His perfect plan.”

Fourteen references were made to determination to survive amongst the feelings expressing well-being. Nearly three times as many men as women expressed determination, but all expressions were equally strong. Linda said “Listen, I want to live. Do whatever you have to get it”. She was determined to survive at all costs. Brent expressed it as “determination was going to be the only thing that I could use to help me battle this disease that had decided to make me its home. I became determined to fight back, to fight back to attack this tumor that had attacked me first. I didn’t initiate this confrontation, but I am absolutely going to finish it.”

Eighteen expressions of joy were found almost equally sourced amongst men and women. Typically joy was found linked with successful investigatons and treatment being received for cancer. Arthur said “my own emotions were


28 Galster, "Testicular Cancer Brent Galster,"
intensified by the physical drain for preparing for the scan… My physical reserves and our emotional reserves were gone, so we started to cry, in a mixture of joy, relief, and just plain breakdown.” 29 Two references to expressions of joy made reference to God. Barbara wrote “I can’t even begin to tell you the joy I felt. To have had so many tests, and to have them all come back in my favour was truly a blessing from God. More good news, I was told I would not be required to have either chemo or radiation. Knowing how debilitating these drugs are, you can imagine that my joy, with this news, was overwhelming.” 30 More directly, John found God’s presence in his cancer “there was joy, too, in his presence, a blissful certainty that human beings are the meaning of creation and that God is the meaning of the human being”. 31

More feelings of hope were expressed by men than by women (11 male references, 4 female). But the number of references is so low as to merit a low confidence in the significance of these differences. Taken collectively however, the hope feelings were expressions of high well-being; some for the patient and others for other people. Paul hoped for a miracle. 32 While Christopher hoped for the timely discovery of a new treatment. 33 Arthur hoped that people currently

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30 Bagley, “Stage I Non-Small Cell Lung Cancer,”

31 Laurence Freeman, A Short Span of Days (London: Medio Media, 2010), 19.

32 Leverett, “Grade 4 Brain Stem Glioblastoma Multiforme & Burzynski’s Antineoplastons,”

33 Hitchens, “Tumourtown,”
enjoying good health would appreciate it.\textsuperscript{34} And Ian hoped that future people diagnosed with cancer would receive effective treatment.\textsuperscript{35}

Feelings of \textit{gratitude} were found in some nine references; only one expression was by a woman and eight were made by men. As with the expressions of hope, the numbers were too small to justify making any gender specific comments. The expressions of gratitude made by the patients were similar to Robert when he said “In addition to prayers from my job, friends and in-laws from around the country, people that I knew and didn’t know were prayerful for me. I couldn’t believe that I had touched that many people and who cared for me. It was an encouraging blessing to feel.”\textsuperscript{36} His expression of gratitude clearly indicated his sense of well-being. Similarly, Mack saw others as contributing to his well-being: “The warmth and love of the volunteers at the Cancer Center are indispensable... You just can’t make it without the volunteers. There’s always someone who will come up to you, and without a word, give you a hug. Without all of these people and their efforts – there would be no possibility of the miracles and the good things that have happened in our lives.”\textsuperscript{37}

\textsuperscript{34} Frank Arthur W. \textit{At the Will of the Body: Reflections on Illness}. Boston: Houghton Mifflin, 1991.\textsuperscript{31}

\textsuperscript{35} Gawler, \textit{You Can Conquer Cancer}, 1.


**Pragmatic** was found to be the least correlated of the feelings with well-being (Pr= 0.5) of the group just presented. Albert typified this group when he wrote: “I could see his point of view. In a way I’m glad he has this cold-blooded, factual attitude. What’s real is real, and if you can’t touch it or smell it, it’s not really real.”\(^3^8\) This also indicated that the communication of a doctor who told it like it is was accepted by Albert.

**Needs less satisfied cluster of feelings**

A second cluster of feelings were also found correlated with well-being. But they expressed darker feelings and would be located on the lower arm of the well-being continuum. They were understood as conforming to the Mohan criteria for well-being as needs less satisfied. These feelings were: denial, cheated, shock, overwhelmed, depression, disbelief, frustration, confusion, and devastated.

Eleven references were made to denial. Orville typified this, the commonest expression when he said “I just couldn’t believe it was happening to me. I knew things like cancer – and death – occurred, but I guess I always thought such things happened to someone else.”\(^3^9\) Some authors like Ron associated their denial with a mix-up in their diagnosis. “I knew nothing about melanoma or the stages of cancer, was just stunned at what I was hearing and couldn’t believe that the test results were correct. I told myself it was all a

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misunderstanding that my test results had gotten mixed up with someone else’s results.”\(^{40}\) Lynn made a naked denial. “No! I yelled, over and over, as if somehow the force of my words could make this nightmare not true.”

Many of the men felt **cheated** by the cancer. Christopher “discovered that I felt cheated”.\(^{41}\) Others felt cheated because their treatment outcome was less than expected. “Having been assured by the doctor at Baylor that ‘they never come back in the renal bed’, I now faced my first major disconfirmation. The realization that my friend/surgeon could possibly be flawed in his assertions was most disconcerting.”\(^{42}\) Martina felt cheated because her poor prognosis would deny her plans. “I couldn’t take dying this way. I did not want to die. Things were just getting good. I was in love. I wanted to live”.\(^{43}\)

**Shock** was expressed by more women than men. It was mainly described as arising at the time of the initial diagnosis and some accounts indicated that it affected people close to them. Norma said “The news was devastating and shocking and I tried hard to focus on the information that was being given to me


\(^{41}\) Hitchens, “Tumourtown,”


and all the time wishing that this was just a nightmare that I would awake from.”

“I do remember my husband calling every hour from his work and seeing me everyday. I remember him crying at my bedside praying I would be o.k. He was in shock to see how sick I really was.”

Expressions of the feeling of being overwhelmed were commonest around the time the diagnosis was first communicated to the patient. For some the feeling cleared quickly but for others it persisted for a time. Albert recovered quickly. “It was melanoma, he said – in a monotone, as if he was reciting the rosary. I knew what melanoma was, but not exactly at that moment. Not until the next day did I recall that melanoma was cancer, and a very serious kind, especially when it has advanced to the lymph node. That was the situation – melanoma, lymph node, left groin.”

It was different for Christopher who said “in Tumortown you sometimes feel that you may expire from sheer advice”. He was overwhelmed by the copious advice that he received which was unwanted, causing him irritation and was therefore useless.

Four patients described depression around the time of the first diagnosis of cancer but soon moved beyond it. “Although I could see this glimmer of hope, I was blackly depressed by the news. Everything just seemed flat, life tasted the way food tastes when you’re too sick to eat, flat and tasteless. Despite this, I

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45 MacDonald, “Stage iii Non-Hodgkin’s Lymphoma,”
46 Kreinheder, Body and Soul: The Other Side of Illness, 11.
47 Hitchens, “Tumourtown,”
was not giving up. No point in that, I thought, no matter how bad the odds.”

For Lynn the focus of her depression was beyond herself. “Almost any personal question made me cry, especially anything that reminded me of our daughters, then eight, ten, and twelve years old. Will I see them grow up? How will they make it without me?” Her initial depression lifted when her trust in God returned. For Orville, the depression was darker. He considered suicide. “It all seemed senseless. Why fight to keep alive for a few more months? I was going to die anyhow. Why not get it over with? I thought about suicide, but then I knew I wanted another Christmas with my family. Suicide was not the answer... the days and even the nights are more acceptable now, but I still have moments – and even days – of depression.”

His depression eventually left him but obviously impaired his well-being. Evelyn too dreamed of “suicide and the best way to do it. I pictured myself in my vehicle with the garage door tightly sealed. I lay awake nights trying not to think of my family discovering my body.” But, as mentioned earlier, the reaction of an empathic nurse provided a path out of her depression.

The poor well-being was signalled by Angela’s depression. “As her physical problems worsened she became deeply depressed and virtually incommunicative. After a couple of weeks the depression became so severe that we asked the opinion of a psychiatrist and Angela was admitted to hospital to

48 Dunn, “My Metastatic Kidney Cancer and My Survival”,


50 Kelly, New Meanings of Death, 182.

51 MacDonald, “Stage iii Non-Hodgkin’s Lymphoma,”
start anti-depressant therapy.” 52 Robert Buckman, who wrote about Angela, proceeded to state that her depression, signalling poor well-being, had arisen from bad theology. For Angela, the “bad theology” had arisen from having a fundamentalist belief that God was not curing her as a punishment here on earth to prepare her for greater punishment after death. More generally, bad theology is “almost based entirely on concepts of reward and punishment”.53

All six instances expressing feelings of disbelief were found to occur at the time of first diagnosis. “I didn’t know what an oncologist was so I asked her what an oncologist does. She responded, ‘Oh, he treats cancer’. ‘Cancer … Cancer!’ I shouted and jumped to my feet and started pacing around the reception room full of people. ‘Cancer!’ I shouted. ‘You’re telling me I’ve got Cancer ….Sara, what am I going to do?’ 54

There were nine references to frustration equally distributed between the men and the women. They were frustrated by their slow improvement with treatment or by unpleasant side-effects. Martina said “I would just get to sleep and then my pump would kick in. Another thing is I would sweat constantly from my head. You also smell like someone just urinated on you the night before and


you have not been able to have a shower yet. That is not pleasant.”\textsuperscript{55} Clearly Martina was frustrated. And there were other causes of frustration.

Rosalie was one of two to express feeling frustrated at being diagnosed with a rare cancer. “No one made a fuss over it being LMS (Leiomyosarcoma). I did not know it was so rare and hard to treat. I asked questions, got no answers”.\textsuperscript{56} Annie’s parents were frustrated by her “physical condition and by the way she wouldn’t let anybody ‘in’ to help her.”\textsuperscript{57}

\textit{Confusion} was expressed by seven women and by one man only. All instances contained lots of unanswerable questions? As Samantha wrote “But if I were getting better, why did I feel so bad? So desperately alone? So alienated? Despite living at home with my family without financial worry, despite having a book published, and temporarily becoming a minor celebrity, despite getting a real grown-up job in publishing, despite the constant rise in my cell count … why was I thinking that perhaps life would be easier if I got sick again? Not really sick, but …just a little bit. Just to take the pressure off. Just to give myself a bit of breathing space from a works that expected too much.”\textsuperscript{58}

\textsuperscript{55} Martina, “Grade 4 Brain Stem Glioblastoma Multiforme & Burzynski's Antineoplastons,”
\textsuperscript{57} Buckman, \textit{I Don't Know What to Say: How to Help and Support Someone Who Is Dying}, 30.
3 Connections

Figure 4.3: Word Frequency Cloud for Chapter 4

This chapter was the first of three presenting the QDA findings within the story dataset. The focus on well-being is evident in the cloud, being the most frequently occurring word (71). The other top frequency words were: cancer (54), feelings (53), found (29), emotions (22), expressions (20), and patients (19). This indicates that in this chapter, cancer patients’ feelings and emotions were expressions of their well-being at the time.

Ovarian cancer patient Rosemary’s story introduced this chapter. The goal was to study what could be found about how cancer patients understood their well-being by making a study of their stories. Rosemary’s emotions changed often and ranged from fear to joy. In chapter 7, John Paver’s reflection in his *theology of the Cross* is presented as he strove to resolve the emotional paradox
in his life of the interplay of weakness and strength, similar to the emotions expressed by Rosemary and other patients.

A graph was presented showing the results of the CAQDAS analysis of what the storytelling revealed. Nine parameters were identified, of which feelings, were shown to have a primacy. The most popular others were self-talk, advice to and from others, meaning for life and the best and worst parts of having cancer.

Having made these findings, the journey of this chapter proceeded to visit the content of the feelings node more fully. The analytical process commenced with a word frequency analysis and followed with a comparison of the top ten feelings. Stronger and darker terms were found in the womens’ expressions of their feelings than in the mens’. The top two feelings for women were fear and devastation, whilst for men they were happy and acceptance. A deeper analysis, performed by clustering the feelings based on word similarity, showed the strongest correlation for eighteen expressions. Quotations from patient stories were included to indicate the bases on which analytical findings stood. The quotations and observations were presented in two groups based on the Mohan definition of well-being as needs more satisfied and needs less satisfied. The strongest correlated in the needs more satisfied set included comprehension, acceptance, happy, confident, and determination. Among the needs less satisfied set were found feelings of denial, of being cheated, of shock, being overwhelmed and of depression.
The results presented in this chapter could be seen to justify the idea that: feelings/emotions are valid indicators of well-being for cancer patients; that they answered the question asked earlier in the chapter by finding that a patient’s well-being did not fluctuate as rapidly as their feelings; suggesting that spirituality acted to smooth the fluctuations of the feelings; thus providing material for reflection in chapter 7. Beyond the realm of the emotions, the journey will move into the remaining indicators of well-being. The next chapter presents the findings of the study of the remaining indicators of well-being. Further, it suggests the existence of links between these well-being parameters and spirituality and prayer.
Chapter Five: Spirituality linked to well-being

1 Introduction

This chapter continues presenting the results that arose from exploring how the storytelling revealed the well-being of the patient. In the previous chapter, the analysis revealed the primacy and complexity of emotions as the patients expressed their cancer experience. But there was more.

The coding exercise had revealed that the following nodes were also well correlated with well-being (Pr > 0.94): self-talk, advice to and from others, meaning for life and the best and worst parts of having cancer. The
frequency (popularity) of each of these had been shown in the previous chapter as figure 4.1 which has been reproduced for convenient reference.

Table 5.1: Spirituality linked to well-being.

The manifestations (nodes) of Spirituality (in green), derived from the patients’ stories are shown located adjacent to the stages of spirituality in the Ranson model (in blue). Such close correspondence with the Ranson model of spirituality and the correlation of spirituality with well-being (Pr > 0.94) leads to the conclusion that the patients’ well-being is intimately connected to their spirituality.


These expressions of well-being are compatible with the stages in the Ranson model of spirituality as can be seen in table 5.1 above. The well-being expressions are shown in green lettering opposite the corresponding descriptor in the Ranson model of spirituality. Thus the exploration of each of the remaining well-being descriptors that follows, becomes an exploration of these elements found in the patients’ stories and their spirituality.
2 Patients’ self-talk

The dataset of stories contained 175 references to self-talk, which was taken to comprise the internal conversations that have influenced their feelings and behaviours.\(^1\) In the process of coding, self-talk was found expressed variously in the paradigms of psychology, spirituality and common parlance: containing elements of intuition, awareness of inner needs and reflection.

Scanning the content that had been coded as patient self-talk revealed that instances occurred throughout. Particularly, expressions of patient self-talk occurred in relation to all of the well-being sources shown in figure 4.1, repeated above. Many patients used questions in their self-talk. Analysing the content of the patient self-talk node revealed degrees of complexity in their situations. Exploration of the dataset, by clustering based on word similarity, showed that the parent node Well-being when clustered with the child node patient self-talk had a Pr= 0.93 which indicated that this could be used with a high degree of reliability as a data source.

The patients had revealed complex self-talk through their description of the many influences on their well-being. Typical was Brent who revealed why he told his story:

I don’t believe in total recovery when it comes to cancer. This is a lifetime illness, once you’re diagnosed; your life is changed forever. There is no returning to the innocence of your pre-cancer days.... The only way that I was able to endure was a strong support system, a loving wife and child, faith in god, and blatant

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arrogance and stubborn anger at what was happening to me. I was and continue to be determined to fight and struggle through my illness with my family. Not because I want to be a hero, or inspire other people to be better, but because you either try or die. There’s no reasoning with cancer or nicely asking it to cease and desist. If you allow it to run rampant through your body without trying to fight back, it will take you down and will not apologize. I thought about my 13 month old son and my new wife, the wonderful new additions to my family that I may lose if I gave up. I thought about my mother, who once told a friend that the worst thing that could happen to her was one of her children dying from a terminal illness. Since I was already halfway there, I wasn’t going to be responsible for her misery... She continues to be the adhesive bandage that holds our family together in times of crisis and is the person that I draw much strength from.¹

Throughout his narrative, Brent’s well-being had fluctuated. This was signalled by his progressive loss-of-control along the trajectory of his testicular cancer and the acceptance of his changed life that he expressed near the end. His self-talk provided a wonderful insight into his well-being through the frankness and clarity of his narrative. His experience remained uniquely his, but his self-talk also provided glimpses into the spirituality of others. Many narratives contained the elements highlighted above. Figure 5.1 following is a graphical presentation of the results obtained when the constituent story elements of the patient self-talk references were subjected to word frequency analysis relative to the contents of the well-being node. The results were shown ranked by their individual Pearson correlation coefficients. Instances of self-talk that correlated at Pr= 0.5 or better were taken to be contributing positively to the author’s well-being and hence worthy of reporting in this statement of results.

The purpose in writing the story for oneself was most strongly correlated with *self-talk revealing well-being* (Pr = 0.76) is shown in figure 5.1. Also correlated was that patients wrote for others (Pr = 0.57). Further analysis of the self-talk showed that achieving some control through the storytelling was well correlated with well-being (Pr = 0.69).
The answer to the question “why the patients told their stories” was in fact not the same for all and was not done with a single intention. The majority of patients telling their story did so with a declared intention of helping others; however many realised benefit for themselves through storytelling. Clearly, the most correlated purpose with well-being, indicated by this analysis, was...
that the authors were working through the impact of cancer in their lives, through storytelling. ² Leandra’s story supported this finding in that she declared her primary purpose in writing to be for herself. Leandra wrote:

I sat down and finally wrote it all out. I hadn't done that yet and it felt really nice to have it "on paper" and gone from my head. During my whole "ordeal" I couldn't seem to write or read for that matter. I couldn't concentrate. Well thought you might like to hear the whole story from beginning to end. I cried like a baby the whole way through typing it. It was like putting it down made it feel more real...... but at the same time it felt like a story about someone else. I cried so hard because I can't believe all that happened to me...... You get so caught up with your daily battle that you don't seem to realize all you've been through until you really think about it and write it down".³

Barbara also saw that posting to websites like “CancerGuide and reading the stories of others that had/have cancer, “has been very therapeutic for me. I now know my highs and lows are normal, that my fears are normal, also my anger. Being invited to tell my story has unleashed some of the negative feelings and fear. I'm grateful to have been given the opportunity to share my experience. Thank You."⁴ Further, some patients provided advice to others in the hope that that they could enjoy the same benefits or at least not make the same mistakes. Leroy invited others to contribute and to visit the John Hopkins Cancer Center website. He felt that this was an empowering and a self-helping way for them to work through their cancer. He

² Figure 5.1 gave the Pearson correlation (Pr) as 0.76 for node purpose in writing story for self with well-being.


also alluded to an advantage of web chat which he said can become a two-way conversation with near instant feedback to postings. “I'm going to be talking about my experiences, and I hope that many of you will write in with your own stories, suggestions, complaints, or just send a note when you're feeling overwhelmed by all of this and just need to vent a little. I'm sure you'll all get tired of hearing just about me, so my goal is to turn this into a real dialogue. I hope you'll be back here tomorrow.”

Such “venting” resulted in instances of emotional support from other patients following the story.

Things weren't going the way that Mitch believed they should. He had survived and thought that life should be good:

I actually found survivorship a bit difficult. For six months, so much of my life was about cancer. You always read these stories about people who learn so much about themselves and the value of life through cancer. I was waiting to smell a flower and magically realize the power of life. I was looking to rediscover the beauty of the world. I was searching for that spiritual moment where I discovered the meaning of life. None of this happened and I was getting frustrated. My hair was coming back, my soreness was starting to go away, but something was missing. I felt like an idiot.

Brent stated it more clearly when he wrote that “being able to communicate your feelings about the illness and the effects that it has on you

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and those close to you is invaluable. It is "Free Therapy". Garry said “Tell your story again, write it down, share your feelings. I think you will find that it can actually make your memories of that time more meaningful and ease some of the residual pain.” He suggested that providing advice to others through telling your story is to benefit oneself.

Garry suggested that in writing for one's self the patient was also writing for others. Certainly a large reservoir of sage advice existed then and continues to expand. Paradoxically however, many patients expressed a reluctance to accept advice from others and yet said that their present purpose was to write for others. Certainly the patients' stories that were written for others were stories of “hope”. This was clearly stated in Brent’s story told earlier. Mitch wrote about his sister’s ovarian cancer experience in a manner that would provide both information and hope for any readers:

When I was 22, my sister (26) was diagnosed with germ-cell ovarian cancer. We were told there are many different kinds of ovarian cancer and this was the "best one" to have because it was curable. The cure was a regimen of chemotherapy that lasted three cycles of drugs called Bleomycin, Etoposide, and Cisplatin. This regimen was actually borrowed from the treatment of testicular cancer developed in the early 80s that has been so successful. It was a trying and scary time for my family, but after some baldness, lots of nausea and exhaustion, my sister was indeed cured. In fact, she gave birth to a healthy boy less than 2 years later and is currently expecting another boy in October 2003.

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8 NOTE: Figure 4.1(repeated for convenience at the beginning of this chapter) shows 350 references to advice to others and just 12 references to advice from others as contributing to the patient’s well-being. This paradox is addressed in the next chapter where the discussion of these results is presented.
UPDATE: She had a second healthy boy in September 2003, and a healthy girl in January 2007.9

Clearly too Ernest wrote for others when near his death from cancer. He said “I write as an older Carmelite, in what my father used to call "the twilight years of life", and I am moved to write this book to share what I consider to be a great gift to the contemporary church”.10 His religious order had demonstrated their belief in the value of his writing for others when they published his book posthumously.

Lois called her writing a detoxification that provided both benefit to herself and also became a source of hope for others. She described the impact of her cancer on her intimate relationship with her husband Art in a sensitive manner designed to provide hope and encouragement to others struggling to retain their sexual intimacy disrupted by the cancer:

The main coping devices for me these past 31 months have been to talk openly about my illness and impending death, to read about it, to talk to other terminally ill patients and their families, and even to teach about it. Is this a counterphobic way of dealing with my fears? Probably, but it is also a detoxification process, for the more I encounter death, the less I have come to fear it…Art and I took a second honeymoon and headed south into the sun where we spent 2 weeks walking the beaches, bathing in the ocean, and coming to life and love again. Art was hesitant to approach me sexually at first. He somehow felt it might be indulgent of him and overtaxing to me to seek sexual gratification when I still appeared so frail and debilitated. I, on the other hand, felt a need as never before to assuage my own anxieties, for I had become heir to the generally accepted myth that a terminally ill individual will be neither interested nor able to function effectively in sex. With the

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9 Mitch, "Mitch's Testicular Cancer Story,"

aid of much loving communication, patience, and leisurely responding, we were able to regain the fullness of relatedness as well as the freedom of release that lovemaking in its richest sense affords.\textsuperscript{11}

The self-talk of patients frequently contained references to the family as Brent’s story above illustrated. The analysis showed that the patient’s self-talk that involved \textit{family support} was closely associated with well-being.\textsuperscript{12} Lois’s experience illustrates her relief when she found a way to discuss her cancer with her younger son through the medium of a university assignment:

Our younger son, age 21, is attending Penn State and majoring in human development. Last year he asked if he might come home to do a taped interview with me as part of a communication course assignment. He had always assumed the role of the family comedian and up to this point I had found it very difficult to talk to him about our feelings, as he would always turn me off with a flip comment. I suspected he was choosing a way where he could be in control, on his own terms, to discuss my impending death. I guessed right, and our encounter turned out to be one of the most moving and meaningful exchanges I have ever had with anyone near and dear to me. He wanted to know how it felt to be in my position and, in turn, shared his own feelings. More importantly, he wanted to know how I felt about the way he had turned out and expressed his feelings about how I stacked up as a mother.\textsuperscript{13}

Steve received a different kind of support from his wife when they divorced. The process and outcome enhanced their well-being. “Perhaps


\textsuperscript{12} NOTE: Support of family had a Pr=0.42 based on clustering similar words with those contained in the well-being node. This indicated that the contents of the family support node had a meaning with respect to well-being.

\textsuperscript{13} Kelly, \textit{New Meanings of Death}, 196-211.
you will not be surprised to learn that we found our own way through divorce - we realized quickly that legal fighting was a very bad idea. Bad financially and bad emotionally. We rejected the system of opposing lawyers who can easily set one spouse against the other (a system mandated by "legal ethics"), and instead wrote and filed our own agreement. And we are still good friends."

Brent cited above revealed, what is sometimes seen as a consequence of writing primarily to provide hope for one’s family, namely a tendency to downplay one’s own symptoms. Only six references to downplay symptoms were found in the patient self-talk node but they were not strongly correlated with well-being (Pr= 0.55). Brent had tried to protect his family at the cost of a worsened prognosis. Orville had struggled with this dilemma too. “I open my eyes. It is early morning. My wife is asleep beside me. First I thought about death, and now I think about cancer. No, it was not a dream. I do have cancer. But for just an instant, I thought things were "all right" again. No sentence of death, no chemotherapy treatments, no nightmares, no sleepless nights, no worrying about low blood counts, no pain. But I realize things will never be the same again for myself or my family. This would have happened, though, without the presence of cancer. Yesterday

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never happens again. The "good old days" are a part of the past, terminally ill or not. "15

Brent’s self-talk had led him to a small measure of control. After he completed his treatment he was able to say “I don’t believe in total recovery when it comes to cancer”. This realization gave him a feeling that he had some control of his cancer trajectory. Forty two references to some control were found in the self-talk node. These exhibited the second highest correlation with well-being after purpose in writing story for self (Pr= 0.69 and 0.76 respectively). This contrasted with control none which was poorly associated with well-being (Pr= 0.36). It is obviously important for a patient’s well-being to want and to actually take control of their treatment. Attainment of control happened only after engagement in a process involving comprehension at some level of the patient’s own cancer. Eric said “I prepared myself as best as I could. I knew that the better the condition I went in, the better I would come out.”16 Chuck achieved well-being that he described as “peace” after stealing a look at his history:

That was about a year ago and I have had good news on each visit to Dr. Murphy's office. On one of the visits, I made up my mind that I was going to read my entire file no matter what. I waited until the nurses were not watching and took the file from the rack in the hall outside my room. I was reading it when the nurse came in and told me she had been looking for the file. ‘Oh, I'm checking the rads,’ I said. She looked puzzled and left the room without the file. I finished reading it and then put it back in the rack… I have been at peace since my diagnoses and my prognosis and I understand a

15 Kelly, New Meanings of Death, 196-211.

lot of things that I would not understand if I had not read the file. Some parts of it were somewhat scary, but I wanted to know the whole story.\textsuperscript{17}

Although Chuck did not fully understand the technical terms, the knowledge that he had obtained gave him a greater sense of control and an improvement in well-being. Gerald strongly stated his belief in the importance of knowledge as control. “I soon discovered that recovery is more a mind game than a physical achievement.”\textsuperscript{18} These patients understood that the physical management of their cancer remained the domain of the medical team but how they understood their own cancer significantly affected their prognosis.

Patients who saw that their well-being depended on a need to achieve some control of their treatment gave rise to the question “do you trust your medical team? Yes or No?” This question was coded under the nodes \textit{trust medical team no} and \textit{trust medical team yes}.\textsuperscript{19} Paul realised that like engineers, doctors, whilst smart are limited by their experience and professional networks when prescribing treatment:

After working with engineers for nearly 20 years it is easy to see that they are just people like you and me. They don’t know everything. They are not smarter than everyone else. Smart. Just not smarter than everyone else. This obviously applies to doctors


\textsuperscript{19} The node \textit{trust medical team no} was better correlated with well-being (Pr=0.42) than \textit{trust medical team yes} (Pr=0.36).
as well. Smart. Sometimes brilliant. Not smarter than everyone else ... This became obvious to me when my initial oncologist wanted to try the same old therapies on me that had so far not worked for anyone else in my condition. In my business we were forced to figure out how to put drilling rigs to work in conditions they were never designed for. When the customer asked us to do this we put a bunch of engineers on the task and tried to figure out a way. Can do. This is an attitude that was not readily apparent at my first hospital and oncologist. Don't keep doing the same things over and over again expecting or hoping for different results.20

Similarly, Rosemary expressed some disillusion in her self-talk as her efforts at understanding were thwarted by seeming self-interest amongst her doctors. “Again, I was confused about treatment options. Medical oncologists spoke of new chemotherapies, surgeons wrote about operations and radiologists touted, what else, radiation therapy. It was obvious that each saw only part of the picture. Where was the person, outside of any one of these fields, who could integrate all this and decide what was best for my situation? Was I supposed to be that person, myself?”21

Terry showed no trust in his medical team when he said “My doctor's only promise to me was that he would make me "streetable" before I left the hospital. Initially I did not understand that saying I would be "streetable" was

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a nice way of preparing me for a life of disfigurement.”22 This illustrates the mismatch that was often found when a patient’s well-being was adversely impacted by a mismatch between the patient’s and the doctor’s cancer metaphor. Obviously Terry’s doctor was avoiding the use of a battle metaphor but his concept of “streetable” had a similar effect.

The issue of cancer metaphor was coded under the two nodes of battle metaphor no and battle metaphor yes. The purpose of this was to obtain evidence of the extent of the use of the battle metaphor and also to uncover the other types of metaphors that cancer patients use. The battle metaphor no had a correlation (Pr = 0.58) in the cluster analysis against well-being; in contrast to battle metaphor yes less significant correlation (Pr = 0.33). This indicated that other metaphors for cancer and cancer treatment than those focussing on battle are associated with better well-being.23 The dominance of the battle metaphor was mentioned in chapter one and will be next discussed in relation to indicating a benefit that could arise from future research in the final chapter eight.

By way of summarising this section, the CAQDAS tools provided confidence in recognising the elements of patients’ self-talk as valid indicators


23 Cluster analysis gave Battle metaphor no a Pr=0.58 and Battle metaphor yes a Pr=0.33 indicating that metaphors for cancer and its treatment alternative to the battle metaphor were more closely associated with well-being.
of well-being. The analysis produced results showing that the patients wrote their stories primarily to “detoxify” their personal cancer experience, to use Lois’ word; but there were the concomitant benefits of providing information and hope for others and of receiving empathic encouragement for themselves. Some patients improved their well-being through their self-talk by gaining a measure of control over their treatment, despite difficulties that arose because of miss-matches in the cancer and treatment metaphors of medical specialists and of the patients themselves.

3 Advice to and from others

What did the analysis reveal about the nature of the things that were found under the guises of giving advice to others and receiving advice from others? The node advice to others contained 350 references but the node advice from others contained only 12 references. Although more males gave and took advice than females, the content of the references was very similar for both genders.24 So what was found in the analysis of the advice from others that was taken up?

Two patients commented that they received a large amount of advice and revealed why they rejected it. Christopher was overwhelmed by the volume and inappropriateness of the advice that he received.

In Tumortown you sometimes feel that you may expire from sheer advice. A lot of it comes free and unsolicited. I must, without delay, begin ingesting the granulated essence of the peach pit (or

24 See figure 4.1 which is a chart of the well-being sources for cancer patients that shows that 204 references to giving advice to others by males and 146 by females. It also shows that only 9 references were made to taking advice from others by males and 3 by females.
is it the apricot?), a sovereign remedy known to ancient civilizations but now covered up by greedy modern doctors. Another correspondent urges heaping doses of testosterone supplements, perhaps as a morale booster. Or I must find ways of opening certain chakras and putting myself in an appropriately receptive mental state. Macrobiotic or vegan diets will be all I require for nourishment during this experience. And don’t laugh at poor old Mr. Angstrom above: somebody has written to me from a famous university to suggest that I have myself cryonically or cryogenically frozen against the day when the magic bullet, or whatever it is, has been devised.”

But he did not reject all advice. “As against all that, I did get a kind note from a Cheyenne-Arapaho friend of mine, saying that everyone she knew who had resorted to tribal remedies had died almost immediately, and suggesting that if I was offered any Native American medicines I should move as fast as possible in the opposite direction. Some advice can actually be taken.”

Sylvie too experienced the volume of advice being proffered and was saddened because she realised that vulnerable cancer patients, unable to discern its relevance to their own treatment, followed false often harmful trails:

So when I read the advice of some of the well-meaning advice givers who suggested that I refuse the mastectomy and opt for other alternative treatments, or just leave it to God who would heal me instantly, it made me sad. It made me sad because there are women out there who would choose that advice without consulting their doctor, and die needlessly, primarily because they would rather not face the truth about their illness… Thankfully, I am of the belief that God works

through doctors just as much as working directly with my body to heal it.\textsuperscript{26}

Her spirituality provided Sylvie with a context within which to identify God’s help partnering the efforts of her doctors enhancing her personal well-being and helping her empathise with other cancer patients. She was one of the few who wrote directly that she benefitted from the advice of others.

What was said in the 350 references to \textit{advice to others}? To manage this large volume of text in the relevant references, a round of axial coding was done under the child nodes of \textit{well-being}, which were characterised as examples of advice intended to offer hope. The coded texts were then closely analysed for relevance to this theme. Three of the new nodes suggested themselves after reading the text. These nodes were: \textit{relating personal experience}, offering hope and advice mediated by \textit{sage thoughts}, and through reference to \textit{spirituality and God}. The fourth new node was advice offered to achieve \textit{bonding} empathically with other cancer patients; this latter was found in some text in five percent of stories that originated from internet blogs and similar published research.\textsuperscript{27} How these child nodes were clustered with the parent well-being is shown in figure 5.2 following.

\begin{itemize}
\item \textsuperscript{27} Kuang-Yi Wen et al., “From Diagnosis to Death: A Case Study of Coping with Breast Cancer as Seen through Online Discussion Group Messages,” \textit{Journal of Computer Mediated Communication} 16 (2011): 331 - 61.
\end{itemize}
The very act of relating one’s own cancer experience was seen to contribute to the well-being of the narrator, whilst offering hope to others; figure 5.2 indicates the strength of the correlation between relating personal experience and well-being.

Clearly this was the case for Sylvie who worked through her breast cancer by posting her story on the internet:
Until today, my future was bright and full of incredible promise. And now, I face an uncertain and frightening future. I have been diagnosed with breast cancer...I will be using this journal to tell my story, to share the adventure with all of you, in hopes that my story will perhaps help someone else who may be struggling with this as well. I know I am not alone... According to the World Health Organization, more than 1.2 million people will be diagnosed with breast cancer this year worldwide. ...I am also told that the overall survival rate over a 20 year period is slightly over 50%. These are terrifying statistics, and after posting this message, I plan to completely ignore them. I refuse to give them further thought or consideration. They are not important to my healing process. They can only serve to frighten me and make me question my resolve to survive.

Above all, this story is not about how I survived breast cancer. It is about how I beat the snot out of it. It is about the triumph over pain, tears and sadness I am about to go through. It’s about how I, and my family, stared into the face of fear and said “Get lost! I don’t DO fear!”

I decided to deliver my story in real time, as it happens, in this journal. This is my therapy, and my way of sharing the story in its raw, unedited form. It is my hope that other people who encounter difficulties can read this and gain strength from knowing that they are not alone.28

28 Fortin, Did You Just Say Breast Cancer? ,

Sylvie enhanced her well-being through her “therapy” which also provided hope for others. Twenty other stories contained 32 references similar to those of Sylvie. Slightly more than 50% of this research’s studied stories had been posted to the internet, although most were published on professional websites of groups such as the Cancer Council of Victoria or the Mayo Clinic. Posting to the internet enabled others to respond in real time. How those published as blogs produced a mutual bonding experience is seen later in this paragraph where Sylvie’s story continues.
Whatever an author’s motivation in writing, much of the advice would, if taken, enhance well-being. Some 33 pieces of good advice were identified under the *sage thoughts* child node of the parent node well-being. The following are presented as representing the group. They are indicative of the themes of *telling my story, pain, fate, time, marriage* and *God*.

“Tell your story again, write it down, share your feelings. I think you will find that it can actually make your memories of that time more meaningful and ease some of the residual pain.”

“You are entitled to mourn what you can no longer be, but do not let this mourning obscure your sense of what you can become … Pain taught me the body’s power to shape thinking. But my thinking was shaping the pain even as it was being shaped by that pain — the circle is unbroken. Do not curse your fate; count your possibilities.”

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29 Cluster analysis for *sage thoughts* based on word similarity with *well-being* exhibited significant correlation with a Pr = 0.70 as is seen in figure 5.2.


"For some people, it's the 'why me.' That never hit me because 'why anybody?'\textsuperscript{32}

"That pure chance could be so generous & so kind...It can also be cruel at times. One thing it is not is personal."\textsuperscript{33}

"What advice does the man who beat the odds have for other people facing cancer? 'You're not dying this minute, so live this minute and the next and put them together and you've got an hour. And damn it, you never know where it's gonna' lead. You could have a lifetime of minutes.'"\textsuperscript{34}

"This cancer thing can destroy a marriage, or it can be the glue that sets and holds it together forever."\textsuperscript{35}

"Read a psalm each morning, and you'll meet people disappointed by life yet still finding hope in God."\textsuperscript{36}


\textsuperscript{36} Susan Sorensen and Laura Geist, \textit{Praying through Cancer: Set Your Heart Free from Fear} (Nashville: Thomas Nelson, 2006).
Another body of content in the stories that was significantly correlated with well-being was **spirituality and God**.\(^{37}\) Fourteen references were found and some difference was seen in the spirituality being expressed by creedal and non-creedal cancer patients. For all patients, the cancer diagnosis was an unwanted, mostly unexpected interruption with immediate impact to their spirituality. Self-professed agnostic, Carl expressed his spirituality in the face of his cancer. “This is just beautiful - so wonderfully eloquent. Isn't this the heart of it all? That we are lucky to have lived at all, to have loved and lost and to hopefully leave just a little behind in the memories of those who come after us?”\(^{38}\) Albert expressed a more self-centered spirituality when he wrote “We long for a miracle, for a shiny new self. There must be something there, an inkling of a real possibility, or why would we continue to crave it? There is something within us that we project outward, but it is not really to be found outward because it is ourselves that we seek.”\(^{39}\) Alan, a devout Catholic wrote:

> our parish priest, Fr Peter, put himself out to hear my confession before hospital admission. As confessions go, it was a bit of a mess from my end. I wanted to say something about the person I felt I had become. It was a jumble of words but Fr Peter didn't

\(^{37}\) Cluster analysis performed for **spirituality & God** based on word similarity with **well-being** exhibited meaningful correlation with a Pr =0.55 as was seen in figure 5.2 earlier in this chapter.


interrupt. When I finished Fr Peter leaned over and assured me that there would be plenty of time to reflect on the person I was after I got out of hospital. Fr Peter retires this year and I think he just may have heard one or two confessions under these circumstances before. Anyway, we came to that part in the rite where the penitent is offered absolution. Again, I felt lightened, I felt somehow better; to be honest I felt sort of elated.40

Larry revealed a complex spirituality when he wrote:

Another thing... Had I prayed about it at all? Not a prayer! And I believe in God, too. I just thought it was up to me to find the path out of my dilemma. So I began to pray. Not for healing, but for peace to see us through. And God sent me His peace. Like waves of the ocean coming to shore, washing over me, slowly freeing me from my distress...

I can't answer these questions... I am a statistical sample of 1! There is no control group that I can point to who died, not taking the vaccine. But I could not stand by and wait for the melanoma to reappear, doing nothing to kill it in the meantime. There are no fair-fighting rules with cancer. Melanoma will not give you chances to recover. It will kill you.

Once I decided to LIVE, doing nothing was not an option I ever thought of taking …

Every day is a fantastic gift. A day I didn't think I would get. I can get goose-bumps at a sunrise! Seeing my family grow - and seeing grandchildren... I remember the days I never thought I'd see these things. It colors everything about me. I'm a huggy sorta guy by nature. But getting and giving hugs is a gift of immeasurable worth to me now.

No one ever promised me tomorrow... I guess I always knew that - but it didn't mean anything like it means now, with melanoma. All we have is today. If I really believe I have only today, how would I live it?41

Larry told more than just the story of his melanoma. He provided readers with insight into his thoughts as he wrestled with the probability that he would not live long and of his determination to survive beyond the odds.

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He provided hope for others by putting into plain words his understanding of the weakness of statistics to have relevance to individuals even though they could remain valid and true for the population of melanoma patients. He recounted the joy that he experienced in the appreciation of the things of life and in the touch of others. He intended that his story would provide inspiration for others, that they too could find the path of God’s will in their cancer.

None of the patients in the *spirituality & God* node were suicidal or expressed any feelings that connoted bad or even poor well-being. Indeed there were only 8 references to suicide in all of the 160 stories of which only 2 references were related to themselves.

The fourth child node for cancer patients telling their own story that exhibited a correlation with well-being was *bonding with others*. This was only a weak correlation.\(^\text{42}\) Patients who told their story through internet blogs sought some bonding with others who would respond with empathy. Sylvie’s internet blog that told her story was commenced earlier above. She obviously derived a great enhancement of her own well-being and helped others in this process but revealed the dark side of inappropriate advice encountered in this un-moderated domain:

Here are just a few that touched me so deeply... (there are hundreds, and I wish I could print them all here):

\(^\text{42}\) Cluster analysis for *bonding with others* based on word similarity with *well-being* exhibited only a weak correlation with a Pr =0.37 as was seen in the data presented in figure 5.2.
“Prayers of healing, strength and boundless joy are coming your way.”

“Sylvie and Michael — you guys are an amazing couple. I have no doubt that Sylvie will be fine and you both will have many, many years together.”

“I am inspired by your amazing upbeat and positive outlook. I shall keep your example in my mind as a way to handle life’s curveballs”

“God bless you both! Sylvie is lucky to have someone who believes in her and her recover as much as you do. With the faith and love that you share, I have no doubts at all that this hurdle will be overcome, and you’ll enjoy the rest of your lives together!”

“Michel, what a warm and extraordinarily loving husband you are — you are both blessed to have one another.”

I was literally blown away by all of it. As the hours ticked by after the announcement, and the well wishes just didn’t seem to stop, there were moments I just sat there reading them with a baffled expression on my face. People who have never met me before were genuinely concerned about me and praying for my recovery. I just couldn’t believe that so many people genuinely cared about us. Amazing isn’t it? It’s amazing how much love there is in the world! …

And there were also some comments I didn’t expect at all…some made me sad, and I’ll explain why…In times like these, one can expect that some people are going to be absolutely convinced that medical doctors have it all wrong. And for the most part, I do agree that doctors don’t know everything. It wasn’t that long ago that the medical profession didn’t “believe” in germs and the cure—all of the day was leeches and bloodletting. However, medical science has come a long way since then, and I am so grateful that it has. Even 20 years ago, a woman diagnosed with breast cancer didn’t have the advantages we have today and survival rates were much lower. So when I read the advice of some of the well-meaning advice givers who suggested that I refuse the mastectomy and opt for other alternative treatments, or just leave it to God who would heal me instantly, it made me sad. It made me sad because there are women out there who would choose that advice without consulting their doctor, and die needlessly, primarily because they would rather not face the truth about their illness. Thankfully, I am of the belief that God works through doctors just as much as working directly with my body to heal it.43

43 Fortin, Did You Just Say Breast Cancer? ,
In summary of this section, which contains the results of analysing *advice to and from others*, evidence was found that the process of telling their cancer story enhanced the narrator’s personal well-being. Much more advice was found to be given than received. However, some patients took messages of hope from these stories, which contained much existentially validated wisdom. Stories exhibiting a spirituality were significantly associated with enhanced well-being. A minority of storytellers who blogged to the internet achieved bonding with respondents despite sometimes receiving inappropriate advice, due to the un-modерated nature of the internet. Comments on these well-being related results and conclusions follow in chapters six and seven.

4 Meaning for life

Barbara felt that she had received her old life back. “My mental attitude is no longer consumed with my illness, and I again have a sense of well-being about my life and future. I have been blessed, God has given me back my health, He has given me back my life!!”[^44] Many other patients described a new meaning that cancer had given them. “Cancer doesn't just mean having treatment, it means treating your mind and body to a new way of life” was how Gemma expressed it[^45]. Her cancer, like for many others, provided


meaning for life, an especially new meaning. The stories studied contained 398 references to new meaning for life arising from the cancer experience. Of these references 206 were made by male patients, 164 by female patients and 28 by affected relatives and friends. This paragraph presents the results of the analysis of these references and what they revealed about the patients’ well-being. Cluster analysis of the stories based on similarity of the words used to describe meaning for life, with the words used to describe well-being, realised a $Pr = 0.88$. This was taken to indicate a close relationship between the two, i.e. that generally those patients who found new or altered meaning for life, through their cancer, experienced better well-being. The questions being addressed in this presentation of results are what did the patients say when they wrote about meaning for life? Were any gender based differences found? And what did the 28 accounts by relatives and friends reveal?

Gaining insight into the content of what the patients said was commenced by making a tag cloud from the 150 most frequently used words in the meaning for life child node of the well-being parent. Figure 5.3 presents this tag cloud.
Chapter 5: Spirituality linking well-being and prayer

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Figure 5.3: Meaning for life tag cloud
Tag cloud showing the most frequently occurring words found in the patients’ stories that were stored in the node meaning for life. These words were: cancer (204), life (140), time (115), one (96), people (77), now (70), just (67), god (65), years (56), and day (53). Combining god and one yields 161 references, which after cancer, indicates the centrality locating god, taken in the broad concept, as the principal source of meaning in the storytellers’ lives. Every one of the 10 most frequent words conveys a sense of well-being.

After the word cancer, the most frequent words occurring were found to be “life”, “time”, “years”, “people”, “god”, “help”, “work” and “treatment”.46 Although the word “well-being” occurred only 42 times the context of the commoner words supported the link between it and meaning for life. The tag cloud provided insight into a set of child nodes that had potential to unlock the content of the stories in relation to meaning for life expressing well-being.

46 The actual frequencies of the words that occurred most commonly were cancer 205, life 140, time 129, years 102, people 78, living 68, god 65, help 63, work 58, and treatment 55.
Matrix coding query that employed the new child nodes revealed that family became more important to survivors.\textsuperscript{47} This query also revealed that after \textit{family}, \textit{volunteering}, \textit{life as before} but with altered priorities, \textit{employment}, \textit{education} and \textit{sport}, contributed meaning to the lives of surviving patients. More men engaged in volunteering, continued employment and education than the women.

\textbf{Family} became more important for providing meaning for the lives of the majority of survivors. Typical of this group Brent wrote “We are currently going through one of the most difficult times of our lives. We have endured tragedies, illnesses, and internal friction like any other family, and like any other family we have dealt with and moved on.”\textsuperscript{48} Larry typified this group whose cancer gave a new purpose to both his wife and himself. He said that he was always a “happy guy, not subject to depression”. He shared his melanoma diagnosis with his wife:

> I realized that she was living the same nightmare I was. I thought I was alone in the hole I had dug. But I wasn't! This woman, who'd said, "in sickness and in health" those many years ago... She meant it! She was right there with me, when I could only see myself. Together, we decided to live. No, not that evening, but we were together and we would do our best with whatever time we had left together.\textsuperscript{49}

\textsuperscript{47} Matrix coding query was performed based on the new child nodes of \textit{meaning for life} that suggested themselves from the text. These were in order of frequency of references: family (30), volunteering (29), life as before but altered (27), continued employment (15), attenuated employment (20), education (9) and sport (6).


\textsuperscript{49} Loose, "Metastatic Melanoma.”
For another survivor, motherhood helped put her brain tumour behind
her. “Forrest has been able to put her cancer in the rear view mirror and
embark on another big adventure: motherhood. Today, she, her husband,
and her 1-and-a-half-year-old son continue to thrive.”\textsuperscript{50} For Barbara the
adoption provided the meaning. “God blessed me in two ways back then, one;
giving me back my life, the second, bringing this precious little girl into our
lives. We now have legal custody of her and this little 45 pound person has
enriched our lives more than I can say. I will be forever on my hands and
knees giving thanks to our Father in Heaven for both blessings.”\textsuperscript{51} And in two
other references, divorce was cited as allowing life to proceed. Ed said “after
two weeks in the hospital, I was discharged and went to live with my sister
Dorothy for two weeks. (After 20 years of marriage, I separated in 1990 and
divorced in 1994.) My energy was low and I was able to eat very little”.\textsuperscript{52}

\textit{Volunteering} was mentioned in twenty nine references by both men
and women as providing meaning for life after cancer. Double the number of
men said this. Volunteering was more mentioned in stories sourced from

\textsuperscript{50} Cullen Forrest, "Woman Bounces Back from a Brain Tumor – with Humor Intact"
\textit{Survivors During and After Treatment.}

\textsuperscript{51} Bagley, "Stage I Non-Small Cell Lung Cancer."

cancer society websites but was well represented in the stories published in books and newspapers. Some examples of volunteering were quite exemplary such as Dave.

After his diagnosis, [Dave] also began volunteering with his local American Cancer Society office in Sacramento and he hasn’t stopped. Since then he’s chaired committees, sat on boards and helped raise hundreds of thousands of dollars through local and national events including Relay For Life, Making Strides Against Breast Cancer, and Daffodil Days. He had volunteered at 7 American Cancer Society golf tournaments, and last May was the survivor speaker at the 7th Annual Capitol Invitational Golf Tournament held at Serrano Country Club in El Dorado Hills. In September, he was the "special guest" speaker at the annual Harvest of Hope Gala held at Dalla Terra Estate in Granite Bay.53

For others, volunteering involved areas of community service unrelated to cancer, such as Deborah. “[Deborah] is a customer service director for the Great Plains Council of the Girl Scouts. ‘I'm definitely more compassionate,’ she said. "When I see someone on the street that's different, I smile at them, because I know I'm in their shoes, too. I'm just happy to be alive and making a difference.”

For some patients the meaning for life in survival took the form of a restoration of their old lives with the superfluous stripped out. This was the case for Barbara quoted as an introduction to this paragraph. Another, Lois, typified many when she wrote:

Thereafter, I explored a part of my life never fully experienced before, the need to be. Slowly, I began to feel that I was worthy of

just being, that I need not do all the time. For about a year, I slowed down; I stopped to smell the flowers. I shifted my "gotta's" to "wanta's," doing more of the things I really desired without a sense of deadlines. I spent more time with family and friends. I followed my body's lead—resting when tired, practicing yoga. As I relinquished more of the external controls, I gained the strength of inner control.  

In addition to the references to meaning for life made by patients themselves above, the lives of relatives and friend were impacted too. Twenty eight references were made by the relatives and friends of patients were about supporting the person who had cancer. Family members and friends were represented as being affected by the cancer of their loved one. They visualised themselves as in it together. Most references were very practical and some accounts mentioned changes in the relationship between husband and wife. Dan recognised the support of his wife when he wrote “"Even though it's a man's disease, it affects the couple. The macho man has to realize that his wife is there with him, and she's probably not being recognized enough as someone who has been very supportive of him… Despite Dan’s mantra that prostate cancer is only an obstacle to conquer in life, they [Dan and his wife] have had their struggles…And although Dan didn’t experience incontinence as a result of treatment, impotence required the couple to make adjustments."  

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54 Kelly, "New Meanings of Death," 182.

In several stories, the family and friends achieved new meaning for their lives by becoming involved in cancer support groups, in posting blogs to the internet or in media that raised awareness of cancer. James’ daughter wrote:

I told my dad I loved him and that no matter what we would fight this together. [Her father had breast cancer which is usually thought of as a women’s cancer.] [James] shared his story — and his scars — with a reporter from a local television station. More reporters followed. ‘I might say that a star was born. He just lit up when [the news crews] came over.’ she said. ‘That was the best medicine for him. My dad and Dr. Weinstein turned out to be the Odd Couple,’ she said. “They appeared on local television programs, radio talk shows, and were featured in several newspaper articles. Each time, they were spreading the male breast cancer message. [James’] story made international news.

Some results suggested the underlying presence of God in the meaning for life search found by so many of the patients studied.\textsuperscript{57} Theological reflection follows in the next chapter under the same heading to seek an understanding of the reported activities as patients were coming to grips with the requirements of their treatment and of their survival.

In summarising this section on meaning for life, the tools of word frequency tag cloud and matrix coding query provided answers to the questions posed. The CAQDAS results showed that most patients valued family relationships and volunteering as they developed either a restoration


\textsuperscript{57} NOTE: A query under the combined nodes of \textit{meaning for life AND creedal} found 88% of the patients were included.
of their old lives or embarked on a new life. All reference were characterised by patients improving their well-being. Relatives and friends were affected too. Most visualised their role as helping the person with cancer. They were in it together. Intimate relationships changed. Their lives would never be the same again.

5 The best and worst of having cancer

References found in this sub-set of well-being stories were almost equally distributed between males and females. Generally, the references to what the patients described as the best of having cancer referred to the remission period that they enjoyed when their treatment was complete or nearly so. Whereas the terms worst of having cancer included adverse changes during this period but was particularly concerned with the period around the diagnosis and the uncertainties surrounding developing treatment plans and their implementation.

In relation to the best of having cancer it was possible to derive a coherent set of child nodes of well-being. Applying these to the stories yielded the outcomes shown in figure 5.4.

58 The node well-being best part contained 200 references of which 90 are from female stories and 110 from male stories. The well-being worst part node contained 185 references of which 90 are from female stories and 95 from male stories.
Figure 5.4: Best parts of having cancer relative to well-being

Chart showing what cancer survivors said was the “best part” of the cancer experience ranked by their frequency in the stories. The female value is coloured red and appears closer to the vertical axis.

The most popular expression acknowledged the support that they received from their spouse or family (46 references). Males expressed appreciation more frequently than females. “However, we still are married and still in love,” Amy said. “We glory in being close to each other” said Amy of her husband Mack. Jessica said “Being able to hug my grand-children and my husband.” Steve said “our growing relationship transported me to a whole new dimension of life and away from the horror I was experiencing.

59 Skaggs, “Happy Together, Couple Faces Cancer’s Uncertain Road.”

In between treatment cycles, I fell even more intensely in love with Ellen who supported me and gave me something special to live for”.  

The second strong theme in well-being/the best part was remission often expressed as being “cancer free” or “survival” (29 references). The male and female references were almost equal in number and expressed in similar language. “Now cancer-free and feeling like ‘a 15-year-old,’ Joe says the experience has left him a better, happier person”. Robert leaves no doubt about the quality of his well-being in remission. Reflecting on his life and its almost unintelligible tribulations, he sums up everything with the repeated statement ‘I'm a survivor’, and adds 'I've been lucky'. This status gave him pleasure.

Martina wrote “I realize 3 years from diagnosis is not a long time. However, 3 years is a very long time for someone in my condition. Plus the outlook is good. My tumor is dead and continues to reduce in size. At MDA they were ready for me to die. No thanks.”

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61 Dunn, "My Metastatic Kidney Cancer and My Survival."


Utterances by doctors were the third most frequently cited influences to well-being/best part (13 references). They were also cited in references to the worst parts of having cancer; this aspect will be treated shortly. Here the results clearly show that doctors made positive contributions to the well-being of their patients through sensitive communication. Dave’s doctor told him “You’re at 17 years this year. You’re going to have to find something else to die of.” Some doctors with just a few words set the patient up for enhanced well-being like Gerald’s. “I was feeling pretty good and when my friend the urology surgeon told me that I was free of cancer, the world did seem a friendly place once again.” And sometimes too it was not just the words used but the body language of the doctor that authenticated the words and enhanced their power to heal. “Even though my worst fears were realized in what he said, the physician showed, just by the way he looked at me and a couple of phrases he used, that he shared in the seriousness of my situation. The vitality of his support was as personal as it was professional. Physicians I encountered later were optimistic about my diagnosis and prognosis; he was almost alone in expressing optimism about me, not as a case but as a person.”

65 Wesley, “17-Year Prostate Cancer Survivor Feels Great.”

66 White, “Gerald White: A Guided Walk through Renal Cell Cancer.”

67 Frank, At the Will of the Body: Reflections on Illness, 19.
Lesser number of references were made to other well-being/best part contributors which were also difficult to generalise. This presentation of results now moves to what cancer patients said were the **worst parts of having cancer** in relation to their well-being. Interrogating the patient stories, a set of child nodes emerged but were not as coherent as for the **best parts**. A matrix coding query was performed around the child nodes of worst parts and indicated that some of these occurred sufficiently frequently to allow generalisation. The results are shown in figure 5.5 following. The analysis revealed 183 references almost equally distributed between males and females.

As **family** had contributed to the best parts of having cancer through its capacity to support the patient, paradoxically family and friends were the most frequent cited as one of the **worst aspects** of having cancer. Relationships within families are complex at the best of times and the cancer patient is very aware of the minutiae. An unwanted diagnosis to be superimposed on the family, when revealed, can cause the patient to consider it as the worst aspect of having cancer. “I know for my mum the thing she found most difficult to deal with was not the disease but the fact that she faced leaving her children behind with no one to care for them. All of my mother's family had already died and my father had only just gone off with another woman nearly half his age only a couple of months before my mum was

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68 NOTE: The full list of references to well-being contributors found by searching the story data set within the node **well-being/best part** is shown in figure 5.4 two pages back. Those references not expanded above were few in number hence difficult to generalise.
diagnosed. So there was literally just me and my 2 brothers. That was far more painful to her than the disease itself.”

Cancer Patients said that these are the worst parts of having cancer relative to well-being (n=183)

**Figure 5.5: Worst part of having cancer relative to well-being**

Well-being expressions of cancer patients: the worst part of experiencing cancer. (Female references are shown closest to the vertical axis and are coloured red; male references are blue.)

Sometimes too parents describe the impact of their death on their husband and children. Ann said “Worrying about my family.” Evelyn said “Leaving my family.” Even the apparently simple act of telling the family about the diagnosis caused problems as Elena put it “That following was the worst day of my life telling my mother that I had cancer and other family

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70 Craven, "Daffodil Day: Stories of Hope, 2.

71 Craven, "Daffodil Day: Stories of Hope, 2."
members.”

Lois wrote “being out of sync is further exacerbated as both the patient and family struggle to invest as fully as possible in life and each other, in spite of their knowing intuitively that dying must entail a certain amount of mutual disengagement. The terminally ill person and those who will be left behind must, of necessity, prepare to head in two different directions.”

The second of the worst parts of having cancer described by the patients was the extent and severity of the emotions that they experienced (17 references). These results have been presented in the previous chapter. The reference here is to the “needs less satisfied cluster” where the attainment of the patient’s needs became frustrated with a consequent impairment of well-being.

Adverse changes caused by the cancer were the third most referred to bad aspect. The treatment for some cancers is mutilating. This was so for Terry. “My doctor informed me that I could lose half my nose, half my upper lip and possibly my right eye, but that saving my life was his main concern. I suppose I was too young to contemplate dying, but the realization that I could be disfigured was devastating.”

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73 Kelly, "New Meanings of Death," 196.
74 Healey, "At Face Value: My Struggle with a Disfiguring Cancer."
Several similar stories were found in the dataset. For others intimate relationships became altered. “I thought after Dan had his surgery that we’d be just like we were before, and that didn’t happen,” Sally says. “We decided that we have to be close in all facets of our marriage, not just in the sexual part of it. You’re not an intimate couple anymore, so you have to have your intimacy in other ways.”

Traci would never have children after her cancer treatment. “I have been given options and I may have a hysterectomy in the future. So no more kids for me.”

**Treatment reactions** produced similar poor well-being for some 6 patients. Several female patients put the loss of their hair from the treatment as the worst aspects. Laura said “Then cancer came along.” It’s not too bad; the worst part is losing your hair,” my oncologist said. My hair? Hair loss meant I was losing the centerpiece of my appearance!”

Also amongst the less frequently reported well-being/worst parts was the node of **doctor utterances** (4 references). The relationship between the doctor and the patient in oncology is very delicate. Above, we saw the good that happened in the presence of empathy. Steve showed how easily the patient can misinterpret the intention of the oncologist, and revealed how it affected him. “Doctors told [Steve] to go home and get his affairs in order,

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75 Bard, “Couple Shares Lessons on Caregiving.”

77 Sorensen and Geist, *Praying through Cancer: Set Your Heart Free from Fear.*
which is doctor’s code for prepare to die,” he said. “It means to try to tell your
kids everything you thought you’d have the next ten years to tell them in just
a few months. It means to make sure everything is buttoned up so that it will
be as easy as possible for your family. It means to say your goodbyes.”78 And
sometimes a mismatch between the treatment model of the doctor and the
patient was seen to adversely affects the well-being of the latter. Arthur’s
oncologist was being scientific in stating the prognosis but Arthur took it
personally. “The physician added nothing to his abrupt statement. He would
send a report to my family physician; that was it, not even a goodbye or good
luck, just over and out. It was a triumph of science and a lapse of humanity.”
Emerging from this study of cancer patient stories is the fact that the cancer
metaphor being used by the doctor was consistently shown to affect the
patient’s well-being. This theme had been identified earlier and a
recommendation is made in the final chapter for much more detailed
research.

Concern about finances affected men more that women. Another of
the minor worst parts identified, were the patients who ascribed their cancer
to God or to previous sin. This theme was further studied and the results are
found in the next chapter.

http://www.livelifehappy.com/steve-jobs-on-dying/;
[Accessed April 12, 2013].
This chapter commenced with a determination of how the persons’ perceptions of their cancer related to their well-being. It contains the results obtained by CAQDAS tools that broke open the content of the studied stories and that at all times strove to remain grounded in those stories. The analysis focussed on the individual contribution to well-being of each of its parameters, as had been identified within the stories studied. Feelings were found to cluster about well-being and that they provided its strongest indicators with only slight but significant gender based differences. Another parameter of
well-being was patient self-talk. Analysis revealed a paradox in that although the patient wrote primarily to help work through their own cancer it provided sage advice for others which the reasonable person would think would be taken up. However the evidence was that little advice from others was followed. Arising during the analysis of the self-talk stories the idea that prayer was occurring as the patient worked to understand the meaning of the cancer in their lives. References to spirituality and to God were found in the advice to others node that indicated a desire to share with others the presence of God that they found in their cancer experience; this is interesting from a perspective of theological reflection; becoming aware of God’s presence and the act of sharing is quintessential prayer. Meaning for life was found to be another principal parameter of well-being. The patients said that in their survival, family was of paramount importance. Roughly half continued with their former life albeit with altered priorities, whilst the other half embarked on an entirely new path. Volunteering, education and new employment were more frequent amongst males than females.

Looking backwards in this thesis the definitions of well-being and spirituality, established earlier, served this research well by providing criteria against which story elements could be compared to produce the results presented in this chapter. Well correlated links between the patients’ spirituality and their well-being were demonstrated. In the next chapter, the definitions of prayer will be applied in a similar manner to provide data for the
hermeneutics. Chapter seven contains the reflection on all of the results and chapter eight, the conclusions.
Chapter Six: Praying revealed in the patients’ stories

1 Introduction: realities of prayer in cancer

This chapter is the third reporting the results of this study. It concerns prayer as it was found within the patients’ stories. The word prayer or its synonyms occurred one thousand two hundred and fifty times in the one hundred and sixty stories studied. Only one percent of the females reported that they “can’t pray”. Almost equal numbers of men and women provided evidence of praying. For the atheists and agnostics, the expressions used were different to those of creedal people, but were consistent with the definitions both of spirituality and prayer adopted for this study

The most popular forms and purposes of praying were thanksgiving, meditation, use of scripture, resignation, praise, petition, and action prayer, taken from most to least popular. This ranking of popularity is derived from the number of references to each form of prayer found in the analysis of the stories. The full distribution of what this research found of the ways that cancer patients pray is contained in figure 6.1, following. In interpreting these findings, a distinction must be made: the difference between sources and references, both terms arising from the CAQDAS tools used to aid the analysis. The popularity of a method or

\[^1\text{NOTE: The question is frequently asked is ‘do atheists really pray?’ In response the reader’s attention is directed to chapter 1 where Yin de Shakya identifies wish, hope and intention as internal essential elements of prayer. These are forms of atheist self-talk and are synonymous with prayer by creedal people.}\]
purpose of prayer is expressed through the number of references that were coded within the patients’ narratives. The number of references is

\[\text{number of references} = \text{number of references coded within patients' narratives}\]

\[\text{number of patients} = \text{number of patients quoted in narratives}\]

\[\text{number of references} \neq \text{number of sources}\]

\[\text{number of references} \text{ includes contributions from one patient to multiple sources, whereas number of sources includes contributions from multiple patients to a single source.}\]

\[\text{Every reference was considered, and the analysis remained constantly alert to ensure that conclusions arose from true and balanced representation of the two.}\]
The data plotted in figure 6.1 provided a context for this chapter; the view into the storytelling that it provides is through the window of prayer. More cancer patients made reference to thanksgiving prayer (57 patients) than to meditation (34 patients) or to quoting scripture (23 patients).\(^2\) However, based on popularity (number of references) thanksgiving prayer and meditation were equal with 23% each; and prayer quotes from scripture or poetry were found in 13%. Eight percent of the prayer references expressed resignation to the will of God which comprised the dominant form of thanksgiving for males; less than half as many females expressed resignation to God’s will in their thanksgiving prayer.

The facts associated with popularity (reference numbers) and the numbers of patients who made the references, suggested the major logical divisions used in this chapter on *Praying revealed in the patients’ stories*. These are *quoting scripture/poetry, thanksgiving prayer* and, *meditation*. The following paragraphs detail the layers of prayer that were contained in these findings. They also contain the observations made, including the gender based differences. Following the practice established in the earlier chapters of this thesis, preference is given to using the words of the narrator to ensure authenticity and to provide evidence of grounding as required by the GT method.

\(^2\) NOTE: More patients (sources) wrote about thanksgiving prayer compared to meditation or to quoting scripture/poetry (57:34:23 sources respectively), although the number of references (popularity) was equal (138:138). The next in popularity based on number of references (78) were patients quoting scripture or poetry in their account of prayer.
2 Quoting scripture and poetry

Those who either quoted scripture or poetry are presented first because this creates a context for prayer emerging from the narratives. Also, they were amongst the top three prayer references. Some 30 patients made 80 references to their spirituality and prayer based on Christian scripture or expressed in poetry. Table 6.1 shows the detail of their prayer by kind and gender.

<table>
<thead>
<tr>
<th>TYPE</th>
<th>REFERENCES (Numbers coded)</th>
<th>SOURCES (Number of patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Imagery/poetry</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>New Testament</td>
<td>2</td>
<td>33</td>
</tr>
<tr>
<td>Old Testament</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Psalms</td>
<td>0</td>
<td>22</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>12</td>
<td>68</td>
</tr>
</tbody>
</table>

Table 6.1: Scripture and poetry quoted in prayer by gender

More male patients expressed their prayer through poetry or through an image of God than did the females. Many more females prayed using Christian scriptures: the references were almost equally distributed between the Old and New Testaments (NT); although the *Psalms* were the most used form of prayer used from the Old Testament (OT).

**Old Testament themes**

Excluding the Psalms, five of the storytellers made thirteen references to passages from the OT in their prayers. Two themes were expressed: (1) maintain a cheerful heart; (2) achieve some understanding that somehow that God is allowing this experience and is present in it.
Lyn quoted (Proverbs 17:22) to express her belief that a positive spirit is better for well-being: “A cheerful heart is a good medicine, but a downcast spirit dries up the bones”. Laura was quoting (Isaiah 48:10) consoling the patient “See I have refined you, but not like silver; I have tested you in the furnace of adversity”. Laura quoted (1 Samuel 16:7) where the Lord reminds Samuel that it is not the outside appearance that is important but what is in the heart.

Laura expressed an acceptance of God’s will in her cancer by telling of the Bible verse that her husband chose for their wedding day:

On our wedding day, my husband and I gave each other a special gift. We each chose a Bible verse for our marriage and presented it during our vows. How wonderful that God directed Gordon to Proverbs 3:5-6, knowing cancer was in our future. I love how the author of Proverbs said that we are to trust in the Lord and not lean on our own understanding, which is always flawed and based on human experience! How could I understand what God was doing when He called me to go through cancer? But in His infinite wisdom, He knew that cancer would produce fruit in my life. My own understanding of it was human, but His was divine.3

Laura demonstrated the depth of her faith in this declaration of her acceptance of God’s will in her breast cancer. She further demonstrated her acceptance when she told the story of (Esther 4:14-17) when she wrote:

The story of Esther is a moving account of an orphaned Jewish girl whose beauty catches the eye of the Persian king. Since Jews were not highly favored in Persia, Esther keeps her heritage a secret as she becomes the new queen. But when the king’s evil chieftain, Haman, vows to destroy her kinsmen, Esther wisely intervenes. She risks her own life by going before the king and identifying herself with a doomed people. She is God’s woman in the right place at the right time. We, too, are God’s women in the right place at the right time. We may struggle with God’s plan, and we are given a choice to look at cancer

as a burden or as an opportunity. We can say, "Why me, Lord?" or we can say, "Use me, Lord!"^4

Barbara also found an expression of God's will for her in her cancer. She found God’s presence as she journeyed with him expressing it in her desire to be like Enoch (Genesis 5:24). “How grateful I am that You walk with me on the path of life—a path that will eventually bring me to glory. I pray I will be like Enoch of the Old Testament, who walked with You and was no more because You took him away. I know that as I keep walking with You, one day we will be closer to Your house than to mine—and that will be a glorious beginning!”^5

**Though the psalms**

A range of expressions were identified in the patients’ use of *Psalms*. These themes did not flow from exegesis but from the patient's cry. The themes of hope, trust in God, prayer for delivery, confidence in God (rock), and praise were frequent.^6 Joyce’s pastor suggested she read (Psalm 27); taking his advice says she felt "strengthened".^7 Pam also expressed confidence and strength through finding God’s presence in her cancer saying “(Psalm 105:4) says, ‘Seek

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^4 Geist, “God’s Woman in God’s Time,” 158.


^6 Patients referred to the following Psalms in their prayers: (13: 2,5,6), (18: 31-32), (27:), (33: 20-22), (34: 1-7), (40: 2-3), (42: 1-2), (45: 11), (68: 19), (73, 26), (91: 14-16), (105: 4), (112, 1-7), (127: 1), and (139: 1-2, 5).

the LORD and His strength; seek His face evermore’ (NKJV). This instruction is not subject to my feelings”.8

New Testament themes

Passages or themes from the NT were found in the prayer of fourteen patients who made thirty-five references in all.9 The principal themes were: firstly, the perspective that scripture brought for the patient and secondly, the presence of God in the cancer experience.

The first cluster of NT quotes contained examples of patients who found a new or altered perspective on their life with cancer. Lyn’s husband was a pastor who had lost his first wife as a newlywed. Lyn wrote:

To watch me face an uncertain future was more than he felt he could bear. One day he came upon a car with a bumper sticker that read, 'Jesus is enough’. He was so overcome with worry and fear of losing yet another wife that he wondered out loud, ‘Is He really?’… My husband answered that question two weeks later when he preached a powerful sermon entitled "Jesus Is Enough." In it, he reminded all of us that God doesn’t need to do another thing for us on this earth. He has given us His one and only Son, and in Him we have everything we need to cope with this life and every promise for eternal life. Jesus is enough!10

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8 Pam Formosa, “Prayer is not a Feeling,” in Praying through Cancer: Set Your Heart Free from Fear, ed. Susan Sorensen and Laura Geist (Nashville: Thomas Nelson, 2006), 136.

9 NOTE: Of the 14 patients (sources) who quoted the NT in their prayer only one was male and he made one reference only. Three female patients made 23 of the total of 35 references; the remaining references were made by ten female patients. Despite this “bias” the main themes were found to be identical.

Lyn referenced (Philippians 3:7) in her prayer. Barbara had quoted an earlier chapter (Philippians1:21). “For me, living is Christ and dying is gain.”

Laura’s cancer experience led her to find a new life in Christ. “Do not be conformed to this world, but be transformed by the renewing of your minds, so that you may discern what is the will of God- what is good and acceptable and perfect”. (Romans 12:2).

The second strong theme was how the patients found God’s presence in their cancer experience. Susan was influenced by the symbolism of the patient’s arms during a mastectomy, being “spread horizontally like Jesus’s were on the cross”.11 She identified with “I have been crucified with Christ; and it is no longer I who live, but it is Christ who lives in me”. (Galatians 2: 19-20). She experienced God’s presence in her so strongly that she went on to say “Thank You for this opportunity to be crucified with Christ. It is no longer I who live, but Christ who lives in me. I worship You as my loving Father who walks with me on this road to maturity in Christ. I worship You as the Sustainer and Provider who is more concerned about my growth than my cushy life! I praise You, my faithful and powerful Lord”.12

Missy Morrow threw a “pity party” when she first heard of her diagnosis of cancer. The first guests, who arrived very early, brought “gifts” of fear, anger, doubt, and dread. The last guest to arrive was Jesus.


12 Sorensen, “Crucified with Christ,” 57.
I raced toward Him and quickly opened His gift to discover: The last guest to arrive was Jesus. “I raced toward Him and quickly opened His gift to discover:

- Hope... promise for the future
- Strength... the ability to endure
- Grace... God’s help,
- Comfort... in pain, trouble, and anxiety
- Peace... calmness
- Healing... restoration of mind, spirit, and body
- Joy... a sense of well-being
- Love... compassion and devotion shown by God

After opening all the presents, I realized that Jesus, with the beautiful gifts He freely gives, was the only One I needed or wanted to stay.  

Missy Morrow based the idea for her party with the perfect gift on “Every generous act of giving, with every perfect gift, is from above, coming down from the Father of lights, with whom there is no variation or shadow due to change.” (James 1:17).

Another passage expressing God’s presence was used by Susan, Lynne and Nicola to describe their prayer when they experienced aridity. “Likewise the Spirit helps us in our weakness; for we do not know how to pray as we ought, but that very Spirit intercedes with sighs too deep for words” (Romans 8:26-27).

A very powerful quote was recorded by John that expresses the intensity of God’s presence that he experienced in his cancer and offers a key to reflection through its reference to the three persons of the Trinity:

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For this reason I bow my knees before the Father, from whom every family in heaven and on earth takes its name. I pray that, according to the riches of his glory, he may grant that you may be strengthened in your inner being with power through his Spirit, and that Christ may dwell in your hearts through faith, as you are being rooted and grounded in love. I pray that you may have the power to comprehend, with all the saints, what is the breadth and length and height and depth, and to know the love of Christ that surpasses knowledge, so that you may be filled with all the fulness of God”. (Ephesians 3: 14-19).

Through poetry and images

Nine poetic references were found within the male storytelling; just one from a female. Three themes were identified, being mindful of the present day, gratitude for support of family and hope. Rosalie was working hard to live the present day to its full. “Yesterday is gone, Tomorrow is not here, Live for Today!”

Orville was mindful of the present day and thankful for its beauty, whilst being aware that he would die. He put it as:

Now I am ready to tackle this day. I wrote a poem to explain how I feel about life:

\begin{verbatim}
Let me touch the green of Spring once more,
And caress the eager dawn.
Let me hear the midnight thunder
And see the skies explode again.
Let me be there when the snow begins to fall
From darkened skies some silent night,
And let me dream once more
Of sunlit days and silver nights,
Before I die.\end{verbatim}

\end{verbatim}

\begin{verbatim}
\begin{verbatim}

\end{verbatim}
\end{verbatim}
Paul saw hope in the prayer of St Francis. He prayed “it is in dying that we are born to eternal life. Amen. This is a goal. But I can say this prayer. And I still want you to whip cancer's ass. Bon Chance!” Robert also expressed trust and hope through his poem:

Come to the edge
He said. They said
We are afraid.
Come to the edge
He said. They came
He pushed them, and
They flew……………

Alan was very grateful for the help of all those around him when he quoted the “Footprints” reflection after his surgery. “I thought about this reflection while I was in Intensive care … It occurred to me that I wouldn’t recognise God’s footprints in among all the footprints that surrounded mine on this journey. My wife's have been right next to mine the whole way, and surrounding these have been my family’s. Then there are those of friends, colleagues, students, carers - dozens and dozens of footprints.”

No image fully captures the experience of cancer. Patients often struggled to understand it fully. Arthur’s image of “gravy” typified this as he strove to seek meaning for his unexpected survival of both a heart attack and cancer.


When I was ill, all I wanted was to get back into the ordinary flux of activity. Now that I am back in the ordinary, I have to retain a sense of wonder at being here... Like Job, I have had my goods restored to me. Secure in the knowledge that I am dust, I enjoy what I have...I will remember a poem I keep over my desk by the late Raymond Carver, called "Gravy." A man, an alcoholic, is about to die, but he changes his habits and lives for ten years. Then he gets a brain disease and again is dying. He tells his friends not to mourn "I've had ten years longer than I or anyone expected. Pure gravy. And don't you forget it"...I try not to. In recovery I seek not health but a word that has no opposite, a word that just is, in itself. When I seek the meaning of my recovery, the opportunity of illness, I call it gravy... Gravy is watching the sunlight on the river. Here is half of what I have learned from illness: Sky is blue, Water sparkles.\(^\text{20}\)

In brief, nearly a third of the references revealed that scripturally based prayer, images and poetry helped them cope with the particular manifestations of their cancer. Further reflection on these findings follows in chapter 7 after the findings on the other revelations of prayer, contained in the stories, are made.

### 3 Women and men pray a little differently

During the analysis of the cancer stories studied, gender based differences became apparent. Whilst the most frequent form of prayer overall was found to be thanksgiving and it dominated in the women’s stories, it was less so however for men. Meditation was more popular amongst men; this is not to say that men failed to thank God or that women failed to meditate. These statistics constitute evidence that there were differences in the practice of each gender. The data of figure 6.2 reveal more of the structure of these differences in relation to thanksgiving. Typically, females reported thanks to God for the

support of their friends ahead of support received from their families. Males ranked family support ahead of friends in giving thanks. This finding of differential gender response is explored in the discussion and conclusions chapters.

Considering meditation, the analysis showed that men practiced all forms in greater numbers compared to the women except for the *lectio divina form*. And the data analysis has revealed gender based differences on other forms of prayer. These will be discussed in the following paragraphs under the heading of the specific type of prayer where the differences indicate potential pastoral significance.

4 Thanksgiving

This section expands on each of the *thanksgiving* categories in figure 6.2 and addresses the finer structure of *to whom* and *for what* cancer patients express thanks in the dataset of stories.
Ten items of thanks were identified: for friends, for support of family, for the finding purpose and a new life, to God for being present, just thanks, to God for being Saviour, to God for listening and people responding, for professional support received, for present and past gifts including laughter and finally for survival.

For support of friends

Nicola was recovering from tracheotomy surgery performed to relieve lung obstruction necessary because of the metastases from her primary breast...
tumour that was thought cured eight years earlier.\textsuperscript{21} Most people would be devastated to receive such mutilating but necessary surgery. Any self-pitying thoughts that Nicola may have experienced, were kept within herself and her prayer was one of gratitude for all the friends who were supporting her, as Lynn recounted:

She let go of my hand and put her index finger over her track tube so she could talk. 'Dear God,' she said. 'Thank You for all the blessings You brought into my life and for all the love that people have shown me. I know You love me and are working for my good through all these kind people and their kind gestures.' She took a deep breath, trying to force enough air into her lungs to finish.\textsuperscript{22}

Nicola's prayer of thanks for her friends typified what other women wrote.

Pam said "I was made aware of the many gracious people who prayed for me."\textsuperscript{23}

Martina said "Nigerians really lifted me up in prayers and spirits when I was sick. I have many friends there."\textsuperscript{24}

\textbf{For support of family}

Men too expressed thanks for the support of their friends but more frequently were thankful for their family and particularly for their wife's loving

\textsuperscript{21} \textit{Metastasis} is a term that describes a secondary growth which can result from invasion locally, or from spread by the lymphatic or blood vessels or across cavities. J. Walter, H. Miller and C.K. Bomford, \textit{A Short Textbook of Radiotherapy} (Edinburgh London New York: Churchill Livingstone, 1979), 153.

\textsuperscript{22} Lynn Eib, \textit{When God and Cancer Meet} (Wheaton, Illinois: Tyndale House Pub, 2002), 121.


companionship. Typical of such thanks was Paul who said “Well, here we are again. Thank God. Thank all the wonderful people that have loved and supported me throughout. Thank you Jennie my beautiful and wonderful wife. You are truly an angel. Thank you for coming into my life. I am not only still alive, due in large part to your efforts and support, but I am a better person because of you. Thank you.”

Mack blogged “This cancer thing can destroy a marriage, or it can be the glue that sets and holds it together forever... We are a team. We have so very much to be grateful for.”

For Larry his melanoma was much more than a glue. He thanked God for “[a] fantastic gift. A day I didn’t think I would get. I can get goose-bumps at a sunrise! Seeing my family grow – and seeing grandchildren... I remember the days I never thought I’d see these things. It colors everything about me. I’m a huggy sorta guy by nature. But getting and giving hugs is a gift of immeasurable worth to me now.”

When a woman thanked God for her husband, she often displayed a deep insight into his feelings. Norma blogged “I had such a supportive husband. He


unfortunately felt quite helpless & very frustrated about the fact that he could not
even drive me to my many appointments. He was appalled by some of the words
& attitudes that some of the doctors used & frustrated by all the delays, loss of
reports & the ambivalence of some of the reports.”  

Norma’s experience provided a salutary warning to doctors and health
professionals that their unthinking use of certain metaphors and careless practice
can deeply affect the experience and hence well-being of their patients.

For purpose and the chance of a new life

Thanks for a new sense of purpose in life that the cancer provided were
found in 31 references. Eighteen references were found to thanksgiving prayer
for the chance of a new, better life even if the cancer was not cured. James was
diagnosed with chronic myeloid leukaemia and his future was uncertain, yet he
could thank God for clarifying his objectives in living during and beyond his
treatment regime:

As I sit here now and as we walked out of the office Thursday, it's
almost like I don't have cancer at all. I guess it's because I was in an
emotional trench for the week previous. My condition is still serious.
Heck, six years ago before the advent of Gleevec, I'd be in the hospital
right now. I'd be getting chemo and/or radiation and looking for a bone
marrow donor. Instead I'm sitting here in front of my computer feeling
great, feeling positive, feeling blessed. God is giving me a chance,
science is making it happen.  


[Accessed October 11. 2012.]
Leandra’s story was different, but her experience led her to a “prioritized list of things to do”. She was aged just twenty four at the time her cancer was diagnosed. She was a dancer and choreographer, whose life was hijacked by an advanced stage synovial sarcoma; the doctors gave her a three to six month survival probability requiring massive surgery including the amputation of one leg. The treatment was very aggressive. She gave thanks for her new life emerging symbolically from the narrative of her story. She told it best:

Seven weeks of radiation, four cycles of chemotherapy, rivers of tears, lost friends, molting hair, major weight gain, and countless hours of worry have changed me. Not all for the worse either. Cyberspace full of friends, a renewed faith, a joy for life, a prioritized list of things to do, a respect for nature, a new, wonderful relationship with my family, a sense of power from survival, confidence to really live. I always look for the silver lining and sometimes it takes a really long time to find it, but it's always there. You can bank on it.  

Other storytellers like Barbara found what she called the roadmap for a new life after cancer within the religious texts of her faith, but never explicitly laid out therein, and very different from her life before cancer. She quotes:

My flesh and my heart may fail, but God is the strength of my heart and my portion forever” (Ps 73:26). When you're in the middle of a major illness, you think: When I get well, my life will be normal again. You think normal will happen automatically when your health is restored. But there's an emotional transition between sick and well, and it doesn’t come with a road map or an instruction sheet. When my treatment ended and the doctor said I was in full remission, I found myself in totally new territory. Expecting to feel happy and full of joy, instead I found myself tense -and lonely. Now that was an emotion I hadn’t expected ... It took hard work, plenty of prayer and help from my doctors and friends to reset my attitude.

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Today I’m determined to see remission as a time of rebirth – a time of new life and hope.\textsuperscript{31}

Other women like Lynn, Susan and Laura published books telling their personal stories and they included those of many other women as part of their new life after cancer experience.\textsuperscript{32} These were stories told in the hope of helping people dealing with a cancer diagnosis and were active prayer by these women. Often they named the histology but mostly paid attention to the complex of emotions that the women experienced and gave thanks for new opportunities. Thirty two percent of the story dataset were narratives of breast cancer; this was the largest representation of a single type of cancer found in the stories studied.

Publications by men were more confined to a narrative of the author’s personal experience. However men established and maintained several websites on the internet to help others. Steve was typical of these.\textsuperscript{33} His Cancer Guide website provided an opportunity for a person to tell their own story in their own words, and to read the posting of others. The website also provided information under hyperlinks such as cancer basics, specific cancers, statistics, practical aspects and to mind and attitude. However the majority of the cancer


websites are set up and maintained by large Cancer Societies representing local, national and international communities such as the Cancer Council of Victoria, the Mayo Clinic, or the American Cancer Society.\(^{34}\)

The story of Dawn that appeared on Steve’s *Cancer Guide* website, described her new life that emerged from the deep depression subsequent to her renal cancer and her friend’s death.

For the next year, I went to work and then got back into bed, not getting out until it was time to go back to work. I cried all the time. I couldn’t stand going anywhere we’d been together, although I would try, but end up leaving in tears. Finally, I began taking RCIA (the Rite of Catholic Initiation for Adults) classes at the local Catholic Church. I started to live again, make new friends, and emerge from the shroud of grief that had been suffocating me. I joined the choir and became a cantor. I got a new job with an increase in pay. I rejoined the race.\(^{35}\)

Martina thanked God for her new purpose and life following her treatment.

> “I feel like I have found my way. I thank God for all I have been given at the end of every day. I have been blessed.”\(^ {36}\) Judy said “Cancer changed my life for the better. It has taught me so much and I have gained so much through it. I cannot imagine myself having done it all without the prompting cancer gave me.”\(^ {37}\) Linda also saw God providing a new purpose when she wrote “I learned that God does

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\(^{36}\) Martina, “Grade 4 Brain Stem Glioblastoma Multiforme & Burzynski's Antineoplastons.”

provide a way. He allowed cancer to enter my life, and then he took that and made me a better person. He allowed me to survive and he has a purpose for my life." In addition to thanks for a new life and purpose, Judy and Linda demonstrated deep mature faith. Linking a loving God with benefit from a disease like cancer is a stumbling block for many Christians and a nonsense for non-believers as will be further mentioned in the paragraph on atheist and agnostic prayer. Whilst many words are written about the paradox of God being loving and spiritual benefit arising from great suffering, Judy’s testimony should not be trivialised because it arose primarily from her lived experience rather than from any hypothesis.  

It was plain that prayer, especially that of thanksgiving to God for a new life and a new sense of purpose contributed to the well-being of many cancer patients.

**To God for being present**

Men and women alike expressed thanks to God for being present through and during their cancer experience (25 references in 16 sources). This was the third most reported form of thanksgiving prayer. Every reference to God’s presence clearly contributed to the well-being of the narrator. And some of the metaphors were very beautiful; some were biblical in inspiration and some arose from established devotion. Alan is typical of this latter which can be seen in what he wrote:

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I went from theatre to intensive care. Have you read the Footprints reflection? You know a man dreamed that he walked along the beach with God one night, turned and saw only one set of footprints. It turned out that God was carrying him. I thought about this reflection while I was in Intensive care (I was awash with opiates at this time). It occurred to me that I wouldn’t recognise God’s footprints in among all the footprints that surrounded mine on this journey. My wife’s have been right next to mine the whole way, and surrounding these have been my family’s. Then there are those of friends, colleagues, students, carers - dozens and dozens of footprints.  

Barbara, best-selling author of *Plant a Geranium in Your Cranium*, found God’s presence during her frequent CT and MRI procedures. The outcome of these procedures is never known at the time the procedure is being performed, so patients undergo them experiencing considerable anxiety; often too, the experience is very unpleasant, claustrophobic, and many find MRI terrifyingly noisy. Barbara’s beautiful metaphor, of being protected in her tiny rock cleft by the hand of God’s presence, removed the terror and she experienced great peace. She wrote:

When I’m in that small, confined space, I picture myself hidden away in “a cleft in the rock,” covered gently with God’s own hand as His magnificent glory thunders by. And in that loud, tight, toilet-paper tube of a place, I feel an unusual sense of comforting peace.  

*I thank You, Lord, that Your response to Moses is Your response to me: “My presence will go with you, and I will give you rest.” What comfort this brings. For in the day of trouble, You will keep me safe in Your dwelling; You will hide me in the shelter of Your tabernacle and set me high upon a rock. Then my head will be exalted above the enemies who surround me. Because of Your daily presence, I experience Your joy. You place me in a cleft in the rock and cover me with Your hand. Thank You for Your gentle care and protection.  

Father, I am especially thankful for Your presence in my brokenness.  

I’m grateful, brokenness brings wholeness in a variety of ways. Broken  

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hearts, broken bodies, broken dream—and then, in the midst of my brokenness, I feel myself pressed against the unshakable presence of God. And there I find peace; there I find strength and courage for the next step. There I find You!  

Barbara’s testimony is evidence that even, in the midst of physical noise and psychological trauma associated with cancer treatment, one can have a contemplative experience of dwelling in God’s presence. Other instances of such contemplative experience were found in the stories studied. This is significant because the reality expressed by these patients flies in the face of the commonly expressed belief that meditation and contemplation require quiet surroundings and lots of technique or discipline to achieve. Contemplative experience is not something that one does, but is a gift of God. In cancer, the contemplative experience often seems serendipitous, arising unexpectedly but can be a source of great peace for the patient; and contribute to their well-being “brokenness bringing wholeness” as Barbara wrote. This theme is followed later in the section headed meditation findings.

Just thanks

This heading includes a potpourri of 23 references occurring in 16 sources that spoke clearly of thanksgiving prayer but were unspecified to the extent that the account evaded coding otherwise. Typical of these was John who posted to the internet in wonder at his survival from his lung cancer treatment, “Why am I

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here? I don’t know. But I’m sure grateful.”

Evelyn’s thanks was broad and came with a realization of her survival from a stage II non-Hodgkins Lymphoma; she said “successful, but must confess that I really did not realize all the complications that might have arisen until after the procedure was over. I think that was a blessing actually.”

**To God for being Saviour**

The statistics arising from coding queries made under the headings *thanksgiving to God for being Saviour, conversion, and the power to testify* are displayed in table 6.2 following.

<table>
<thead>
<tr>
<th>Thanksgiving</th>
<th>Sources</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>God for being</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conversion</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Power to testify</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>14</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 6.2: Thanksgiving: God for Redemption

More women than men spoke about thanksgiving to God for the means of working out their personal salvation through the cancer experience. Despite there being fewer men offering thanks in these terms, both genders used similar expressions. Susan saw the transformation of her life, by first thyroid and later

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breast cancer, as steps in her transformation that commenced with her becoming a Christian.

Thank You, Lord, that when I became a Christian I became a new creation. You discarded the former way of life and put a new, clean heart in me. You began Your work and will carry it on to completion until the day of Christ Jesus. Thank You for the transformation You have begun in me. I confess that my selfish ways and desires have often gotten in the way of Your desire for me. Forgive me for ... How grateful I am for Your promise to cleanse me if I simply confess my sin to you. Thank You for this opportunity to be crucified with Christ. It is no longer I who live, but Christ who lives in me. I worship You as my loving Father who walks with me on this road to maturity in Christ. I worship You as the Sustainer and Provider who is more concerned about my growth than my cushy life! I praise You, my faithful and powerful Lord.45

Jim accepted the reality of his cancer, although unwelcome, as part of God’s plan for him. He expressed a desire for a cure, but if that was not God’s will he hoped that the clinical trial may benefit others to come and that his life might be an example. Being able to thank God in his circumstances is evidence of a mature practical Christianity.

I am thankful for the Lord who has my best interest at heart. He purchased me with the sacrifice of his own son before I ever was. Now, his ways are not my ways, therefore I may not understand "why" until he explains it to me. Perhaps it is to touch someone to take a step forward toward Jesus. Perhaps it is to be on the cutting edge of a cure for renal cell carcinoma. By participating in a clinical trial I may help someone else, even if I am not helped myself. I went from what I thought was a little problem one Friday to incurable cancer on Monday. Thank goodness the Lord was there with me and continues to walk by my side. 46

Gustavo used the internet to give his testimony expressing thanks for all those who contributed to his survival. “I am working now, full time and feeling

45 Sorensen and Geist, *Praying through Cancer: Set Your Heart Free from Fear*, 58.

almost back to my pre-cancer self ... I would not be here speaking to you today if it was not for my faith, my positive attitude, good friends, my family, my wife and Steve Dunn’s site. He himself is an inspiration and it was always my goal to be just like him... NED, [no evidence of disease] alive and happy!" 47

Amongst those mentioned in this testimony is Steve who, whilst he was alive, maintained a website that contained similar testimonies and messages of hope. This research found no references to thanksgiving for God as Saviour in first-person publications in the printed media by males but notes that many males use such sites as Steve’s website to tell their story for others; editorial policy by the publisher may be influencing the selection and content of stories. First-person publications in the print media by women were found to be common and contain the majority of thanksgiving references to God as Saviour.

For God listening and people reading the patient’s story

The number of coding outcomes is very small for these two categories of thanksgiving as shown in table 6.3 which shows that there were only seven in

the total of two hundred and twenty six references to thanking God and others for listening to the narrative.

<table>
<thead>
<tr>
<th>THANKSGIVING</th>
<th>Sources</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>By the story teller</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Those listening</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>7</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 6.3: Thanksgiving for being heard

Significantly more females than males take the opportunity to tell their personal story and that of others via the medium of print and thank their readers for reading them. This may be arising as a reaction to feelings of isolation or separation, commonly experienced by women with cancer and less expressed by men. Women experience a need to tell their cancer story and are grateful when it is received by others. Many women gain their support from other women and dominate in support groups and on the internet.48 Rosemary’s experience of sharing with other women proved to be a positively cathartic experience for her as well as providing real support to others. “Lastly, I want to thank all who have written to me to ask questions, show concern, tell me their stories or offer prayers. It has meant a lot to me. Some have said they found my story

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inspirational. I meant it to be informative; I mean this update to be informative, whether or not you agree with my decisions.”

Sylvie posted her story on the internet. The language is less crafted than that seen in print but creates a certain sense of immediacy. Her blogs prompted frequent and numerous responses. She expressed gratitude for most of these. But she mentions that some of it was not welcome; it was like the snickering that Christopher had experienced. Often too, beyond its inappropriateness and lack of empathy, internet blogs can also be ill-informed in relation to technical aspects of cancer management. Print publication is subject to more rigorous editing and thus less likely to cause harm to the cancer patient or to contain false information.

**For professional support**

Fourteen sources, comprising ten men and four women, made seventeen references between them to thanks to God for the professional support that they received. Ed said “9 hours and I was later told by the nurses that Dr Wain never left the room. God bless him!” Gustavo was grateful for the skill of the “brilliant surgeon who did not cut any off my frontal lobe. Two days later I was home.”

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53 Perez, “Widely Metastatic Kidney Cancer.”
Paul thanked God for his doctor “one of the doctors at Burzynski’s clinic told me I was a walking miracle. I know this. I thank the Lord. I pray every day.”

Obviously a doctor’s positive attitude and personal metaphor impacts strongly on the wellbeing of the patient. Other coding, recording comments by the MD, comments about the MD and comments by health professionals makes a similar conclusion; the results of coding analysis were presented in chapter 4 which detailed the findings of this research on wellbeing as found in the patients’ stories.

**For present and past gifts including laughter**

Accompanying the cancer diagnosis frequently comes the realization that life will never be the same. Fourteen people, gave thanks to God for their past blessings and six for the gift of laughter. Elizabeth, in response to her hair falling out during chemotherapy and her daughters sharing her experience by shaving their heads in solidarity, thanked “Jesus for the gift of laughter. I am grateful for the opportunities to laugh even in the midst of difficult circumstance. Thank you for those who laugh with me and keep laughing when I need it most.” Nicola’s thanks were focussed on her former gift of song. “I always enjoyed singing in worship, praising God and thanking Him for all my wonderful blessings. Prayers

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54 Leverett, “Grade 4 Brain Stem Glioblastoma Multiforme & Burzynski’s Antineoplastons.”


came easily to my lips, especially prayers of thanksgiving, because I had a lot for which to be thankful."\(^{57}\)

The coding analysis found that more women thanked God for past blessings than men but there was no difference in the way that they expressed their thanks. Daniel wrote “My achievements have turned into God’s miracles in my life. God has turned a devastation event into many blessings for me and hopefully the lives that I have touched."\(^{58}\)

**For survival**

<table>
<thead>
<tr>
<th>THANKSGIVING</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
</tr>
<tr>
<td>Survival</td>
<td>4</td>
</tr>
<tr>
<td>For being alive</td>
<td>4</td>
</tr>
<tr>
<td>Healing</td>
<td>5</td>
</tr>
<tr>
<td>Regression</td>
<td>2</td>
</tr>
<tr>
<td>Pain free</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

Table 6.4: Thanks for survival

Analysis of the coding for **thanksgiving for survival** revealed five different but related reasons\(^ {59}\). Individually they comprise less than two percent of the coded references; but they are mutually related and so are grouped under the generic heading of **Survival**. Table 6.4 above shows the components of this group.


\(^{59}\) NOTE: Related because they arise from the physical manifestations of cancer and the sequelae.
Considered as a group, the survival testimonies comprise eleven percent of the coded references and show a fifty percent greater response amongst the females than amongst the males. Only in their thanks for being pain free does the male coding equal that of the females; but the numbers are so small as to have inconclusive statistical significance. However the individual testimonies are significant and in every case they supported the association of prayer with wellbeing.

The realization of survival came in different ways and at different stages in their disease’s history for the individuals in the study. Barbara described her thanks for her survival after her six month check-up which, for her, was confirmed at the one year check-up by a repeat of negative tests:

I went in for my 6 month check-up last September, and I was scared to death!! But, through the Grace of God, I was FINE! All tests came back negative!!! At the end of March 1998, I went back to MD Anderson for my 1 year check-up, and again, Praise the Lord, all the tests came back negative again!! I am feeling wonderful! My energy level is returning, my mental attitude is no longer consumed with my illness, and I again have a sense of well being about my life and future. I have been blessed, God has given me back my health, He has given me back my life!!

For other survivors, thanks came on more gradually and not in response to a peak event such as a periodic medical review; they expressed thanks as their realization of being alive or being healed entered their consciousness.

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Helen said “I just blow it off and thank God I’m still alive”.61  Linda said “My gosh, those are minor things, I’m so fortunate to be here”.62

Others expressed thanks for assistance provided in managing their pain. Evelyn wrote “They had me on morphine for a while but that did not help it just put me to sleep. I prayed to God to please help me and spare me the pain or at least make it tolerable. I kid you not, God answered my prayers.”63 Laurie attributed her freedom from pain and sickness, associated with chemotherapy, to God:

I started chemotherapy in April and finished in the later part of July. As terrified as I am of needles and anything medically related, God was right there with me through the entire process. I was able to remain active and never felt any real pain or sickness. He allowed me to continue working a full time job, while finishing evening courses until I graduated in August. I was so excited about God and all that he had done in my life when I walked across that stage, knowing that I was graduating Summa Cum Laude, with a 4.0 grade point average AND that I had no more detectable cancer cells in my body.64

Having revealed this research’s findings on the ten aspects of thanksgiving prayer, the text now returns to the larger domain of how cancer

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63 MacDonald, "Stage iii Non-Hodgkin’s Lymphoma."

patients pray in other ways. Figure 6.1 provides the context for the remaining paragraphs of this chapter and is repeated here for the reader’s convenience.

![Figure 6.1](image-url)

**Figure 6.1 (repeated): How cancer patients pray.**

The popularity of the forms of prayer found in the stories of 160 cancer patients as determined by frequency of coding count of references. *Meditation, thanksgiving, and scripture quoted* were the most popular forms and gender based differences are seen. (The female value is coloured red and appears first in each pair of bars in the figure).

5 Can’t pray

As if the diagnosis of cancer and its sequelae were not bad enough physically, many devout people found that they just could not pray. Analysis revealed that because of this dark night experience many came to realise that their wordless resting in God is in itself a form of prayer, contemplation. Having commenced contemplative prayer during a time of significant life change, they
continued the practice for the remainder of their lives. Lyn Eib provided a deep insight when she wrote:

Two wonderful verses about how to pray when you feel you can’t pray. They were right there in the Bible, sandwiched between Paul's discussion of suffering and his explanation of how we can be victorious even in difficult times! ... It was okay that I felt I couldn't pray. The Holy Spirit would pray for me. He would take my "groans" that were too deep for words right to God Himself. And even better than that, the Spirit would know what to pray for me. He would pray according to God’s will. I love how The Message renders Romans 8:26: ‘If we don't know how or what to pray, it doesn't matter. He does our praying in and for us, making prayer out of our wordless sighs, our aching groans.’ That's one amazing God! He knows that at the times we need Him most, we may not be able to express ourselves to Him, so He has His own Spirit do it for us! After I found that verse, I would often just sit, my hands on my lap, palms toward heaven, tears rolling down my cheeks, praying. I never said a word. I couldn't even form cohesive thoughts in my mind, but I prayed. I didn't worry what or how to pray. I simply allowed God’s Spirit to take my innermost thoughts, my deepest fears, to God and pray for me. In time I was able to pray again myself, but sometimes even now I still practice the kind of prayer I learned when I had no other way to pray.65

This quotation from Lynn was one of only five references saying that “I can’t pray” to be found in the stories studied; they were all from female patients.66 Nicola said “in fact, if you had told me there would come a time in my life when I wouldn't be able to pray, I would have laughed at the suggestion and insisted it could never happen. But it did. In those first dark days after diagnosis, I literally couldn't pray. When I would read my Bible and then try to pray, the words simply would not form. Instead, tears rolled down my cheeks, sometimes just a trickle

65 Eib, When God and Cancer Meet, 126.

66 NOTE: To preserve anonymity and ensure consistency the first name will be used when quotations are made from narrative text in the data-set. The usual Turabian style is used when the complete original text is referenced.
and sometimes turning into heavy sobs. The only thing I felt like I wanted to pray was a desperate cry for healing. What else was there to say?” Clearly Nicola, who in better times prayed daily, could no longer find words. She was an eight year survivor from breast cancer and was now reacting to the discovery of secondaries in her lung and to imminent tracheotomy surgery. Through this unwelcome change in her prognosis, and her persistence with her Bible reading, Nicola’s practice of prayer shifted away from words towards contemplation.

Like Nicola and Lynn, Pam became unable to pray. For her, the cause was the severity of her chemotherapy and the uncertainty of survival and of any possibility of life beyond the present:

This was not like me. I did not feel like praying. In the past, I felt the need to pray and the joy of praying. I daily experienced the privilege of coming to my heavenly Father. I now found myself unable to pray as I wanted. Was it the chemo drugs or a preoccupation with what my future might hold? … Then one day I recognized my error. I was relying on my feelings! Feelings are not the measure of truth … Gratefully, too, I was made aware of the many gracious people who prayed for me. What a loving provision God made when He put concern for my welfare on the hearts of others. It still humbles me to remember the sustaining power of those prayers… [later Pam prayed]

*Thank You for those who pray for me. You have placed this desire on their hearts, and I am grateful. Thank You for Your indwelling Holy Spirit, who comforts and intercedes when thoughts don’t come easily. Thank You for the privilege and provision of prayer even when my feelings deceive me.*

After her treatment, Pam became aware that her friends were praying for her throughout this period when she herself had been unable to pray and she thanked God for this support. Her thanks for the indwelling of the Holy Spirit and

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the reference to comfort when thoughts don’t come easily, indicate that she had become comfortable with just resting in God as a form of prayer.

It is pastorally significant that from the “can’t pray” of Lynn, Nicola and Pam in responding to the diagnosis or worsening of the prognosis, that the beginnings of contemplative prayer became apparent in their lives. So often the confusion associated with selecting the best treatment, the long captive times of waiting, the trauma of the treatment delivery, and the uncertainty of the outcome, lock out any prayer that depends on words or on discursive thought. Offering the idea of quietly resting in God can provide an improvement in the patient’s well-being by revealing His presence in the midst of what can seem to be utter chaos and devastation.

6 Meditation

In the preceding paragraphs the theme of meditation has been seen both arising from thanks made to God for being present in the cancer experience and also emerging from the lack of ability to pray in the face of the cancer. The outcome of the CAQDAS, showed meditation to be as significant as thanksgiving in the ways that cancer patients reported praying. This section concentrates on revealing the contents of the cancer patient stories studied corresponding to the

69 SEE Meditation above.
node *meditation*. This is a presentation of the results that emerged from the GT methodology.

Meditation was found to be more practiced by male patients than by females. Figure 6.3 following shows the breakdown into the different forms of meditation found, with each being expressed relative to its popularity which is indicated by the frequency of the coded reference, *form of meditation*. Males practiced all six forms of prayer generically labelled meditation, viz. *contemplation, Christian meditation, lectio divina, aspirative prayer, mindfulness,* and *music and guided imagery*. Women were represented in lectio divina, contemplation, and music and guided imagery but less so than men. Further, no gender specific practices were identified. John, Ernest and Ian were the only writers to provide detailed information about the meditation techniques that they found useful in their experience with cancer.\footnote{70 John Main, *The Way of Unknowing* (London: Darton Longman and Todd, 1989); Ernest E. Larkin, *Christian Meditation: Contemplative Prayer for Today* (Singapore: Medio Media, 2007); Gawler, *You Can Conquer Cancer*.} For most, cancer had disrupted their prayer life and they struggled to various extents and in different ways to accommodate their new circumstances. Others, as was noted previously came to meditation in response to their cancer. A small number of references to music as meditation were found (19 references in 10 sources). Ed described “listening to music in a new way …letting it wash over me uncritically.” John talked about the peace that arises when music is as natural for the patient as eating or making love or sleep. Ian described exercise and meditation as making music. He offered a new metaphor in which the patient’s positive attitude towards the cancer
could be seen to be playing as a member of an orchestra in which the “Big God” was conducting.

A sense of the immediacy of God’s presence within the oncological experience, according to the individuals’ spirituality, was noted in most of the one hundred and twenty eight references coded under meditation.

Figure 6.3: Six types of meditation.

Six types of meditation were found in the cancer patient stories studied and they are shown here ranked by popularity (based on frequency count of coding). Gender based differences were seen in all analyses. (The female value is coloured red and appears first in each pair of bars in the figure.)

John typified the majority of the entries about meditation in the dataset when he wrote that “it is the acceptance of our own being, as we are, at this moment in our life’s journey. That is what meditation is about. It is not trying to regain control over life, not trying to change God’s mind, not trying to change our
fate or destiny, not trying to reinstate the threatened ego as managing director of our personality. Meditation leads to an acceptance of the reality of the human situation as it is here and now.”

Reaching such acceptance and integration of the cancer patient’s current experience with their experience of God’s presence, however understood, characterises the experience as prayer and enhances their well-being.

Some accounts in the dataset, like that told by Joan Boresynko, described an unexpected contemplative encounter, narrated by one of her cancer patients in a group support session:

One of our cancer patients named Mary told her group a beautiful story of a very different but essentially similar experience. Mary had known about her ovarian cancer for just a few months and, having completed surgery, was midway into a short course of chemotherapy. She and her husband decided to drive to the Adirondack Mountains to rest from the strain of the previous months. They were sitting by a clear mountain lake on an early spring day in the late afternoon, listening mindfully to the songs of the birds and the sounds of the wind. The setting sun was fanning out into a mosaic of reds and blues that shimmered as it reflected on the still surface of the water. Suddenly, Mary lost the usual perception of herself looking at the water. Instead she felt a powerful experience of being at one with the water, the birds, the sky, the earth, and her husband. The boundaries between herself and her perceptions had melted away. Later Mary realized that the experience had lasted for about ten minutes, but it had seemed timeless.

Struggling to put her emotional state into words, Mary focused on transcendent peace, at-one-ment with the universe, and total love. She went on to say that she now felt less fearful about the cancer because she had experienced firsthand that human consciousness was not limited to the individual.


Mary’s union with God experience was very real and unexpected but gently led her to an acceptance of her cancer.

Albert struggled to work through his melanoma within the context of his Jungian beliefs. He saw no benefit in regular practices like meditation but described a need to recognise contemplative transformations undergone when the Self is thought of as the centre of the Psyche:

where the ego and the unconscious, the sacred and the profane, meet and unite… It is always there. But it is very important to actually perceive its physical presence. Unless the conscious meeting takes place, the healing process does not reach its full potential. We are reminded of Faust to whom the spirits said, "We were always here, but you did not see us." Or of Jesus who lamented, "I came among you, but you knew me not."…
These bodily sensations may at first be somewhat disturbing, but as one grows more trusting of the "totally other," they can become positively ecstatic. A stream of fire runs through the body, healing the ills in every area it enters. It is like an instant surge of health. It is a momentary union of body and soul. When it happens, you feel whole, at one, and healed of your ills. Ideally this meeting of sacred and profane happens on a daily basis…
The soul lives on the very edge of miracle. When I find my soul, even if it happens just for a moment and only once in a while, I feel right then as if a miracle has occurred. The soul is the part of me that is most truly myself. And it is also, I would say, the part of every person that is most truly similar to the image of God. So, if that is true, the experience of soul is also the experience of God, as if our soul-self touches and coalesces with God. That is a tremendously big idea: The soul-self is where the human and the divine meet and affect each other. Furthermore, if we are there, if we live on the plane of soul, then we are as sound and healthy, both physically and emotionally, as it is possible for a human being to be.73

Ernest wrote from within a different context to that of Albert with its Jungian overtones. He described how he had researched and practiced the various forms of Christian meditation found in the Carmelite tradition, which included lectio divina, aspirative prayer and, especially during his cancer, mindfulness and contemplation. He found God’s presence in his daily Mass and Holy Communion which he saw in the light of Karl Rahner’s “mysticism of everyday living”.

Recollection is no flight from life, but “facing up to ourselves as we really are, confronting ourselves instead of seeking solace in chatter, conversations, mere external dissipations” Holy Communion commits me to “accept my everyday just as it is. I do not need to have any lofty feelings in my heart to recount... I can lay my everyday before [God] just as it is, in all its pettiness and triviality”. Christian recollection is another word for Christian mindfulness, and these two are at the heart of our search for God that is anchored in the two daily periods of contemplative prayer that is Christian Meditation.

Ed found that his well-established practice of meditation was interrupted by his oesophageal cancer. His treatment was quite debilitating and it took him some time before he was able to resume the practice of meditation.

I had been meditating for 20 years, so daily meditation was nothing new. My sister Dorothy sent me audio tapes of Dr. Richard Moss that were very helpful. I also began to listen to classical music in a new way -- letting the music wash over me uncritically. I also went for a weekly massage, believing that this was a way of stimulating my immune system and getting rid of some of the toxins of chemotherapy. I took money out of my pension fund to pay for this, figuring that if I didn’t survive, I wouldn’t need the pension anyway. The chemotherapy itself was uneventful except for an allergic reaction to one of the drugs, which drug was promptly suspended. I was hoping that the

74 NOTE: Ernest Larkin saw no difference in the terms “mindfulness” (Buddhism), “attentiveness”, “awareness”, “recollection”, “practice of the presence of God”, and “mysticism of everyday living” (Rahner).

chemotherapy would shrink the tumor, but a pre-surgery scope didn't show any serious shrinkage...

The j-tube stayed in. I was growing to hate Ensure, which I was taking by tube and in three glasses a day. I felt no hunger or appetite but ate by the clock. Many times after eating, I would get a feeling of seasickness, which usually passed in about 45 minutes. My energy level was poor, but I forced myself to do daily physical exercises. I didn't get back to meditating for a long time.\textsuperscript{76}

Eventually Ed was able to return to his practice of meditation at regular times. By comparison, many others who reported a “can't pray” experience, changed their more discursive forms of prayer to practice meditation.

Ed required some medical management of a depression that set in during the repeated surgeries that he underwent. He mentioned that he received benefit from listening to classical music when he “let it wash over me”. Several other patients mentioned music and imagery as an aid to meditation or a substitute. Orlando derived benefit from music therapy in the management of his leiomyosarcoma.\textsuperscript{77} Rosemary said “I made an anti-depression music tape.”\textsuperscript{78}

No patients in this study explicitly mentioned the Bonney Method of Guided Imagery and Music but the research literature provided by Lars Ole Bonde contains dozens of articles describing the benefits of music and imagery on cancer patients and represent the method as a form of mindfulness

\textsuperscript{76} Mitchell, "Ed Mitchell's Story of Esophageal Cancer."


\textsuperscript{78} Grimm, "Rosemary Grimm's Experience with Ovarian Cancer."
meditation. This theme is further addressed in the next chapter which is devoted to discussion.

In summary, five forms of meditation were practiced by cancer patients. The evidence arising from this research, showed that more males meditated than females. No evidence of significant gender-based differences was found in the practices described. All stories, except for that of Ernest, reported a substantial hiatus in meditation during the treatment phase but that they returned to it later. Ernest’s cancer progressed rapidly but his story remains inconclusive in respect of a pause in meditation. Identifying these findings from within the storytelling on the experiences of meditation point to the comparisons with the research of psychologists and to the writings in the spiritual classics to be presented in the next chapter.

7 

Atheist and agnostic prayer

Atheists and agnostics do pray but not in the same sense as Christians, Jews or Muslims; and they may reject the concept of prayer altogether because of their limited comprehension of it. This research used the code atheist or agnostic talk in performing the analysis of the data-set as a synonym for prayer; through CAQDAS, thirty one references were found in the prayer dataset of six hundred and ten references. Such self-talk is an expression of wish, hope or intention that the cancer will become better which, as Yin de Shakya had written,

\[\text{Lars Ole Bonde, “Guided Imagery and Music: The Bonny Method and Related Topics, a Bibliography,” (Denmark: Aalborg University, 2010).}\]
is prayer. “My figuring is, take the chance, they’re just about ready to lick cancer anyway and with these transplants pretty soon they can replace your whole insides” Christopher expressed a hope which is similar to the hope expressed in Christian prayer. However he does not direct his hope to a God but expresses his internal feelings to the listener who he assumes to be a reasonable person through the reference to “these transplants” that will “lick cancer” of which he expresses no fear. Further in *Tumour Town* he continued, “four decades later, those other glorious “wars,” on poverty and drugs and terror, combine to mock such rhetoric, and, as often as I am encouraged to “battle” my own tumor, I can’t shake the feeling that it is the cancer that is making war on me. The dread with which it is discussed—“the big C”—is still almost superstitious. So is the ever whispered hope of a new treatment or cure.”

Despite describing his laryngeal cancer in a war-like metaphor, Christopher was not depressed or remorseful. His acceptance of his cancer was an act of realism. His self-talk had made him appreciative of his life although it offered him nothing further. Enjoying using his most valued gift of speech was behind him. In a sense he had already died. His ability to speak had been destroyed by his tumour:

My chief consolation in this year of living dyingly has been the presence of friends. I can’t eat or drink for pleasure anymore, so when

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they offer to come it’s only for the blessed chance to talk. Some of these comrades can easily fill a hall with paying customers avid to hear them: they are talkers with whom it’s a privilege just to keep up. Now at least I can do the listening for free. Can they come and see me? Yes, but only in a way. So now every day I go to a waiting room, and watch the awful news from Japan on cable TV (often closed-captioned, just to torture myself) and wait impatiently for a high dose of protons to be fired into my body at two-thirds the speed of light. What do I hope for? If not a cure, then a remission. And what do I want back? In the most beautiful apposition of two of the simplest words in our language: the freedom of speech.82

In the midst of this sad emotional self-talk, Hitchins became a listener and for the first time treasures the talk of people he recognises as his friends as he casts his gaze externally to his immediate situation hoping for a treatment induced remission. But not all the advice that Hitchins received was so welcome. Many people insensitively told him that they were praying for his conversion and that his cancer was God’s punishment for his public atheism. This he called “snickering”. In Talking Heads he wrote about the snickering:

Like so many of life’s varieties of experience, the novelty of a diagnosis of malignant cancer has a tendency to wear off. The thing begins to pall, even to become banal. One can become quite used to the specter of the eternal Footman, like some lethal old bore lurking in the hallway at the end of the evening, hoping for the chance to have a word. And I don’t so much object to his holding my coat in that marked manner, as if mutely reminding me that it’s time to be on my way. No, it’s the snickering that gets me down.83

Such insensitivity although offering nothing to the person with cancer is a common but unwelcome experience of atheists. Soon after the death of Carl,

82 Hitchens, “Tumourtown

Winnie Winland in a Facebook entry wrote that “I'm not surprise[d] to know that some people had the audacity to come up to Ann after her husband’s death asking if he had came back to god. Was that all they cared about? Whether Carl Sagan was a god-believer? It's disconcerting. Anyhow, I'm moved by Ann Druyan and how she valued her days in life with Carl Sagan much more than the prospect of seeing him again in the afterlife (If there is one).”

The evidence shows that snickering comments made to atheists and agnostics are distressing to them. The people that snicker are demonstrating a “poor theology” that demands punishment for unbelievers. The responses made by atheists are interesting in that the atheistic persons’ responses indicate that they greatly value the life experience that they have enjoyed. This can be in contrast with many creedal people who take life for granted. It is only after a crisis, like that provided by cancer, that many come to some appreciation of the gift that life itself is. Maybe this is why thanksgiving prayer is so common amongst cancer patients almost irrespective of their personal spirituality as is revealed in this research. Cancer brings all people to an appreciation of their life and gifts.

The spirituality of atheists is complex. In exploring options they often wonder what it would be like to have a faith that included belief in a god. But they see no logic in the practice of creedal believers as they understand creedal belief

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to be. They prefer to receive advice from like-minded people. Mike was an atheist, whose wife had breast cancer. He blogged and Nora Miller responded:

This is a time when we kind of wish we had faith since it can be a source of solace and comfort. I can't make myself believe however and actually seeing my wife suffer the pain and nausea of chemo makes me doubt even more the existence of a god. If I were to somehow magically come to believe in a God it could not be the all loving God the xtians want to believe in. How could a loving God put the people he ‘loves' through all this and be good. Besides the no obvious source of support that comes from a religion and a religious community is the imposition of a faith I don't share upon us by those who do. All the prayers offered is just something we have to gracefully ignore in order to keep the peace and acknowledge the intent of the prayers and well wishes.

[Reply by Nora Miller]
Mike, it might seem a little easier to bear your struggles if you had religion behind you, but as you note, a lot of xtians face a real crisis of doubt when they realize that their god has apparently abandoned them to the vagaries of illness and pain. I agree that it amounts to the most solid evidence for the human-mind source of all religious fantasies that anyone would say "god so loves you that he sent you this burden of disease to improve yourself." Belch. I hope you have some non-religious friends who can help you through this.  

Mike thought that religious belief made struggles easier to bear. However he expressed the dilemma that is often expressed by religious people too when they ask “how can a loving God send such suffering to those whom He loves?” And Nora offered a similar belief in the fantasy of religion and hopes that Mike can receive like support from non-religious friends. Indeed many devout religious people also struggle to understand how a good God can allow those He loves to suffer so greatly.

In summarising the findings of *atheist self-talk*, the CAQDAS assisted the analysis of the stories studied and found similarities with prayer as defined for this research.\(^{86}\) Internally, *self-talk* expresses wish, hope and intention for improvement; externally it seeks actualization through engagement with others especially like-minded people. The cancer narratives indicate that atheists and agnostic people displayed an intense appreciation of life and a heightened awareness of the value of genuine sympathy; the latter is clearly distinguished from malevolent patronising or snickering as Christopher put it.\(^{87}\) Their prayer becomes action prayer when its expression is via postings and blogs on websites such as the thinkatheist.com/forum/topics/help-think-atheist-fight-cancer website.\(^{88}\)

### 8 Good prayer and “bad prayer” in cancer

The label “Good Prayer” can be ascribed to all the quotations in this chapter to date. All have contributed to the patient’s well-being. So what is bad prayer? Does bad prayer exist? Prayer arising within the context of *bad theology* can be called bad prayer. Angela wrote that *bad theology* can best be defined as theology that is oppressive, manipulative, destructive and narrow. It is almost always based entirely on concepts of reward and punishment”.\(^{89}\) Arthur wrote that:

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\(^{86}\) See Chapter 2: 3. Prayer defined.

\(^{87}\) Hitchens, “Tumourtown.”

\(^{88}\) Mike. “Atheist Cancer Stories: Wife with Breast Cancer.”

I confess that I did ask myself how the tumors had gotten there to begin with. I do not recommend such thinking. It seems better to believe that cancer just happens. But at the time I could not resist asking "why me?" And this question led me to a sense of past inadequacy. A woman I know who has ovarian cancer believes that it was caused by an anti-nausea drug she took when she was pregnant. Unlike most of us, she can ask herself "why me?" and find answers that are not fantasies of self-blame. But for those who do not have such a direct physiological cause, the answer to "why me?" is bound to involve guilt. As the prayer I learned as a child in church said, "We have left undone those things which we ought to have done, And we have done those things which we ought not to have done, And" — here's the punchline — "there is no health in us." What terrible words to put in the mind of a child! It becomes all too easy for an ill person to work back-ward: If there is no health in me, then I must have done something wrong or at least left something undone. This kind of confessional thinking led me to all sorts of regrets. It is proper to meditate on how you have lived so that you can become the person you want to be. But it is a sad mistake to believe that cancer is caused by something you have or have not done. To believe my own inadequacies were so spectacular that they gave me cancer is just vanity.\(^{90}\)

Asking the question “Why me?”, as did the lady with the ovarian cancer, is common in cancer, but when accompanied with excessive introspection around bad theology such as previous sin it can become a form of bad prayer. Arthur understood it as a vanity or a falsity of self-blame, but for so many it leads to depression and for a few, to suicide. Elizabeth Kübler-Ross described this as rage and anger during which God is often the target\(^{91}\). And indeed, one of this research’s exemplars, Lyn provided an example of rage and anger directed at God:

So, it seemed logical, at least to my emotional self, to ask God why everything was so hard. “Why aren't things going easier for me?” I


cried out. "Would it be too much to ask to feel normal again for just a couple of hours?" But I heard only silence from heaven. At that time, the treatment for colon cancer was weekly for a year (with a break every few weeks). About five months into my treatments, I was driving to my oncologist's office and talking to God. "I don't think I can take this anymore," I told Him. (I figured that since He knew even my thoughts, I might as well say them out loud and get them off my chest.) "I've been praying to You and lots of people have been praying to make this easier on me, but it's getting worse. I'm not a quitter, so I'll keep going. But I don't know if I can take another seven months of this," I said as the salty tears rolled down my cheeks.92

Lynn was really angry with God, but this was not bad prayer, but rather angry prayer. Anger is an entirely proper emotion within the sense of loss. She had no misgivings arising from her past life. She would soon move on to a phase of acceptance and thence she became a cancer patient advocate committed to helping others with cancer. And her prayer showed a healthy transition from her angry prayer to good prayer. This research contained other examples of people making transitions from angry prayer to good prayer but contained little evidence of people remaining in a state of bad prayer.

Bad prayer was also seen as sourced in inaccurate and outdated medical information in some cancer narratives. This was demonstrated more frequently in the accounts of internet blogs and was identified by Sylvie who wrote that misguided information like that proffered by some of the respondents to her blogs about her breast cancer could have caused her harm if she had refused surgery:

But some made me sad, and I'll explain why…
In times like these, one can expect that some people are going to be absolutely convinced that medical doctors have it all wrong. And for the most part, I do agree that doctors don't know everything. It wasn't

92 Eib, When God and Cancer Meet, 4.
that long ago that the medical profession didn’t “believe” in germs and the cure—all of the day was leeches and bloodletting. However, medical science has come a long way since then, and I am so grateful that it has. Even 20 years ago, a woman diagnosed with breast cancer didn’t have the advantages we have today and survival rates were much lower.

So when I read the advice of some of the well-meaning advice givers who suggested that I refuse the mastectomy and opt for other alternative treatments, or just leave it to God who would heal me instantly, it made me sad. It made me sad because there are women out there who would choose that advice without consulting their doctor, and die needlessly, primarily because they would rather not face the truth about their illness.

Thankfully, I am of the belief that God works through doctors just as much as working directly with my body to heal it.93

A carer’s poor attitude can harm the spirit of the cancer patient, causing feelings of depression or hopelessness resulting in bad prayer. Melvin Thompson identified two possible attitudes that a carer might adopt: “either ‘You are dying. You are not like me, for I am living’, or ‘You are living; although your life, like mine, is fragile’”.94 Clearly, the second of these can promote love, acceptance and wholeness of personal life (integrity), whereas the first is destructive of all these things.” Amy was the wife of Mack, who had oesophageal cancer. She described her interaction with a chaplain who exhibited the first of these poor attitudes:

Father David, a chaplain they visited with, told Amy that this cancer would advance. “He asked me what I would do then, for we had already had our miracle,” Amy said. "What a thing for a chaplain to say! I'm sure he wasn't thinking, for I've never read that miracles are rationed."

This same chaplain appeared at Mack’s bedside one night during a life-threatening emergency. He told Amy and the doctors and nurses in Mack’s room that he’d felt a hand on his shoulder, shaking him awake.

93 Fortin, Did You Just Say Breast Cancer?

94 Thompson, Cancer and the God of Love, 32.
Father David said he felt that Skaggs needed him, so he put on his clothes and drove to the hospital. While he was reading Mack his last rites, Mack regained consciousness.95

Father David was focussed on himself and lacked sensitivity to Mack’s situation and needs. So his interventions can be seen as inappropriate at best or of little value to the patient or to Amy. At the end of this cancer story, Amy wrote that “on January 21, 2002, we reached the nine-year milestone,” she said 'that is a miracle!'"

In summary of this section, prayer can be described as bad if it adversely affects the well-being of the cancer patient. Sourced in the patient, it is characterised by self-blame which can be real or just perceived. It can also arise from advisers or carers, who despite their intention to help, provide inappropriate or ill-informed advice that affects the patient’s well-being. By contrast “good” (healthy) prayer was exemplified by all of the examples quoted in the earlier part of this chapter. The patient storytelling contained a majority of references to prayer that quoted scripture, to prayer that gave thanks and to meditation. Reflecting back on the previous chapter good prayer was seen associated with finding and resting in God’s presence in the cancer experience.

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95 Mack Skaggs, "Happy Together, Couple Faces Cancer's Uncertain Road."
8 Connections

Figure 6.4: Word Frequency Cloud for Chapter 6.

This chapter was the third presenting QDA results: this chapter focussed on prayer. God (132) is at the centre and one (36) is prominent, as was presence (22). The prayer (97) of cancer (129) patients (42) includes thanksgiving* (85) and meditation (43).

*thanksgiving here combines thanksgiving (31), thanks (29), and thank (25) to yield a total of (85) as quoted above.

In this and previous two chapters, the journey saw the deployment of its methodology to the dual ends of making findings and of presenting the results of the CAQDAS: it found that the cancer patients studied revealed their well-being through their emotions; it found that spirituality expressed through the self-talk was prayer; and that patients’ prayer arose from gratitude, which for many led to an altered life and for some new ways to pray. The next chapter advances the journey by engaging in the discussion of these results and making comparison
with the published research of oncology professionals and with the prayer experience found in the spiritual classics. Thus it establishes its place in the contemporary literature for the research findings derived from the stories studied. It looks towards the goal of the conclusions, stated in the final chapter: on the significance of storytelling as it reveals the proper relationship of prayer and well-being for oncology patients; and of the relevance of classical spiritual writers for today’s cancer patients; and of its meaning for oncology practitioners.
Chapter Seven: Reflections on prayer beyond asking

1 Introduction

At all times this research strove to let the patients speak: it strove to hear deeply, in order to understand what they were saying. This chapter is about what this study “heard” the patients say about prayer and about well-being and to compare the findings with published research and reflect on it. The storytelling of each patient’s cancer experience provided the data source. Storytelling is prayer arising from the spirituality of the person. Grounded Theory was used as the method to perform the unpacking and qualitative analysis of the findings. As mentioned the approach taken was from the “bottom up” in the sense of John Polkinghorne. Thus, predicating reflection that was not layered exclusively into the top down discipline specific shells of oncology, psychology or theology, but which contained many transitions when making interdisciplinary comparisons and contrasts. GT was effective in reaching an understanding of what the patients were saying. Throughout this research, the reflection followed the cycle described by Nancy Ault in that it

“moves from experience to reflection and back to experience”. The phenomenological part of the methodology involved a double hermeneutic: it required achieving an understanding of how the patients were making sense of their personal cancer experience and also required that this research strive to understand the emerging themes. This reflection strives to place the findings into the domains of published oncology and theological researchers. In respect of the latter, the theological reflection sought to find where the patients had found God’s presence in their cancer. Such reflection follows in this chapter, and the conclusions that arose follow in the next chapter.

To date most oncological research has been quantitative. The researchers employed a methodology primarily designed to satisfy the paradigm of the researcher’s discipline, mainly medicine or psychology rather than centering on the patient. In such professional discipline-driven research, it was frequently stated that prayer takes the form of petition or intercession, arising in response to the unwanted and potentially life-threatening experience of cancer. This was particularly seen in the documentation of researchers

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influenced by the “medicalization of culture”. The research being discussed here, revealed that in addition to petition and intercession, the prayer of cancer patients extended far beyond just “asking” and that prayer was strongly associated with well-being. This research made no a priori assumptions in relation to its model than: (a) to assume that the approach to be taken was qualitative and not quantitative, (b) that the patients’ stories were rich in meaning, requiring unpacking to understand what the patient had expressed, and (c) to accept that every patient’s cancer experience was unique and, even if uncommon, had value.

This research identified many themes through its analysis of the stories and the detailed results were presented in the previous three chapters. The goal here is to discuss the correlations that emerged from critical analysis of the patients’ storytelling and further, to seek validation in the light of the findings of oncological and theological researchers.

The ensuing dialogue of this chapter takes in: the relations between prayer and well-being; the quintessential prayer elements of the patients’ self-talk and meditation; and the paradox of patients telling their personal story to help others, while often not taking sage advice themselves. It concludes by

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5 Cancer and the associated problems (including well-being) are seen by doctors as an illness requiring intervention. Obviously, cancer must receive medical management. But if management is limited to this, significant aspects of the patient’s needs are left unmet. Medical dominance often results in managing only the medical dimension of the patient’s oncological problems. James N. Nelson, *Psychology, Religion, and Spirituality* (New York, USA: Springer Science + Business Media, 2009), 532.

6 In this QDA “correlation” expresses similarity of words and does not imply causality or relationship in the senses found in quantitative research.
identifying significant findings on the healing associated with the storytelling process and revealing a special kind of listening beneficial to the patients.

Chapter five demonstrated that a patient’s spirituality gave rise to well-being and also to prayer, suggesting a mutual link. This finding is consistent with the evidence that is starting to arise from other researchers. The GT methodology showed that patients expressed their well-being in a number of ways in their narratives and that differences were discernible between women and men. Consistent with the GT approach taken in this study, Sarah Winch suggested: that quality of life must be seen from the patient’s perspective; and also that quality of life and well-being were synonyms. The Krishna Mohan definition for well-being was used because recognised the need to keep both the subjective and existential elements of the patient’s cancer experience in balance. This had identified a depth and sophistication of well-being expressions that are not seen in the definitions of discipline limited research, such as are frequent in psychology and medicine. Psychological and medical research can become constricted in relevance and application when the

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methodology fits the patient into a pre-conceived, incomplete definition set of prayer or well-being.

2 First reflections

The patients’ perceptions of cancer and particularly the words used to describe their feelings, in the stories of this study, were understood to be clear indicators of the patient’s well-being at the time and arguably, they were also expressions of prayer. Generally the analysis showed that the patient could quickly pass through several stages of emotions after the initial diagnosis.

John Paver had experienced similar fluctuations of his emotions during his cancer. Reflecting on this interplay of weakness and strength in his cancer experience, he advocated what he called a theology of the cross. “There is interplay of weakness and strength, death and life. We are weak in him, but we shall live with him, by the power of God. The crucifixion of Jesus was not the final work in the life of Jesus, but the crucifixion and its implications seem to be the essential word before the final word.” Paver points to the paradox of weakness and strength manifest in his theology of the cross as having a parallel in the extreme emotions experienced by cancer patients and as he experienced them in his own cancer. Paver wrote “Paul, when talking to the Lord about the reasons why he was experiencing all this pain, complained so

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10 See the early sections of chapter four pp 96-99.
11 John E. Paver, Theological Reflection and Education for Ministry (Great Britain: MPD Books, 2006), 74-5.
much that the Lord said to him: ‘My grace is sufficient for you, for my power is made perfect in weakness.”\textsuperscript{12}

Amy Smith and her colleagues had reported similar findings of frequent changes in a sense of well-being along the cancer trajectory.\textsuperscript{13} The patients of this research in their narratives had used 68 different words to describe their feelings, which ranged from \textit{confident} to \textit{upheaval} at the extremes. The top two expressions by women were \textit{fear} and \textit{devastation}, whilst for men they were \textit{happy} and \textit{acceptance}. The stories of this study contained no explanation for these gender specific expressions. That the female emotional descriptors were darker than those of the men in this study, could be understood to mirror the findings of Wendy Trenor and her colleagues who, in their psychometric analysis of rumination, found that women are depressed more often than men; which they attributed to increased brooding rumination by women when compared to men.\textsuperscript{14} They had concluded that the brooding factor of rumination is associated with greater levels of depression; hence, the darker emotional expressions of the women.

Clive Seale’s phenomenological finding on the qualities of character displayed by people with cancer, in news reports, concluded that “courage predominates in character portrayals of women, whereas a hard-working

\textsuperscript{12} Paver, \textit{Theological Reflection and Education for Ministry} 74. Paver cited 2 Cor 12:9.
\textsuperscript{13} Smith, “How Women with Advanced Cancer Pray: A Report from Two Focus Groups,” 314.
character is more the preserve of men".\textsuperscript{15} If the women in this research were “fearful” and “devastated”, then \textit{courage} would be a characteristic necessary to progress towards survival. Whereas for the men the \textit{hard-working} characteristic, described by Searle, would be appropriate and consistent with my findings.

The first reflections suggest that GT, whilst remaining a method of gleaning information could not inject an exegesis that was not already contained in data that was existentially real. This research was sometimes unable, in a situation with well correlated findings, to find a rationale for the prayer or well-being expressed. The psychometric analysis of Trenor and colleagues above in postulating a brooding factor to account for the darker emotional expressions, found in their studies, goes further than the possibilities of GT but would require further empirical experiment to be conclusive. Searle' phenomenological suggestion that the “hard working” characteristic of males is the reason would be challenged by many; his journalistic experience obviously led him to this rationale; however, his conclusion is consistent with the findings of this research but in neither is a rationale found.

John Paver offered a theological reflection for the strength/weakness paradox experienced by many with cancer which would provide a comprehensive conceptual framework for their cancer experience. His concept, which can be paraphrased as “no cross without the resurrection” is

well founded in the Bible and in the lives of Christians over two millennia. Paver offered a rationale which is based in the Christian belief in the salvation that is effected through the death and resurrection of Jesus Christ. This is visible in the celebration of the Paschal mystery in the Paschal candle whose light symbolises God’s continued presence in all of the events of life; the joy and thanks expressed by the patients studied are the fruits of the Holy Spirit in the minds of Christians. In a recent interview Archbishop Welby had said about his grief at the tragic loss of his daughter “That was one of the moments when — and my wife would say the same — when we were closest to the reality and presence of God in the bleakest, bleakest darkness. But He was there with us, in the darkness, Christ was with us. I can’t remember ever … any moment where there was such a sense of grief and such a sense of love, present at the same moment. Love from God to us. And grief at the loss of our daughter.”16 Despite the grief occasioned by loss and the traumas associated with cancer, reflection revealed that faith in God in the Christian tradition, provided a constructive means of moving on, that was indicative of the best well-being possible in the circumstances. In some manner, cancer patients could find God’s presence existentially in the cancer experience.

Further reflection follows after two charts are repeated for convenient access to the findings of what the patients said about well-being (figure 4.1) and about how they prayed. (figure 6.1). The current analysis of the storytelling revealed that well-being was strongly correlated ($Pr=0.95, n=1946$)

to other parameters particularly to self-talk (9%), advice to others (18%), and meaning for life (19%). And along with the expression of emotions, these three are all indications of an active spirituality and of prayer.

![Well-being Expressions by Cancer Patients](image)

Figure 4.1 (repeated): The expressions of well-being.

The expressions of well-being made by cancer patients broken down by gender, plotted against the total number of references to child nodes of the well-being parent node found in the collection of cancer stories. (The female value appears first in each pair of bars and is coloured red). The 1491 references exhibited a Pr of 0.95 based on word similarity.

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17 Refer to figure 4.1 repeated above for convenience. The total number of references to well-being expressions = 1946, with a Pr = 0.95. NOTE: Pr denotes Pearson Correlation Coefficient.

In the story dataset, patients were seen to pass through stages, which could be understood as an indication that well-being cannot be ranked absolutely but relatively, as if locating along a scale between better to poorer, except when the patient remained in a “bad” state typified by being depressed or suicidal. The Mohan definition of well-being required a subjective element. Expressions of well-being that were found in a patient’s narrative were considered evidence that this subjective element existed. This is consistent with there being a strong relation between prayer and well-being, albeit not a causal relation, but rather one of congruence based on similarity of words found in the patients’ stories.

The complete set of ways that cancer patients pray was presented in figure 6.1 (reproduced following) where the 605 coded references to prayer are differentiated into their types. The commonest types of prayer, comprising more than 50% of the whole were thanksgiving, meditation and resignation; whereas asking prayer was just 12%.

19 NOTE: This dataset of stories contained 465 instances where the coding indicated YES spirituality existed and only 18 NO’s.
Chapter 7: Reflections on prayer beyond asking

Figure 6.1 (repeated): How cancer patients pray.

The popularity of the forms of prayer found in the stories of 160 cancer patients as determined by frequency of coding count of references. Meditation, thanksgiving, and scripture quoted were the most popular forms and gender based differences are seen. (The female value is coloured red and appears first in each pair of bars in the figure).

This mirrors the finding reported by Laird and colleagues who found that meditative prayer was more common than petitionary or colloquial prayer.  

The discussion now moves to reflecting on the details of prayer that can be considered as contributing positively to well-being. It commences with the petitionary and intercessory forms of prayer that asks. It moves to the more

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unique findings of this research in discussing prayer quoting scripture, prayer that thanks, the deeper quintessential elements of cancer prayer of self-talk and meditation. Finally, it discusses the consequence of cancer storytelling with its pastoral implications under the heading listening.

3 Prayer that asks

Much of the published research oncology literature that mentions prayer, concerns prayer that asks. In common with these researchers, this study also found accounts of cancer patients praying for what they wanted personally. Patients made petitions such as for a cure for their cancer (25 references) or for both spiritual and physical healing (21 references). Some offered prayer for others (16 references to intercession). Cluster analysis, based on word similarity with well-being, indicated a slight level of congruence based on the Pearson Correlation Coefficients, for petition (Pr = 0.51), for healing (Pr = 0.50) and for intercession (Pr = 0.47). John Pérez and his colleagues had described a lower level of depressive symptoms in patients using intercessory prayer because, he said, of the greater social support occasioned by praying for others. A gender difference in relation to frequency was noted within petitionary prayer in the stories studied, where 18

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references were found amongst female patients and only 7 amongst the males.

Briefly in summary of asking forms of prayer, the findings of this research were shown to be consistent with published findings. In common with them, it indicated that these asking prayer forms were only moderately correlated with their storytellers' well-being. However a significant degree of self-less-ness could be seen in that intercessory prayer formed the bulk of asking prayer; the good that was requested was for another, not solely for the person praying. Reflection on the findings of this research on the more common forms of prayer beyond asking follows: and much stronger correlation between these more common forms of prayer and well-being will be shown. But before that, reflection on prayer that quotes scripture, poetry or images is presented because it shows the importance of gratitude as a source of prayer and well-being.

4 Prayer that quotes scripture, poetry or images

The basic issue underlying this reflection on patients who used scriptures, poetry or images in their prayer is where they found God in the cancer experience. From the patients' perspective, the quest was similar to St Anselm's "faith seeking understanding" or paraphrasing this to reflect their more existential focus, "faith seeking connection" with God's presence. For


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Christians the faith is in the action of the Holy Trinity in their lives. For atheists the faith is belief in the existence of basic all-embracing laws in nature.

The patients who visualised God’s presence in the cancer as one or more of the three persons in the Trinity were following centuries old Christian tradition. Anne Hunt had traced the “extraordinary rich veins of Trinitarian spirituality” in the Christian gospels. In another work Hunt traced the centrality of the Trinity in expressions of God’s presence in the teachings of Christian spiritual writers such as Hildegard of Bingen, Julian of Norwich and Teresa of Avila to mention just a few. The Holy Spirit was seen as being present in the difficulties: consoling, teaching and praying for and with the patient. Julian of Norwich saw a healing presence of the Holy Spirit that arose when the sick person sought to understand the “dread” of their “weakness”. In Revelation 73, she said “He will not be able to know the gentle strength of the Holy Spirit until such time as he understands what is meant by this dread of pain, of physical death…These doubts which tend towards despair God will


have turned into love through our knowledge of his love.”

Expressing this in terms of this research, Julian is saying that the self-talk of the cancer patient is prayer and that God is present in it.

This was seen in several passages used by the patients in their prayer. Five patients expressed gratitude for the presence of Christ living in them through the cancer; and desiring to be with Christ; Jesus was described as the guest bearing the perfect gifts. Missy Morrow saw the perfect gift of Jesus as coming from the Father. John provided the key to this theological reflection when he quoted Apostle Paul’s prayer to the readers of his epistle to the Ephesians. 

This beautiful passage makes reference to all three persons of the Trinity: to the Father as the source of all life and gifts to us; to the Son as dwelling in our hearts; and to the Spirit with power to strengthen our inner spirit. This belief Christians have through faith. Despite the many problems experienced in their cancer experience, this group of patients expressed their realisation and gratitude for God’s love and presence through his Word.


29 NOTE: Patients quoted that the Holy Spirit will pray when you can’t (Rom. 8: 28-30); provide comfort (Jn. 14:26); bring fruits to the cancer such as joy, peace, control (Gal. 5:22)

30 NOTE: Patients saw their suffering as a share in the crucifixion of Christ. (Gal. 2: 19-20); (Rom. 12:2); shared Paul’s desire to be with Christ (Phil. 1:21-25); Missy Morrow saw Jesus as bringing perfect gifts of hope, grace, comfort, peace, healing and love citing (James1:17)

They found the gift of “grace” in God’s presence in their cancer. Missy Morrow quoted “Every perfect gift, is from above, coming down from the Father of lights, with whom there is no variation or shadow due to change”.32 She wrote of her cancer as if it were a party to which guests came. The first guests brought gifts of fear, doubt, anger, and dread. The last guest to arrive was Jesus, who brought gifts of grace, hope, comfort peace healing and love. “After opening all the presents, I realized that Jesus, with the beautiful gifts He freely gives, was the only One I needed or wanted to stay”. She saw these gifts as coming from God whom the scriptural passage called the “Father of Lights.” This mirrors the Christian understanding of the way that the mystery of the “Trinity” informs the human experiences of life. Indeed, in this understanding, God does not need to be named or labelled in order to be present. God is present always.

The references to the prayer of atheists and agnostic patients contained faith as a source; but for them faith was taken slightly differently. Comparing atheists with religious people is difficult.33 Some “reconceptualising” of atheist prayer is undertaken in this research through the definitions of spirituality and prayer. But none of our patients claiming to be atheist made any reference to any source document such as the Bible. However cancer was the common


experience of the atheist and religious patient alike and some difference in how they pray was seen in their self-talk. The atheist patients very much valued “being alive” even though life was hard at the time of writing. Carl had described a “joy in the present”. 34 Their descriptions were very pragmatic. None used images or metaphors. Rosalie quoted “Yesterday is gone, Tomorrow is not here, Live for Today!” 35 More traditionally the quote reads: “The clock is running. Make the most of today. Time waits for no man. Yesterday is history. Tomorrow is a mystery. Today is a gift. That’s why it is called the present.”36 Even in its truncated form Rosalie’s use of “present” as a homonym, in her quote, is very much in keeping with the ideas of mindfulness and gratefulness of David Steindl-Rast. The atheist stories contain an indication that “telling it like it is”, in common parlance, may offer better well-being than inappropriate metaphor use with its inherent possibility of being incompatible with that of the oncology professionals treating them.

5 Prayer that thanks

Thanksgiving prayer received the highest number of references compared to the other forms that were coded; and this was found to be so in


36 NOTE: This quotation probably predates modern English. It is found in Alice Morse Earle, Sun Dials and Roses of Yesterday (Harvard University, USA: Macmillan Company, 1902).
the stories of both genders. However, expressions of thanksgiving were seen more frequently in the women's stories than those of men.

Figure 6.2 (repeated): To whom and for what cancer patients express thanks
The popularity of the things for which patients prayed found in the stories of 160 cancer patients as determined by frequency of coding count. Grateful prayer was distributed amongst ten items. Gender differences were seen in all parameters. (The female value is coloured red and appears first in each pair of bars in the figure.)

This finding was clearly shown in figure 6.2 (n = 226) which was derived from 605 coded references and also displays the greater popularity of other forms of prayer relative to the asking forms discussed in the previous section. Figure 6.2 demonstrated to whom and for what cancer patients expressed thanks. The nature of the thanksgiving was coded under ten headings. Each of these ten parameters exhibited differences between men and women. To achieve clarity in the discussion and to create groups of sufficient size to allow generalization, the findings are discussed here merged into four groups.
The groups listed in descending order of size are giving thanks for **support received**, making direct reference to thanks **to God for survival**, **just thanks** and expressing thanks for having **purpose in life**. All of the patients expressing thanks had demonstrated a spirituality in their accounts and had provided evidence of positive well-being. Slightly less than half of these references were made by creelal patients and the remainder were unassigned; i.e. their story made no reference to a religion or to being atheist or agnostic. This combined data is shown in figure 7.1 following.

**Figure 7.1: Combined groupings of to whom and for what cancer patients express thanks.**

This grouping merges 10 parameters of thanksgiving prayer into 4 clusters. (For purpose, for support of friends and family, to God for being present, to God for being Saviour, to God for past gifts, for survival, just thanks, for professional support and to people for reading story). Such expressions of gratitude comprise evidence of well-being. The findings of both genders are combined here. (n = 226 coded references).

The figure is a pie chart showing the groupings that are followed in this discussion of the findings on how cancer patients pray with thanks. This grouping merges 10 parameters of thanksgiving prayer into 4 clusters. (For purpose, for support of friends and family, to God for being present, to God for
being Saviour, to God for past gifts, for survival, just thanks, for professional support and to people for reading story. The findings of both genders are combined here. (n = 226 coded references).

The discussion on prayer that thanks follows now using the names of the four groups as headings: Thanks for support received, thanks made to God directly, just thanks, and thanks for meaning in life.

**For support received**

The largest group (n = 84, 37%) described gratitude for the support that they received from their families, friends or from those who read their published stories. It was noted in the previous chapter that both men and women thanked others: women thanked their friends ahead of thanking their families; whereas, the men recognised their families ahead of friends in making thanks for the support that they received. This research records this fact but found no explanation to be contained within the dataset of stories. The psychology literature proposes no definitive mechanisms either but does contain supportive paradigms. Clive Seale reported a similar finding in his research on cancer reporting in newspapers. And, offering a rationale, said: “Women are more likely to be portrayed as skilful emotional labourers drawing on other women for support … whilst the meaning men are shown as bringing to the cancer experience is more likely to arise from pre-existing qualities of character [family].” Tetyana Pudrovska also proposed a theoretical framework in which the cultural image of women had them caring for and

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37 Seale, “Cancer Heroics: A Study of News Reports with Particular Reference to Gender.”
nurturing their family. In cancer for women this becomes a practice of protecting the family by looking towards their friends. For males their hegemonic masculinity continues directed to their families, for whom the provider role continues to dominate even in cancer. Typically too, men have less intimate relationships outside the family than women, thus potentially augmenting their depression.

A third reason for thanks for support received, arose from gratitude to the professional staff who delivered their treatment. Fewest references to thanks were made to doctors (10 references in 37 sources). However, when doctors were given expressions of thanks, they were made in strongly grateful language. This is consistent with what Nila Webster wrote “He bowed his head, he closed his eyes, and he said, ‘that’s not fair.’ That level of empathy went straight to my immune system. It also gave me the opportunity to say, ‘But doctor, whatever life gives us is a chance for us to grow and become more whole people’. Once again, he closed his eyes, bowed his head, and said ‘Bless you.’ A benediction from a doctor can be as meaningful as pharmaceuticals or surgical instruments.”

Cancer patients experience an unequal relationship of power in relation to the treating doctors and often act from feelings of vulnerability. This research found more adverse testimonies, made by patients about their doctors, than favourable. Thus indicating that there is a need for the undergraduate education and continuing professional development of medical staff to support their knowledge and skill in the domain

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of spirituality. This would produce an improvement in well-being for the medical staff themselves and for their patients. Further, research into the kind of metaphors that doctors and patients bring to oncology would contribute immediate benefits to clinical practice and pastoral care. It may be that the oncology professionals’ cohort are protecting themselves from the repeated exposure to cancer or that they lack a depth of understanding of their own spirituality or that of their patients. Sadly, mismatches between the metaphors of some doctors and patients of this study were found to be frequent and the ensuing poor communication was shown to occasion poorer well-being.

**God directly**

Prayer made directly to God expressing thanks, forms the second largest group (n= 64, 28%). Patients thanked God for past gifts, for being present, and for the certainty of salvation. This is not surprising considering that 64 patients had provided direct evidence that they believed in God. Could not this response of thanks be linked with faith? The objects of thanks here are evidence of the action of God in the patient’s lives. On this basis they trust that God will be present to them throughout the trajectory of their cancer. This is faith, not a set of beliefs, but a trust indicating confidence arising from past experience. Such faith is linked to expressing thanks and to an attitude of gratitude and is found in traditional spirituality literature and only recently in what is becoming a burgeoning gratitude literature, both medical and

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psychological. \(^{41}\) Katherine Perch described ways to cultivate *gratitude* for medical benefit. \(^{42}\) David Steindl-Rast, a Benedictine monk, described a more spiritually grounded approach to *gratefulness* that is widely followed in the western world. \(^{43}\) One can wonder whether the findings on thankful prayer have provided some evidence, in the larger context of spirituality, that faith provides an explanation for the gratefulness expressed in the cancer storytelling. It certainly provides evidence for linking prayer with well-being.

Some support for this conclusion can be found in *the Clinical Psychology Review*, where Alex Wood and his colleagues concluded that gratitude and well-being are strongly associated in a “link that may be unique and causal”. \(^{44}\) Joan Borysenko supported this when she said that the Steindl-Rast practice of gratefulness aids well-being by cultivating mindfulness which will be discussed more fully in the next section on “meditation” within the section headed “Quintessential Prayer”. \(^{45}\)

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43 Steindel Rast, *Gratefulness the Heart of Prayer: An Approach to Life in Fulness*.


Just 5 of the 160 patient dataset took issue with God over their cancer. Despite this minority, this research’s findings on thanksgiving prayer can be taken as supported by the common viewpoint of medical oncology researchers on the commensal relation existing between spirituality, prayer and well-being.46

**Just thanks**

A small group (n= 47, 21%) of stories contained references to praying with thanks. They were thankful in a variety of ways which included thanks for their survival, or for healing, or for tumour regression, or simply for being pain free. The group is too individual to allow generalisation beyond saying that their expressions of thanks were clear indicators of gratitude for an aspect of their cancer that was immediately present to them. This is consistent with the findings of psychological researchers like Katherine Perch who see that people who “appreciate what they have instead of always reaching out for something new” enjoy better well-being in their situation.47 Further, it is consistent with the writings of Brother David Steindl-Rast who saw the “fullness of prayer in grateful living”.48

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For meaning in life

The final group (n=31, 14%) contained expressions of thankful prayer for the outcome of a re-organisation of their priorities in life and the creation of a new sense of purpose that the cancer had occasioned. Real spiritual growth is evident here: with three of the Gutierrez descriptors of the spirituality cycle stages being evident in (1) the experience of cancer; (2) making reflective interpretation of their situation and (3) how they entered a stage of prolongation.49 A variety of activities was found in the patients' stories which were identified in chapter 6. They included gratitude for the creation of a new normal (roadmap), deepening of faith, publication of books, development of websites and of posting internet blogs. All were activities to which they had never afforded the same priority before the cancer. The cancer was always described as unexpected and unwanted but was never ignored or denied by the patients in this study. All found ways to move forward into some form of survivorship through realising a new meaning for life. Victor Frankl, in describing the sources of meaning in life which was a goal of his logotherapy, wrote “Let me summarize. Life can be made meaningful in a threefold way: first, through what we give to life (in terms of our creative works); second, by what we take from the world (in terms of our experiencing values); and third, through the stand we take, towards a fate we no longer can change (an incurable disease, an inoperable cancer).”50 All three of Frankl's ways to


meaning for life were found within the narratives of this research. Martha Meraviglia, in describing her research on breast cancer survivors, also identified Frankl’s three ways and further found that “meaning in life and prayer are associated with greater psychological well-being.”

This study also found evidence that a significant percentage of storytellers described thankful prayer for the chance of some certainty in their life during and beyond cancer. Deborah Witt-Sherman’s work on breast cancer survivors described what was seen in this research when she wrote “Time, support, coming to terms with trauma, active self-healing, new perspectives, the creation of new mindsets, and acceptance of a new normal allow women to develop a new way of being in the world and provide an opportunity for growth”.

Recent medical and psychological interest is increasing into the domains of spirituality, gratitude and well-being. Prayer must no longer be seen as a psychological aberration requiring management. Results are reported that associate well-being with thanksgiving prayer in a positive way; but not exclusively so. Some researchers report depressive symptoms associated with some forms of prayer. This latter will be discussed in the next


chapter under the heading “prayer and well-being antonym”, where the strengths and weaknesses of this research are presented.

Synopsis of prayer that thanks

Reflecting back on this section presenting discussion of prayer that thanks, and striving to understand why cancer patients were indeed often found to be praying with thanks, required several layers of understanding. Different understandings between medical, psychological and theological researchers were revealed. James Nelson had noted “this, along with the disciplinary isolation that began in the early 20th century, has kept psychologists and theologians or scholars in religious studies relatively unacquainted with current work in each other’s fields. Christian theologians and scholars in other religious traditions often respond to older theories that are no longer of wide interest within psychology, and psychologists are often unaware of important aspects of the religious traditions that they study.”53 The strictly medical or psychological paradigms, whilst explaining some of the patients’ thanksgiving prayer expressions, exhibited limitations often seen to be imposed by giving priority to fitting the data to a paradigm rather than making the patient the focus. Future qualitative research may provide quantitative researchers with more complete definitions for the parameter driven methods and result in a commensalism that benefits the research in all disciplines and the pastoral care of cancer patients.54

colleagues would see a more complete mutual context arising from better collaboration amongst researchers deploying different methodologies. Psychiatrist and ophthalmologist Lee Sannella pointed to a need for professionals also to look inwards and re-evaluate their discipline’s historical acceptance of empirical methods, writing “we must begin to look again … at much of what scientism has tried to debunk as meaningless and worthless fantasy … we must embark on … the demythologizing of the myths of scientific materialism.”

The spirituality of **gratefulness**, particularly in the form described by David Steindel-Rast, offered the commonest link with the expressions of prayer for thanks found in the story dataset of this research. And the gratefulness paradigm was more consistently associated with the causality of the well-being of the patient than any other single factor in this cancer story dataset. A central theme of Christian spirituality is that gratitude arises from and expresses love. The patients studied expressed gratitude to God for being present in their cancer experience: thanks for God’s presence in the love of their families or friends; thanks for new purpose; thanks for past gifts. The love of their families, or friends or treating professionals or for new purpose or for survival. As one large group of patients expressed it as “thanks to God for being their Saviour”. God had shown love through the sufferings and death of

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Jesus. They found God in their own sufferings. The resurrection was proof that Jesus has power over suffering and death. Christians believe that abundant life is promised even though in the present cancer experience God may seem to be absent: “In a little while the world will no longer see me, but you will see me; because I live, you also will live”. (John 14:19).

This research indicates that further investigation into the concept of love giving rise to gratitude could offer benefits to the well-being of cancer patients. In his thorough review of gratitude and well-being publications, the research outcomes of Alex Wood and his colleagues confirmed our findings on thanksgiving and gratitude and advocated future research. He said that “future research is needed into establishing the mechanisms whereby gratitude relates to well-being”. 57 This is one of the indications for future research that is contained in the next chapter under a heading of the same name.

However, before moving to indications for research into grateful prayer, this discussion narrative must probe an inner layer of prayer that reveals itself as deeper than just asking or thanking: in self-talk and meditation.

6 Quintessential prayer

The discourse around this research’s findings on meditation and patient self-talk was considered as quintessential prayer when contextualised in traditional forms of spirituality and prayer. Patristic literature was consulted in order to inform this discussion by referencing the vast experience of Eastern and Western prayer over several millennia. To assist with the discussion at this level, all of the types of prayer identified in this

research, were clustered into three roughly equal groups, by number of sources (patients), as shown in figure 7.2 following. The clusters were thanks, meditation and asking prayer.

David Ranson had proposed a dynamic cycle of spirituality that contained four stages, or phases, derived from Bernard Lonergan; namely attending, inquiring, interpreting and acting. These offered a germane context for the discussion of the results of this research about self-talk and meditation. The experience of cancer was often described by our storytellers as moving them back and forth between emotional phases as was seen in the findings on the emotions reported in chapter 4.

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Figure 7.2: The ways that cancer patients pray clustered around the most common themes.

This is the same data as shown in figure 6.1 but here it is presented as the number of individuals clustered into the three commonest groups. These individual patients (sources) were coded from within the group “Yes I pray”; it does not include the 10 patients whose story lacked evidence of praying.

The frequent emotional shifts can be seen to mirror the cyclic movements of Ranson’s spirituality paradigm which provides for both forwards and backwards movements such as from acting back to inquiry (when the cancer diagnosis is made) then to interpreting (when meaning for life is being discerned) and thence making a return to acting.

The asking and thanking clusters are reminiscent of the “I-thou” structure that Martin Buber first identified and that Sebastian Painadath described as an “essential dynamic” of prayer. He would locate asking and thanking prayer as the dialogue of the “I” within the divine “thou” domain.

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Further he would see the *meditation* cluster as constituting the second essential dynamic which transcends the *I-thou* structure and “takes the person to the experience of the transcendent mystery and universal presence of the divine”. Painadath’s second phase is the ultimate quintessential form of prayer because of its essentially “naked” striving for union with God. This is reminiscent of the “naked intention” described by the unknown 14th Century author of *the Cloud* when he writes in the *Book of Privy Counseling* “see that nothing remains in your working mind but a naked intention reaching out to God, not clothed in any special thought of God, what he is or how he works, but only that he is … He is your being and in him you are what your are, not only because he is the cause and being of all that exists, but because he is your cause and the deep center of your being.”\(^{60}\) Clearly the author’s advice is to accept yourself as you are; you are your own cross.

A diversity was seen in the asking and thanking prayer ways and in their intentions and in that meditation was similar. The discussion of the findings of prayer continues under the headings of *meditation* and *characteristics*.

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Meditation

Figure 7.3: Meditation word frequency plot.

This plot gives a sense that the practice of all forms of prayer including meditation lead to GOD at the centre. The plot is a precise measure, whose lettering size is proportional to the number of times that a word or its synonym occurs within the text coded as meditation.

In this word frequency plot, the text size is directly proportional to the number of times that the words occurred in the most frequent 100 words coded under meditation. The words God, meditation, and prayer occurred more than 286 times each. Words denoting positive and good outcomes were prominent. Further, the following types of meditation were found represented with high frequency: contemplation, christian meditation, lectio divina, and mindfulness.

Counting the frequency of occurrence of words provides a reflection of the themes that are contained in the dataset. This plot of word frequency is not offered here in any statistical sense but rather as a linguistic profile.

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61 The following are the frequencies of the occurrence of these words in the stories under within the node meditation: prayer (286 occurrences), positive (240 occurrences), good (222 occurrences), help (134 occurrences), and healing (84 occurrences).
intended to indicate the themes that were important to the storytellers and of significance for the integrity of analysis.\textsuperscript{62}

Deeper analysis of the narratives identified three main findings in relation to the meditation, of the cancer patients. First, slightly more men practiced meditation (taken as an ‘umbrella’ term) than women. Second, no gender specific practices were found. And third, most of the patients, for whom meditation was a familiar practice, experienced a brief \textit{hiatus}. Completeness requires mentioning that some other patients commenced meditation following a “can’t pray” experience; there were 7 females and 3 males in all.

Firstly, just a few more males (76 sources) were shown to practice meditation than females (84 sources).\textsuperscript{63} Anna-Leila Williams and her colleagues recently reported a similar gender finding amongst cancer family caregivers. Her results showed that females experienced more gender based barriers to meditation.\textsuperscript{64} Williams cited a contradictory report by Patricia Barnes and her colleagues, in their collation of the National Health Statistics, who had reported that women used “meditation at a higher rate than men”.\textsuperscript{65} However a close reading of the Barnes report failed to find her evidence for this conclusion. The references to meditation there showed an overall increase in the use of meditation between 2002 and 2007 but contained no gender

\begin{flushleft}
\textsuperscript{63} Figure 6.3 contains the data showing that slightly more males than females practiced meditation.
\textsuperscript{65} Leila Williams, “Barriers to Meditation by Gender and Age among Cancer Family Caregivers,” 26.
\end{flushleft}
breakdown.\textsuperscript{66} The Barnes report was based on the US population; this is a restricted demographic compared with that on which this research is based. Further research is needed to determine decisively whether, as indicated by this research, that more men than women practice meditation and to propose a mechanism for this effect.

The second of the findings, was that five of the six commonest forms of meditation were practiced by both men and women.\textsuperscript{67} The practice of prayer using aspirations was reported only by males; however the small number of references provides no basis for any further conclusion beyond this observation. Significantly more men than women described contemplation and Christian meditation. No detail was found within the patients’ narratives that could account for this. And neither was evidence found in the research literature for such a gender difference. Also, no gender specific outcomes of meditation were found in this research. Certainly a general improvement in well-being was seen in the narratives and this is well reported in the literature. Only one article was found that reported a physical benefit to females from meditation.\textsuperscript{68} The meditation practice resulted in longer telomeres in a small sample (N=15 + 22 control participant) females; Hodge and colleagues associate this with longevity. In summary, both women and men were found to practice meditation with benefit to their well-being.


\textsuperscript{67} Figure 6.3 contains the data giving rise to this statement.

Thirdly, patients regularly meditating, reported a *hiatus* during their cancer experience, but returned to their practice on the other side of the “dark night”. Which they described as a dark night of the “soul”, of the “senses” or a “night of nothingness”. Much of the psychological literature would depict such a dark night experience as abnormal and to be avoided. However cancer patients cannot avoid the onset of the cancer. Nor can patients avoid the silences and the *not-doing*. So it is a reality that arose from their cancer experience, not a pathology arising from some delusion sourced in an unhealthy sense of *self*.

All of our patients reported returning to meditation after a *hiatus* except Ernest Larkin. The common “dark night experience” is more consistent with that described by St John of the Cross, for whom the dark night of the soul was a purification preparing the patient for greater union with God. John of the Cross did distinguish between the dark night experience and depression.

Ernest Larkin, an exemplar for this research, was the exception, in that he described the dark night, but not in the context of his own cancer. It is probable that his cancer trajectory was too short to show differentiation. Looking back in time, seeking previous references to the “dark night”

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metaphor, used in the context of illness, one can find that Augustine Baker, a Benedictine monk (c. 1657 CE) wrote a chapter in his book, *Sancta Sophia*, about how prayer is to be practiced in sickness. Baker characterises spiritual aridity as a common experience amongst seriously chronically ill patients. Baker left no doubt that sickness offered opportunities for meditation in a contemplative form that he called *not-doing*:

> The state of sickness; which though it do exact a greater solicitude and vigilance, as being a disposition to a condition irreversible, yet in itself it is a more secure state than that of external employments, in as much as those are such as are apt to draw our affections from God to sensual objects; whereas in sickness all things do rather drive a soul to seek and adhere unto God, since all other comforts do fail her, and all pleasures become distasteful to her … for the chief business of a sick person is forbearing and holding of patience; in a word it is rather a not doing than doing.73

Baker’s reference here to praying by “not doing” rather than “doing” is understood by scholars of spirituality as being a reference to a “cloud of unknowing” that an unknown 14th century author had described in his treatise, *The Cloud of Unknowing* and the *Book of Privy Counsel*.74 Evelyn Underhill saw a transcendence in what she called this “‘ascent to the Nought’ experience in which one is ‘broken, yet not divided’”75. When considered from the paradigm of Christian spirituality, the “dark night” can be understood to be a purification in preparation for greater union with the “One”.76 But the


75 Evelyn Underhill, *Practical Mysticism* (USA: Dutton 1915), 122, 125.

possibility of confusion with depression always exists because although “the two conditions may … be distinct in their causes… we cannot so distinguish them, at least as experienced.” So in discerning whether this hiatus in prayer is a normal process in reaction to this patient’s cancer or is an abnormal condition, it should always be considered whether the person gains inner transformation (spiritual dark night) or feels that nothing can replace what is lost or that life has become meaningless without any obvious reason (depression).

The dark night experience of all of the patients who experienced a hiatus in their meditation practice was most likely just that, because it was causally associated with their cancer, being thus a “normal” experience. Paradoxically, such an “inability to pray” could be understood as quintessential prayer.

The findings reported on meditation and the discussion to date have produced a contextualised account with a sound justification for their transferability: because of the rigorous application of GT methodology in performing the analysis. It has provided indicators of parameters that would benefit from future quantitative evaluation.

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Characteristics

The findings of this research lead to visualising meditation as a process in which the patient finds and dwells in God’s presence, however understood, within their cancer experience. The characteristics of meditation found in the storytelling were: seeking and dwelling in union with God (or the One); being mindful and integrative of present moment experiences (cancer); and could contain both active and passive elements. Such meditation is seen as prayer, although not exclusively so. Self-talk is prayer, but not all prayer is self-talk.

One of the storytellers studied was John who expressed his concept of meditation as “Acceptance of our own being, as we are, at this moment in our life’s journey. That is what meditation is about.”\(^{79}\) In another place he had emphasised \textit{presence} rather than \textit{function} in meditation writing “when we meditate we are not trying to do anything: we are simply attending to the reality of the divine Presence and learning to be in that Presence.”\(^{80}\) John saw that it was characteristic of all meditation that the patient reached an acceptance of and integration of the current cancer experience with their experience of God’s presence, however understood. Further, that this union with God was in the present moment. He frequently stated that the use of a mantra was essential to maintain the mindfulness and to ensure perseverance.\(^{81}\) John’s own spiritual journey into meditation had commenced when he, as a Christian, was taught to meditate by Swami Satyananda, a

\(^{79}\)Freeman, \textit{A Short Span of Days}.


Hindu. As a Benedictine novice, he was told to relinquish this “eastern practice”. And only years later, after enduring a long period of aridity, “spiritual desert” he called it, did he revert to meditation with a mantra after reading the *Conferences* of John Cassian, (c. 360- c. 435 CE) an early influential Christian mystic.\(^8^2\) The tradition and practice of “living in the present moment” is found in the writings of many spiritual classic writers. Typical of these is the eighteenth century French Jesuit writer Jean-Pierre de Caussade.\(^8^3\)

Typifying the classical literature of practical mysticism, Evelyn Underhill described meditation as “orison” and set out the analogy of St Teresa of Avila to the four ways of watering the garden of the soul, as a good example. “[Meditation in the first stage in which the person actively works] is like drawing water from a deep well… whilst in the fourth and highest stage, God Himself waters our garden with rain from heaven, ‘drop by drop’ [the person is totally receptive to God’s action]”.\(^8^4\) Underhill had no doubt that meditation was prayer and that the ultimate effect was “the cultivation of this one flower-this Rosa Mystica which has its root in God”. Underhill described “a progressive surrender of selfhood under the steady advance of conquering love; a stilling of that ‘I, Me, and Mine’”.

The meditation practices of this research’s dataset are characterised by an integration that was made between the cancer experience and the patients’

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\(^8^4\) Evelyn Underhill, *Mysticism* (Meridian, 1955), 311
spirituality. The operational aspects of meditation were never seen separated from the religious/cultural context. This is in common with both the Eastern and Western meditation paradigms as is revealed in any review of classical spirituality literature.  

Amanda Brown and her colleagues agreed with the antiquity of meditation when she placed the origins of mindfulness beyond Buddha’s time and into the ancient yogic practices thousands of years earlier.  

However in the comparatively recent medical research literature since Herbert Benson, meditation is operationalized into a technique without a spiritual context. Benson wrote “The Relaxation Response is a universal human capacity, and even though it has been evoked in the religions of both East and West for most of recorded history, you don’t have to engage in any rites or esoteric practices to bring it forth”. Benson showed that his transcendental meditation (TM) produced the same beneficial physiological changes as Zen and Yoga without requiring a religious or spiritual context. However nine years later Benson asserted the benefit of a belief context for achieving the benefits of the


88 Benson claimed that his Transcendental Meditation(TM) technique produced identical decreases in oxygen consumption, respiratory rate, heart rate and blood pressure plus increases in alpha waves as were measured during Zen meditation and Yoga. His technique for practicing TM required no religious or spiritual context. Benson, *The Relaxation Response*, 70.
relaxation response, when he described the “Faith factor” as an adjunct to his TM.  

Psychologists, influenced by Benson and following Jon Kabat-Zinn’s practice of mindfulness meditation also view it as a technique, unrelated to any belief system. “Because mindfulness is really about attention, it is, in essence, universal rather than Buddhist…and is taught within the context of [Mindfulness–based stress reduction] MBSR not as a Buddhist practice but as a common sense approach to self-observation, self-awareness.” This issue cannot be solved from the studied patients’ stories but is highlighted as needing further collaborative mixed method research into the origins and mechanisms of meditation.

Nancy Schoenberger and her colleagues also noted the relatively recent interest in meditation by medical and psychological researchers, and they note that this group have introduced a dichotomy between prayer and meditation. This is in the face of the research findings that show that meditation practiced in the context of a spirituality is prayer and is associated with better medical outcomes. Brenda Cole and her colleagues concluded that “this study suggests that a spiritual framework is not only desired by


patients, but may be essential for a meditation-based program to be helpful for the terminally ill."\(^{93}\) No definitive indication was found in the psychotherapy literature concerning the context of spirituality for the effectiveness of meditative practices.\(^{94}\) However, the empirical literature is somewhat problematic in part because of vague definitions of meditation or of spirituality or because of deficient measurement techniques. The current research supports the benefit to well-being of meditation practised within a spiritual context. Clearly in the stories studied, meditation took several forms that comprised quintessential prayer in the minds of the cancer patient storytellers.

Recapitulating: the storytelling of this research and the traditional literature always placed meditation within a religious/cultural context. There was a seeking and dwelling in union with God (or the One) that was integrative of present moment mindfulness experiences (cancer) and could contain both active and passive elements. It is an essential part of the patient’s spirituality and was seen to contribute to patients’ well-being. Increasing numbers of recent medical researchers and psychologists, are reporting findings that point to the substantial medical benefits accruing from meditation and the increasing use of meditation by patients. Benefits that are equivalent to those arising from medications are reported.\(^{95}\) Hence, a necessary corollary is that meditation


must be seen as an essential part of the medical management in oncology, not just as something complementary to medical treatment. Further such recognition is supported by the intense research interest and use in practice being reported now by psychologists and psycho-oncologists into how best to bring the benefits of mindfulness-based stress reduction (MBSR) to their patients. Caution demands a declaration, that what is advocated here is not a use of meditation as a sole treatment, but that it merits a place amongst other therapies being administered simultaneously or within a medically planned sequence.

The patient story dataset had reported one patient who explicitly described how he integrated the complementary therapies of exercise, music and mindfulness meditation during his survival.

Only one patient mentioned the Bonney Method of Guided Imagery and Music, but the research literature provided by Lars Ole Bonde contains dozens of articles describing the benefits of music and imagery for cancer patients. However in the previous chapter, a small set of references to music was described and they demonstrated association with music, meditation and a sense of harmony. The three references to music that were made by women

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96 Kabat-Zinn, "Commentary on Majumdar Et Al.: Mindfulness Meditation for Health," 731.


98 Lars Ole Bonde, Guided Imagery and Music: The Bonny Method and Related Topics, a Bibliography (Denmark: Aalborg University, 2010).
were practical and directed towards achieving well-being during their treatment; one taking music to accompany her treatment sessions.\(^\text{99}\) And another made what she called an “anti-depression” music tape\(^\text{100}\). Carolyn Van Doort had described just such a psychotherapeutic process when she described group or individual sessions that may pursue:

- Relaxation with music
- Insightful meditation with music
- Spiritual awareness, and
- Therapeutic issues of insight, change and self-development.\(^\text{101}\)

Her paradigm is very focussed on the individual patient who “sets the pace”, even in group sessions, and consistent with the findings of this research. Achieving such a patient focus only results from the kind of active listening that is described shortly. Whilst the number of references cited above is small, the accounts are real and cannot be discounted. However the practise of Van Doort and the Bonney method indicate a potentially rich field for future research and practice that seeks to enhance well-being in oncology.

A further imperative for such future research is found in the accounts of classical writers like Hildegard of Bingen, who recounted the peace and harmony that music brings into peoples’ lives.\(^\text{102}\)

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7 Help others and help oneself

All of the storytellers were motivated to help others by recounting their cancer experience. Was it just serendipity that they enhanced their personal well-being through doing so? And why did so few of them take the sage advice provided by other storytellers? And is there a corollary from this for doctors, health professionals and pastoral carers? The findings of this research in relation to the first two questions is presented in this section. And the corollary that involves “listening” forms the body of the next section.

Taking the first question, was the individual healing that is described just serendipity? Ramsey and colleague wrote that writing and reading positive narratives can provide both inspiration and hope for others. And MacIntyre likens narrative for the author as a journey during which the meaning of life is revealed. The process of the writing impacts strongly on the writer and the product, the finished narrative, can help others. Trisha Greenhalgh and her colleague said that narrative by a person can reveal inner existential qualities such as hurt, despair, hope that can assist the process of healing.

The findings of this research are quite similar. Cluster analysis of the parameter *relate personal experience relative to wellbeing* revealed a strong correlation of Pr= 0.78. Further, all of our 160 cancer patients published

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their story to help others; their narratives contained 350 references to this. The results stated in chapters 4-6 revealed concomitant personal benefits. Lois had said that telling her story helped her “detoxify her personal cancer experience”.106 Larry typified 31 other patients when he said that he had “gained a measure of control” through telling his story.107 Sylvie in common with five other references to well-being that were posted to the internet said that she had valued the “bonding with others” that she experienced.108 However, many of the patients who did not post their oncology experience to the internet, but attended “support groups”, did achieve empathy and improvement of their well-being in the process. Such an increase in personal compassion and empathy for others as was found in this research mirrors the reported common experience of MBSR participants.109

Cancer is not an addiction, but the voluntary storytelling engaged in by the patients in this research can be compared to that which occurs during the first set of steps (stages 1-3) of Alcoholics Anonymous, which is successful in improving the well-being of approximately two thirds of the participants.110 The research of Kuang-Yi Wen and her colleagues had found that participation in


face-to–face groups had improved the well-being of breast cancer patients.\textsuperscript{111} Alun Jones had suggested that the therapeutic value of storytelling arises because it “allows a person shifts of consciousness and so to embrace the present and decide how to live whatever life is left.”\textsuperscript{112}

Answering the first question about the benefits accruing from telling their story as “certainly not serendipity”, seems justified in the light of the evidence provided from within the storytelling and supported by published research. Storytelling by cancer patients can be seen as part of a healing or therapeutic process; and is concomitantly associated with well-being.

Now to address the second question about why patients give advice but don’t take it? Any reading of the narratives of this research would reveal a large collection of sage thoughts offering the potential to help other cancer patients. In the whole dataset, 350 coded references to giving advice to help others can be found; whereas only 12 references to taking up such advice were found. Of the small number of patients taking advice, more men than women favoured the information content of the advice. P. Klemm and colleagues had reported similarly about males in their computer based support groups for prostate cancer.\textsuperscript{113} The storyteller was absorbed with his or her

\textsuperscript{111} Kuang-Yi Wen et al., "From Diagnosis to Death: A Case Study of Coping with Breast Cancer as Seen through Online Discussion Group Messages," \textit{Journal of Computer Mediated Communication} 16 (2011): 333.


own cancer and was intent on helping others, hence was not ready to take advice. Encountering sage advice, it may be, that they did not know what was relevant to their own cancer and so let it pass. Or is the amount of inappropriate advice received so great, that they hear but fail to register any relevant parts? Christopher described being overwhelmed by advice. He wrote that “in her famous essay on Hollywood, Pauline Kael described it as a place where you could die of encouragement. That may still be true of Tinseltown; in Tumortown you sometimes feel that you may expire from sheer advice. A lot of it comes free and unsolicited.”

Other patients, whose storytelling referred to the pool of sage advice said that it was irrelevant to their treatment.

Without denying the truth of these postings about the storytellers desire to help others and their unwillingness to heed any sage advice, the rationale posed above that the storytelling provides a means of healing, is the most likely. This being so, an important and necessary corollary follows that a special quality of listening is needed by all practitioners; whether doctors, nurses, health professionals or pastoral carers. The “listening” to the cancer patient’s narrative must occur in such a way as to facilitate the telling of the story in order to provide the most effective help towards the patient’s well-being. Certainly, the pastoral implication would require a quality of listening that enables the patient to continue and complete the narrative in preference to solely giving advice. The next section considers the characteristics of this

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special listening that is paradoxically active yet remains “passive”. The discussion commences with what the patients said in their narratives and then places them within the context published oncology practice.

8 Listening, Presence, and Silence

That listening is important is taken to be a corollary of the fact that cancer patients gain healing through the process of telling their stories even though the intended beneficiaries were stated to be other cancer patients. Listening is considered to be the “best way to improve the quality of cancer care and survivorship”.¹¹⁵ Some of the small body of recent research supports the importance of listening but is largely confined to just the medical components of the patient’s narrative, ignoring their spirituality, the psychosocial and existential aspects of their cancer.¹¹⁶

One article by H. Ryan and colleagues extends listening to “recognising and managing psychological distress in cancer patients” but describes communication “barriers” that they largely source in the patient rather than with the practitioner. This perception may arise because of the dominantly physician and measurement centered approach taken in what is essentially a “review article”. Oncological practice seems still seduced by the medical model


of health that follows the allopathic principle of primarily treating the cancer to restore physical health; the patient’s well-being is seen simply as the absence of disease. This attitude ignores a patient-centered palliative approach, or its converse “futile treatment” as Sarah Winch put it. A treatment can be futile from the medical perspective when it could not achieve the particular medical outcome. Or further, the “radical” treatment approach at all cost, appears deficient in the face of evidence such as the healing that is seen to have arisen through the storytelling by this studied set of cancer patients. In addition to the physical aspects of treatment, evidence based practice indicates that a special kind of listening must be applied to cancer patients’ narratives that succeeds in achieving more than imprisoning the distress of patients within the medical history, so allowing the doctor to be detached or withdrawn.

The “deep listening” that Matti Häyry attributes to Emmanuel Levinas “that once we truly see the face of another, we cannot turn away from it anymore” he deems is appropriate for oncology, but he advocates “shallow listening” for most other domains of life. John Kearsley described a most wholistic concept of active listening. He wrote “Stories have healing power – not only in the content, but in the telling comes healing. Unlike the predictability of many clinical outcomes in medicine, the outcomes resulting from interpersonal communion may be neither predictable nor

118 Winch, Best Death Possible: A Guide to Dying in Australia, 43.
120 Matti Häyry, "A Defense of Shallow Listening," Bioethics 19, no. 5-6 (2005): 566
understandable. When we do listen to people’s stories, we make room for mystery and healing to occur. A healing effect on the teller, as well as a healing effect on the listener.” 121

This is truly patient centered and incorporates concepts that storytelling provides a healing benefit for the patient and also for the listener. Samuel Klagsbrun in writing about the lessons that he had learned after 42 years’ experience as a doctor in oncology said that his second lesson was “the awareness of the power of being there and the power of listening.” 122 His first lesson “in this area of medicine [was] namely, that often it’s the staff members – even more than the patient- who need attention”. The discussion now moves first, to how such listening and presence were seen by the patients, second, how reports by contemporary publications conformed with the narratives of the patients, and thirdly, how oncological professional educational paradigms could improve by planning for education rather than training in communication.

What the studied patients said

Patients included “listening” within their writing about communication with their doctors. Analysis of this story dataset revealed that 37 patients made 139, mostly unfavourable, references to the communication with their doctors. They complained that their doctors failed to see their cancer from any other perspective than their own. They emphasised that the doctor’s very different paradigm to their own had affected their well-being adversely:

Doctors who cut people open have to believe in the reality of the flesh and the blade and the one-to-one relationship of virus to blood to cell to lymph node. Dr. K. might become paralyzed with self-doubt if I got him believing in the Willie story. But we patients need our fantasies and our dreams and our mythologies. Let him see it his way. His way has respectability, and it even works well most of the time for most things. The whole world out there can't be totally wrong. But let me also see it my way. My way is not a delusion. It is my experience, my reality, my psychological truth. And it makes me well. I could have been dead three times in the last ten years if I didn't have this "psychological reality" to pull me through… Why is their reality any better than mine? What is reality anyway? That limited, rigid, objectively-evident view of reality probably caused the sickness in the first place. The effort it takes. The tension. Always conforming and repressing and holding our behaviour with effort to that hypothetical norm that has become the agreed-upon standard of sanity.\textsuperscript{123}

Albert certainly did not see his cancer from any commonly held metaphor and whilst he could understand the medical viewpoint, his appreciation of his cancer experience was entirely dictated by his own experience, his own “psychological reality”, as he called it. Researcher Alun Jones had written that “people are not bound by theories and that the ontology of experience prevails over the technical and epistemological”.\textsuperscript{124} Jones was one of a few published medical researchers to afford such centering on the patient experience.

However, effective listening can be difficult for the doctor because even when patient-centered language is deployed, a possibility exists that no effective communication will occur. Alun Jones put this succinctly when he

\textsuperscript{123}\textsuperscript{Kreinheder, Body and Soul : The Other Side of Illness. Studies in Jungian Psychology by Jungian Analysts.}\textsuperscript{124}\textsuperscript{Jones, "The Awful Rowing toward God": Therapeutic Conversations with a Woman Following Major Surgery," 1198.}
described the failed communication between patient Rosemary and her oncologist:

My oncologist had referred to this meeting as a, "discussion of the treatment options." He used all the current patient-centered jargon. But he didn't discuss anything. He merely told me what my treatment would be: cytoxin and carboplatin every four weeks. It seemed a very cookie cutter approach. And from my reading, it didn't sound very current. When I asked about Taxol, he made it sound more experimental than I knew it to be. I said I owed it to myself to get a second opinion about something this life threatening. He graciously offered to refer me to his associate. I declined. I wanted a consultation with someone not only out of his office, but from a different medical school. He was from USC. I wanted to hear from UCLA.  

Even though her doctor was focussed on communicating the treatment options effectively by using "all the current patient-centered jargon". Rosemary felt that he had not listened to her, evidenced by failing to engage in any discussion with her. And further she saw the treatment that he proposed for her to be “a cookie cutter approach”. She lacked confidence in him and so his patient-centered jargon had failed probably because of his poor listening to Rosemary.

Steve also had described his lack of trust and confidence in his oncologist whose listening was overtaken by his desire to obtain patients for his clinical trial:

I asked if I could also have the radiation if I wanted it and still be in his trial, but he said no. I asked him why not and it was clear that the reason was that it was against the rules of the trial. And this is the critical part - the reason was not that getting both treatments was not in my interest. I could also tell that he "wanted" me for his

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125 Grimm, "Rosemary Grimm’s Experience with Ovarian Cancer".
trial - that he had an interest in having me participate that went beyond giving me the best treatment. At that moment everything changed - no longer could I assume that the doctors either knew what the best treatment was or that they would even act in my best interests. Well that was it.\textsuperscript{126}

Steve’s lack of trust had been occasioned by ineffective patient focus in the listening of the oncologist as had been the case for Rosemary, just told. Paul’s narrative provided evidence of impaired communication because of the hospital’s focus on money. This was dominant in his mind because the theme formed the bulk of his narrative:

Most [doctors/ hospitals] mean well. Some are just trying to get paid…I had paid for the session the day before. This day they didn’t need any money…He also did not need to get paid that day … [named hospital] needed me to pay for the first meeting in advance. Before they would even book an appointment. However, they didn’t want the money from me they wanted it from my insurance company. Of course they wanted to be connected to the deep pockets. Luckily my insurance company moved quickly and we were ready to go in a day or so.\textsuperscript{127}

The first part of the discussion of what the patients said about their doctors and their listening was seen to be largely unfavourable and can be summarised thus:

\begin{itemize}
  \item Doctor’s cancer paradigm dominated the consultation.
  \item The communication lacked any centering on the patient.
  \item A “cookie cutter” approach by the doctor was resented.
  \item Trust and confidence in the doctor were lacking.
  \item Emphasis on money and/or research recruitment was resented.
\end{itemize}


But the findings were not all negative. A smaller number of patients in the dataset (15 sources, 23 references) clearly articulated what they had wanted from the communication with their physicians. Sometimes such expectations placed extreme pressure on the physician who, whilst cognizant of the individual's diagnosis and on average the prognosis, was experiencing difficulty in providing the right kind and amount of information in a sensitive manner. Just how much information is enough for the patient? Leandra said “He talked so slow... I wanted to choke out the bottom line... I couldn't wait to hear my fate.”

Her physician was being cautious because it was really impossible for him to tell Leandra her “fate”, but she was impatient for some information about her future. What he said was just right for her. She wrote “The news was promising. He had found a study that outlined the use of a drug”. He had listened to Leandra and discerned just the right kind and level of information to indicate where her hope could be placed realistically. In a similar story Gerald had said “In my case, it was not necessary for me to hear the urologist's explanation of the CT films. The gelatinous appearing mass where there should have been a left kidney left no doubt as to its malevolence.”

Another consideration required for the success of active listening was found amongst the minority group of patients; this was the necessary awareness of the mind numbing shock that occurred at the moment of the

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patient hearing the word “cancer” in relation to their illness. Dave wrote “[The urologist] said, ‘You have a prostate cancer diagnosis.’ I didn’t remember another word. When you hear the words, ‘You have cancer,’ you don’t remember any other words.”\textsuperscript{130} Obviously this diagnosis was beyond anything that Dave expected. And he described the resulting inability to hear any other words from the physician. Other patients from this study had recommended having another person present during the examination who would have better recall. But such a disclosure based on a singular “tell it like it is” paradigm has nothing to contribute to active listening.

This research appears to have revealed that the roadblocks to good communication were sourced in the treating physician rather than in the patient. This is in contrast to much of the published literature that associates the cause of “roadblocks” to the patient’s poor communication. The published literature reports that patients “tend to be dissatisfied with poor communication [more] than with any other aspect of their care”; reported first by Keatings and colleagues and then by Stickley and Freshwater.\textsuperscript{131} So what can be understood from this seemingly contradictory finding from the patients studied that the roadblocks to active listening seem sourced in the treating practitioners?


Melding listening with contemporary oncology practice

The answer to this apparent contradiction will be seen through the discussion of listening, which now needs to delve more deeply into how listening must be empathically patient-centered and become “active” listening that is therapeutic. It is necessary to explore what the modern literature says and meld that with the findings of this study. The patients had said that the pre-condition for the kind of listening that they wanted from their oncology practitioners required confidence, belief and trust. Similar physician characteristics had been noted by Susan Harris and her colleague whose research indicated that “women’s positive experiences with physicians were characterised by communication based on active listening, awareness of the woman’s knowledge of their illness, honesty, and partnership.”132 She also mentioned the importance of touch in such active listening.

The earliest references to this special kind of active listening were found in the pastoral theological literature. Thomas Hart identified and linked two of the themes of this study when he wrote “Listening to another may not seem like much, but its effect happens to be very therapeutic… Listening is not always easy. It takes time, and the time may be inconvenient besides. It demands really being for the other during that period, fully present and attentive, one’s own needs and concerns set aside.”133 Heart’s pastoral


experience associates healing with active listening in which the listener is fully present to the patient.

Frances Moran distinguishes the types of listening and what she describes as a "pastoral style" of listening seems very appropriate for meeting the characteristics desired by the storytellers of this study. She makes two requirements of the listener if the active listening is to be therapeutic for the patient. "That the listener brings an inner world to the listening context and that this inner world influences the listener's ability to listen". Self-knowledge to this extent by the doctors would in all likelihood have obviated our patient's adverse comments. Only a few references were found in the medical literature to “active listening” per se. The majority were sourced in nursing literature and mostly they refrained from allocating blame and placed the solution to the “problem” in undergraduate education programmes (of doctors, nurses, health professionals and pastoral carers) and in improvements to continuing professional development. These will be discussed in the next section that advocates paradigm shifts in education and in lifelong learning. The nursing articles represent the problem of poor communication as one that is shared by all involved in oncology, the practitioners and the patients alike.

Effective active listening is complex, involving becoming aware of the context of the cancer experience in the life of an individual patient as well as awareness of the personal impact of a life devoted to treating cancer on the physicians themselves. Further, the oncology professional must have the

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ability to abstract their personal reality and focus on the patient. Forrest Lang and colleagues described a taxonomy of skills, *Patient’s Perspective on Illness* (PPI), that a physician might deploy when striving to discern the patient’s clues. The proposed taxonomy included: “(1) expression of feelings, (2) attempts to understand or explain symptoms, (3) speech clues that underscore particular concerns of the patient, (4) personal stories that link the patient with medical conditions or risks, and (5) behaviours suggestive of unresolved concerns or unmet expectations.” Whilst the PPI is a generic set of clues, active listening requires that clinicians develop their personal way of deploying them and develop ways to confirm what the patient seems to be saying. The individuality of each patient should not be overlooked.

More recently in 2005, Kathryn Robertson identified three sources of roadblocks that can be experienced by oncologists striving to achieve active listening. These were judging, suggesting solutions, and avoiding the patient’s concerns. And she introduced the concept that not all issues need be addressed at the first meeting which should be conducted in such a manner that the patient felt comfortable enough to allow revisiting the issues at subsequent consultations. Reviewing the unfavourable comments made by the patients studied about their doctors, all would have benefited if their doctors had been aware of Robertson’s advice.

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In working around Robertson’s roadblocks, the listener would talk less and in ways that would be directed towards facilitating the patient to complete their narrative. Jerome Groopman mirrored these findings when, in an interview by Neil Baum and Robert Dowling, he concluded his practice pointers for doctors with: “Actively listen to patients, process what they are saying, and don’t interrupt them.” An active listening session, despite its focus on the patient, should not be boundless in time. The goal is to enable the patient to experience a genuine feeling of being heard and understood. Listening to the whole story is not a goal of active listening. The attention required for active listening should always remain within a timespan that is reasonably comfortable for the patient and for the listener alike. The reasonableness of keeping the length of the listening session within the attention span of both patient and professional alike was described by Austin Cooper. M.R. Stuart and colleague referred to a fifteen minute hour. Halifax reminded us that how much time is spent with the patient is less important than what transpires within that time. Frances Moran postulates an imposition of limits to the time of listening in order to protect the inner world of the listener. Laurence Savett cautioned about “burnout” that can arise through compassion overload.

138 Austin Cooper, personal communication on “Active Listening Duration,” 2013.
141 Moran, *Listening: A Pastoral Style*, 132
Moving five years on to 2010, John Kearsley uncovered what could well be the final layer when he linked active listening with the healing power of storytelling mediated through self-emptying. Keasley saw this as making space to connect the essential self of the physician with the person of the patient.¹⁴³ Such shared presence is a deep spiritual experience for both. And requires a shift of focus from the physical curative aspects of disease towards becoming “healers of the sick”.¹⁴⁴ A process of self-emptying is needed on the physician’s part to realise this sense of presence. Henry Nouwen said “Every time we pay attention we become emptier and the more empty we are the more healing space we have to offer”.¹⁴⁵ A practice of mindfulness is described by Dobkin and Stewart who say that it both helps the physician’s own spirituality and also brings a practice of attentive observation to the consultation: a real presence of being.

How best to achieve such a high goal of presence when even the individual cancer patient’s cancer trajectory is shrouded in uncertainty, for patients and doctors alike?¹⁴⁶ The attainment of the high goal involves all practitioners in oncology including pastoral workers. It results from mutual collaboration. It requires that the current set of technical skills be enhanced by the creation of an environment conducive to active listening. This includes

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gifting presence both to the patients and also to all practitioner colleagues. Daniel Rosenblum identifies as important, that doctors and nurses take sufficient time to listen, to recognise the importance of presence that does not abandon the patient even after the failure of a specific therapy “My chemotherapy may not have helped her, but her frequent visits to my office did.” Donald Jamieson, a permanent Deacon, illustrated how presence and active listening came together in this description of the circumstances surrounding June’s death:

Presence is one of the best gifts that people can bring to patients near the end of life. It is a quiet gift of time, during which the visitor shares the dying person’s immobility often in silence. Don commented on the value of the nurse’s presence and listening to John [June’s husband] at the time of June’s death and in so doing indicates to us that he himself believes that listening to the terminally ill person constitutes good pastoral care. On the night of June’s death, John’s choice of readings and prayer were consistent with her wishes. It is true prayer to listen to the patient and to find God’s presence in the situation. This is far better for the patient’s well-being than to pray in ways that provide more comfort for the carer than the ill person; it is a form of praying that is beyond asking for more comfortable or less painful circumstances. Care is most effective, for the ill person, if it is based on an understanding of the kind of contact that they want. Careful listening achieves this. People who visit or provide treatment to the terminally ill achieve the best well-being for the patient and themselves when they become comfortable with the silences and quiet arising during their presence to the patient.

This passage contains so many of the elements that make active listening benefit the patient’s well-being. The elements of presence, careful

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148 Donald Alexander Jamieson, "Walking with Forgotten People: Some Aspects of Pastoral Care with Older People," in Pastoral Care of Older People, ed. Elizabeth MacKinley (Barton, A.C.T.: Centre for Aging and Pastoral Studies, 2004), 7-12.
listening, comfort in the silences, respect for the patient’s spirituality, and prayer in the way that the patient wants, are all visible here. It is also a story of prayer that enters a level of faith beyond petition or intercession that is beyond asking. Laurence Savett reinforces what Jamieson said “Unless we [doctors] … learn the importance and practice of deliberate silence, engaged listening, and restrained response, we will miss the opportunity to provide our presence and comfort to those about whom we care”.\footnote{Laurence A. Savett, “The Sounds of Silence: Exploring Lessons About Silence, Listening and Presence,” Creative Nursing 17, no. 4 (2011): 168.}

In advocating such a patient centered approach to active listening most of the published articles describe benefits that are associated with the practitioner, whether doctor or nurse, getting the real story that enables the correct diagnosis and valid treatment decisions to be made.\footnote{Shipley, “Listening: A Concept Analysis,” 125-34; Savett, "Journeys: Stories of Nurses' Careers," 3-4; Lang, "Clues to Patients' Explanations and Concerns About Their Illnesses,” 226.} However one article by John Kearsley, echoed Cicely Saunders who had said “[patients] need someone who will come to this meeting not bearing any kind of technique, be it therapeutic, pastoral or evangelistic, but just as another person”.\footnote{Cicely Saunders and D. Clark, Selected Writings: 1958 – 2004 (Oxford University Press, 2006); Kearsley, “Therapeutic Use of Self and the Relief of Suffering,” 99.} Kearsley also reminds the reader of Nouwen’s “self-emptying” as a requirement for compassion. Saunders described a truly and completely patient-centered approach that is entirely compatible with the findings of this study and goes beyond in ways that endorse other parts of this work. Nouwen

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describes a self-emptying on the part of the practitioner that provides a greater healing space.

The idea of providing a presence that is genuinely patient-centered was seen to arise from a melding of what the patients of this research said about their oncology practitioners with the thrust of recent published articles. Benefits were seen to accrue to the practitioners who through self-emptying and mindfulness brought a special presence to the consultation with the patient. Their listening to the patient was seen to be paradoxically active yet remained passive: Not ignoring the medical details necessary to provide treatment, but providing a healing focus; in order to achieve the goal of active listening, to match the needs of oncology practice in the twenty-first century, necessitates a paradigm shift from training to education for the undergraduate oncology practitioners and in the continuing professional development.
9 Connections

Figure 7.4: Word Frequency Cloud for Chapter 7
This was a chapter that discussed, compared and reflected on the findings of the previous three chapters. The cloud is representative in that it shows the centrality of the principal themes that emerged both from the QDA and the reflection: the QDA themes were cancer (112), research (75), prayer (63), and well-being (60); the themes of reflection were god (45), one (25), meditation (78), listening (70), thanks (33), life (31), spirituality (30), presence (31), healing (26), self (25), and support (18).

This chapter commenced with a declaration of its intention to be faithful to what the patients’ storytelling revealed about prayer in achieving understanding. The principal question followed in reflection on the stories was where was God in the cancer experience? Some showed their faith in God through the scripture and images and poetry that they quoted. Atheist faith was differently sourced, but their self-talk was about finding joy in the present moment.
Reflecting on the revelations of the patients’ storytelling uncovered unexpected information and advice often exceeding the storyteller’s original intention. The commonly expressed intention was to help other patients through publishing their personal story. Evidence of prayer that asks (petition and intercession) was seen within the stories studied and was found consistent with contemporary published research. However prayer that thanks was more commonly expressed. But who would have expected that prayer that thanks would be so common? Some thanked God directly, some thanked others for the support they received and some for the meaning for life that their cancer experience had occasioned. References to meditation were found and, within the stories studied, were never separated from a religious or cultural context. This contrasted with some research authors especially in relation to mindfulness meditation about which there is some confusion in the literature. More collaboration amongst researchers would benefit themselves and cancer patients. Their strict adherence to publishing in the jargon of their discipline risks the isolation of their findings to that discipline and may compromise the validity of the findings because of disciplinary bias in selecting the methodology; whereas, publishing in jargon free language makes their findings accessible to the greatest number of their inter-disciplinary colleagues.

This collection of stories pointed to the existence of much sage advice. The discussion noticed the fact that little of this pool of sage advice was taken up. The question arose, “why?” The evidence was that the patient achieved healing through telling their story. This finding was supported by the literature. A conclusion of this thesis is that medical and pastoral intervention
must facilitate this storytelling by practising active listening. That is by listening in ways that enable the storytelling. Such listening should be sensitive to respect the metaphor and religious practice of the patient; which can pose difficulty for oncology professionals or pastoral workers whose knowledge may be deficient in the beliefs of many patients. The corollary is that listening plays a major role in the healing of the patient. But current medical and health professional education is shown to fall short because of its emphasis on training rather than education. Graduates, who may be deemed competent to practice at the time of graduation can be ill prepared to accommodate the future changes in a profession whose knowledge and skills base is one of the most rapidly expanding of all fields of human endeavour. Consequently, the education of all oncology practitioners must enable graduates to adapt to such change whilst simultaneously being totally empathically patient-centered. Bringing a patient-centered presence to the consultation benefits both the well-being of the patient and also the practitioner. John Paver had drawn attention to the Whiteheads idea, that he further developed into a ministry model, in which the practitioner experienced God through patient storytelling, particularly through a deeper understanding of the listening metaphor. This chapter, in seeking coherence through reflection on the findings of this research on the patients' stories, found that the methods of GT and IP provided significant understanding of what the patients said, but little or incomplete insight into the reasons behind their feelings about their cancer. By

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comparison theological reflection was seen to be more wholistic: the patient’s faith in God, experienced as Trinity, enabled many to find God’s presence in their cancer experience.
Chapter Eight: Conclusion

1 Introduction

This study has found, from frequent narrative disclosures, that prayer, storytelling, and well-being are closely linked for oncology patients. This link was found to be associative in nature. The stories published by 160 cancer patients were studied by a mixed method of GT and IP with some unexpected results: which included the above finding, a corollary, and provided two indicators for the future.

The GT method allowed an analysis which was unbiased by pre-judgement or the forcing of data into pre-conceived protocols. Reflection on the findings of this research concluded that, beyond linking prayer with well-being, healing, that was both spiritual and physical, accompanied the process of the patients’ storytelling. Such conclusions emerged from within the patients’ stories and were confirmed by comparison with published discipline-centered research and the experience published in the spiritual classics. These conclusions gave rise to the corollary that the practice of active listening has the potential to enhance the well-being both of the patients and of the oncology professionals caring for them.

Shifting the focus from the patient to the oncology professional, produced two indications: Firstly, preparation to meet the requirements of truly patient-centered active listening, can greatly assist the oncology professionals to integrate their cancer practice with their personal spirituality. Such preparation
would be undertaken continuously, during the undergraduate education and consolidated subsequently through ongoing professional development. Secondly, a paradigm shift is needed so that researchers from different oncology disciplines can better understand the products of each other’s research. More open communication amongst and between quantitative and qualitative researchers offers the potential to enhance the quality of their research and optimise the benefits for the patients, whose well-being is the sole reason for all clinical intervention and research.

2 Prayer

Early in chapter one, prayer was defined within the context of spirituality. Eighty three percent of the storytellers gave evidence that their story arose from a spirituality; although only half followed a particular religious practice. The Ranson model of spirituality was found relevant to the oncological experience encountered in the studied groups, whether they were patients, oncology professionals or pastoral workers. No single definition of prayer was used in this study. Representative characteristics of prayer were identified from the three stories of prayer presented in chapter one and appropriate elements used as criteria for what would be taken as prayer during the analysis of the patients’ stories. A strong identification between prayer and the self-talk of the cancer patient was found.

But in what sense were atheist and agnostic patients deemed to be praying? They would, in all likelihood, deny that they prayed. They did not believe in “God” in any form. Yin de Shakya, who professed to be a Zen Buddhist
atheist, provided one of the characteristics of prayer used for this study. She
deemed that the “wish, hope and intention” leading to elements of “actualisation,
engagement and execution” constituted prayer.1 These are congruent with the
Ranson spirituality phases of “interpretation” leading to “acting”. Prayer for de
Shakya involved generating the intention to engage with people and the world in
beneficial not harmful ways. She took the internal self-talk exercised during
these processes to be prayer, and that is the sense in which it was found
productive for this study. Self-talk, so conceived, combined an internal process
and a transcendence that reached beyond the individual.2 This element of self-
talk was also identified as prayer in the writings of Larry Dossey, an agnostic
medical practitioner.3 And the characteristic of self-talk was also found in
Lawrence Freeman’s reflections on the life of John Main, one of the cancer
patients studied. Freeman said “prayer changes our life, because it unites our
experience of life with our experience of God”.4 It is the patient’s self-talk, arising
out of the cancer experience that becomes contemplative prayer when it leads
to a resting in God in the present moment.

The characteristics of prayer when applied to the patient story dataset,
revealed many instances of the prayer of petition and of intercession. These


2 Chapter five, under the heading “Quintessential Prayer”, presents the findings and discussion that would visualise the process of patient self-talk as constituting prayer beyond asking and thanking forms and being generically categorised as meditation.


This study was able to add that the storytelling of females contained twice as many references to intercession as were found amongst that of the males.

Another significantly under-reported finding was that the commonest form of prayer utilising words was thanksgiving. This would not be expected \textit{a priori} but was a validated finding because it was the experience of actual cancer patients who independently made similar statements. One third were grateful for the support that they received from their friends, families and the professional staff providing their treatment. Slightly less than one third thanked God directly. This gratitude was surmised to arise from a spirituality based in faith, because of its consistency with the cited practices of people like the Benedictine monk David Steindl-Rast, the psychologists Joan Borysenko and Alex Wood.\footnote{Brother David Steindel_Rast, *Gratefulness the Heart of Prayer: An Approach to Life in Fulness* (New York/ Ramsey: Paulist Press, 1984), 198; Joan Borysenko, "Practicing Gratitude," *Prevention* 56, no. 11 (2004): 3; Alex M. Wood, Jeffrey J. Froh and Adam W.A. Geraghty, "Gratitude and Well-Being: A Review and Theoretical Integration," *Clinical Psychology Review* (2009), 1.}

Fourteen percent of the group expressed thanks for the meaning that the cancer experience had introduced into their lives. The expressions were very individual, reflecting the uniqueness of each cancer patient’s journey. The theme of gratitude for the meaning that survivorship provided, was seen to be associated with greater psychological well-being found in the literature especially...
for breast cancer survivors. However this study suggests that thanks for a “new normal roadmap” would apply to most of the cancer patients.  

The findings of this study on the relationship of patient self-talk and meditation were detailed in the section of the previous chapter headed “Quintessential prayer”. In the medical and psychological discussion on meditation, there was an emphasis on transcendental and mindfulness forms which were presented as intentionally separated from any spiritual context. Such a separation, however, was not universally agreed upon by psychologists. By contrast, meditation was found to be described more wholistically in traditional spirituality literature. The psychological literature would say that the hiatus that this study reported was an abnormality that would require treatment. Whereas St John of the Cross described it as a “dark night” and a normal experience which he clearly distinguished from depression. Other spiritual writers wrote more wholistically in ways that provided a comprehensive context for the findings of

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7 The pathologies of the patients who expressed thanks for the new meaning given to their lives by the cancer were: Sarcoma, Ca Kidney, Hon Hodgkins Lymphoma, Osteosarcoma, Melanoma, Thyroid and only two Ca Breast. Published literature documents little beyond Breast and Prostate cancer.


this study in relation to the *hiatus* and meditation in general. Augustine Baker writing in 1657 CE called the meditation of chronically ill people a “not-doing” and the anonymous author of *the Cloud* writing in the 14th Century CE had called it a “cloud of unknowing”.¹²

Another significant finding of this study was that instances of six forms of meditation were found in the stories. This is taken as an indication of the importance of meditation for oncology patients because of its contribution to their well-being: and that traditional spiritual writers provided a more wholistic spirituality based context within which to locate the experiences described in the stories. Medical and psychological researchers could expect similar benefit by extending their literature searching further back in time, beyond what has been electronically indexed.

In summary prayer was seen to be a reality for the cancer patients of this study. Further, they practiced all kinds of prayer. Their prayer was seen to include but extend beyond asking for what they wanted for themselves or for others. Out of their cancer they were able to thank God. They recorded thanks for their family and friends; they were thankful for realising a new meaning for their lives. Some, who meditated, were able to pass beyond a *hiatus* whilst a few were led to meditation through the cancer experience. A paradigm that linked self-talk with contemplation emerged from the stories. Many of the patients found God’s presence in their cancer experience; this was unexplained from within the stories,

but consistent with the belief of Christians. In reflection, undoubtedly the presence was the God in whom we live, move and exist; for others the presence was of an “unknown God”; but the reality is just the same. For almost every patient, their prayer occasioned well-being.

3 Prayer is associated with well-being

A strong associative correlation was concluded to exist between the prayer and the well-being of cancer patients. This link was not proven to be causal but can be designated as associative because it emerged strongly from the consistency and similarity found in the storytelling of 160 cancer patients.

The basis for concluding a strong associative link between prayer and well-being was twofold. Firstly, it emerged from the rigorous qualitative data analysis of the stories told by the patients of their personal cancer experience. Secondly, it was confirmed by a strong congruence of this study’s findings with professional publications in medicine, psychology, pastoral care, and spirituality.

From the storytelling

The emotions expressed by the patients were found to be true indicators of well-being. Patients moved through emotions, sometimes quickly, or experienced several simultaneously; but those most commonly expressed, correlated positively with well-being, achieving higher values of the Pearson Correlation Coefficient. The results of that analysis formed the body of chapter three. Further, the computer assisted qualitative data analysis had revealed other indicators of well-being: these were self-talk, advice to and from others,
and, meaning for life. All of these arose from the spirituality of the patient and were understood to be the prayer of the patient. Word frequency analysis had linked them to well-being as was shown in the findings reported in chapter four. Whilst more often than not these “parameters” indicated good well-being, some paradoxes were seen. For example, the “family” was said by some to be one of the better aspects of having cancer because of the support it provided, others cited it as one of the worst aspects because “it [family] was more painful than the disease itself”. The results of the analysis of the matrix coding reported in chapter four provided a clear link between prayer and well-being that was mediated by the patient’s spirituality. Further the primacy that thanksgiving prayer, exhibited in the stories, indicated a link between prayer and well-being. Chapter five presented the findings on the things that constituted the objects of thanks. The detail showed that almost exclusively, the objects of thanks indicated well-being. And even the hiatus in their meditation practice, which some reported, proved to be transient and there were no reports of depression or suicide amongst this group.


14 Matrix coding showed a link between Well-being and Spirituality (1350 positive references compared to 58 negatives). It showed Prayer related to Spirituality (442 positive references to 3 negatives). Thus Prayer is related to Well-being (156 positive references to 0 negatives).
Figure 8.1: Storytelling links prayer with well-being.

This Venn diagram represents the union and intersection of prayer and well-being that arises from cancer storytelling within the sample space of cancer as revealed in this study. The sample space CANCER contains all of its subevents. Storytelling, Prayer and Well-being are subevents of Spirituality (largest circle) within the sample space CANCER. An intersection is seen containing all three subevents at the very centre. Thus indicating that they are mutually inclusive events. Meaning that, for this research, Spirituality gives rise to Storytelling which is identified with Prayer and Well-being.

Further, the null event that the three subevents are disjoint events is excluded by the intersection. Thus it cannot be maintained that there is no relation between Prayer and Well-being.

A more visual way of appraising the results of the qualitative data analysis, is contained in the Venn diagram above as figure 8.1. It represents the way that this analysis of the patients’ stories was contextualised in support of the contribution of prayer to well-being for oncology patients.\(^{15}\) Because of the

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overlap of the three circles (intersection) representing storytelling, prayer and well-being at the centre of the diagram a relation is shown to exist between them.

In relation to the conclusion of this thesis it indicates that prayer and well-being are related. A causal relationship is not indicated. Further, the existence of the intersection indicates that the null case of no association of prayer with well-being is untenable based on their absence from the patients’ stories.

Looking back over this section, it was concluded that prayer is associated with the well-being of the cancer patients studied. The link was described as associative; it is not proven as causal. The qualitative data analysis performed established this. And a strong congruence was found with published literature. A Venn diagram depicted the mutual inter-relatedness of spirituality, storytelling, prayer, and well-being. Prayer was found to contain many layers, commencing at asking, moving to a more selfless thanksgiving and then to meditation which latter, in chapter six, was called quintessential prayer. The depiction of each layer of prayer was characterised by its contribution to the patient’s well-being. Further, considerable support for linking meditation with well-being was found in the literature of Spirituality and in the relatively recent medical and psychological literature.

From congruence with literature

The hermeneutics of this study have identified many aspects of the prayer of cancer patients that were particularly correlated with well-being. Four such were spirituality, gratitude, mindfulness, and healing. Similar themes were encountered in the literature that, when considered overall, were significantly in
agreement with the findings reported. These themes are indirect links through the cycle of the patients’ spirituality to their prayer and to well-being.

Early in chapter one, the great diversity found in the definitions of spirituality were acknowledged and the cyclic concept of David Ranson adopted for this study. This enabled the finding that 83% of the patients studied gave evidence of acting from a spirituality. This cohort included patients who were religious as well as those who were atheist and agnostic. The analysis had demonstrated strong correlation between spirituality and their well-being. John Peteet and Michael Balboni, in a review article, reported that at least 11 studies of post-traumatic growth had shown beneficial links with spirituality in oncology. A recent phenomenological studied by Ryan Denney and colleagues showed that the cancer survivors studied showed spiritual growth across several domains of spirituality. They also concluded that those close to the patients experienced spiritual growth. Barbara Carroll also reported her phenomenological study that showed nurses personal spirituality influenced the care (physical, social, religious and psychological) offered to their patients thus affecting the well-being of the latter.

16 The analytical results presented in chapters 4 and 5 indicated this strong correlation between spirituality and well-being.
The recent research interests of psychologists in meditation, mindfulness, depression and developing “measures” determining various sub-sets of well-being are substantially in concert with this study’s findings.\textsuperscript{20} Articles published by some psychologists saw the patient’s well-being in terms of coping. Consequently in their conception, spirituality sometimes becomes the source of a problem. Kenneth Pargament wrote that “exclusively secular forms of coping that fail to attend to the demands of the situation make as little sense as exclusively spiritual forms of coping that are equally disconnected from the realities of life”.\textsuperscript{21}

Support arises from the rising interest in mindfulness meditation in psychology. Yaowarat Matchim and colleagues had reviewed publications from 1987-2009 on the effectiveness of mindfulness-based stress reduction (MBSR) among breast cancer survivors and concluded that the practice was effective in coping with the stress, so contributing to the patient’s well-being.\textsuperscript{22} Nicholas Allen led another review of mindfulness-based psychotherapies which concluded the value of such interventions as “helpful strategies” in managing a wide range of mental and physical health problems.\textsuperscript{23} The reporting of this survey typified the

\textsuperscript{20} Recent psychological interest has increased into the domains of spirituality, gratitude, and mindfulness as was discussed in the previous chapter. The term “measures” denotes parameters that are used in a quantitative way to investigate relationships that exist in the data. For example the Short Form 12 or 36 questions (SF12 or SF 36) were found used to assess the physical health component of well-being. Or the Spiritual Well-Being Scale (SWBS) of Elison and Paloutzian is used by researchers to assess the spiritual aspects of well-being and self-esteem.


evidence from research and practice in medicine which although supporting the link between prayer and well-being does so as “therapeutic interventions” which this study would deem to be sub-sets rather than a more wholistic concept of patient care. In the medical literature well-being was often seen operationalised to “quality of life” as interpreted through the lenses of various “measures”. In oncology, meditation is generally deemed a “complementary therapy” and therefore not in the mainstream. However, Jon Kabat-Zinn, as noted in the previous chapter, argued for it to be seen as a mainstream therapy best administered simultaneously with more physically based treatment. That stated, the medical literature described significant improvement in well-being even when seen through “operationalised” lenses.24

For two millennia and more, within the context of spirituality, people in sickness and in health, have experienced well-being through their prayer. Evidence for this is found in the classical literature of spirituality, a representation of which has been cited in relation to the findings of this study.25

John Paver in describing the theology of the Cross that he reached during his personal cancer experience provided a wonderful example of biblical theology that gives hope without ignoring the accompanying pain and suffering.26

24 The section in the previous discussion chapter on “Quintessential prayer, meditation and characteristics” shows that medical practice provides empirical evidence of the congruence of prayer and well-being; not attenuated by the limitations of the empirical quantitative model used in the conduct and reporting of medical research.

25 Chapter one of this thesis in defining prayer, includes references to the writings of John Climacus, Unknown author of the Cloud of Unknowing, Augustine Baker and Evelyn Underhill, being a representative sample of spiritual writers spanning two millennia.

26 John E. Paver, Theological Reflection and Education for Ministry (Great Britain: MPD Books, 2006), 74-75.
Neither did he ignore the “weakness”. St. Paul had written “My grace is sufficient for you, for power is made perfect in weakness” (2 Cor. 12:9). This became the focus of John’s prayer in his cancer and led him to write “The crucifixion was not the final word in the life of Jesus, but the crucifixion and its implications seem to be the essential word before the final word… before these can be the final word we must experience the power of the cross in our lives. Paul is saying: ‘Before the power of the resurrection can become effective in my life, I need to grasp the redemptive nature of the cross’.”

John’s theme of no cross without the resurrection was found echoed in this study where many patients gave thanks for the hope of a new life during and after their treatment.

The advice of spiritual writers is much more experientially proven when compared with that occurring in contemporary oncology literature. By this is meant that the well-being of more people has been associated with prayer than is recorded in association with contemporary oncology practice. It can be objected that contradictory evidence exists of harmful results arising from spiritual practices. And this is true. However, caveats can be found. For example, Chester Michael and Marie Norrisey emphasise that different prayer forms are better suited to different personality types as expounded in the Myers-Briggs Personality type indicators. And John Chapman counselled that “I hold to my view that we ought to try to do what we can, and not what we can't. Also

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27 Paver, Theological Reflection and Education for Ministry, 74-75

28Isabel Briggs Myers and Peter B. Myers, Gifts Differing (Palo Alto, Calif.: Consulting Psychologists Press, 1980); Chester P. Michael and Marie C. Norrisey, Prayer and Temperament: Different Prayer Forms for Different Personality Types (Charlottesville, Virginia, USA: The Open Door Inc., 1991); Margaret Dwyer, No Light without Shadow (Thornbury: Desbooks, 1995).
that we should stick to the spiritual books which suit us, not to those which give us no help.” 29 And John Cassian writing as early as c. 420 CE about the benefits of occupying a hermitage cautioned that “withdrawal into total solitude was found to lead to moral collapse, mental eccentricity, even to madness”. 30 His advice contained “rules” so that each person’s prayer would lead to their well-being. And writing in c. 1550 CE Augustine Baker had clearly indicated that his chapter on prayer was intended for chronically ill people.

In reflection on the literature of spirituality, the context of the cancer experience is paramount. Peter Meir and his colleagues relate an aphorism that captures the problem in part when he wrote that “People who talk to God we call saintly; people to whom God talks we call schizophrenic”. 31 It can be easy for professionals to debunk the experience of the centuries. However the writings of the spiritual forebears of both Eastern and Western traditions do provide a confirmation of the relationship between existentially based prayer and well-being. A principal finding of this study was that the prayer of oncology patients contributed to better well-being. This finding is entirely consistent with the growing number of researchers of closely related fields, of gerontology, religious

involvement, and both physical and mental health. It is also consistent with the links between spirituality/religion and quality of life of cancer patients.

4 Shifting the listening paradigm

Many cancer patients were seen to achieve healing through their storytelling. This being so, a necessary corollary follows. That "therapeutic interventions" must afford a primacy to helping all patients to tell their story as a part of the treatment process. The corollary is that active listening is essential because this study and a burgeoning literature has found that the healing afforded by active listening is as potent as current treatment modalities. Thus creating issues, since neither the undergraduate courses nor the continuing professional development, provided the necessary education in patient centered communication through active listening for doctors, nurses, health professionals, and pastoral care workers. In order to facilitate the emphasis on active listening, the paradigm for preparing doctors and their oncology colleagues must shift. A paradigm shift is needed to move the praxis from teaching [training] to learning [education] in medical and some health professions.

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The education of pastoral carers has experienced this large shift which has been implemented through the introduction of opportunities for supervised reflection on clinical practice both as undergraduates and in professional practice.\textsuperscript{35} Australian radiation therapist education has included similar experience for its undergraduate students since the 1980’s and for professional development since the 1990’s.\textsuperscript{36} And during the same period, nursing has clearly separated training from education which is described in an increasing literature.\textsuperscript{37}

Postulating a shift in paradigm that moves active listening more towards the centre of professional practice neither denies any aspect of current treatment protocols nor the realities of the busy complex inter-related roles of oncology practitioners. The benefits of such communication were described by Susan Harris who advocated the inclusion of education on listening and communication skills into undergraduate medical programmes.\textsuperscript{38} O’Connor wrote that the time has passed when such “skills training” could be handed down by a trickle effect.

\textsuperscript{35} John E. Paver, \textit{Theological Reflection and Education for Ministry} (Great Britain: MPD Books, 2006).


from more senior practitioners. To be fully effective, it should not be just training but education in undergraduate courses for doctors, nurses, other practitioners and pastoral workers. In addition such undergraduate education should include psychosocial aspects and spiritual care. This latter is reported to be lacking from 88% of nurse education and from 86% of medical education.

The patient narratives revealed issues arising when the oncologist, nurse, health professional or pastoral worker fell victim to one or more of the problems that arose even when the communication was patient-centered. The narratives contained instances of poor well-being associated with miss-matched paradigms or too much technical detail or just not hearing the patient.

Currently, Oncologists who strive to practice active listening, experience many endemic requirements of practice that militate against it. Open communication will only occur when pressures on the listener, such as arise from a “need” for research recruitment, financial efficiency, personal preferred metaphor and the like are relegated to the background; not ignored, but no longer dictating the tenor of the current communication. And workloads of treating staff in oncology are high and surrounded by stressful issues such as public accountability, recruitment of subjects for clinical trials, conduct of research and maintaining knowledge of new drugs and protocols. And in the midst of this is the practitioner’s desire to achieve a goal such as that first stated by Sir Peter

Mac Callum of “providing the very best treatment for the cancer patient”. But the importance of quality patient-centered active listening makes it critical that every effort be made to shift the paradigm and make it the normal practice.

In summary of that special kind of active listening, it was seen that, apart from identifying the difficulties above, no “solution” was found from within the story dataset that would improve listening to the patients. The recent professional journals identify the benefits that accrue to both patients and practitioners alike from active listening. Thus, improvement for the future must come from the suggested alterations to the paradigm underpinning both undergraduate education and continuing medical education. Sharing by researchers in the qualitative and quantitative domains offers the potential to extend the usefulness of discipline specific content for all oncology researchers. Oncology professionals do research for the benefit of the patients held in common, so why not share the knowledge?

5 Strengths and weaknesses

The use of Grounded Theory (GT) as the principal methodology of this study has been rewarded with clarification of the ontological concerns and

42 Cancer Institute Peter MacCallum, "Our Peter Mac.,” (Melbourne: Cancer Institute, 2012), 3; This was first stated by Dr Sir Peter at graduation ceremony for Radiation Therapists in 1964. Personal Communication.

produced “epistemically credible” conclusions. However there were three domains that contributed limitations to this study: they were the GT methodology itself; the individuality of each cancer story; and in the discussion of the findings on the “well-being antonym”.

**Mixing Grounded Theory with Interpretative Phenomenology**

The methodology of this study used GT as one method in combination with a second method, IP. This contributed both a strength and a weakness to this study. A strength because the one method refined the weakness of the other.

A weakness of the GT method applied alone is its requirement that hermeneutics and any theory emerge entirely from within the dataset; rarely in this study was the reasoning behind the story revealed by the patient. This lack of the patient’s reflection is a weakness of the GT method for this research. However the data-set was shown to represent the spectrum of cancer aetiology and to be balanced in terms of gender representation. The analysis of the thick description of the story dataset was facilitated by using the QSR-NVivo software package which provided certainty over the theoretical saturation and the tools for the coding and queries and the many iterations necessary to reach the evolving theory. And the strength of correlation resulting from clustering around clearly identified themes has produced some clear and significant conclusions.

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45 NVivo is a proprietary software package of the developer QSR International. Version 10 was used for the computer-assisted qualitative data analysis performed in this research.
IP requires something of a double hermeneutic: in that the patient’s storytelling results from their reflection on their personal cancer experience, although mostly not communicated; and this research sought to understand and reflect on the meaning of what the patient said. What is absent is a disadvantage of the IP method used on its own. However, the findings on prayer and well-being described in the previous three chapters are very well correlated. Thus providing a solid base for comparisons with research in the related fields of oncology, psychology and theology.

The combination of GT and IP as methods to form a methodology is a strength because it fully respects the individuality of each story. This success establishes the validity of the conclusions and confirms the appropriateness of this mixed methodology for this qualitative research into prayer and well-being in oncology or other life-threatening illnesses.46

**Individuality of Story**

The individuality of each cancer story also contributes strengths and weaknesses. This is not uncommon in IP qualitative analysis deploying GT methodology. Individual narratives are not told in any pre-scribed format and so do not contain identical information as would emerge from questionnaire execution, nor are they presented in any standardised format. The events that are described arise from many factors coalescing in cancer, resulting in complex

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and often unexpected findings.\textsuperscript{47} This posed difficulties in coding and with making conclusions from small data-groups. However, evidence-based internal agreement in relation to many of the parameters was found with high frequency, and when highly correlated, were deemed meaningful, certainly within the dataset. Smaller frequencies of numbers do not necessarily indicate little support, just that this issue fell outside the scope of the person writing or that they did not deem it to accord with their purpose in writing. Any lack of ability to generalise certain findings because of paucity of numbers does not invalidate the experience recounted; and may indicate an opportunity and a domain for a more quantitative appraisal in the future. The reality of the experience, when understood as the patient intended, must be respected and constitutes its value. A small group of exemplars had been included to offset this a little because they offer more wholistic content than many of the other narratives. The exemplars were chosen because they represented both the creedal/non-creedal elements of the dataset.

Each story is individual, telling of the patient’s cancer experience. The storytelling revealed what each person felt and thought, but only a few narratives extended further to query deeply the “why” of their experience. This made it difficult to proffer evidence-based reasons for even very commonly described and linked experiences.\textsuperscript{48} Rationales suggested in the discussion of the findings of this study were sometimes found in shadow, as it were, in the publications of


\textsuperscript{48} NOTE: For example: No discussion on the patients who commenced meditation following a “can’t pray” experience, in the previous chapter, was possible beyond noting the actual numbers because they were too small to permit generalisation.
quantitative researchers. A great need was revealed for improved communication between all researchers in oncology. Greater knowledge of the paradigms of other researchers in germane disciplines and collaboration is needed if that research is to move beyond being self-serving and to help clinical and pastoral professionals bring the benefits of the research to the cancer patients whose well-being is our common purpose. Further qualitative research along the lines of this project, offers the potential to inform quantitative researchers because its methodology is grounded in the actual experience of cancer patients without making any a priori assumptions and does not disregard narrative content outside the researcher’s pre-conceived categories. Further research conducted using a phenomenological and GT methodology would create the context described as needed by researchers like Neal Krause and his colleagues who in his review of the quantitative measures of prayer wrote “Moreover, current measures of prayer as a coping resource have missed a good deal of contextual information”.49 Looking in both directions, quantitative research methods and qualitative methods can provide a valuable mutual context for the other.

**Prayer and well-being antonym**

This study provided only a small amount of evidence of the occurrence of “poor” well-being associated with prayer. The Krishna Mohan definition of well-being was adopted in chapter one. It was chosen because of its combination of the subjective element of balance with ability to satisfy needs was compatible

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with the variable emotions expressed by the patients. And in chapter three the emotions were shown to be valid indicators of the patient’s well-being at the time. It was suggested there that the emotion being expressed at a particular time could be located along a scale of well-being between “good” and “poor”. Consequently poor well-being could be understood as a graded antonym of good well-being. The relative paucity of associations of prayer with poor well-being could be explained because this story data-set was derived from storytellers whose purpose was to help other people with cancer. Certain bad experiences may have been omitted from the narrative.

However some prayer was found to be accompanied by poor well-being in the story dataset (n=11, 2.2%). Those patients clearly articulated four such sources. Firstly, Angela attributed “bad prayer” to bad theology. By this she meant theology that was oppressive, manipulative or narrow. She described a patient praying within a theology that was based entirely on concepts of reward and punishment as experiencing adverse well-being. Secondly, Arthur described a lady experiencing ovarian cancer who was “paralysed” with guilt because of an anti-nausea drug that she had used during a pregnancy. Thirdly, Sylvie attributed bad prayer to misguided medical information. Although later she said ‘thankfully, I am of the belief that God works through doctors just as much as working directly with my body to heal it”. And fourthly, Melvin described

52 Sylvie Fortin, Did You Just Say Breast Cancer? (USA: Radiology Technician Schools, 2006).
bad prayer that arose because the poor attitude of a chaplain had caused feelings of depression and hopelessness. He had preferred the chaplain to have operated from the premise of “you are living; although your life, like mine, is fragile”.

The few references made in the published literature against which these findings could be matched, were found to be expressed in the guise of the physical or psychological health outcomes of bad prayer. Brandon Whittington and Steven Scher, from their study of subjective well-being associated with six different types of prayer found that prayers with an “egoless” nature exhibited positive effects on well-being whereas those that were more “ego focussed” had negative effects.

Colleen McClain and her colleagues reported that her data indicated that “spiritual well-being offered some protection against end-of-life despair”. Even though her article seems to support our “findings” on bad prayer, very few of the other published medical articles can be cited in validation. The McClain and colleagues article contains a simplistic definition of spirituality and in its methodology, devotes a primacy to using measuring instruments to determine the non-wholistically defined “spiritual well-being”. Quantitative research is

56 McClain and colleagues use the “Hamilton depression rating scale” and the “Beck hopelessness scale” and process their data to suit the requirements of these measures; thus creating a pessimistic concept of well-being.
extremely complex but is often accompanied by simplistic definitions of parameters such as spirituality, prayer and well-being, making the relevance difficult to interpret in relation to the findings of qualitative research such as this project. The researcher’s paradigm encountered in much medical and psychological research in oncology, seems influenced by what they label as poor well-being for cancer survivors; whose essential determining feature is the large monetary cost of complex management. From their perspective, the management of the oncology patient is much more expensive than that of the control patients in surveys because they require much more medication and considerably more psychological and pastoral intervention. Consequently the well-being of the control patient is deemed good and by contrast that of the study patient is deemed poor. Such an approach links patient well-being with cost and is largely ignorant of prayer and spirituality. Well-being that is determined in this way is difficult to relate to the Mohan concept of this study and even more difficult to relate to the effects of prayer.

Neal Krause and his colleagues reviewed the research of the quantitative measures of prayer in relation to health [well-being] conducted prior to his paper in 2000. He found deficiencies with definitions, and with sampling and with limitations in the measurement approaches similar to those identified in the discussions above on the findings of this study found in the previous chapter. They wrote that “a central premise in the present study is that the best way to develop sound measures of a mature faith is to turn to older adults themselves,

and learn more about how they perceive and practice prayer”. Krause and his colleagues described the situation where the expected outcome of prayer failed to happen [disconfirmation of expectancy] and the patient would just give up. In particular, there is some evidence that the disconfirmation of expectancies may create a sense of learned helplessness and a loss of hope.

Krause and his colleagues clearly state the consequences of terminal patients losing hope. The patients may have stopped praying which is a dark night of prayer experience. In this study, if this experience persisted, would be labelled bad prayer giving rise to poor well-being; but if transient, it would be considered a normal hiatus experience. The loss of hope may have been occasioned by futile treatment in which the oncologist has commenced a treatment regime that could never deliver the desired treatment outcome. Or it may be futile because, in the opinion of the patient, God is seen as denying them the cure or freedom from recovery or other petition that they may have made. Such futile treatment is clearly a source of bad prayer and is linked with poor well-being. If a proposed treatment can be identified as futile, then making it more realistic offers the possibility of avoiding what would have been adverse consequences. Sarah Winch put it that “understanding this [futile treatment] will help you to get the best death possible”.


John Peteet and Michael Balboni in their most recent publication argue that “Distress or struggle over spiritual concerns (eg, feeling abandoned by God) has been found to be prevalent among patients with advanced cancer”.  

To support this they cite four references.

Reflecting back on this part of the study and on the contemporary research findings, an idea emerges that lack of reference to patristic writings by oncology professionals weakens their research design with consequent difficulty in providing for the patients’ well-being. Simply put, what was taught by the Desert Fathers from Anthony onwards was made systematic by John Cassian, comprised nearly two thousand years of contextually relevant experience of what works in prayer and what does not. This study found little evidence of bad outcomes associated with prayer. Such paucity may have arisen from the fact that the stories in the dataset were written to provide hope for other cancer patients and so any adverse outcomes may have been omitted. Reference to other publications found relevant references that indicated benefits from future research and collaboration between qualitative and quantitative researchers.

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6 The place of this research

This research adds to and takes a place within other research into prayer in oncology. Maintaining harmony with this body of knowledge, it makes an addition that contains some challenges. It establishes its credibility by being rigorously grounded in a collection of published patients’ stories that is representative of the distribution of cancers and is entirely derived from the hermeneutics of their experience. Further, it has shown that in oncology, theological reflection provided the most comprehensive insights into the patients’ own reflection on their cancer experience than seen by comparison with the research results of oncology or psychology professionals.

For cancer patients

For cancer patients this study offers hope. It reveals that they receive a great contribution towards healing through the process of telling their story and of being heard. It shows that truly patient centered active listening assisted the patient greatly. It shows that irrespective of the form or absence of their belief in God, that a patient’s spirituality can greatly improve their well-being throughout their cancer trajectory. Habits of prayer, formed in the “good” times, are affected by the cancer diagnosis but will assist them attain the best survival possible.

Contribution to the hermeneutic circle of oncology

Within the vast collection of oncology research, this study takes a place. It locates the practice of prayer within the context of human experience. Thus it is part of the hermeneutic circle by furthering the interpretation of the behaviour
of cancer patients and opening up further areas for the continuation of the

circle.\textsuperscript{64}

Its findings are consistent with and more completely explained by the
accounts Christian practice than by the incomplete findings of qualitative medical
and psychological researchers.\textsuperscript{65} However its findings can add to the evolution
of psychology in its relationship with spirituality and specifically religion, in the
field of mindfulness meditation. It challenges the notion of the dichotomy of
mindfulness from any religious context by asking that such proponents study it
more wholistically in the light of more than two millennia of practice that is
documented in the writings of both Western and Eastern religious Spiritual
Classics.

This research further contributes to the hermeneutic circle by raising three
related issues for the benefit of other researchers. Firstly, difficulties were seen
with understanding the communication between discipline specific researchers,
suggesting that they become more familiar with the paradigms of their oncology
colleagues. Secondly, qualitative research potentially provides a context for
quantitative researchers; and can assist them refine the parameters of their
“measures” such as FACT-Sp. This could enhance the validity of the measuring
tool by making it truly and comprehensively relevant to its object. Thirdly,
improved inter-disciplinary communication offers the prospect of matching the


\textsuperscript{65} Prominent amongst the myriad of Christian writers of spirituality are Plotinus (205-c.270 CE)
[union with the One], St Augustine & Dionesius (354-430 CE), John Cassian (c.350 CE), the
unknown author of the \textit{Cloud of Unknowing} (14\textsuperscript{th} Cent. CE), Baker (c. 1567 CE), and Evelyn
Underhill (c. 1955 CE).
professional’s cancer metaphor to that of the patient with positive improvement in the well-being of all parties.

Validates use of QSR-NVivo software for GT

The success of the GT methodology when coupled with computer-assisted qualitative data analysis has been demonstrated through this study: it enabled rich qualitative data to be analysed and useful conclusions to be made; and the high level of interest in my YouTube video on the eSeminar: The Storytelling Nature of Cancer Patients with Greg Brown constitutes evidence of the usefulness and validity of CAQDAS.66 This study has produced a paradigm that is useful for future research.

This study has provided another instance evidencing that analysis following a GT methodology has the potential to produce parameters that quantitative researchers could use to enrich their use of “measures”. Further it challenges the manner in which research findings are published, in the jargon of even germane disciplines, that limit the comprehension of the results and conclusions by researchers in other disciplines.67 It also challenges discipline specific researchers to find and understand the definitions that have developed over millennia through qualitative research particularly in the literature of


spirituality. Research conclusions that are derived within very narrow definition sets are very limited in use to researchers working in other domains.

This study has demonstrated that useful results can arise from GT based on a phenomenological analysis. Also that further benefit can arise from continued use of this methodology. But in failing to provide a rationale for every finding, it has demonstrated that researching matters as complex and intertwined as cancer, prayer and well-being, better communication is necessary between quantitative and qualitative researchers in the medical, psychological and religious fields. And that the research be truly patient centered. It is not possible that each oncology researcher become professionally expert in the paradigms and methods of all of the other disciplines, however greater effort directed at improved mutual understanding will be rewarded.

7 Future use of this study by patients and professionals

The well-being of patients and also that of the cohort of oncology practitioners can be enhanced by the findings and conclusions of this study. For patients, it can provide a context for their journey through cancer. As individuals and collegially, doctors, nurses, practitioners and pastoral workers too can better offer patient-centered care and receive improved personal well-being. Helping others helps oneself in the process.

For patients, the experience of receiving a cancer diagnosis can be most disorienting. There are so many uncertainties about the treatment and the prognosis. And good advice abounds as this study revealed. It becomes confusing to know what is relevant and where do “I” fit in. A context is revealed
within the findings of this study into which a patient may locate themselves. It contains information about spirituality, prayer, thanksgiving for a new purpose in life, and accepting their emotions as indicators of well-being. It does not contain individual advice but recounts that the testimonies of others can give hope. It can help a patient feel better about telling their story. Indeed, for many, to feel less selfish when they tell their story. And that not all doctors will understand their situation as they themselves do, which may be due to mismatched metaphors or the sheer pressure arising from the care of so many cancer patients.

From the perspective of the professionals the study has revealed a need to know one’s own spirituality in order to understand that of others. Effective active listening depends on such understanding. This study supports the notion expressed recently by John Peteet, Michael Balboni and in 2007 by Harold Koenig that it is important for doctors and nurses to develop an understanding of their own spirituality. Heidegger believed that everyone should explore what 'Being' means to them as individuals; he does not provide the reader with a ready answer to the meaning of Being. He believed there is no ready answer. Similarly, spirituality, like 'Being', has to be explored by the individual, there can never be

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a definitive definition for a phenomenon which is so personal and concerns the individual’s innermost feelings or psyche.69

Potentially, the findings of this study could become a guide for future psychosocial interventions to prioritize and tailor information and support resources, both human and financial, when needed most. Specifically for medical practitioners there were indications for a shift in the paradigm from training to education: Such a paradigm shift requires the introduction of issues of spirituality into medical undergraduate programmes; it requires further development in continuing medical education, to provide a basis and greatly needed support for improved active listening and well-being support of the doctors themselves. This study found evidence that such trends in the curricula in nursing education existed already and was finding its way into their continuing professional development. Radiation therapists had commenced these developments earlier as had the education of palliative care workers due to the example set by John Paver, the first ecumenical chaplain appointed to the Peter Mac Callum Cancer Institute in 1985 CE.70 Through his collaboration with developing the radiation therapy degree course at the RMIT University of Technology and later pastoral supervision at the University of Divinity.

Bringing the potential of such future uses, as this study identified above, to reality, requires that the paradigm shifts mentioned above must inform the design of curricula of all oncology cohorts to make them better characterised as

70 John E. Paver, “The Contribution of Theological Reflection and Pastoral Supervision to Theological Education,” (MCD, 2001); John E. Paver, *Theological Reflection and Education for Ministry* (Great Britain: MPD Books, 2006); Brown, “Therapy Radiography Subject Guides”. 
education than training. The following section identifies specific areas for future oncology researchers that arose from this thesis.

8 Indications for future research

This study found that more can be known about parameters that are currently affecting patient well-being. Further, indications were found that if other areas were researched, potential benefits could accrue to both the patients and the oncology professionals themselves. The following are research activities with potential to take this study further:

- Active listening that assists patients tell their story.
- Further identifying and seeking resolution of the difficulties reported that patients experienced communicating bad news to their family members.
- Developing metaphors for cancer that place the emphasis onto the patient rather than the cancer as the prevalent “war metaphor” fails to do. Are there alternative metaphors? To what extent does the faith background provide a series of images which help re-create this experience in a different and wider context?
- Resolving issues raised by patients’ adverse comments about their doctors. Mismatch between the practitioner’s metaphor and that of the patient.

Areas about which this study found few or no references within the story dataset, but the results obtained suggest potential for benefit from future research:

- Seeking explanation for the “why” of the patients’ responses to their cancers.
- The issue of gender based differences in the prayer of oncology patients. Further elucidation is possible beyond the confusing accounts encountered in some contemporary literature.
- A deep investigation of the faith-gratitude-well-being link.
• Research aimed at finding a new methodology or modification of existing methodologies that would improve the communication amongst discipline driven quantitative researchers and also mutually between them and qualitative researchers.
9 Connections

![Word Frequency Cloud for Chapter 8](image)

**Figure 8.3: Word Frequency Cloud for Chapter 8**

This conclusions chapter draws together all of the findings, comparisons and reflection previously made. The cloud is consistent with the conclusions that prayer (89) and well-being (89) seem to be related for cancer (59) patients (44). Other frequent words are spirituality (40), listening+active (22+17=39), meditation (15), communication (13), one (14), and god (11). These words are consistent with the theological reflection that the Christian paradigm was the most wholistic of those found in the oncology literature. The diversity of the other less frequent words in the cloud is indicative of the summative nature of this chapter that integrates this research.

The journey of this study has reached its *terminus*. Clearly, the storytelling of cancer patients had been revealed to be prayer which contributed to their well-being. A strong correlation between the prayer and well-being of cancer patients was manifest. The processes of reflection and comparison found strong mutual
congruence between: the findings of this research, the professional oncology practitioner literature, and the classical literature of spirituality. Consequently, giving strength to the conclusions of this research. In the ways identified, although differently, most cancer patients found god (or one) in their cancer experience. Further, the study revealed a corollary that active listening, facilitating the storytelling, contributed to the well-being of both the storyteller and the listener. Such conclusions contribute to the hermeneutic circles of oncology and theology.

From this *terminus* other roads can be seen. If taken, they would lead directly to benefit for the well-being of cancer patients and the whole professional oncology cohort including pastoral workers. Such roads are: (a) a greater depth and breadth in the theological study of the faith-prayer link throughout the oncology domain; (b) identifying and promoting more positive cancer metaphors to that of war for use by patients and oncology professionals; (c) implementing a paradigm shift from training to education continually through the undergraduate and the subsequent continuing professional education phases; (d) enhancing the communication of the outcomes of research, quantitative, qualitative and theological, to achieve a richer measure of sharing amongst colleagues.

10 Epilogue

Active listening has emerged as a potential key to the well-being of cancer patients and the oncology professionals alike. Don Jamieson, a deacon working in pastoral care seemed to know this when he quoted a piece about what it means to be a good listener, written by an unknown author.
You are NOT LISTENING to me when:

- You do not care about me;
- You say you understand before you know me well enough;
- You have an answer for my problem before I’ve finished telling you what my problem is;
- You cut me off before I’ve finished speaking;
- You finish my sentences for me;
- You find me boring and don’t tell me;
- You feel critical of my vocabulary, grammar or accent;
- You are dying to tell me something;
- You tell me about your experience making mine seem unimportant;
- You are communicating to someone else in the room;
- You refuse my thanks by saying you really haven’t done anything.

You ARE LISTENING to me when:

- You come quietly into my private world and let me be me;
- You really try to understand me even if I’m not making much sense;
- You grasp my point even when it’s against your own sincere convictions;
- You realise that the hour I took from you has left you a bit tired and drained;
- You allow me the dignity of making my own decisions even though you think they might be wrong;
- You do not take my problem from me, but allow me to deal with it in my own way;
- You hold back your desire to give me good advice;
- You do not offer me religious solace when you sense I am not ready for it;
- You give me enough room to discover for myself what is really going on;
- You accept my gift of gratitude by telling me how good it makes you feel to know that you have been helpful.⁷¹

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