SPONTANEOUS REMISSION OF CANCER

AS TOLD BY CANCER SURVIVORS

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"THE EXPERIENCE OF SPONTANEOUS REMISSION OF CANCER AS TOLD BY CANCER SURVIVORS: A SYSTEMATIC REVIEW OF QUALITATIVE PRIMARY STUDIES"

"This study was conducted in 2017 as the first author's Dissertation for the University of Brighton MSc in Public Health in the Division of Medical Education - Postgraduate Medicine - at the Brighton & Sussex Medical School.

Special thanks to Peter Frost who has supervised this project throughout and to Camilla Jaine Jones for her support.

I chose to study Spontaneous Remission of Cancer to remember those who opt out orthodox treatments because they are often forgotten as the price of their choice. However, I do not intend to advice or recommend any treatment in particular and I respect all choices.

I wish to dedicate this project to all the very special people diagnosed with cancer I have personally met during my nursing career and whose strength, determination and fighting spirit have been a source of inspiration for this research project and beyond"

DECLARATION OF AUTHORSHIP

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ABSTRACT

THE EXPERIENCE OF SPONTANEOUS REMISSION OF CANCER AS TOLD BY CANCER SURVIVORS: A SYSTEMATIC REVIEW OF QUALITATIVE PRIMARY STUDIES

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Background: Spontaneous Remission of cancer (SR) is defined as: "the partial or complete disappearance of a malignant tumour in the absence of all treatment, or in the presence of therapy which is considerate inadequate to exert significant influence on a neoplastic disease(1)" . To the best of my knowledge, there are only single studies published to date. Hence, the need for a systematic review of primary studies which aims to present cumulative findings that are more substantial than those from single studies.

Purpose: This study seeks to investigate the experience of Spontaneous Remission of cancer from the point of view of cancer Survivors. What do cancer Survivors say about what they experienced prior to the remission? Are there any common patterns across the stories?

Methods: A systematic review of seven qualitative primary studies was performed by analysing the accounts of 99 participants.

Results: The common theme across the experience of all the 99 participants prior to the remission is the undergoing of an 'existential reorganisation' which entails subjectively meaningful life style changes and experiences.
Following the initial shock of diagnosis and prognosis, cancer survivors across the studies experienced and described profound life style changes and experiences during the recovery process occurring at spiritual, psychological, emotional, physical levels and, in some cases, within social environment and relationships.

Conclusions and implications: The commonality of the subjects' responses does suggest that certain factors warrant further investigation on whether a causal relationship exists between these factors and the course of illness. In terms of patient care, we need to go beyond the biological model to embrace and address psychological, emotional and spiritual needs as they are of crucial importance to the health and wellbeing of patients.

CONTENTS

Introduction……5

Chapter 1: Background of Spontaneous Remission of Cancer

Background…… 8

Physiological hypothesis……11

Psychological Hypothesis ……14

Psychoneuroimmunology: A bridge between hypothesis?……18

The natural course of cancer……21

Incidence of Spontaneous Remission of Cancer……24

Theoretical Background: *Phenomenology……*25

Chapter 2: Research Findings

Introduction to findings……28

Existential reorganisation: The psychological level……32

Existential reorganisation: The emotional level……44

Existential reorganisation: The social level……53

Existential reorganisation: The spiritual level……62

Existential reorganisation: The physical level……72

Chapter 3: Conclusions and discussion

Conclusion and discussion……81

Implications……84

Limitations of the study……86

References……88

Introduction

Spontaneous Remission of cancer (SR) is defined as: “the partial or complete disappearance of a malignant tumour in the absence of all treatment, or in the presence of therapy which is considerate inadequate to exert significant influence on a neoplastic disease(1)” .

Cancer is probably one of the deadliest and most feared of the diseases. According to recent statistics around 160,000 people in the UK, die from cancer every year(2). Moreover, the experience of cancer itself and the side effects of its conventional treatment remain physically and emotionally devastating.

The field of Spontaneous Remission of cancer research experienced a major turning point in 1966 with the publication of two monographs including 176 and 61 detailed cases of SR (1, 3).

Spontaneous Remission of cancer albeit considered rare, is an indisputable fact which study could lead to a better understanding of such rare documented experience.

Medical databases contain case reports(4-7), literature reviews(7-9), qualitative primary studies(10-12), and at least one meta-analysis of randomised controlled

trial which, investigated regression of solid tumours in patients receiving placebo or no anti-cancer therapy to inform of spontaneous regression(13). From a medical point of view, the most common factors preceding SR of cancer appear to be high fever, bacterial infection, immunological factors and surgery (14-17).

This study seeks to investigate the experience of Spontaneous Remission of cancer from the point of view of cancer Survivors. What do cancer Survivors say about what they experienced prior to the remission? Are there any common patterns across the stories? To answer these questions, a systematic review of seven qualitative primary studies was performed by analysing the accounts of 99 participants. To the best of my knowledge, there are only single studies published to date. Hence, the need for a systematic review of primary studies which aims to present cumulative findings that are more substantial than those from single studies.

Chapter 1

Background of Spontaneous Remission of Cancer

Background of Spontaneous Remission of Cancer

The field of SR research experienced a major turning point after the two monographs published by Everson & Cole and by Boyd. Up to date, SR research is still in its 'young' phase with only two conferences held on the subject, one in early 1974 hosted by Everson and Cole at Johns Hopkins University in Baltimore and the other one held more recently in Heidelberg, in Germany in 1997 - *proceeding of a conference on spontaneous remission in cancer, 1997 (18)*.

When we use the word 'Spontaneous' in the remission of cancer, it somehow suggests the disappearance or the regression of the disease without any evident or apparent cause (19). William Boyd wrote on the word 'spontaneous': 'It has a suggestion of something happening without a cause. That of course is absurd, for everything has a cause, apparent or inapparent' (3). Challis & Stam also agree that some current unknown variables must be involved in the initiation of the regression. In their comprehensive review of cases from 1900 to 1987, Challis and Stam reported that certain physiological factors appeared to be most associated with SR (4). Across the literature, the only unorthodox factor was the psychological. In the following literature review, I will present and discuss the relevant literature presenting physiological and psychological explanations for SR.

Spontaneous regression is a phenomenon that has occurred for as long as cancer has been recognized and diagnosed. Yet, the first meta-analysis of spontaneous regression of cancer was first carried out in 1918 by Dr G. Rohdenburg, medical director at Columbia University in New York. In his meta-analysis Dr Rohdenburg tracked and analyzed 302 cases of spontaneous regression.

In his study, Dr Rohdenburg noted that the vast majority of cases of SR were preceded by fever, which he described as an "acute febrile process". In most cases, the patient experienced a very high temperature that "continued without remission for several days" (20).

The most common condition found to induce the high body temperatures was Erysipelas, an acute streptococcal bacterial infection of the skin, although cases of smallpox, pneumonia, malaria and acute tuberculosis have also been observed.

The relationship between cancer regression and fever was noted as long ago as in the 1700s (19). Professor W. Busch tested this hypothesis later in 1866 when he injected a patient with cancer with live Streptococcus pyogenes bacteria, which led to a erysipelas infection and consequently to a complete cancer regression (21). The theory was then actively pursued in the first half of the 20th century by Dr William Coley (1862-1936), a bone surgeon at the New York Cancer Hospital (now

the Memorial Sloan-Kettering Cancer Center), which led to a therapy that became known as 'Coley's toxins'. Lloyd J., MD who was associate director of Memorial Sloan Kettering, and CRI's medical director from 1971-2011, wrote that: "Those who have scrutinized Coley's results have little doubt that these bacterial toxins were highly effective in some cases" (22)

However, for various reasons, in 1963 the concoction was classified as a 'new drug' by the US Food and Drug Administration (FDA), and is now limited to use only in clinical trials.

Drs Tilden C. Everson and Warren H. Cole, both from the University of Illinois College of Medicine in Chicago, rigorously reviewed cases of spontaneous regression reported in the medical literature, describing cases from 1900 to 1965, and concluded that 176 of these cases were genuine-albeit inexplicable. The monograph by Everson & Cole included cases from literature, personal communications, and their own patients records from 1900 to 1965, inclusive. These cases all met the current definition of SR. Cases whose diagnoses was not confirmed, or treatment was implemented, were rejected. Everson & Cole omitted cases of leukemias and lymphomas because of their natural changes in growth rates and retinoblastoma because at that time histological evidence to confirm the presence of this cancer was not available (1).

It is from Everson and Cole that we have inherited the definition of spontaneous remission that we still use up to date. Around the same time (1966), Boyd reported a monograph containing 98 well-documented cases of SR. Like Everson and Cole, Boyd excluded cases of lymphoma and leukemia due to their natural fluctuation in their disease process(3). Of interest, the most common cases of SR in Boyds – retinoblastoma and breast cancer- were not the same most common cases of SR in Everson and Cole: Renal Cell Carcinoma, choriocarcinoma, neuroblastoma and malignant melanoma (23). This discrepancy points out at the importance of selection criteria.

Physiological hypothesis

Challis and Stam reviewed the literature from 1966 to 1987 to update the reviews by Everson and Cole and by Boyd. They noted that a large number of authors who report cases of SR fail to discuss the possible mechanism or reasons that may be involved. After summarizing 489 cases between 1900–1987, they concluded that literature on SR was still unable to provide unambiguous explanations of the mechanisms underlying the regression. However, the most reported factors associated with SR were immunological, endocrine, surgical, necrosis, infections,

operative trauma (4). The only unorthodox treatment reported was the psychological.

Across the literature, hormonal mechanisms were suspected after complete remissions of malignant melanoma reported during pregnancy and following delivery (24). Moreover, there are at least three case reports of remission of acute leukemia following termination of pregnancy, which further suggested some hormonal involvement in the process (23, 25). Everson and Cole cited five cases of regression of metastases from ovarian carcinoma following oophorectomy. However, clinical therapeutic trials using hormone therapy were reported to be 'disappointing' (26, 27).

Another physiological factor associated with regression appears to be tumor necrosis and angiogenesis inhibition. As tumors depend on adequate blood supply and on the production of new vessels, to compromise blood supply has been seen as a possible cause of remission (28-30).

In 1995, O'Regan Brendan and Caryle Hirschberg, at the Institute of Noetic Sciences, performed perhaps the most exhaustive research on this subject.

In this review, they catalogued 1574 cases of spontaneous regression of cancer. O'Regan determined that only 261 cases were sufficiently documented, 30 of which were cases of lymphoma and leukemia (31).

Of note, O'Regan (1995) redefined SR as:

"Spontaneous Remission is the disappearance, complete or incomplete, of cancer without medical treatment, or with treatment that is considered inadequate to produce the resulting disappearance of *disease symptoms* or tumor"(31). On a semantic note, Dr. K. Turner suggested that the wording 'disease symptoms' be replaced with 'metastases or non-tumorous malignancy' so to avoid the incorrect interpretation that SR may include the disappearance of symptoms such as fatigue or pain (11).

To conclude this paragraph, we can say that the field of research of Spontaneous Remission of cancer is still in its early phases. No definite conclusion can be drawn on what causes remission. However, from a biomedical point of view, the most common physiological factors preceding Spontaneous Remission of cancer are: immunological, endocrine, surgical, angiogenesis inhibition and infections.

I wish to highlight that the emphasis and aim of this project is to study the stories as told by cancer survivors rather than a dispute about the evidence on Spontaneous Remissions.

Despite considered rare, Spontaneous Remission of cancer remains a fascinating phenomenon that certainly leaves abundant questions to be answered in future research studies.

Psychological hypothesis

In addition to potential physiological pathways involved in Spontaneous Remission of Cancer, psychological factors have also been proposed.

Researchers have conducted qualitative primary studies where they directly interviewed persons who have experienced SR. These studies found that many persons experienced a profound psycho-emotional shift prior to the remission. For example, Schilder et al. report that people who experienced SR were pushed beyond their usual coping mechanisms into a 'wider set of characteristic that is normally accessed' (12). Vendegodt et al. (32) found instead that 'recovery of the human character and purpose of life' preceded SR. Hubscher reports that a psychological change preceding SR was about transcending the implications of

one's cancer diagnosis and deciding to live a full life (10). Yet another study, found that people experienced profound changes in their existential and spiritual thoughts prior to the remission (33).

The work of Dr. Steven Greer et al. found that mental survival provides another look at a possible link between remission of cancer and psychological states of mind. Dr. Greer et al. conducted a ten years study of women who were admitted to hospital for breast biopsy in 1977. Factors determined and accounted for at each follow up period were: psychological stress from mastectomy, depressive symptoms, marital, sexual and interpersonal adjustments. Moreover, researchers identified five categories of psychological responses to diagnosis that were linked with more favorable outcomes and mortality. Psychological categories were: *denial, fighting spirit, stoic acceptance, anxious/depressed acceptance, hopeless/ helpless response.* At five years after biopsy, those patients whose responses showed denial or fighting spirit (15/20, 75%) had more favorable outcomes than those who showed stoic acceptance or helpless/hopelessness (13/37, 35%). At ten years follow-up, although mortality was high, outcome remained better for those who responded with denial/fighting spirit (11/20, 55%) than the counterparts (8/37, 22%). (34).

In 1975, Dr. Yujiro Ikemi et al. also reported 5 cases of spontaneous remission in which they noted psychological commonalities amongst the patients. Those included a dramatic change in outlook on life and in 4 of the cases a passionate religious fate and trust to 'leave their outcome to fate or the will of God' (35).

Similarly, in a study of 6 cases of spontaneous remission from advanced cancer, Drs Baalen, De Vries and Gondrie found that the group shared common psychological characteristics such as: changed behavior, spiritual beliefs and relationship toward the environment, significant changes in their attitude toward their illness, treatment and relationships with other people. Authors concluded that the psychological factors involved in the SR of cancer are: *trust, challenge, commitment and control* (36).

Another example of such remarkable stories of remission comes from a study conducted by Dr Paul C Roud, first published in 1986. Dr. Roud interviewed 9 patients who had experienced extraordinary survival after a 'terminal diagnosis' of cancer. The patients' physicians were contacted and asked to confirm the exceptionality of these cases which in order to qualify to study probability of survival was to be 25% or less. In all the cases except one, probability of survival

was less than 10% with four of the nine patients been given less than 0.1% probability of survival (37).

Common psychological factors identified by Dr. Roud across the stories were:

- A confidence that they would not die;

– A belief that positive expectations were critical to the healing process

- major psychosocial changes in the months following their prognoses: Unlike their attitudes before illness, once they were confronted with the prospect of death, life suddenly became very precious;

– A sense of responsibility for all aspects of their lives, including recovery;

– A patient-physician relationship characterized as trusting, meaningful, and healing;

- An Intense desire to stay alive.

Other psychological reasons for SR reported in literature are hypnosis and altered states of mind such as trance, meditation and prayer. At the time researchers from the Institute of Noetic Sciences were preparing their extensive report on SR, the International Medical Commission of Lourdes had recognized 65 cases of

'miraculous' healing which is defined as the complete regression which is inexplicable other than by faith or prayer (31).

To conclude this paragraph, many in the research and medical community are now beginning to acknowledge that psychological factors do play a role in remission and survival rates. However, what this role is, and how much influence psycho-spiritual factors have in the remission and survival of cancer (and not only) – is unknown. As Caryle Hirshberg pointed out in "Spontaneous Remission – the spectrum of Self-repair"(38), rather than discount reports of Spontaneous Remission because of their most often anecdotal nature and inadequacy of diagnostic information, one should ask: 'are there cases of remission that are strongly linked to psychological and spiritual changes, and if so, how might they best be studied?'

Psychoneuroimmunology: A bridge between hypothesis?

Psychoneuroimmunology (PNI), also referred to as psycho-endo-neuro-immunology (PENI) is the study of the interaction between psychological and physiological processes. Notably PNI takes an interdisciplinary approach by incorporating psychology, neuroscience, endocrinology, immunology, physiology, genetics, pharmacology, molecular biology and more.

Several authors have investigated the pathways and suggested that Psycho-neuro-immunological mechanisms exert a significant influence in the health status and on a variety of disease onset and conditions in humans (39-42). For example, in a pilot study with 40 participants with malignant melanoma and cancer of the colon, Seligman, Rodin and Levy (1991) investigated the effects of Cognitive Behavioral intervention on the immune system response. Patients were randomized in two groups. One received conventional treatment only (chemotherapy and/or radiotherapy). The other received conventional treatment combined with 12 week program (once a week for 12 weeks) consisting of cognitive therapy and relaxation training. At the end of the study, the group who had received the additional 12 weeks program showed a sharp increase of NK cells (Natural Killers are a type of lymphocytes and a critical component of the immune system)(43). Similar results were found in another study were adult males were assessed immediately after exposure to controllable or uncontrollable stress (noise) as well as 24 and 72 h later. Personality variables as moderators of the stress-immunosuppression relationship were considered. This study shows that Subjects who perceived they had control over ‘controllable’ and ‘uncontrollable stress showed no reduction in NK activity. By contrast, subjects who perceived that they had no control over the stressor showed reduced NK activity which persisted as long as 72 h later. The

researchers concluded that: “The results suggest the importance of perceived control (psychological factor- my emphasis) in moderating the short- and long-term effects of stress on NK activity”(44).

In 2003 *Brain, Behavior, and Immunity* published the *Biological Mechanisms of Psychosocial Effects on Disease* supplement commissioned by the National Cancer Institute. This seminal volume reports science reviews and commentaries by leading experts in psychoneuroimmunology (PNI) and it is particularly relevant to cancer research as it served as a catalyst for PNI research conducted in a cancer context(45). PNI and its discoveries led to a paradigm shift that has emerged in the past decades to advance the current orthodox mechanistic understanding around tumour biology, cancer treatment and cancer outcomes.

The innovation of PNI rests in the discovery that systems once thought to be separate are instead connected by systems of communication that links them. The neuroendocrine, the nervous and the immune system send and receive messages from within the organism and the outside environment. PNI indicates that psychological changes can produce significant chemical changes in the body especially regarding the number of hormones that are released by the pituitary and pineal gland which exert a cascade effect on other systems such as the

immunological. (46, 47) Moreover, PNI has discovered that states of mind like grief, stress and joy can alter immune responses and that the immune system can affect the brain and state of mind. (48, 49)

Since one of the physiological factors associated with SR is the immunological response, it is interesting to speculate how psychological factors can interplay in that cascade of neuro-immunological reactions that might elicit cancer regression.

To conclude this paragraph, PNI could represent a bridge between physiological and psychological hypothesis by scientific inquiry and methodological research into systems that once thought separated are now understood to be connected.

The natural Course of Cancer

What is the natural course of cancer? In other words: what would happen if cancer was left untreated? Here is a study on the natural course of Breast cancer, conducted by researchers at the Norwegian Institute of Public Health in Oslo: they tracked two groups of women with similar health profiles and backgrounds, and signs of Breast cancer. One group was screened by mammography every two years from 1996 to 2001, whilst the other group was screened only once at the end of

that 6 years period. After the six years period, they found that the rate of cancer was 22 per cent higher in the frequently screened women. Researchers found no obvious reason to explain the higher rate of cancer in the frequently screened group. This left the researchers with a question: where had the cancer gone in the 'unscreened' women by the time they had their final mammography? Here is what lead researcher, Dr Per-Henrik Zhal reported: 'it appears that some breast cancers detected by repeated mammographic screening would not persist to be detectable by a single mammogram at the end of the six years. This raises the possibility that the natural course of some screen-detected invasive breast cancer is to spontaneously regress'(50).

Similar rates of regression was found in patients with non-hodgkin's lymphoma where researchers found that in a study of 83 untreated patients, 19 cases (23 per cent) reported spontaneous regression (51).

Another study conducted by Doctors at the Saitama children's medical centre in Iwatsuku, Japan also observed cases of spontaneous regression in cases of neuro-blastoma, the childhood cancer that attacks the adrenal glands. Doctors observed and monitored neuro-blastoma, without any other intervention, in the cases of 11 years old infants with tumours less than 5 cm in diameter. After six months of only

passive observation, the tumours were reduced in every case, although none had completely disappeared by end of the study. The researchers concluded that: 'regression of neuro-blastoma is not a rare phenomenon' (52).

A recent large-scale study, published in 2016, comes from the Department of Internal Medicine, University of Alabama at Birmingham, United States of America. Researchers conducted the first ever meta-analysis of spontaneous regression of advanced solid tumours in patients receiving placebo or no anti-cancer treatment to inform of spontaneous regressions. After judging for good quality studies, they analysed 61 RCTs evaluating 18 different solid tumours in 7676 patients receiving placebo or no anti-cancer treatment. Their conclusion was: 'Spontaneous regressions are seen across all advanced solid tumours. Some malignancies demonstrate higher rates of spontaneous regression and may be relatively immunotherapy responsive' and (at page 133) '… this phenomenon is not uncommon and is widely observed across all cancer types'(13).

The latter study is perhaps the only meta-analysis performed so far on such a significant large number of patients.

Incidence of Spontaneous Remission of cancer: How often does it occur?

Across the literature authors have estimated that the true rate is one every eighty to hundred thousand cases (24). Though some authors objected that spontaneous remission and fluctuation in the size of tumour happen more frequently but are 'overlooked' and only those rare cases of 'dramatic' and long-lasting' event are reported (25).

Several authors have observed an under-reporting of SR (12, 18, 53). Overall, the possible reasons of under-reporting appear to be:

1) Difficulty in establishing what criteria must be met to consider a case SR;
2) Ambiguity in what is considered adequate treatment for a particular individual at a specific stage of a specific cancer.
3) Physicians tend to report only those rare cases of 'dramatic' and long-lasting' SR;
4) Nature of current allopathic treatment reduces chances for SR;
5) Physicians do not have the time or the expertise to write an article for publication;
6) Journals do not accept articles on SR due to the rarity of the topic;

7) SR subjects may have stopped allopathic treatment, not been followed up and oncologist is not aware of remission.

Whether the incidence reflects the true value of Spontaneous Remission or not, we simply cannot know. Dr K. Turner in her study on Spontaneous Remission of cancer noticed that the SR subjects she interviewed were found by word of mouth and their cases were not published. Followed this observation, Dr Turner recommended the creation of an online international database in which physicians could quickly and easily report cases of SR. I welcome this proposal which might enhance the accuracy of the estimated incidence of Spontaneous Remission of cancer.

Theoretical framework: Phenomenology

This study was grounded in *Phenomenology* in that it focuses on the human experience subjectively. This approach emphasizes the participants' perceptions, feelings and experiences.

Phenomenology focuses on the study of manifestation in relation to consciousness. There is a basic concept in the phenomenological approach for which whatever we know about the world, even what we define as objective truth, begins with and is based in consciousness (54). In other words, human beings are not passive perceivers of an objective reality but rather they interact with reality through their

interpretation and understanding of it. In this sense, Phenomenology moves beyond the rigid distinction between inner and outer, object and subject and acknowledges the interaction and the connection between consciousness and reality.

To conclude this paragraph, Phenomenology highlights the importance of perceptions and stresses that people live by and through their perceptions, being rational or irrational. Its focus is on the experience of individuals and the way in which they perceive and attach meanings to the events. Therefore, phenomenology provides a pertinent framework in understanding SR of cancer from the Survivors point of view, especially because the focus of this project is in the subjective experience of it.

CHAPTER 2

Findings

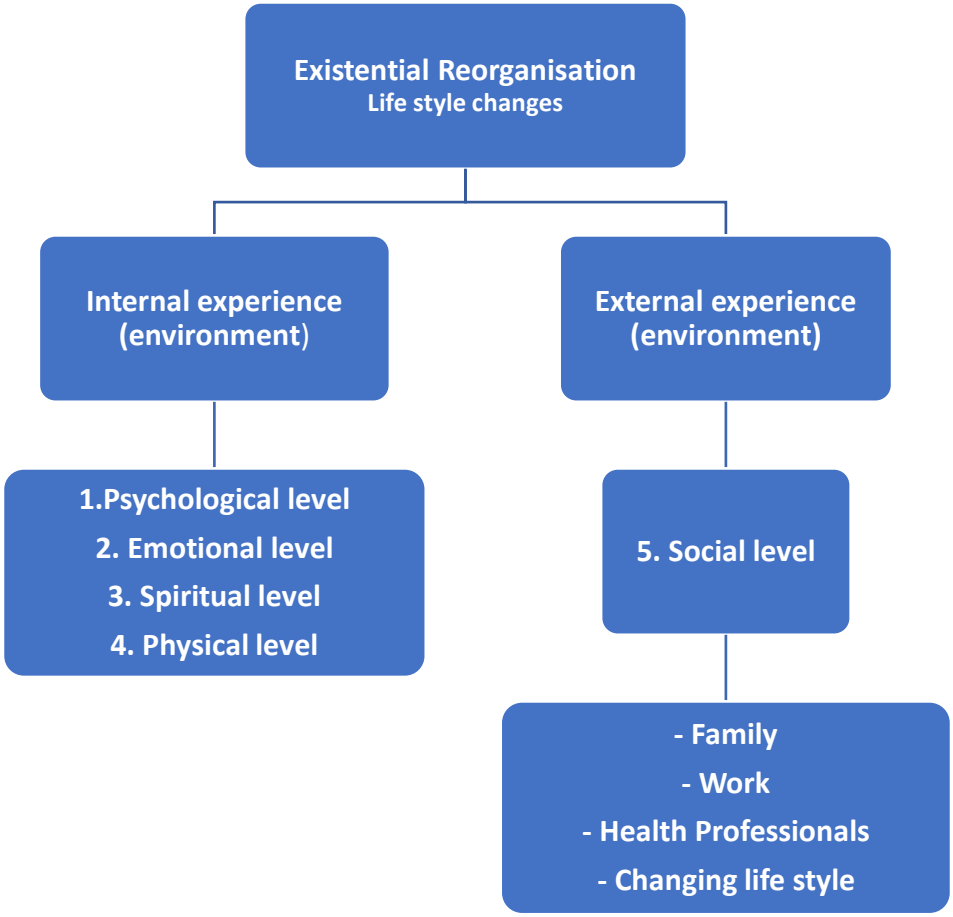
Introduction to the research findings

The seven studies analysed the extraordinary stories of 99 people who experienced exceptional recovery from cancer as confirmed –for the majority of them- by the physician. Each person described the process of recovery highlighting experiences that were of particular meaning for that person. One common theme across the experience of all the 99 participants is the undergoing of an **'existential reorganisation'** which, entailed subjectively meaningful **life style changes** after the diagnosis of cancer and the knowledge of the prognosis.

Following the initial shock of diagnosis, cancer survivors across the studies experienced and described profound life style changes during the recovery process. These profound changes concerned internal – **spiritual, psychological, emotional and physical** - and in some cases external – occurring within their **social** environment and relationships.

One of the commonalities across the different levels of changes experienced prior to the remission included the individuals finding their paths and taking charge of their lives. This was expressed in a very personal way that reflected the personal meaning and importance of each cancer survivors.

Graphic 1. Factors preceding SR of cancer



The existential reorganisation and changes appeared to have increased Cancer survivors' coping mechanisms and influenced their experience of Remission.

The diagnosis of a potentially terminal illness such as cancer has turned to be a 'wake-up call' as pointed out by Dr. Blu Wagner (study 5), giving individuals an

opportunity to re-prioritise life and claim a more authentic approach to living that is in line with each individual core-values.

The spiritual theme was present across all studies, though this was not necessarily religiously oriented. I find this not at all surprising considering that a diagnosis of cancer, like no other disease, can precipitate anyone at the crossroad between life and death.

Perhaps, the suffering inherent to severe diseases, such as is cancer, offers the key to unlock the doors of deeper spiritual experiences that were not accessible before. Study 4 presents a similar speculation in terms of ability to access different aspects of personality through "pervasive **psychological change**, leading to different coping than the patient previously had shown in similar situation"(12). In other words, cancer had activated potentials that every individual had within himself, albeit dormant.

The existential reorganisation led to a profoundly altered self with a renewed life style and way of coping. The diagnosis of cancer led people into **a profound journey of change and transformation.**

Common to all these narratives was a change in their philosophy, in their way of being and living life. This focused on active participation in everyday life. *Cancer*

survivors turned cancer into an opportunity almost, to make it a priority in living to the fullest. Cancer did not hold primacy as individuals transcended the implications of their diagnosis and undertook significant steps focusing on their wellbeing rather than preparing to die.

All the levels of existential reorganisation involved *prioritising* activities and relationships that were important and conducive of wellbeing. Across all seven studies, all the participants described positive coping mechanisms and positive internal responses at the emotional, psychological and spiritual levels. In most cases, those internal positive states were coupled by positive external relationships with family, friends and health professionals. Prior to the remission, survivors described changes within their environment such as family, work, home that implied the end of negative, unpleasant and sometimes toxic experiences in favour of more positive, meaningful and fulfilling ones.

Patients reported **having *positive feelings*** *such as trust, hope, positive expectations, faith, confidence, taking responsibility, being active* throughout the process from diagnosis to treatment to recovery.

The following paragraphs describe the existential reorganisation at different levels. Due to the complex mix of psychological, emotion

al, social, physical and spiritual components encountered in the accounts of cancer survivor, it has been challenging at times to 'label' and reduce such rich accounts of experiences into narrow themes. However, I trust that the overall work will give a feeling of the experience of remission as told by cancer survivors.

Existential reorganisation: The Psychological level

Graphic 1. Psychological subthemes

Activism, fighting spirit, taking control

From the time participants had received the diagnosis, Cancer survivors showed a sense of **activism**, a **'fighting spirit'** and a positive determination to face the disease: they **took control of and responsibility** for their health and life by taking an active stance and **making decisions** according to what they felt was best for them.

After the diagnosis, individuals underwent through a process of introspection: they decided to take control of the healing process and to make decisions even though at times controversial. Some subjects discussed the struggle to stay alive as a fight or a battle. One participant suggested that this orientation is common in all exceptional survivors: "*A basic common denominator is a willingness to fight, a scrappiness, an unwillingness to lay down and die."(37)*

This active stance is notable in cancer survivors' narrative and their frequent use of active verbs with personal pronoun such as 'I did' 'we decided' (referring to the physician. Some examples from study #3 reflect this stance in the early stage of diagnosis*: "I have decided", "I was really scared, but I knew that I had to take the bull by the horns and run with it. I had to do whatever I could do to get rid of it or to manage it."(61)*

Similarly, another Cancer Survivor:

*"No, I need to **take charge of this**. I need to do what I have to do here. And I'm not going anywhere."(62)*

Taking control was also expressed in the selection of the treatment team. For example, a patient who switched doctors described her experience: *"…the second time when I didn't feel the doctor was listening to me, then I just went ahead and switched doctors"(61)*.

Similarly when Herold was given 15% to 20 % chances of survival with chemotherapy got up and said to the doctors

"The odds aren't good enough. I'm going out to see Dr.. (at an Alternative Health Centre)"(10)

Gathering information

Taking an active stance was expressed in seeking information and educating oneself about the disease process and the options available. One Survivor who had served in the military, applied a military metaphor to fighting cancer by gathering the right information: "*I had just completed military service for 22 years. It was*

three months after my discharge. I understood that cancer was a kind of war. And in a war, you need intelligence"(61).

In many cases from study 3, fostering a positive attitude entailed an active process of data collection, examining the various physicians, and seeking a second opinion. Many referred to making joint decisions: *"we (my physician and me) decided…"* or "*getting a second opinion…and maybe a third before you do something."* Cancer survivors were quite clear, however, on their respective roles: *"I expected him (the physician) to do everything he could"* and *"I would do everything I could to beat the odds"(61)*. Another Cancer survivor stated: *"Sometimes the doctors don't always know everything that's out there. It takes a proactive patient to be successful"*. And Ethan said: "*I intend to live after I get well, (…) I was going to do the best that I could to find as many people or as many different forms of treatment that had worked'* (10)

Along with the feeling of trust toward health professionals and the treatment plan, one of the positive attitudes that I noted across studies was about a sense of 'taking control', 'feeling of empowerment' over decisions during the process of recovery. For example, one cancer survivor in study 2 describes his focus on taking control of his recovery process rather than planning for his death:

"I went to a bookstore (..) I found (..) "Beating Cancer with Nutrition." So I thought, yeah, I'll give this a try, you know….I think a positive mind is very important. And your attitude. I'm determined not to let this uh, control me. I'm gonna control it. The cancer, that is"(11).

Making decisions

In study 3, taking control emerged when discussing with their physicians' decisions regarding their treatment. One participant noted, "*I felt like I was in control, like I was making the decisions*"(61) and another patient said: "*Then it's time to get busy and take care of yourself, be responsible for yourself"* - Colin(10).

Taking control of one's own recovery process is not always an easy path to take. Sometimes it required making decisions that were in contrast with the point of view of physicians and family members. For example, a cancer survivor explains that – after gathering information prior to make a decision - taking control of his recovery process required going against his family's wishes:

"*They [CA survivor's daughters and wife] were quite keen for me to have the surgery. But the more I thought about it and the more I inquired about the side-*

effects and the success rate, I just did not believe at all that that was the way to go (….) I felt completely confident that it was not the way for me to go for surgery. And I'm so glad that I didn't"(11).

Field notes: In this quotation, there are also subthemes of taking an active stance, gathering information, trusting one's own intuition and deciding. This example is suggestive that taking control is not only an educational process but also requires having trust in one's own judgements and feelings.

I found more examples of making decisions that went *against medical advice* in study 6:

"...*And I sat up in bed...I'm not taking this treatment. I'm going to tell him I'm not coming in. I'm not taking those treatments. And I didn't.."*– Anna(10)

Fredric decided against medical advice not to have radiation:

"How can that stuff do any good? I think it was just my stubbornness, I just didn't want to do it".(10)

Bernice diagnosed with invasive cervical cancer was recommended radical hysterectomy. However, she was reluctant and did not feel that that was the answer for her. *"Take it all out. Cut it out...I mean, to my mind, it would have that*

much more of an opportunity to reoccur. They say, you could take it out and it could still show up in your brain, if it's invasive. So that, to me, is all the more reason [to not have surgery]'. Like what's the point?"(10)

Similarly, Ginny decided against the medical advice to receive radiotherapy post-surgery:

"That seemed so foreign to anything I wanted, to go into that building and be shot with any kind of anything. I just had a real aversion to it. And it just didn't seem right for me. And so I just didn't make an appointment"(10)

Self-talk, I am not going to die attitude

Many Survivors across the studies shared a belief in the connection and interplay between Mind and body. They believed that mental, emotional (and spiritual) aspects of the human being are not isolated and disconnected parts. On the contrary, they directly influence each other having a profound effect on physical health and wellbeing.

In study 2, a survivor talked about the possible effect of cognitions, such as **self-talk**, on recovery:

"I wanted to heal and now know that… you can't say 'I want to heal' You have to say 'I am healed'. Cause if you think that you are healing, you'll always be healing. Or if you want to heal, it means you are not healing. You know, so you have to really think of yourself as 'healed'… I became aware of my ***self-talk*** *and adjusted it when I's hear myself say, 'I want to heal', when I should have said, 'I am healthy".(62)*

The causal theory that leads mental activity to physical changes is expressed in the point of view of another cancer survivor:

"So, my understanding is that ***it's the mind*** *and that the mind is able to modify, reconfigure, or have an effect on the physical body and that's basically what this [healing work] is"(62)*

For some survivors, self-talk had a fundamental role throughout the process of psychological reorganisation. However, this required constant affirming and rehearsal:

"(..) *You have to make a decision and* **you have to confirm that decision over and over and over.** *You don't make a decision once. The universe will check you out, "Are you sure? What about this? What about that?" All kinds of things will come up. You'll get opportunities to change your mind, as I had an opportunity to change my mind that life was worth living (..) You have to keep doing that"* - Colin(10)

Constant rehearsal and re-affirming were fundamental also for David:

"*And so, I started saying, I'm confident. (…) I'm healed (..) I'm fine"(10).* David had also strong faith in the scriptures.

A hopeful attitude was not a mindset that simply happened to exists but rather the result of an active and thoughtful process of 'taking responsibility' for all aspects of one's own life. As noted in study 7 by Dr. Roud "creating and maintaining an optimistic life stance was an active, willful process"(37). This is illustrated in the following quotation from one cancer survivor:

"When I think about my illness, I just distract it, and knock it down to not get depressed. I just try and pick myself up. I never dwell on it"(37).

Another cancer survivor from study 7 describes the internal psychological process that helped him shift from hopelessness to active coping:

"I can remember lying in the hospital in Boston with my throat cut out and all the tubes coming out of me. I was sinking, succumbing, and thinking to myself, 'What's the point of it all. It's too much to overcome.' Then, all of a sudden, I could hear a click inside of me like throwing a toggle switch. I could hear that switch go on and

suddenly I began to energize. I sat up and said to myself, 'C'mon! You figure out a way. Get around it. Go through it or go over it! You can do it!".(37)

Belief in survival

In light of the prediction of imminent death, many subjects expressed a remarkable **belief in their ability to survive**. For example, in study 6 one subject said:

"*I never thought I wasn't going to get better.*" He remained confident even though two physicians independently confirmed that the likelihood of survival was (at best) 1 in 1,000, and treatment other than palliative care had been terminated. Similar internal states of positive expectations are expressed by another: *"They told me I had lung cancer and probably wouldn't last very long. **I decided** for myself that they were all wrong"*.(10)

Ginny mentioned her faith and determination to 'beat it' and her desire to do certain things with her life:

"Mostly it was my attitude that "I'm going to live" (..) I just set about trying to figure out what I was going to do. I always felt somehow, I'd beat it".(10)

A man in study 5 with lung cancer who was told he had only 6 month life-expectancy stated that after learning about his terminal prognosis, he simply decided that he was not going to die. He stated: "*So I said that's ridiculous. I'm not going to have that.*" The physician who provided information about this patient wrote, "His recovery is nothing less than miraculous."(33)

One Cancer survivor in study 7 described his reaction to the oncologist recommendations for chemotherapy treatment:

‘'*Look, if you go for this treatment then maybe we can give you three or four more years.' But they didn't understand. I'm saying, 'Goddamnit! You're talking about giving me three or four more years. I'm talking about beating the rap. I'm going for a win! I'm not going for three or four more years. That doesn't interest me!”(37)*

Colin (study 6) said that not accepting the prognosis and making a decision of not to die was the key of his recovery. He was told he only had a few months to live after his initial diagnosis of lymphoma, and told the same four years later with a recurrence. Colin rejected the validity of the prognosis wholeheartedly. He said:

“...I don't remember asking but I was told I'd probably die within four months, one of the things I wish medical people would not do. (..) I said, no, that's not true. That's not now I feel, that's not what my intuition tells me”.(10)

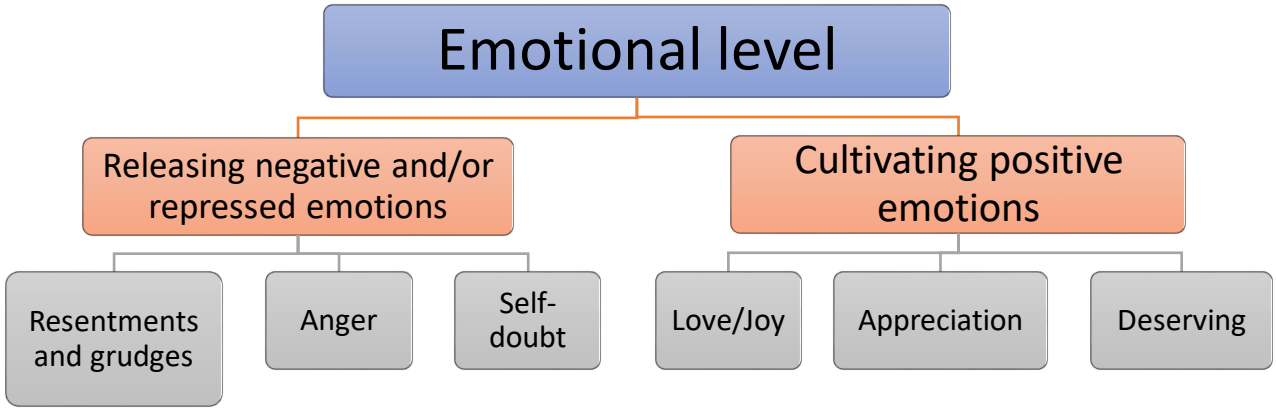
One cancer survivor in study 7 suggested that making specific choices over other did not really matter: "*All that's required is your belief in the approach you choose and that particular system will work for you."(37)* Two other survivors who thought that God had intervened to save them maintained that belief in survival was essential: *"If you ask God to help you, He's going to help you. But you have to believe He's going to help you."* (37)

Finally, a cancer survivor (study 2) describes her frustration with the prognosis offered by her oncologist, and how that awoke in her an 'I'm not going to die attitude':

"*The doctor said to me 'We can give you five more years to live' And I thought, "I want to live more than five years!" (..) So I kind of went out with an attitude of, 'This isn't going to beat me. I'm going to do this.".(62)*

Existential reorganisation: The Emotional level

Graphic 1. Emotional subthemes



1. Releasing negative and/or repressed emotions.

Many cancer survivors experienced an emotional reorganisation prior to the remission, which entailed a release of negative and/or repressed emotions. This release was expressed by **letting go** of some of their family and personal concerns. For some letting go was a process of forgiveness. For example, Ethan says:

"I reviewed my life and forgave everyone and everything that ever hurt....I went through my past and thought about everything in it that happened to me and forgave...that's what I was doing was releasing pent-up feelings and pent-up emotions"(10)

As cited by Huebscher in her work on spontaneous remission of cancer, A. Paul Ortega, a Mescalero-Apache Medicine Man, has said (1988):

"we throw a rock in the hate bag each time we hate. Hating or holding a grudge is a way of carrying around resentments"(10)

As part of their existential reorganisation, forgiveness was a way for cancer survivors to liberate themselves from the "hate bags", to release themselves from resentments and grudges.

Some Survivors felt that prolonged negative emotional states such as self-doubts, fear and anger contribute to the onset of cancer and others discussed the role of letting go of a negative emotion in order to contribute to the physical process of recovery.

For example, one cancer survivor who overcame liver cancer, says about releasing anger:

"There was a certain situation that I was in for 15 years of my married life that made me very angry. But I did not truly understand it, and I didn't really know how to express the anger… but that anger lodged in my liver. (..) So I can see how my thoughts and feelings contributed to the sickness (..)".(10)

Similarly, Ginny described anger as a contributor factor for cancer and saw cancer as a way out of difficult situations:

"I think there was anger and probably that is why I got cancer. I just thought, "Well, it's an acceptable form of suicide." I was tired of all these people demanding so much of me, so I'll just die".(10)

Bernice also found that expressing anger (as opposed to suppress it) was very helpful:

"(…) I think anger was probably the strongest thing. Just releasing anger to me even still in my life, I find is the most healing thing I can do and it's the most disallowed emotion in our society".(10)

Similarly, the release of self-doubt was an important step in the experience of remission. David called this kind of **self-doubt** that surrenders to what others may

suggest or tell after the diagnosis *"signing for that package"*. He described what happened after his initial kidney removal for cancer:

"*They sent me home with the idea that it was terminal, that I'd live a few months. (…) I started signing for that package. I had a teaching on that. Don't sign for that package unless it's from God. And I started signing for some of these dumb packages, the pain, the symptoms, the problems".(10)*

Similarly, in study 2, a cancer survivor explains her theory on the connection between physical expression of disease – in this case of cancer – and the psychological and emotional dimension:

"*.I believe that it (the cancer) has been caused by these patterns that I was describing to you that don't get released, that they are continually overlaid over and over and over, wherever they are..".(62)*

Emotional changes in the way of expressing and therefore releasing emotions was also common in study 7. A middle-aged survivor explained the nature of his changes following diagnosis and prior to the remission:

"*My relationship with everyone that I cared about improved. My sensitivity, my level of awareness, my ability to be with other people just skyrocketed. I made incredible*

growth in that way. I used to cover up my feelings. Now there are no pretenses. My feelings are right on my sleeve. When I'm angry, you'll know it; if I'm simply displeased, you'll know it. If I'm feeling loving, you'll know it. What I'm thinking, I'll share". (37)

Some survivors also view releasing negative feelings as a fundamental part of reducing unnecessary stress during the healing process. As Ginny commented: "*stress reduction is a necessary part of my treatment"(10)*

Bernice discussed how letting go of her anger (especially towards the traditional health system) helped her more easily in handling family issues:

"*Just releasing anger to me, even still in my life, I find is the most healing thing I can do (..) So I'm saying: ''I have a right to my feeling and when you trespass a certain boundary with me then I can express that I'm not happy about that' (..) I feel like because I'm at more peace with myself, I can really like separate from that emotional fire".(10)*

2. **Cultivating positive emotions - love, joy, happiness, empowerment, trust, hope, appreciation, trusting in intuition.**

Releasing negative emotions also implies a shift that leads to embrace and experience positive emotions, such as love/joy and happiness towards oneself and/or others. For some cancer survivors in study 2, these feelings arose naturally during their journey through cancer, whilst for other such feelings were influenced by mental and emotional practices such as meditation, visualisation and psychotherapy.

In study 2 one participant from Japan described the importance of sending love to his cancer in order to heal it:

"*… I sent love to my cancer and pain decreased and I slept fine… I touched this (points to the former site of his cancer) and said to my cancer: 'I love you, I love you'. And pain decreased. That's why I sent my love to my cancer always from morning until night… unconditional love, that's unconditional love. I said to it, 'Thank you (points to the former site of his cancer) very much for existing".(62)*

Similarly, another survivor says:

"*You know, what healed me was the power of love (..) and I think that love is very much what healed me in many senses..".*(62)

Finally, another cancer survivor reported that her recovery process started when she began to cultivate positive feelings of harmony, balance and joy:

"So, what I was trying to do was to manifest in my body a totally healthy host. And so, once I really started to re-frame my life and create a life that was based on harmony and wellness and balance and joy, my body really started to respond".(62)

Similarly, Anna (study 6) learned to express herself:

"*I'm very determined that I'm a person....I'd say for the last four years. I've been more determined that I'm right just as well as the next person's right. I don't care if I lose friends. I don't care if my family's crabby at me".(10)*

Participants reported a sense of **appreciation** to family members accompanying them to clinic and regular visits. One man (study 1) reported the important role of his daughter in attending clinics appointments, while another man reported that his daughter moved to be closer to him and stated *"not a day goes by that she is not here to see about me".* (63)

A woman described her husband taking days off from work to accompany her to her treatments and they would "*go out to lunch together.. [to have] time together*

because we didn't know if I was going to make it or not". Similarly several participants noted that they *'couldn't have made it without'* their spouse. Friendships were also important source of positivity. One participant noted he had *received '..over 400 visits while I was in hospital.. friends come.. [..] and talked to me and gave me* ***encouragement..".*** (63)

One participant noted that the illness experience *"completely changed my life…it was probably one of the best things that ever happened to me because it really made me wake up and…put a different perspective on life where I appreciate things more"*. (61)

One woman (study 3) described her cancer as **a turning point** contributing to improving her feeling of 'deserving':

"I suddenly realized that I had to change my life, that I had to do myself up and do up my house.…I went to a flower shop and told the shop assistant: 'I want a bunch of flowers (..) Make them up into a big bunch that will look like cheerful wild flowers'. The shop assistant said: 'Oh, you must have a birthday'. 'No,' I said, 'I have cancer.' And then I began living life differently. I began to understand that ***I was deserving".***(61)

One cancer Survivor (study 2) describes the importance of cultivating intuition in determining her treatment plan and remission:

"*(..) I heard a voice that said, 'Not that way, not this time'.. He [the physician] became very frustrated, told me that the diagnosis was very serious and that I needed to follow his exact rules and guidelines in order to get myself better. If not, I did not have a good prognosis. Nonetheless, I told him that I was not going to do that and I don't know why. I just knew that that voice meant something".(62)*

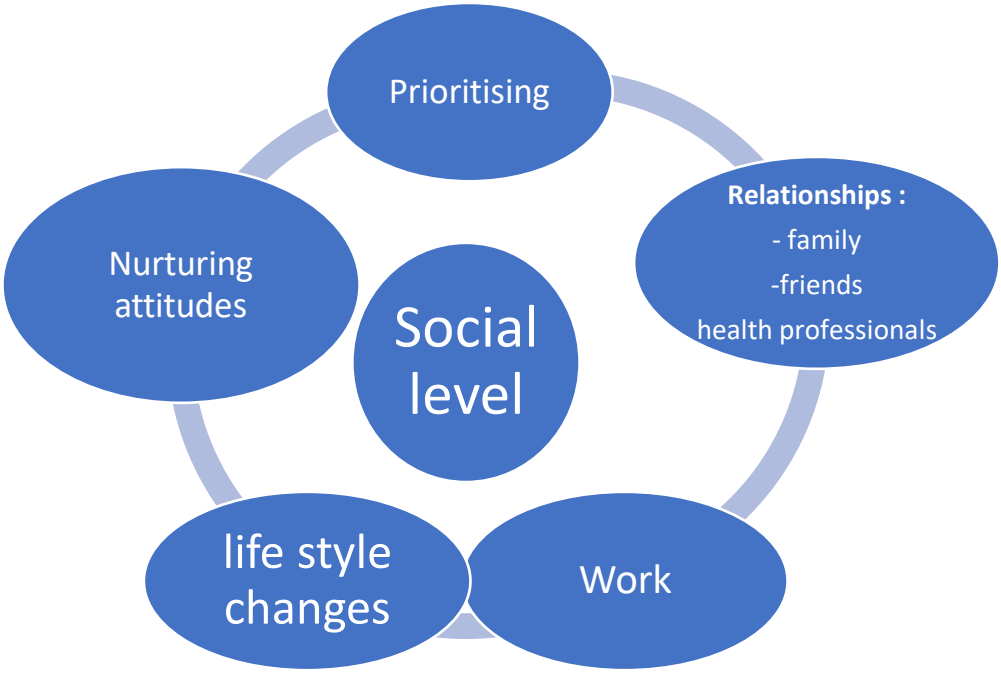
Similarly, Ginny mentioned the importance of 'listening to oneself'**:**

"..you have to really kind of guard your time and allow yourself a chance to just listen to you and be yourself and be In tune with the universe, or God, or whatever you want to call it".(10)

It is of interest to notice that when subjects in study 7 were asked, "What advice would you give to other seriously ill cancer patients?" they declined to make specific recommendations. They did not assume that what had worked for them would be the right plan to adopt for anyone else. On the contrary, survivors believed that they discovered what would be healing through a process of introspection and intuition. Similarly, they suggested that others must look within to find their own answers.(37)

Existential reorganisation: The Social level

Graphic 1. Social subthemes



Relationships, prioritising, social support, friends, work.

Most participants articulated the importance of relationships with others as major factors in dealing with their experience of remission. Relationships with families, friends and health professionals were positive in nature in that they nurtured positive states of feeling supported and cared for. For example in study 1 one

participants *noted "the combination of the physicians and God and my family and my friends is the reason I am here today'* and another said *'going through something like this without somebody there by your side.. it is dang near impossible". (63)*

Survivors also deliberately shaped their environments. Survivors let go of activities and people whom they did not genuinely care about (study 4 and 7). The illness seemed to free them to finally, lead the lifestyles that they had always wanted to. For example, one male subject in study 7 left a job he had disliked for 35 years; another moved from the city and bought a farm; one salesman quit his job to become a jazz musician; and a female subject became a "born-again" Christian(37). Yet another survivor let go of a conflictual relationship with her brother, sold a busy tiring business and spent more time with her family.(12)

Cancer survivors experienced a wake-up call post diagnosis that prompt them to re-evaluate and re-prioritize what is important. For example, Israel shifted the way he looked at his work:

"I used to live to work. And I made a real big change (…). I Decided I should just work to live (..) I know that it helped me put the proper priorities on my life, my wife's and my relationship.... the quality of our life, the way we treat each other. The way I'm

a father to my children, and a husband to my wife are more important because of having gone through this thing with cancer". (10)

Ginny felt that she needed to let go of some familiar roles. She felt she had been hanging on to a parent role for years and decided to let go of taking responsibility for all the family. She had a spouse, children, and aging parents and an in-law she cared for. She placed her aging parents in a care home. She became more assertive:

"..And so I just decided I was going to live. And I was going to stop being a Pollyanna. And I was going to learn to say no. And I told my parents they had to move to the Care Home because I was going to die and there wasn't going to be anybody to take care of them....I said [to my husband], "I need you to be with me"...I changed some of the things I did and I just learned to say no. I said [to my husband] "when your mother calls, you're going to take the call. I'm not going to be the go-between anymore."(10) By reorganising her role within her family, Ginny was also able to let go of some repressed anger.

Relinquishing negative relationships can be literally as vital as being supported by positive ones. For example, In study 2, one survivor describes how a social relationship gave him a renewed reason to live:

" It's picked up since I've met someone really nice that I enjoy being with. If that person wasn't around, I'd probably drink myself to death or something….You got to have something to live for. If you have nothing to live for then you know, why bother"(62)

Finally, the existential reorganisation triggered by a supportive family environment is evident in study 4: a man of 66 years old describes his experience of remission from liver cancer. Following the diagnosis, the patient met with his sons and described how he **felt encouraged** by them. He **decided to 'make the best of it'** for example by making several trips with his new girlfriend to places he had never been before and wanted to see. Remarkably, he stated that *"My life really started then"*.(12)

Field notes: It is worth noticing that whilst the family support was an important factor, it was the patient internal process of appreciation and 'decision making' of 'make the best of it' that, in my opinion, was a fundamental stepping stone in his experience of remission.

Others described that they were now focused on living in the present**.** This renewed focus implied prioritising changes in life style and activities that have particular meaning and foster positive emotions. This is reflected in study 3 in the statement

"I am doing the things I love".(61) In another example, a woman describes going from being a high-power professional to being a master gardener, which helped her *"feel much better and happier"*.(61) This change in philosophy became important as people faced the challenges of living with a chronic condition as illustrated in this vignette: *"about a month after finishing treatment, I went sailing with friends, and I had a wonderful holiday. I saw that there is life after cancer or even with cancer.…There's something, some inner mechanism, that make me live life to the full, and I don 't allow the cancer to rule my life or dictate what I do"* .(61)

The **relationship with the physician** described by participants was also remembered with positive connotations of availability and honesty *"like they were honestly there for you, I always felt like when I was there that I was in their hands"* another Survivor noted *that ".. it didn't dwell on the death part of it so much, but* ***he gave me hope"****(63).* A participant described the physician as *"a friend and advisor". (63)*

Feelings of confidence and trust were also articulated. For example in study 1 participants described confidence in the clinic and in that they were getting the best care for their disease.

*"I would 100% rely on his suggestions of what he needed to do.. I would do whatever he asked me to do gladly" and "…I've always **trusted** him to make the best decisions"," The doctor and staff are the expert, and **I trust them** that they are going to do what they need to do and what I need and tell me, and I try to do what they tell me".(63)*

Similarly, Harold discussed his confidence in the people at the alternative health care centre where he received his intravenous Vitamin C treatments for his cancer metastases: *"They knew they were gonna get it done so the confidence in them is the biggest help."(10)*

In study 3, most of the narratives revealed an active role in decision making concerning their medical treatment. The patients followed their physician's recommendations only after **building a relationship of trust**. At that point, they acted according to their physicians' recommendations. It is important to note that this attitude was not passive surrender, on the contrary, although they trusted their physicians, **they wanted explanations**: "Doctor, I'm in your hands, just explain what's going on "(61). In another example, a participant stated: "I was going to do everything, everything in my power to fight against it (cancer)…, I listened to them (physicians) and (I) made the decision". (61)

The relationship with the physician became – in some cases - even a reason why they wanted to live. For example, A male patient (study 7) with a poor marital relationship and a limited social-support network explained: "*There's another reason why I want to hang around [survive]-my doctor is so proud of me living all this time. He brings me downstairs and shows me to the girls [female secretarial staff]. He always asks me if there's anything I need*" (37). Another subject, treated at this same clinic for advanced breast cancer, was asked if she thought that the relationship she had developed with hospital staff influenced her remission. She replied:

"*Oh yes! Oh yes! All these people are very caring. The girl at the desk calls me by my first name. It makes you feel good and you want to continue improving"(37).*

Field notes: This expressed trust on health professionals coupled with the patients release from the decision-making process that we see in study n.1 is in contrast with bucking the system in study 6 and 'taking responsibility in study n. 2 and 6. What seems to be a common pattern though is the positive attitude of trust and confidence. Whereas in study n.1 Cancer Survivors placed Trust and confidence on health professionals, we can comfortably say that in study n.2 and n.6 Cancer

survivors placed the same feelings on themselves, trusting on their intuition and abilities.

Nurturing Attitudes

Participants perceived **positive attitude from health professionals** also as important in the recovery process. One person stated *"If [the staff] would show more compassion to the people, then I think that.. we would save a lot more people' 'compassion goes a long way in treatment".* One participant expressed gratitude for the physician and *"his calm, quiet, compassionate nature"(63).* Hope and honesty were important factors when discussing sensitive issues with the physician. For example, in study 1 one patient remarked*: "[the doctor] didn't say, 'okay you are dying'. He said 'we don't know, I've got other patients who have had the same situation that you've got and one patient had been [diagnosed] seven years ago and she was still doing fine… it didn't dwell on the death part of it so much, but he gave me* ***hope"(63)****.* Similarly, another physician was reported saying: *"your situation is so new.. we're seeing good responses with patients and it's just so new.. you are only going to hear the worst cases [from the internet]; you are not going to hear about those patients who do well"(63).* The importance of hope was also expressed in study 1 in relation to conversations with other survivors *"It was*

good to know that there was somebody else – even a few people out there who had fought it, and beat it; that was really ***hopeful*** *to me"(63).* One patient found discussions with other survivors very powerful as *"they are there for one reason only and that's to let you know that you can survive this disease"(63).*

Field notes: I noted that in study n.1 some participants also reported tension, strife and discord in their families. Some reported to feel somewhat 'overwhelmed' by family attention. Others reported friends who did not visit *"…said they were afraid of hospitals and didn't want to see me like that.. that was very hard to take".* It would be interesting to know if these participants found a source of support and compensation elsewhere for example from the internal connections with the Self, nature and God which were identified in study n.1 but not focused upon

Existential reorganisation: The Spiritual Level

Graphic 1. Spiritual subthemes

The spiritual theme was present across the seven studies.

Personal field notes: In study n.1, the theme of internal connection included 'an awareness of connecting with the Self, nature and God'. Unfortunately, the same study focused its report on external connections only, leaving very limited opportunities for the analysis of internal connections reported by Cancer survivors in this study.

I found that spirituality and emotions were interconnected and was not always a straightforward dividing line between them. For example, Israel, a cancer survivor from study 6 discussed the role of faith (spiritual) and fear (emotional) and how they played their role in his recovery process. He spoke as a choice between one or the other as "faith and fear cannot exist together" and added that he had to take "a step into faith':

"If the Oncologist had prescribed something that, through our own prayer and meditation, we had discerned was life-giving and of the Lord, we probably would have opted for that, chemotherapy or radiation or whatever. But in our prayer and in our discernment, the Lord did not lead us that way. So it did not seem like something we should do out of faith. Out of fear I should have done it. But out of faith, I shouldn't have done it"(10).

Some survivors spoke about their experience of cancer and remission as a **spiritual journey.**

For example, one Cancer Survivor (study 2) explains:

*"Being diagnosed with cancer set me off on this **spiritual** journey in which I eventually come to realize I have control over everything that happens in my life. And it's basically through your attitudes and your thoughts. (..)But, and you know,*

it's your thoughts that create everything. So yeah, we're – we're God's reality show"(62).

Similarly, Ginny (study 6) says: "Ya know, when you're faced with death, it really makes you think, "now, what am I thinking about this?" My masseuse [from the alternative health care center], I credit with starting me on my spiritual journey" (10).

Of interest, in study 2, as pointed out by Dr Turner, one of the sub-believes held by many subjects was in fact the supremacy of the human spiritual life from which mental and physical aspects develop as consequence. Cancer Survivors spoke about these aspects in terms of 'energy', which originates in the spirit. For example, one survivor in study n.2 explained:

"*We are energy first, and as you get closer to matter, to gravity, we get denser and we end up with this physical-ness [.....] So we really are – we're just energy"(62).*

For some cancer Survivors prayer had a central role in their own personal experience of remission. In study 4, a 10 years old boy diagnosed with giant cell tumour of left femur reported that the pain disappeared and he gradually improved during an ongoing prayer by the village community that lasted nine days (a so called Roman catholic novem)(12).

Another woman just prior to the remission of her metastatic choriocarcinoma, was advised by a healer to pray and forgive her neighbour whom she had a conflictual relationship and had threatened her and her child (12).

Fredric (study 6) felt that God had a lot to do with his remission and remembered that “there was a lot of praying going on”(10). Israel also relied a lot on prayer during his process of remission(10).

Anna explained how prayer helped her after her diagnosis of cancer and through her recovery:

"...I accepted that I had cancer. I felt it's up to God if I'm going to get well. I just prayed a lot and it seemed to help."(10)

Sarah (study 5) a Catholic nun, saw her spirituality as contained within the organized structure of her religion. When she was diagnosed with cancer, her daily practice of contemplative prayer became more intense and somehow shifted in meaning as she explains that the:

"*whole meaning of the Catholic sacraments took on tremendously more meaning for me . . . and that has stayed with me.... I called upon the power of the sacraments*

*that I had received ... and I'm much more aware of the significance of what those sacraments can be in our live*s." (33)

Spiritual aspects emerged throughout Cancer Survivors accounts; some participants gave detailed description of how connecting to one's spirituality could lead to remission and healing. Some Cancer Survivors also used the word energy across all levels of spiritual, mental and physical aspects. For example, in study 2 one survivor says:

"*I now believe that God created us in God's image. God created us and the universe out of the 'stuff'or energy of God's self… Some may say that I am out of my mind. I would have to agree. I believe my mind has kept me blind to the presence of God all around and within me […] I am learning to let go of the past and appreciate the experiences that have brought me in the present moment. I no longer feel separate from God. I see God whenever I look. I see God in the face of each and every one of you. I see God in the mirror"(62).*

As in study 5, also in study 6 participants expressed a sense of spirituality that was not religiously oriented. Harold described Nature as the intermediary to a higher power:

"Oh, yes. We're spiritual persons. You don't have to belong to a church and go to be a spiritual person. Ya can believe in God and things. (..) Anybody who gardens or watches things grow knows there's somebody bigger than we are"(10).

Ginny also found spirituality in Nature rather than in religious terms:

"*I just have found God outdoors. We raised our family in the mountains...on the lakes waterskiing. I love to camp; I love to be outdoors. I do believe in God....We're very religious but not organized religion...."(10).*

Actions and spiritual practices varied across stories. For example, Bernice practiced Buddhism during her 'decision period' on what to do and Colin practiced meditation. David chose to read the scripture, pray and received laying on of hands. He also listened to Christian tapes and read 'positive, faith-type books'(10).

David and Ethan described the experience of laying on of hands prior to the remission:

"*But when I have that type of problem, I speak to that lump, that pain, that symptom in the name of Jesus and tell it to leave. And if I need some support, I go get some friends of mine that believe the way I believe (..) And they lay hands on me and they pray with me and the thing always leaves; it's got to leave"(10).*

Also, Ethan describes his experience of laying on of hands:

"*And she did some things to me, said some words, said a prayer and put her hands on me and I felt this strange feeling like something was just lifted away from me"(10).*

Chen, who lived in China, began practicing Qi Gong when she was told she was terminal, and attributed her healing to that practice.

Many patients expressed the need to **seek higher levels of meaning** during their experience of remission. Often, this was integrated with a sense of altruism. Many patients attempted to turn their personal experience into a message they wished to promulgate. In study 3, many participants felt they had a 'calling' and a 'mission'. For one participant, this mission was almost a pledge:

"I feel I have a kind of mission (..) and it's also one of the things that I really believe helped me and helps me cope well….It's awesome, it gives you a sense of tremendous power, will, motivation, and the feeling you can conquer anything" (61).

The spiritual level of reorganisation also implies getting access to activities that are of particular value for the person. Twenty-five years before diagnosis one cancer

survivor experienced a conflict with his church, which led to the breaking of the relationship. During what appeared to be a severe progress of his cancer, the patient suffered periods of hallucinations and delusions. He requested for a priest who visited regularly and gave him extreme unctions leaving him 'calm, satisfied and peaceful'. The patient had imagined that if he would ever heal he would not let the relationship with the church be broken again. He developed explained high fever during two consecutive evenings and he produced an enormous quantity of faeces the day after. After these episodes, the man improved and 6 months later the CT scans showed no abnormalities(12).

The experience of cancer has set some patients to a journey of spiritual transformation that has a profound effect on the way of seeing life. For example, one CA survivor (study 2) says: "*Cancer has ignited a **spiritual transformation** in me. As I said previously, I saw life as an experience to endure. I saw the glass as half empty. I now see life as an experience to experience and my cup runneth over"(62).*

Many participants found a more authentic sense of meaning and purpose in life as opposed to a previous sense of 'existential vacuum'. Many participants reported a spiritual change which, included a feeling of connection with nature and other beings, a sense of unity, peace, perfection of life, unconditional love, a divine

undertow. Participants experienced a shift in awareness and level of consciousness that impacted their behaviour and coping mechanism and as ultimate consequence they experienced less emotional stress and fear.

Ginny discussed her path in life as follows: "*I came here on this earth at this time for some purpose. And I feel that this [dealing with the cancer diagnosis] is what my purpose in this lifetime is....And we all come here for a reason...we need to find out what the purpose is"(10)*

The spiritual shift and the antithesis between the old and the new found perception emerges in Hope's statement in study n.5:

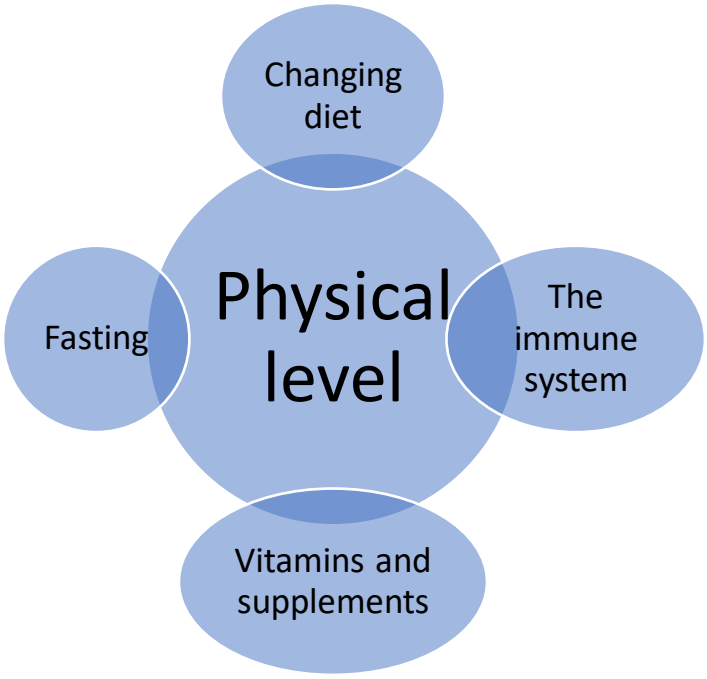
"…So, I stopped going to church. ... Of course this experience [spontaneous remission from cancer] put God in a whole different light"(33).

Mary during her process of healing from cancer, began to awaken to a realization of the presence of the divine in everything. Jennifer returned to the Episcopal church of her childhood when she realized the seriousness of her cancer diagnosis, and believed that talking to God was the most important spiritual thing that she had done during her recovery:

"The cancer experience was probably a turning point for redirecting me in my spiritual path. Sometimes events kind of propel you deeper or in a new direction, and I certainly think being so ill and so frightened was an impetus for me to do that ... I started meditating . . . and it's Buddhist meditation but it fits in beautifully with Christian beliefs to me. ... All these different approaches to God . . . are all valid and probably all true (..)"(33)

Existential reorganisation: The physical level

Graphic 1. Physical subthemes



One of most frequently discussed reorganisation at the physical level was about **changing diet.** This code was applied in study n.2 whenever a subject discussed changing regular food or fluid intake in order to promote healing. Dr. Turner noted

some common trends amongst Cancer Survivors and these included removing from one's own diet:

- most meat;
- diary;
- sugar and refined grains;

Simultaneously, some survivors chose to increase the consumption of fruit, vegetables, whole grains and purified water.

In study n.2, also emerged that some participants referred often to an 'alkalizing' diet, which is a diet that aims to maintain an overall alkaline PH in the body as opposed to acidic. Those survivors believe that an alkaline PH creates optimum conditions for health and stopping cancer growth.

Fasting for brief periods was also a trend. A cancer survivor explains what he changed in his diet after he was admitted into hospice care (study n.2):

"*So I drunk water and it's a fasting actually (..) I couldn't eat anything at that time. Only water every day. But I, even [though] I was not treated by any medical treatment, my body was actually getting better and better. That's the first step, only water, only drinking water. My body was changing only better… And chew only organic food.. and [colon] irrigation"(62)*

Another Cancer survivor explains the major changes he made not only to his eating habits but also to his lifestyle in general to help recovery from his stage 4 cancer. His point of view also highlights the importance of making changes that are holistic in nature:

"Just going on a basic, good, predominantly raw vegan diet alone and supplementing it with lots of juices, like lots of carrot juice, which of course is packed with nutrients. And the reason why the juices are so important is we have depleted basically all of our produce. Even a lot of the USDA certified organic produce does not have the same nutritional value it once did. So that's the reason for using juices as a supplement. There is logic behind it. It's concentrated, packed nutrition. So we get a lot of nutrition to the body. All of a sudden the body says, 'Wow!' It's like watering the lawn when it's dry. I'm getting all the nutrition that I need and all of a sudden diseases start to go away. …You know, we've got to get away from Western medicine and go back to basics and just make changes, simple lifestyle, very, very basic stuff — just change your diet, exercise, fresh air, sunshine, faith in God, reduce stress, balance, temperance"(62).

Similarly, another cancer survivor describes major changes in her diet, which included an unintentional fast, in preparation of surgery and chemotherapy:

".. you can't eat sugar, flour, dairy products. It's mostly vegetables, fruit and no red meat whatsoever, a little chicken here or there or fish but I didn't do a steady diet of that. It was mostly green stuff. And juicing cabbage is very important. So we did that. And you know, when you quit eating – I lost 50 pounds in two months, because for a while I didn't dare eat anymore because they were saying your eating habits, certain things you eat, are worse for it [the cancer]. So I was afraid I was feeding it. So I quit eating for a while. And then slowly I started, you know, putting the right food back in. But you kind of — because your system isn't used to that — you kind of get sick. So it's a big change to your body. But then once you get used to eating like that, then that food is what tastes good and the other food doesn't taste that good anymore, the processed food…and I cut out alcohol. I pretty much just drink water. I don't drink pop, no milk. Just pretty much water is what I drink"(62).

Herold (selected an alternative health centre and began vitamin C therapy and consumption of carrot juice. Although he had faith in his physician, he felt that their focus was on giving drugs only(10).

Ginny refused radiation following her lumpectomy and opted for high dose intravenous vitamin C, drank a lot of carrot juice, had therapeutic message , attended counselling including a neuro-linguistic programming therapist and made generally life style changes including reading books, journaling, drawing and imagery(10).

Israel alongside his spiritual practice, engaged in fasting, used laetrile with a vegetable base, drank carrot juice and made other dietary changes(10).

Some CA survivors believe that nutrition strongly contribute to the recovery process. For example, Ginny says:

"(…) I believe one should strive for optimum health and well-being, improve their nutritional level and enhance ***the immune system****. With the help of [the alternative health care center] I have been able to do this. Not only have I "survived for five years", I have enjoyed living (..)"(10).*

In study 2, changes concerning diet included also the intake of herbs and vitamins. Dr. Turner found that Cancer Survivors attribute to these changes a function of 1) detoxify the body 2) restore balance to the body 3) strengthen or activate the immune system in order to eliminate cancer from the body.

For example, one cancer survivor says that one of the most important aspects of healing her physical body was taking a particular immune-boosting supplement. Here is an extract from the original interview:

INTERVIEWER: "Of all the things you just told me about, what do you think was the most influential for your healing, or are they all pretty equal for you?" (62)

Cancer Survivor: "Oh, boy. I would say that, for my body, that would be the Wholly Immune [supplement] that I got, that I started… It has like about 50 different things in it…He [a friend] researched it and he said, "You've got, in that Wholly Immune, you've got seven cancer fighters. If you were taking them on their own it wouldn't be as potent," but he said because they're in combination, it acts as a cancer destroyer" (62).

Similarly another cancer survivor from study 2 discusses an immune-boosting supplement that she used during the process of recovery from cancer:

" ..And it [the supplement]'s got everything in it. To be honest with you, you spend that much going out and getting everything individually. You really do. It's got all the Glandulars in it, it's got Quercetin, it's got Resveratrol, it's got your Vitamins A, C, D, E, it's got it all"(62).

Finally, in study 2, one CA survivor describes his experience and point of view of cancer remission and, how dietary changes may have influenced the healing process:

"*…the immune system returned to being able to do what it was designed to do, without being overwhelmed (..) No spontaneous [i.e., quick] remission or anything like that—it took a couple of years before all the stomach problems cleared up and everything started working properly again. But all I used were herbals and better nutrition to create a "cancer abortion" (62).*

One last comment about the role of changing diet and its connection with the immune system comes from the point of view of another cancer survivor:

"*Testosterone is what makes the cancer go, sugar is what feeds it. The theory I've developed is starve the cancer and let my immune system kill it.…I think everybody has cancer. And I think everybody's immune system fights it differently…If you've got a weak immune system, you don't have a chance. And everything you put in your mouth affects the level of your immune system – plus other factors, you know, exercise and all of that. If you don't have a strong immune system, eventually it [cancer] is gonna get you"(62).*

Field notes: The effort to generalize from the subjects' varied experiences may minimize and even distort the very distinct nature of each subject's healing process. Each subject adopted certain behaviours and beliefs unlike any other. For example, the majority of the subjects described family relationships that were encouraging, nurturing, and respectful-relationships that seemed idyllic in many ways. However, there were few exceptions across studies. One survivor said that he and his wife fought constantly and that his son had wished him dead. Another example: subjects in general were adamant about the need to be informed and actively involved in their treatments. However, there were few exceptions in study 1 and 7, of survivors who said that she simply put all her faith in her doctors and never asked them any questions.

To conclude this paragraph, when discussing physical level of reorganisation, there was consensus amongst subjects that their diet played a significant role in their exceptional results. Many subjects in study 2, 5 and 6, with one exception, made radical dietary changes, eating much more nutritiously than previously. In contrast, as noted in study 7, the researcher watched one of the survivors during the interview, as he ate a breakfast of coffee, white toast, eggs, and bacon, and then lit up a cigarette (37).

CHAPTER 3

Conclusion and discussion

Conclusion and discussion

Clearly, the purpose of the present study was exploratory. I did not seek causal explanation of spontaneous remission of cancer but rather the focus was on the subjective experience of remission as well as to identify common themes across stories.

Across the seven studies analysed, all participants described profound and subjectively meaningful lifestyle changes and experiences prior to the remission involving different levels of the human being. Thus, I have called this process 'existential reorganisation'. We can think about existential reorganisation as profound life style changes and experiences involving the internal environment at the psychological, emotional, spiritual and physical level and the external environment at the social level, including experiences and changes within family, work and social environments.

To summarise, changes and experiences included the nature of self-talk, belief in survival, activism, feeling in control, releasing negative emotions and cultivating positive ones, an awakening in spirituality, positive social connections, reappraising and resolving unpleasant issues and taking care of the body.

These findings are consistent with the evidence available on the subject. In the studies of Dr Yujiro (1975) and Dr. Baalen (1987), dramatic changes in outlook, attitude, relationships were also found emerging factors in cancer Survivors(35, 36). Furthermore, Dr. Greer found that at five years after biopsy, those patients whose responses showed denial or fighting spirit (15/20, 75%) had more favorable outcomes than those who showed stoic acceptance or helpless/hopelessness (13/37, 35%) (34).

Though this project did not seek causal explanation, it is interesting to speculate on how, if they do, psychological factors could influence remission.

Perhaps answers may come from psycho-neuro-immunological (PNI) research, which has investigated the effects of psychological interventions on mediating factors, such as immunological responses and hormonal changes that may play a role in cancer remission. As this study unfolded, I noticed several connections between the stories of cancer survivors and the findings from the literature review.

For example, in a pilot study with 40 participants with malignant melanoma and cancer of the colon, Seligman, Rodin and Levy (1991) investigated the effects of Cognitive Behavioral intervention on the immune system response. Patients were randomized in two groups. One received conventional treatment only

(chemotherapy and/or radiotherapy). The other received conventional treatment combined with 12 week program (once a week for 12 weeks) consisting of cognitive therapy and relaxation training. At the end of the study, the group who had received the additional 12 weeks program showed a sharp increase of NK cells (Natural Killers are a type of lymphocytes whose function is to destroy cancerous cells and cells infected by viruses)(43). Of interest, one of the emerging themes belonging to the physical level of re-organization was the importance of boosting the immune system.

Similarly, one of the common psychological traits in this study was having a fighting spirit and taking control of the healing and treatment process. Of interest, one study found a correlation between perceived control and the immune system. Adult males exposed to controllable or uncontrollable stress (noise) were assessed immediately, as well as 24 and 72 hours later. Personality variables as moderators of the stress-immunosuppression relationship were considered. This study shows that Subjects who perceived they had control over 'controllable' and 'uncontrollable stress showed no reduction in NK (natural Killers) activity. By contrast, subjects who perceived that they had no control over the stressor showed reduced NK activity, which persisted as long as 72 h later. The researchers concluded that: 'The results suggest the importance of perceived control (which is

a psychological factor) in moderating the short- and long-term effects of stress on NK activity"(44). If that was the case, it may be reasonable to speculate that some psychological traits may have a positive effect on the immunological system and consequently on the body's own healing capabilities.

Implications

As already highlighted, this study did not seek causal explanation of cancer remission. However, the commonality of the subjects' responses does suggest that certain factors warrant further investigation on whether a causal relationship exists between these factors and the course of illness. For instance, as suggested by Roud(37), it could be possible to manipulate, for experimental purpose, the psychosocial variables hypothesized to influence cancer growth. There are no toxic side effects, and the potential exists to improve the quality of the patient's life. Furthermore, there is room for PNI research to take the lead in SR research to investigate those systems that once thought separated are now understood to be connected – particularly, on how psychological factors interplay in that cascade of neuro-immunological reactions that might elicit cancer regression.

Further studies may also consider a longitudinal design, which interviews participants at various points in their healing process in order to avoid bias of retrospective approach. Another area to explore is the investigation of the experience of remission of cancer of those who do receive and complete orthodox treatments in order to compare the experience with those who did not receive or do not complete orthodox treatments.

In terms of patient care, we need to go beyond the biological model to embrace and address psychological, emotional and spiritual needs as they are of crucial importance to the health and wellbeing of patients. Moreover, the role of supportive relationships during the process of recovery, including the one with health professionals, suggests the importance of knowing what the person's support system is alongside with making an effort to improve the communication between patients and health professionals. One aspect of patient-physician communication that we should reconsider is how we give information regarding prognosis. Whilst we tend to give the negative aspects and statistics on prognosis, there is also the information and statistics on those who survives and, albeit sparsely available, on who survives well. Several cancer survivors mentioned the importance of how prognosis is given and how this had a profound influence on feeling hope and making the most of it or preparing to die.

Finally, as O'Regan says:

"I feel we are missing a major chapter in medical research...and that there should be a field of spontaneous remission research. I think these people are a gold mine. These are nature's successes, nature's success against cancer. Why aren't we studying them?"(64)

Limitations of the study

This study has its own methodological limitations.

First, this was a systematic review of primary studies, therefore I did not interview the participants nor I did have the original transcripts. Rather, I originated codes and themes from the results and the quotations published from the original studies.

Second, although the exceptionality of survival was established for the majority of participants, except for one participant in study 6 and ten in study 2, there was no control group who had followed orthodox treatment and experienced remission, to act as a source of comparison.

Third, the primary studies I have analysed are all retrospective studies. Thus, participants' recollection of thoughts and feelings may have been distorted by their positive results. Also, there is a possibility that participants may have omitted to report thoughts, feelings and behaviours that are considered to be socially undesirable (drinking alcohol, using illegal drugs).

Fourth, the results of this study cannot be generalised as they may not reflect the larger population. This is due to the nature of the qualitative primary studies and the recruitment process adopted in some of the studies. For example, study 2 and 6 used a snowball strategy to recruit participants.

Fifth, this project was conducted by one researcher only, which may increase research bias. However, attempts to reduce bias were undertaken by regularly debrief with my supervisor who has reviewed the codes, identified and confirmed main the

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