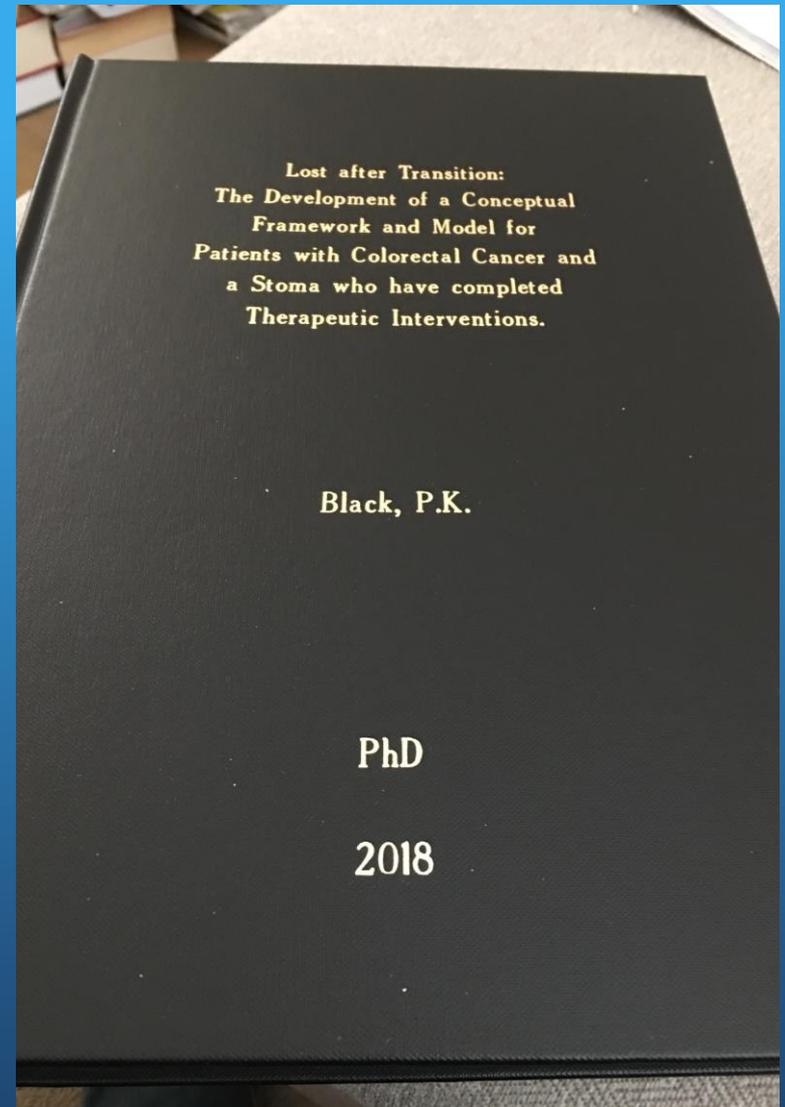


The Metaphor of Cancer.

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My Research.

Lost after Transition:
The Development of
a Framework and
Model for Patients
with Colorectal
Cancer and a Stoma
who have completed
Therapeutic
Interventions.



The study.

I decided after looking at several other means of research that this study would benefit from being a qualitative, descriptive, phenomenological study.

Other forms of research looked at were:

- Ethnography
- Phenomenology
- Hermeneutics
- Grounded Theory

Study design

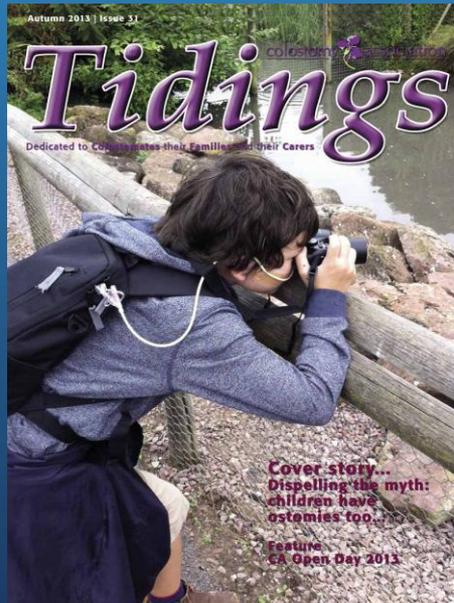
- The two most recent surveys of 369 and 5000 patients who have had a colostomy indicated that there are some long term issues and concerns, many of which arise after treatment has been completed (Notter and Chalmers, 2012).
- However, the positivist methodological approach used in both these studies, whilst yielding valuable insights into patient's wants and needs, had its limitations. Both surveys were designed for generalisations to the wider colorectal patient population and covered a wide range of issues but did not focus specifically on the patient's quality of life.

- Therefore, it seemed appropriate to build on these studies but utilise a different and more in depth approach. The decision was made to use a qualitative design in order to gather rich and detailed insights into the variations of the individual ‘lived’ experience.
- Denzin and Lincoln (1994) and Bryman (2012) consider qualitative research to be a more naturalistic approach which aims to increase insights into social phenomena in terms of the meanings of the people who live them.

Inclusion Criteria.

- Based in England.
- Male and Female.
- 18 years upwards.
- Have had a diagnosis of colorectal cancer.
- Have had a permanent colostomy.
- Have reached the 5 year mark and be considered to be “cured”.
- May have had chemo/dxrt.

- Participants were recruited via Colostomy Association newsletter, Inside Out Stoma group and other Stoma groups.



- Participants wishing to be considered to take part emailed their telephone number to me and paperwork and consent was sent to them.



- One focus group took place and the rest were telephone interviews.



The metaphor of Cancer.

- The concept of cancer survivorship has appeared in articles in cross discipline literature frequently in this millennium due to the longevity of life and the much improved techniques of surgery and adjuvant and neo adjuvant therapies (Doyle, 2008).
- Patients may use multiple, even contradictory, metaphors to contextualize personal narratives, which reflect an internal struggle to reconcile and find meaning in their disrupted lives

- Metaphors can help to illustrate complex issues and can illuminate a description of cancer to the lay public.
- However, they are also capable of creating or perpetuating stereotypes and stigma.
- In oncology, the military metaphor is perhaps the most well-known, with the metaphor '*war on cancer*,' and the importance for cancer patients to have a '*fighting spirit*'. In cancer, particularly, there is a need to balance the instinct to fight, with words of healing and success in the psychosocial dynamic of care.

- Metaphors have spread through daily language, and patients are often unaware of the use or power of metaphor.
- Lakoff and Johnson (1980) suggested that the metaphor goes beyond language and into the realms of thought and action. They define the essence of metaphor as:

“understanding and experiencing one kind of thing while experiencing it in terms of another.”

Czechmeister (1994) suggests that the metaphor is a '*two-edged sword*,' that although metaphors are fundamental for expression, they are also capable of creating confusion, stereotype, and stigma within a population.

For example:

- After the cancer's *invasion* of the body, the immune system launches an *offensive* to *beat* the disease. The *army of killer* T cells and *stealth* viruses *fight* the tumour cells. However, this is not enough to *wipe out* or *eradicate* the *invader* completely, especially if it has spread through- out the body becoming *lethal*. Thus, a bigger *arsenal of weapons*, consisting of *magic bullets* and *blunt instruments*, *target* the *enemy*. If the cancer is still *resistant* to the *cancer-fighting tools*, other *weapons* are injected to *attack* the disease or to boost the body's own *defences*. This *attack* may eventually lead to *defeating* the disease although it also involves serious side-effects as healthy cells are also *destroyed* by the *weapons*.

Czechmeister (1994) also highlights the use of the metaphor, particularly within nursing and the need for nurses to communicate with patients:

“in language as free of stigmatizing and frightening metaphor as possible.”

- Metaphors can add clarity and depth of meaning to a situation. In the patient / doctor relationship when discussing illness and disease, there is often a substantial discrepancy between the patient's everyday notion of illness and the medical concept of disease.



- Even when the doctor attempts to convey knowledge about the disease process, the patient and the doctor rarely share the same understanding.
- It is here that that healthcare professionals will often use metaphors to bridge the gap between illness and the patients lived experience and the world of therapeutic intervention.
- The metaphor offers to both the patient and the physician a common language and shared understanding, offering both simplification and connection.

- Metaphorical language can be more tangible than the factual information that is being given by the clinician.
- Metaphors add clarity and depth of meaning in the relationship between the patient and the disease and the disease and the clinician.

However, of all diseases, the word cancer evokes even the calmest patient and most caring health professional to think about fighting when they are faced with this diagnosis. It is as if it is an instinctive reaction to the news.

- However, Holden and Littlewood (1991) suggest that the ‘cancer patient’ starts a process when a diagnosis of colorectal cancer has been given. Individuals will visualise the cancer with words such as *wild*, *sick*, *mutant* and will see chemotherapy as *chemical warfare* inside the body.
- Western societies find diseases such as cancer need to be anthropomorphised as a “*virtual*” human enemy against which the clinician will ‘*wage war*’ to ‘*fight*’ it with everything they have in their ‘*arsenal*’.

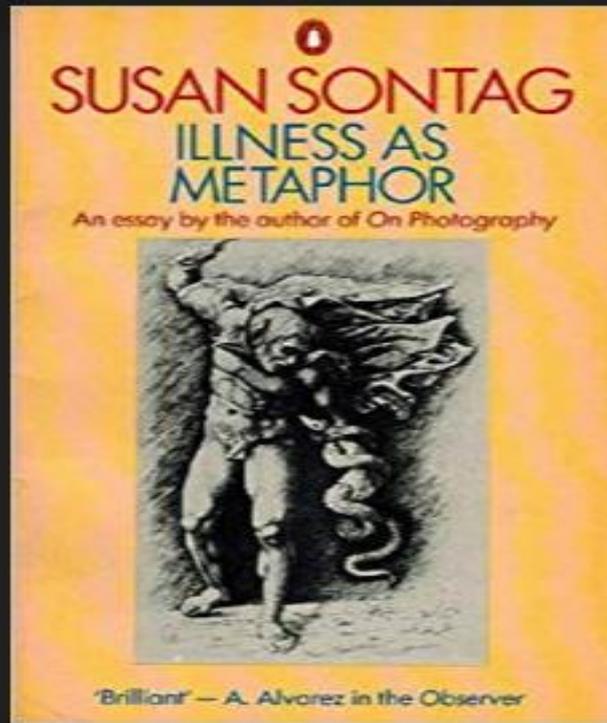
Even after death individuals are the subject of eulogies describing the *'fight'* they had against the cancer and how they *'struggled to win'* but were eventually *'defeated'*. Often this terminology can be psychologically upsetting for the individual and the family, especially when treatment has not worked and the clinician states that it has failed.

Since the initiation of the “*war on cancer*”, there have been significant advances in understanding, prevention and treatment. However, there is no victory yet in the cancer process, yet the military metaphor has been the most prevalent metaphor used in medicine for many years



Illness as a Metaphor.

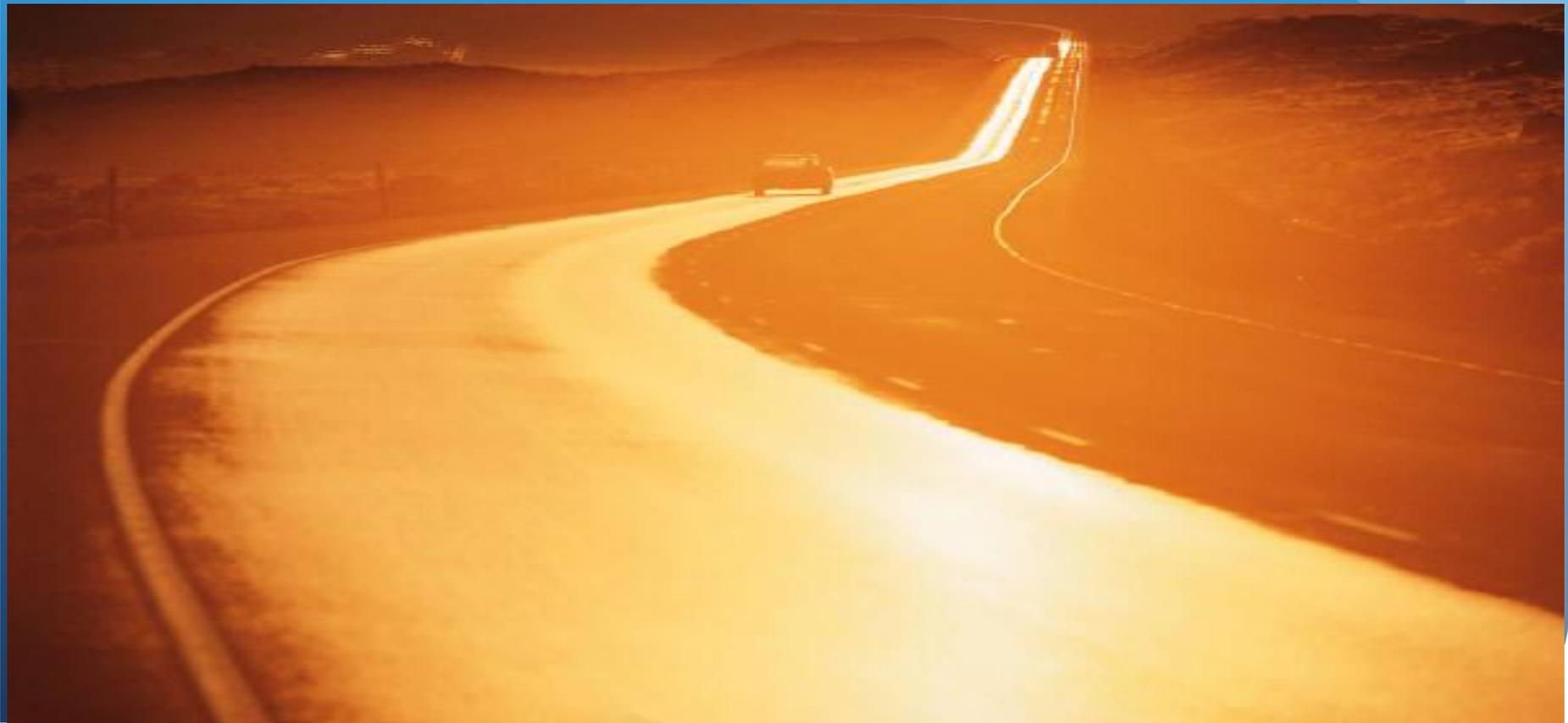
- Sontag (1978) probably has done more to de-mythologise cancer with her book, *Illness as a Metaphor*. As a cancer patient herself, she showed how the metaphors used by health care professionals and the lay public, can perpetuate the individual's suffering:
- *“Nothing is more punitive than to give a disease a moralistic meaning.”*



She describes how metaphors and myths surrounding certain illnesses such as cancer add greatly to the individuals suffering and often inhibit them from seeking appropriate medical care.

- Sontag, in her attempt to demystify cancer suggests that cancer is not a curse, punishment or an embarrassment, it is a potentially curable disease if treatment is abided by.
- However, today the metaphors of dread associated with discussions of cancer have still not dis-embedded the term ‘survivorship’ and these terms continue to put a cultural gloss on cancer.

Another metaphor used in the cancer disease trajectory is that it is a journey but there is no metaphor to say where this journey is going or where it will finish.



It emphasizes the illness experience as part of a larger narrative. Understanding cancer in the context of a longer life journey shifts the focus from a physical, metaphorical battle against disease to the illness experience and patient's holistic needs.

This metaphor also avoids the concept of “failing” treatment. Patients who face terminal illness have simply arrived at a different destination. The journey metaphor allows each patient's narrative to travel along its own path, adjusting and responding to new directions.

The Metaphor and Cancer.

- Metaphors can help illustrate complex issues and can illuminate a description of cancer to the lay public.
- Metaphors can add clarity and depth of meaning to a situation in the patient / doctor relationship.
- The metaphor offers both the patient and physician a common language and shared understanding offering both simplification and connection.

Metaphors have the potential to create meaning if they are used sensitively and respectfully. Providers and patients may use metaphors to contextualise and translate inaccessible experiences. In addition to creating shared meaning, metaphors can also be persuasive.

Conclusion.

- Language can be a powerful tool in health care.
- Metaphors have the potential to create meaning if they are used sensitively and respectfully.
- The images and words chosen to describe a phenomenon highlight certain aspects and obscure others, often revealing a particular ideology

- Sharing values and beliefs through metaphor can be an influential method of reframing concepts such as cancer, through the deliberate selection of imagery and language. Although popular comparisons such as cancer *as a battle* or cancer *as a journey*, may provide some individuals with the language they need to understand and cope with the illness experience.
- Therefore metaphors may offer creative opportunities for facing cancer for the HCP and patient.

Thank You.



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