DECODING CANCER SCIENCE V FICTION
A CANCER PATIENT’S EXPERIENCE AND PERSPECTIVE

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EMOTIONS OF A CANCER DIAGNOSIS

- FEAR
- ANXIETY
- DENIAL
- UNCERTAINTY
- LACK OF CONTROL
- POWERLESSNESS
- ANGER
- SHOCK
- DISBELIEF

- SADNESS
- HOPE/HOPELESSNESS
- GUILT
- BLAME
- ISOLATION
- ENVY
- LACK OF TOLERANCE
- LACK OF INTEREST
- DEPRESSION
The Questions

1.

- Why - What was cause/reason for diagnosis?
- Will I live/die?
- How long have I got?
- Will I respond to treatment?
- Will I have pain from the cancer or as a result of treatment?
- Side effects of treatment
- How will I tell my children? Will I see them grow up?
- Will I be able to look after my family?
THE QUESTIONS

2

- Will I be able to have children?
- How will my loved ones 'cope' with my diagnosis?
- Will I be 'disfigured', sexually desirable/have a sex life after treatment?
- Can I/we pay the mortgage/bills?
- Will I work again?
- Will the cancer come back?
DOMINANT EMOTIONS - ITS PERSONAL

- The totality of emotions can be overwhelming, intense and difficult to ‘unbundle’ (ebbing, flowing, switching)
- Our life experiences, baggage, have an influence
- Personality/identity
- Diagnosis/Prognosis
- Personal support structure/financial situation
- Degree of trust in science/EBM/Clinical Team
DOMINANT EMOTIONS – ITS PERSONAL

- Values we grew up with may affect how we think/deal with cancer
  - Need to be strong to protect family/loved ones
  - Seek support and turn to loved ones or other cancer survivors
  - Ask for help from counsellors/professionals
  - Faith/Spirituality
MY DOMINANT EMOTIONS

- Fear, cancer baggage
- Lack of Control/Powerless (Passive Passenger)
- Uncertainty
- Lower tolerance of others (at times)
- Anger at:
  + My sense from family/friends/associates that they suddenly regarded my competence and abilities as lesser following cancer diagnosis (loss of identity/my place in clan/society)
  + That I might need to depend on others
THE NEED TO REGAIN SOME SENSE OF CONTROL

- How could I support myself through treatment, and were there safe and scientific complementary actions that could enhance my conventional treatment?

- How to regain some sense of personal empowerment and control that was compatible with my trust/belief in my clinical team and my treatment plan

- ‘The Voice’ in my head was saying I should be doing more to support myself through treatment and to facilitate the earliest possible recovery
• Specialist clinical and allied healthcare team

• Reputable sources/websites e.g. Irish Cancer Society, MacMillan, CRUK, ACS, Breakthrough Cancer etc

• Family and friends

• Other cancer patients/patient forums

• Online sources

• Social media

• MSM
MY EXPERIENCE OF ‘INFORMATION’ ONLINE AND SOCIAL MEDIA

- There is a mind boggling amount of advice, services and products being offered to cancer patients
- Cancer patients are a hugely targeted customer sector - commercially very very lucrative
- Information on alternative therapies and cures significantly outweighs evidenced based advice
- An intent to create doubt about conventional treatment in the mind of patients and an attempt to damage/break the trust between the cancer patient and their expert clinical cancer team. Manipulative and a self serving interference in the patient and cancer clinical team relationship
- Anecdotes – feel good stories of cancer patients shunning conventional trm in favour of alternative therapies/diet
MY EXPERIENCE OF ‘INFORMATION’ ONLINE AND SOCIAL MEDIA

- Those promoting alternative cancer therapies deploy some very clever, slick and effective marketing strategies
- Create a veneer of respectability using terms such as ‘Functional Medicine’, ‘Integrative Oncology’ (Integration of quackery into EBM – Dr D Gorski)
- Tap into the emotional vulnerabilities of cancer patients. Zone in on most primal fears and offer solutions (hope)
- Very strong, convincing marketing with simple messages and reasoning, supported by a ‘facade of evidence and research’, PSEUDOSCIENCE as well as disinformation, mis-representation, fakefacts & LIES
- Copious Youtube videos (The Truth About Cancer), podcasts, books and subscription advice offerings
There have always been snake oil salespeople, but what has changed is the incredible reach scammers now have, made possible by a number of modern innovations, eg. Internet, social media, leading to a more acceptable face of ‘wellness industry’ and the interpretation that medical practice can be democritised by popular demand rather than evidenced based best medical practice.
EMOTIONAL TARGETING

• "It's not your fault you have cancer" (e.g. it's the carbs, nutrition guidelines, fluoride, GMOs, etc). This is an incredibly powerful tactic, creates a villain, taps into emotions of blame/anger/feelings of unfairness, and gives an opening to offer 'solutions', which may appear less daunting.

• All you have been told about cancer is wrong.

• Conventional treatment is just SLASH, POISON and BURN (Deeply upsetting and cruel message/tactic, e.g. mastectomy patients, or those who suffer other disfigurements e.g. facial).

• The answer to cancer is in nature.

• More people are being diagnosed with cancer and dying from it. It is a 'modern' disease.
EMOTIONAL TARGETING

- Chemotherapy doesn’t work
- Chemotherapy causes the spread of cancer
- People don’t die of cancer, they die from the effects of treatment
- There is a cure for cancer but it is being hidden
- Cancer is big business, Big Pharma, Big Food
  Cancer experts/oncologists are in the pocket of Big Pharma, Big Food
- If you have cancer, why wouldn't you throw everything at it
COMMON 'ALTERNATIVE' THERAPIES

1 EXCL DIET/ NUTRITION

• Cancer is a fungus – treat with Bicarb
• Root canals cause Triple Negative Breast Cancer, only use a holistic dentist
• Gerson Therapy (patients consume 18-20 pounds of organic fruit juiced DAILY, up to 5 coffee enemas and multiple supplements)
• Laetrile/B17/Amygdalin (cyanide poisoning)
• Turmeric/Curcumin
• Graviola & close cousin Paw Paw
• Spirulina/Chlorella
COMMON ‘ALTERNATIVE’ THERAPIES

- Vitamin D
- Concentrated Cordyceps and Reishi
- Mistletoe
- Black Salve
- Frankinsence essential oil
- Cannabis/Cannabis oil
- Homeopathy
- Acupuncture
COMMON 'ALTERNATIVE' THERAPIES

- IV Infusions of
  + High does Vit C
  + Double helix water (4th state of water)
  + Laetrile

- Budwig Protocol

- Oxygen Therapy & Hyperbaric Chambers (usually recommended with Keto diet)

- Sono Photo Dynamic Therapy (SPDT)
  Photodynamic Immunotherapy (PDIT)

- Vibration Energy Therapy
CANCER - NUTRITIONAL CLAIMS

- Some element of minor regulation applies for alternative cancer therapies there is little/ none for claims of cancer curative benefit in the sphere of nutrition/food. Its like the WILD WEST online and on social media.
- Promotion of diets often has cult like followers who are emotionally aligned with their nutritional beliefs and can be very aggressive in promoting/defending their ideology.
- Various diets are promoted as having cancer preventative and curative benefits without any side effects, e.g. Alkaline diet, Ketogenic diet, Vegan, Paleo, Macrobiotic etc. Common mantra from alternative diet proponents “cancer patients need more nutritional choices” STRAWMAN
- The use of term ‘Adjunct’ is commonly used(wrt diet) to infer No Risk and/or getting around legal fallout from claims of efficacy.
CANCER - NUTRITIONAL CLAIMS

- Superfoods, devil foods
- Antioxidant foods
- Food detoxes/fasting
- Clean eating, ‘Just Eat Real Food’
- Only eat organic, including raw/unpasteurised dairy (unpasteurised dairy products serious health risk for cancer patients)
- Diet/cancer industry is dominated by people unqualified to give nutritional/health advice, eg celebrities, models, chefs, lifestyle journalists, ‘self proclaimed wellness experts’, cancer patients and/or others who have overcome chronic illnesses
CANCER - NUTRITIONAL CLAIMS

- Binary messages - eg. Carbs bad, fats good, sugar feeds cancer, dairy causes cancer etc
- Dietary interventions are represented as a simple way of cancer patient regaining some control/empowerment with no risks
- Marketing messages can be guilt & fear inducing, which can be very upsetting, hugely emotive & traumatic for cancer patients. It implies that we are harming ourselves (feeding our cancer). Nutrition is very important for cancer patients for supporting us during treatment, recovery and preventing re-occurrence. But misleading info can cause phobias and stress around foods, contributing to spoiling the immense pleasure of food and enjoyment of sharing meals with family and friends
- Nutrition claims around cancer are littered with anecdotes, unverified claims of cures, or false claims of cures
She said her oncologists were stunned, but she believes the diet "starved the cancer" and added: "I have never felt as fit and healthy."

Samantha @WeightsnPearls
Breast cancer survivor says she 'cured herself' with lowcarb diet heraldscotland.com/news/15642035....
#cancer: surviving it can mean 'intelligently postponing' orthodox advice and the vested interests on which it is based.

Diana Keough @dikeough
There are as many unique stories of cancer survivorship as there are cancer survivors. buff.ly/2scaZMv
Brave or foolhardy if you 'intelligently delay chemo/radiation' for #cancer? New approach grows wings @sbtrochon!
TheKetoKitchen @TheKetoKitchen_

Replying to @BenBikmanPhD

Carb restriction plus treatment should be standard for many

#BC PATIENTS twitter.com/benbikmanphd/s...

Benjamin Bikman @BenBikmanPhD

This case report finds ketogenicdiet used in combined therapy effective for #breastcancer.

#LCHF

[Article citation]

Efficacy of Metabolically Supported Chemotherapy Combined with Ketogenic Diet, Hyperthermia and Hyperbaric Oxygen Therapy for Stage IV Triple-Negative Breast Cancer.
• Claims to run the world’s No1 health website Mercola.com

• One of his website press releases states his belief that physicians are the 3rd leading cause of death in US

• Mercola promotes and sells a variety of ‘alternative’ products for which he has received multiple letters of warning from FDA. Also sells books (best sellers), CDs, etc

• Mercola has a solution to sell you for most wild health claims he makes

• Provided with an air of legitimacy by appearing on US primetime shows like Dr Oz (Quacks quack together)
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<th>Causes of Cancer</th>
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<td>Root Canals</td>
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<td>Carbs</td>
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<td>Dirty Electricity</td>
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• Claims “Cancer is a Fungus”

• Mercola’s top secret for preventing cancer is to use a sun bed (which he could sell you until recently for $1,400-$4000). He was prosecuted & settled with Federal Trade Comm for $5.3 million in 2016.

• Actively campaigns against mammograms as a screening tool and promotes thermography.

• Mercola sleeps in an EMF-free canopy bed made of mesh silver and an EMF sleeping bag for travel. He plans to start selling these products to his customers soon.

• Other promoters of alternative health products/books align with Mercola to increase their profile and enhance sales with Mercola interviews which are on website (Youtube videos)
PERSONAL CONCLUSIONS

• Although accurate EB information is available online/social media, it is dwarfed by the avalanche of pseudoscience, misinformation, woo and LIES. Personally, I was naive to the extent of predatory targeting of cancer patients with alternative non-evidence based therapies, diets, and associated sales of books, conferences, etc.

• It is upsetting and infuriating that anyone would deliberately and uncaringly exploit and put another human being at risk of serious harm, at one of the most vulnerable times of their lives, knowing that they do not have the requisite skills, knowledge, and experience to give advice to cancer patients.

• Charlatans use very effective marketing and social media strategies, zoning in on the fears, vulnerability and emotions of cancer patients, fear, guilt, blame, hope/hopelessness.

• Lax, or no regulations. Where regulations exist, not strongly enforced.
PERSONAL CONCLUSIONS

• Desperate patients resort to GoFundMe campaigns to pay for unproven and dangerous treatments
• Heartbreaking stories of patients with treatable cancer, foregoing conventional treatment for ‘alternative’ treatment with disastrous consequences or wasting precious end of life time on ineffective quack treatments
• Cancer/medical experts and others including cancer patients, who question, request, challenge the evidence backing certain cancer cures/treatment claims or call out irresponsible and inaccurate claims are often viciously attacked (cult like)
• We caused our own cancer (e.g by eating carbs or our negativity)
• We deserve to have cancer
• Our cancer will return
• We are in the thrall/paid by big pharma, big food, big something
PERSONAL CONCLUSIONS

- People with no cancer expertise (e.g., celebrities/chefs) making statements on social media, evaluating which oncologists are ‘smart’ and which oncologists are not up with the latest ‘emerging science.’ Regulated RDs specialising in oncology are also targets for unwarranted attack from people promoting/selling alternative diet intervention to cancer patients – DUNNING KRUGER EFFECT

- Mainstream print and radio/tv media. Some more responsible than others, but unfortunately click bait sensational stories sell. Some media (and in Ireland) give a platform to unqualified celebrities to promote irresponsible and potential dangerous health and nutrition advice to the public
Evaluating Cancer Claims: Are they CRAP?

Use the questions below to help you evaluate cancer claims from people, websites, social media or videos. Place a 1 next to each section if you answer yes. Add up the final score to decide whether the cancer claim is crap.

**Conspiracies or Claims too good to be true**
- Does the person or website elicit conspiracies of ineffective cancer treatments, cancer cure suppression, or natural cures?
- Are the claims made too good to be true like 'no side-effects' and 'Miracle Cure'?

**Requests for money**
- Are products for sale like herbal/botanical supplements, vitamins/minerals, consultations, books or DVD's?

**Anecdotes**
- Are the stories unverifiable in another reputable source?
- Is the information unsupported by the medical literature?

**Publisher**
- Are the author's medical credentials hidden and difficult to verify? If so, is the source anything other than a .edu, .gov, or Oncology hospital website?

**SCORING:**
0: Acceptable claim but stay vigilant
1: Be careful, possible crap
2: Crap
3: So much crap
4: Crappiest crap ever

Total Score

The Cancer Claims CRAP test is adapted from the CRAAP test created at the Modest Library at California State University Chico for cancer claims by Skyler Johnson, MD at CancerAnswersMD.com
MINI DAMASCUS MOMENT
MY IDEAL – EMPOWERMENT/PROTECTION

1. Following diagnosis and time for patient to absorb prognosis and implications of treatment plan:-

- Patient receives nutritional assessment and personalised nutrition plan, for during treatment, ongoing and following trm from qualified specialist dietitian (not online nutrition guru)
- Patient receives an exercise advice/regime, based on their individual needs, and taking account of their specific diagnosis, treatment plan, age, fitness, mobility and other health conditions – from professional
- Rehab: early intervention can help with challenges that may arise from cancer and/or result of treatment, eg movement restriction, neuropathic pain, sexual dysfunction etc
- Psycho oncology input, can help with providing tools and strategies to cope and have more resilience/support with a cancer diagnosis /treatment
2. A roadmap for cancer patients of reliable sources of advice for supportive and self-empowerment information and advice

3. Cancer experts (oncologists and other cancer professions) to speak out publicly and strongly about misinformation and quack cures being peddled to cancer patients, and reinforce the positive message of following evidenced based advice/treatments

4. Reputable bodies, e.g. HSE, Irish Cancer Society, Breakthrough Cancer to continue to provide evidenced based information but to re-shape the delivery of message to be more empowering for patients. Quickly respond across media/social media channels to counteract dangerous mis-information when it is circulating in the public domain
5. Regulation/legislation to be put in place to protect cancer patients from non evidence based claims of prevention, treatment or cure for cancer. This should include adjunct suggestions that may also be harmful or interfere with conventional cancer treatment.

6. Regulation to ensure that only appropriately qualified, skilled, experienced, regulated and insured professions can provide treatment, and allied health related advice to cancer patients.

7. Active enforcement and significant penalties for those who breach the regulations.