

**Submission
No 41**

**THE PROMOTION OF FALSE OR MISLEADING
HEALTH-RELATED INFORMATION OR PRACTICES**

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The terms of reference for this inquiry relate to the publication or dissemination of “unscientific” health-related information by individuals or groups who are not already covered under the Health Care Complaints Commission’s (HCCC) brief. Covered here could be support groups, individuals who are blogging their health experiences and scammers who are exploiting the desperate.

There is an obvious need to police those who set out deliberately to scam desperate people with promises of a cure in exchange for money. However, these groups or individuals are not in the same category as those who are giving their personal stories or opinions on health matters.

The term CAM (complementary and alternative medicine) is used in this submission to mean any health intervention that is outside the accepted conventional methods.

The publication and/or dissemination of information that encourages individuals or the public to unsafely refuse preventative health measures, medical treatments or cures.

When diagnosed with an illness many will try and find out as much as possible about their condition. They will do their own research as well as join support groups to network with fellow sufferers. Support groups provide emotional support as well as access to information not always approved of by the medical profession.

A recent US study (Keim-Malpass, Albrecht et al. 2013) looked at blogs written by women aged 20-39 years who had cancer. The researchers found that:

“... young women with cancer are open to sharing complementary therapy experiences and uses of CAM on their online illness blogs as part of their overall shared cancer narrative.”

If the inquiry finds that support groups are disseminating unscientific information, will women such as these have to worry about the medical police as well as their cancer?

There is concern that people will abandon conventional treatments that might result in a “cure”. There are anecdotal stories and various blogs where people describe their experiences, but are they influencing people?

There have been studies done that look at the phenomenon of patients refusing some or all conventional cancer treatments. A 2008 Canadian study concluded that people who decline conventional therapy are:

“... [a] unique group of self-directed, confident, and active patients who have thought deeply about the meaning of cancer and about their cancer treatment options” (Verhoef, Rose et al. 2008)

The authors also point out that decision making by patients is not conducted at a single point in time. As time and circumstances change decisions are also modified with, in some cases, patients undertaking conventional treatment (Verhoef, Rose et al. 2008).

Alternative cancer treatments that raise concerns include the Gerson (Gerson Institute n.d.) and the Burzynski (Burzynski 2013) protocols. There are many websites and books devoted to praising or demonising both these methods.

One prominent user of the Gerson treatment is Jess Ainscough. Jess turned to Gerson following the recurrence of a cancer after previously having conventional chemotherapy. She claims to have beaten the cancer and found a new healthy lifestyle. Her mother recently died from breast cancer after following the Gerson method instead of having conventional therapy.

Jess is known as the “Wellness Warrior” and has a strong following on her blog (Ainscough n.d.) and through her media interviews, as well as a new book (Ainscough 2013). She also has many haters in the sceptic community who believe that she is encouraging people to abandon conventional therapy, for example see Packard (2012).

Her mother appears to have followed Jess, after seeing the effects Gerson had on Jess’ life. Would conventional therapy have saved her? Maybe. Breast cancer detection and treatment has resulted in an improvement in outcome in recent years, however studies also show that over-diagnosis plays a part in the “cure” of some cases (Esserman, Thompson et al. 2013). Women are still dying in large numbers from breast cancer despite the apparent success of early diagnosis.

Is Jess cured? No one knows for sure as she is not having any medical check-ups. Should she be silenced because the sceptic/medical community dislikes her message? I don’t think so. She is telling her story, her experiences, and her journey. They are important, regardless of what her critics say. Claims that she is harming others appear to be just speculation with only anecdotal stories, or assumptions, without hard evidence.

There are many other alternative cancer therapies touted online and in books. One method currently causing concern is a herbal treatment using the blood root *Sanguinaria Canadensis*. The preparation is commonly known as Black Salve and information about its use is readily available online, for example see Hollingsworth (n.d.). Recipes for the salve are also available so anyone could make their own.

The horrific outcomes associated with the indiscriminate use of Black Salve are well documented on sceptic sites, for example see Barrett (2011), and the Therapeutic Goods Administration (TGA) has issued a public alert regarding its use (TGA 2012).

Longmore (2011) questions the attempts to ban the use of, or even the mention of, Black Salve. He acknowledges that great care is required in handling this corrosive material. However, he writes that the substance does have pharmacological actions that could be useful in treating some skin conditions and further research into its use and preparation is required.

The formation of the Friends of Science in Medicine (FSM), with funding from the Australian Skeptics (FSM n.d.), has seen an increase in the attack on CAM modalities. FSM claims to want to see “evidence-based medicine” applied to CAM. However, despite this claim the group vigorously objects when tax-payer money is spent on CAM research, which

might ultimately provide this evidence. They also campaign to remove any CAM courses from Universities (Pearlman 2012).

Over a 10 year period the National Health and Medical Research Council provided \$75 million in funds for CAM research. This was described by some in the media as a “cash bonanza” and the President of the FSM, Prof John Dwyer, was quoted as saying that he was “frustrated” by the funding (Broeke 2013). In comparison, the Australian Federal government gave \$23,603 million in funding for health and medical research for the period 2000-11, with a further \$4,688 million from the States (AIHW 2012).

The only way to determine whether people are abandoning conventional therapy in favour of a CAM treatment is by research. Currently the information on this appears to be more anecdote and hyperbole than science. Despite the opposition from the FSM and various sceptic groups, research needs to be conducted – preferably by researchers without contacts to these organisations.

There are registries in Australia that record vaccines given, cancer diagnoses, and others. It should be fairly straightforward to study the behaviour of those on the registers. Do cancer sufferers undergo chemotherapy? Do they also use complementary or alternative medicine? Why do they follow an alternative path? Do people really abandon conventional medicine based on what they read on a Facebook page?

The adequacy of the powers of the Health Care Complaints Commission to investigate such organisations or individuals.

Recent events would indicate that the HCCC has sufficient powers to investigate, and take action against, groups and individuals who are not recognised health practitioners.

The HCCC’s action against the Australian Vaccination Network (AVN) has led to legislative change that permits the HCCC to instigate its own investigations without a public complaint being filed and allows the filing of a complaint even if there is no evidence of actual harm (HCCC 2013).

The AVN were classified by the Supreme Court as health care providers on the basis of providing “education”. This classification could be applied to anyone who publicly talks about health or who publishes health related information.

Consumers are also protected under the Australian Consumer Law (ACL), which is regulated by the Australian Competition and Consumer Commission (ACCC) and the relevant state bodies. Groups or individuals who are charging clients and promising “cures” can be prosecuted under the ACL (ACCC 2013).

It would appear that, between the ACCC and HCCC, there is sufficient power and scope to investigate those groups set up solely to exploit the desperate. They have the power; they just need to use it.

General Comments

I believe that the inquiry should take care to distinguish between genuine advice, which might be considered harmful, and general chatter, which should not. It is also worth noting that some apparent advice on certain online forums might in fact comprise deliberate baiting of sceptical challengers, and this should surely not be construed as serious health-related advice. The current anti-CAM climate has resulted in an all-out war on some Facebook pages, where it would not be wise to take any comment at face value.

If the inquiry does find that it is necessary to police publications, which ones will this cover? We use various methods of communication, including books, TV, radio, magazines, blogs, social media, support groups and conversations with total strangers. All of these methods, and more, can impart “advice” or “education” that could lead to someone questioning accepted medical practice.

The broad scope of this inquiry appears to suggest that the only people allowed to comment on health matters are health professionals. The rest of society must accept, without question, what their practitioner says. They must not ask anyone else for an opinion or discuss treatment options with anyone but a recognised practitioner. This might have worked in the past, but it won't now.

Sick people talk about their illness. People offer advice and their own experiences. You cannot prevent this from happening and people are stressed enough with their illness without having to worry about the medical and sceptic police too.

We regularly hear about breakthroughs that are going to revolutionise medicine. Typically these announcements appear to be made at the end of a research grant and in preparation for applying for new grants. The media plays its part with emotive headlines promising that a cure is imminent. The breakthrough is often never heard of again.

The health consumer has heard it all and yet most people can list several family members or friends who have died from a condition deemed “curable” by the medical profession, despite undergoing conventional treatment. Tax-payers have contributed billions of dollars to medical research but for many this research is meaningless. As medicine has not delivered on the cure that is just “around the corner” desperate people will look elsewhere.

There are also some people who will only use conventional medicine when absolutely necessary. Calling them “anti-medicine” or “anti-science” is not helpful and is not true. They have generally weighed up their options and decided on a course of action that is right for them. Not everyone wants to undergo debilitating chemotherapy when they are probably going to die regardless. So they choose their own path, and they should be allowed to.

Medical practitioners need to treat their patients as partners. Honesty regarding treatment options and likelihood of success is a must. Verhoef, Rose et al. (2008) reviewed other studies and state:

“The need for effective, compassionate, open-minded, and respectful communication is probably the most important theme in the studies we have reviewed”.

This advice is relevant to all illnesses, not just cancer. Mocking, belittling, or ridiculing a person because of their views is not going to encourage open communication or trust.

The current climate of “you’re either with us or against us” does nothing but cause division and foster conspiracy theories. The confrontational methods used by the FSM and other skeptics are not helping either. Consumers need factual information presented in a non-threatening way. Instead of vilifying and ridiculing those who choose to go outside the mainstream, present them with unemotional, balanced information.

The American Cancer Council has what appears to be a very reasoned page regarding the Gerson treatment (American Cancer Society 2012) that does not bully the reader. Perhaps more resources like this are required.

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