Urbanities, Vol. 12 · Supplement 6 · April 2022

Legality and Morality in Cancer Care-The Right to Choose: Constructing 'Otherness' in Medical Pluralism

Falia Varelaki
(University of the Aegean, Greece)
fvarelaki@sa.aegean.gr

Introduction

Cancer, not as a disease but as an experience and as 'something that happens between people' (Livingston 2012: 6), is the third cause of death in Greece after ischaemic heart disease and cerebrovascular disease;[1] approximately 64,530 new cases were recorded in 2020. According to Jain Lochlann, 'in an ideal world, a cancer diagnosis would come with an explanation of cause and move on to successful treatment' (2013: 19). Reflecting on Lochlann's argument, I wonder, what does 'successful treatment' mean?

Cancer treatment, within the context of medical pluralism, includes the biomedical therapeutic pathway which consists of surgery, chemotherapy, radiotherapy, biological therapies, and hormone therapy, but also CAM (Complementary and Alternative Medicine) which includes mind-body therapies (meditation, biofeedback, hypnosis, yoga, Tai Chi, imagery, creative outlets), biologically based practices (vitamins and dietary supplements, botanicals, herbs and spices, special foods or diets), manipulative and body-based practices (massage, chiropractic therapy, reflexology) and biofield therapy (reiki, therapeutic touch).[2]

In Greece, it is illegal to practice medicine and perform treatments unless you are a certificated doctor. It is also illegal to sell and distribute medicines and pharmaceuticals which are not approved by the National Organization for Medicines. Biomedical treatment methods are the official forms of medical practice but many of the patients choose to combine them with complementary treatments in order to relief the side effects caused by the biomedical treatment. On the other hand, alternative medicine, as the 'other' of the modern biomedical system (Ross 2012: 2) exists outside of the Greek health care system. Alternative medicine is usually practiced by healers or doctors and there is no specific legislation on the use and the practice of it.

In Greek, the word *alternative* («εναλλακτικός») means (1) someone or something that may be interchanged or may be used instead of another, or (2) someone or something that challenges established forms and norms. As Ross notes, 'it is significant that alter means "other" in Latin […] and that the notion of alternative references the idea of choice, most commonly between mutually exclusive possibilities' (Ross 2012: 6). Patients who choose an alternative treatment method usually deny any biomedical treatment method.

The plurality of therapeutic options for cancer is impossible to be depicted numerically for the Greek context as there is no National Cancer Registry, hence, there are no data concerning cancer patients in Greece. That means that since there is no official record of people being diagnosed with any form of cancer, there is also no record for their therapeutic choice. Patients as medical consumers acquire 'an active role in becoming informed, making medical decisions, and

[1] Eurostat, 2016. https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Causes_of_death_statistics , accessed 20 June 2021.
[2] National Cancer Institute U.S. https://www.cancer.gov/about-cancer/treatment/cam; accessed 20 June 2021.

determining the course of treatment and care' (Sulik and Eich-Krohm 2008: 7). In a social context where multiple treatment modalities are offered, patients can choose from the 'treatment pool' and follow the biomedical treatment process, an alternative treatment, or a combination of the two.

Here, I examine the conflicting relationship that seems to be raised within the context of medical pluralism. Drawing on material from the ethnographic research that I conducted in a public cancer hospital in Athens (Greece), I explore the context of therapeutic choice, the process of which is resulting into the emergence of discourses around morality, legality and trust (Pardo 2000). Additional interviews had to be made in circumstances of pandemic, thus they were conducted by phone, and they included patients who exclusively followed alternative treatment methods after their cancer diagnosis. Interestingly, no contact with healers or medical oncologists who practice alternative treatment methods was achieved, despite my persistent efforts on sending emails and making telephone calls. Within the context of economic crisis in Greece, people who experience cancer, either as cancer patients and/or medical consumers, find themselves at the intersection of biomedicine and alternative medicine, where they are able to choose which treatment option fits them. The ethnographic analysis is focused on the way that cancer patients and medical oncologists perceive and contextualize this choice. In the first part of the article, I provide an ethnographic starting point for my analysis. In the second part, I analyse the dominance of biomedicine and the construction of the biomedical subject. The third part, focuses on the ways with which alternative medicine is being constructed as the dangerous 'other' or as 'the right of choice'.

'I Chose this "Other Way"'

'It is another Wednesday morning in the field', I thought while entering the hospital's main entrance, only to be disproved as soon as I arrived in the third's floor cancer ward. I felt the agitation when I faced the doctors and the interns going in and out the ward's director office. 'What is going on?' I timidly asked John,[3] a young intern. 'Come with me', he said, 'and find out by yourself'. So I did. John entered room n. 3 with Dr Bella, one of the resident medical oncologists. 'How are you, Jenny?', Dr Bella asked the woman who was lying in the bed in front of us. 'Shitty fine, thank you', she replied cynically, with a blank stare. 'Mrs Prigou, 46-years-old, diagnosed with breast cancer, unknown cancer staging, admitted last night due to paralysis. She is refusing any diagnostic test or treatment. We administer cortisone and we have planned radiotherapy in order to treat the paralysis', said John, looking at me in a rather strange or even conspiratorial way as if he was telling me, 'did you get it?'. Jenny was diagnosed with breast cancer two years ago. She told me, 'I was fine in July. A month later, the pain started. In September, they discovered eleven tumours in my right breast and a doctor gave me only two months to live'. After the diagnosis, she accepted with many reservations to have her breast surgically removed; but then she decided to follow an alternative treatment. She said:

> 'I met a medical oncologist who treats his patient in "the other way" [alternatively], not chemo, radio and all these poisons. He said that he can cure me if I followed his instructions; specific diet, cannabis oil and physical exercise. And he also provided me with some "vitamins", you know, the only medicine that can cure cancer but of course

[3] Following common anthropological practise, I use pseudonyms for my interlocutors, while I adopt a descriptive reference for my fieldwork site.

Urbanities, Vol. 12 · Supplement 6 · April 2022

> it is illegal here in Greece, because if it were legal all that "piddly" doctors would be unemployed now. So, I chose this "other way". And you know what? I'm so fucking tired of trying to explain to everybody in here that I have the right to choose. I don't have to explain myself or justify my choices. How can anyone judge me?'

Jenny was judged as being 'irrational' by doctors for choosing an alternative treatment. In the medical discourse, alternative treatment is seen as the 'wrong choice', while Jenny's doctor was judged as 'dangerous' and 'immoral'. For Gellner, 'in modernity most people take the canons of rationalism and science to be the only way of thinking, while relegating everything else to the informal sphere' (Gellner 1974 quoted in Lazar 2006: 38). Discussing her chose treatment, Jenny told me:

> 'It costed us a fortune, but it was totally worth it. For one and a half year I was just like you. Healthy and pretty. And then, I was not. My doctor told me that there is probably a metastasis caused by the surgery (mastectomy) because cancer is transferred through blood.'
>
> How did you meet that doctor?, I asked.
>
> 'Well, we did our research, of course. We also met some healers, but nobody could provide these "vitamins". We have been told that these are the most expensive you can find in the market, most probably because they are obviously illegal but totally effective. I would have been cured if I didn't have that surgery. That's why I don't trust them anymore'.

I left the room and returned to the ward's director office, Dr Alexandris, with whom I had a long conversation. Referring to Jenny's doctor, He said:

> 'He is an immoral person. He is not a doctor. He looks for consumers to sell his "magic" illegal "mantzounia" [μαντζούνια, herbal mixtures] only to see his bank account grow. He used to be my intern, and this is the worst. He is now performing alternative medicine, maybe for the money […] Unfortunately, this woman [Jenny] is not his only "victim". All these years […] I have seen many patients who are hospitalised here only to die just because he sells hope in a very expensive price […] He has been expelled from the Hellenic Society of Medical Oncology, which means he cannot practice oncology anymore. He is totally immoral as he sells these mantzounia as vitamins, not as medicines and this is how he covers the illegality. He also should be charged for tax evasion; this is also illegal. What do you think, that you buy these "vitamins" for 800 Euros and you get a receipt? […] But he is not the only one. There are many out there, killing people without guilt. Some of them are doctors, others are "healers" […] They are all "agirtes" [αγύρτες, charlatans]. Since we (the Medicine) haven't cured cancer yet they will be more and more […]'

Dr Alexandris was angry with the medical oncologist who treated Jenny's breast cancer with "vitamins", but also with Jenny and the patients who choose an alternative treatment. Dr Kazou, another medical oncologist of the ward stressed other aspects of alternative medicine:

> 'People using this kind of methods are usually uneducated people. They usually live in a village far from the city centre, that means they live in the past. And of course, most

Urbanities, Vol. 12 · Supplement 6 · April 2022

> of the times they are women! Even when you see a man patient, I believe that his wife made him forsake the real medicine. I can't explain it otherwise. I don't see any reason for anyone to make such a bad choice.'

Alternative medicine acquires chronical, geographical and gendered aspects and, therefore, it is constructing not only as the 'otherness' within medical pluralism but also as a practice that belongs to the past and not to the modern scientific present and future. In Greece there are famous stories coming from the past about people who pretended to be healers or doctors, selling the 'cure' for cancer. One of the most known stories is that of the 'miracle water'. In 1976, a 36-years-old lawyer claimed the discovery of cancer's cure in the island of Kos. The 'miracle water' was being distributed in Athens by tankers, and people would wait in line for hours to buy 'the cure'. Complaints were filed about the side effects and the medical associations stressed the danger of its consumption. On 30 March 1976, the 'miracle water' was officially banned as 'dangerous for the public health', the lawyer was convicted for impersonation of authority and illegal distribution of medicinal products. Selling over-costed non-medical products is 'contrary to the rules of documented and evidence-based medical science in accordance with the law' (N. 3418/2005). Still, there are many cases of doctors convicted for the violation of the medical ethics because they convinced cancer patients to follow methods of holistic treatment.

The choice between conventional medicine and alternative medicine is interpreted by medical oncologists as a moral choice in terms of 'right and wrong'. Doctors who follow alternative treatments are morally judged and expelled from official medical structures, as the legitimacy of their action is disputable. According to Italo Pardo (2000: 6), legitimacy as a social process that is culturally constructed, makes sense through an emic approach. In this case, the choice of an alternative treatment is apparently legal but morally illegitimate, as it acquires ambiguous contextualisation for both sides.

Biomedicine: Dominance, Medicalisation and the Construction of the Biomedical Subject

The 'biomedical model' is an expression that describes the dominant medical approach to health and illness in most Western healthcare systems. Since the end of the 18th century, healthcare has been formed by a perception of normality which is constructed through the supervision of the 'medical gaze' (Foucault 2003). According to Foucault, 'up to the end of the 18th century medicine related much more to health than to normality […] (while) nineteenth century medicine, on the other hand, was regulated more in accordance with normality than with health' (2003: 35). Conceptions of health and disease are formed in a way that health is negatively defined as the absence of disease. Hence, since medicine claims the power of constructing or redefining the 'normal', medicine operates as the dominant institution for medical control through the process of medicalisation.

The hegemony of the medical gaze, which arose in the 19th century alongside the development of the anatomo-clinical method, indicates the need for state-level medical policies. The medical gaze and knowledge are located in the structure of symptoms and signs. The symptom is the form in which the disease is presented: of all that is visible, it is closest to the essential; it is the first transcription of the inaccessible nature of the disease. For instance, a cough, fever, pain in the side and difficulty in breathing are not pleurisy itself but they form its 'essential symptoms',

since they make it possible to designate a pathological state, a morbid essence (different, for example, from pneumonia) and an immediate cause (a discharge of serosity). The prognostic sign announces what will happen; the anamnestic sign, what has happened; the diagnostic sign, what is now taking place. Between it and the disease there is a distance that it cannot cross without accentuating it, for it often appears obliquely and unexpectedly (Foucault 2003: 90-91).

Since the 19th century, medicine has been established as science. Techniques such as the stethoscope and the microscope enable doctors to look 'inside'. Robert Koch identifies specific germs that cause disease in humans. The use of ether for anaesthesia and vaccination therapies to address epidemics were some of the greatest revolutions in medicine (Ross 2012: 14). Medicalisation rises in the first decades of the 20th century. At that time, scientific medicine was established, replacing the era of medical pluralism. As Klawiter writes regarding cancer, 'during the regime of medicalization, cancer treatment moved from the home to the hospital; surgeons were installed as the sovereign rulers of the kingdom; breast cancer was discursively constructed as a curable disease, and women exhibiting the "danger signals" of breast cancer were reconstituted as the new subjects of the regime' (Klawiter 2008: xxvii). In the 1890s, the radical mastectomy, a legacy of the progress of the 19th century surgery introduced by Halsted (Mukherjee 2011: 14), became the hegemonic treatment, as the removal of the lesion became synonymous to cure.

In this context, the biomedical approach does not recognise the patient as a whole, rather than as an individual with diseased parts. The patient is expected to comply through 'self-control, the understanding of "proper" information (devoid of "harmful" cultural and social ideas) and the adherence to (expert) biomedical guidance' (Confortini and Krong 2015: 1353); otherwise, as a 'matter out of place' (Douglas, [1966] 2002) s/he is constructed as a 'risky subject' and is morally judged for his or her choice.

The Dangerous 'Other' and the Right to Choose

Mary, a 72-years-old woman, lost her husband six years ago. He decided to follow an alternative treatment when he was diagnosed with lung cancer. She told me:

> 'We went to a healer who could provide us with some vitamins. He imported them from an unknown country, and they really helped my husband. His cancer was actually everywhere in his body, but the healer told us that these vitamins have the ability to detect a cancer cell that is created in the body, they strike it and destroy it without damaging healthy tissues […]'

Mary told me many stories about her friends who chose alternative treatment methods. She follows a holistic approach that includes, first of all, a positive way of thinking; then, physical exercise, relaxation and meditation, rawism and a daily use of enema in order to remove toxins from the intestine. She also shared her own experience on how she was diagnosed a pre-cancer stage but followed exclusively a holistic approach and 'never dealt with this again'. She believes that 'they [the oncologists] fight this [the alternative treatments] due to the lack of evidence'. But, she asks, 'What could be the greater proof than the fact that all herbs, with their beneficial substances, come from the nature?'

Dr Leontis, a medical oncologist who was one of my main interlocutors during fieldwork reverses Mary's argument when discussing the issue of evidence-based medicine. He says:

Urbanities, Vol. 12 · Supplement 6 · April 2022

> 'people seek the scorpion's poison or whatever they assume to be "the cure", according to current trend. This is what healers "use": "the need for hope". Chemotherapy has a bad reputation. This is a fact that we oncologist should accept. This reputation comes from chemotherapy's toxicity but today we are able to deal with this. Another reason for this reputation is the result, chemotherapy didn't use to work with such success as it does today. But do you know what's wrong with all those alternative treatments? Every treatment must be based on evidence. Something that can justify why you do what you do. The argument "from my experience I know that this mantzouni (μαντζούνι) will cure your cancer" is not scientific. Science is the result of knowledge that comes from data. Data are collected through experiments […] In other words, we (the oncologists) have evidence, the others (the healers) don't. And this is exactly the reason why this is totally immoral. Because they know that they don't have any evidence that their "treatment" can cure cancer, and for me it is immoral to know that you sell fool's gold and still do.'

It seems that evidence acts as a legalization process through which treatment acquires its moral and scientific status. Barry claims that 'evidence' has become an increasingly strong rhetoric in biomedicine in the last few years (Barry 2006: 2648). In *The Birth of the Clinic*, Foucault (2003) describes how the medical profession acquired prestige and power through 'scientific' knowledge, resulting in definitions of 'normal' and 'deviant' and the establishment of disease categories. Biopower operates through the production of knowledge but also through the production of a willingness to comply with the rules that knowledge has established. Self-discipline and self-surveillance regulate compliance with the norms but also to 'confess' any deviation from these norms (Pylypa 1998: 21-24).

Kalliopi was 32-years-old when she was diagnosed with breast cancer. She was terrified and confused about the 'right choice' to make. She visited three different medical oncologists only to realise that chemotherapy was the only treatment on offer. She said:

> 'A friend told me about a healer in Italy who was treating cancer patients. "He is very famous but, most important, he saves lives" she said. I knew all the unpleasant side effects of chemotherapy, and that after chemotherapy I couldn't have children, and that was the scariest. And not to die of course. I found a contact and I arranged to go to Italy to meet this healer. I didn't care about the money, my husband had decided to sell the house he inherited from his mother, so money wouldn't be a problem. But when I arrived in the airport my legs froze. Deep inside, I knew I shouldn't trust a treatment which is non-medical. It was a treatment which was not approved from any official agency, it was based on some herbals. And everybody was criticizing me for this choice. All the oncologists I visited told me, "It is your choice, of course, you can try this charlatan but don't come back to me when you will be close to death". So, I decided to make the "right" choice. "Right" for whom I am not sure, though […]'

Choice seems to be at the stake in this debate between biomedical treatment and alternative medicine. For the patients, choice is a right. For the medical oncologists, choice entails negotiable moral aspects. According to the 2002 European Charter of Patients' Rights 'each individual has the right to freely choose from among different treatment procedures and providers on the basis of

adequate information. The patient has the right to decide which diagnostic exams and therapies to undergo, and which primary care doctor, specialist or hospital to use'.

Dr Ivanos, a private practice medical oncologist, claims that:

> 'Patients have the right to choose which treatment is the best for them. The problem is that this alternative industry of health is growing rapidly and attracts unprotected (from the law) patients who will pay for any promise of cure without side effects. But when there is an exchange of money and the product is "too good to be true", what remains for us (the oncologists) to say is: the buyer should be careful.'

Choice of treatment, and by extension alternative medicine, indicates that rejection or acceptance of the biomedical model is a matter of personal ethics. Medical oncologists disapprove the choice of alternative treatments unproven by science, ineffective for curing cancer and totally harmful to the patients, including financially. However, patients who choose an alternative treatment consider this choice as a right. This conflict reveals the political aspect of knowledge which is produced within the context of biomedicine. Hierarchies of knowledge and the attendant moral rankings construct alternative treatment methods as morally illegitimate and dangerous. This complex relationship marks conflicting discourses embedded in a framework where legality and morality are connected, resulting in cultural shifts in the expectation of healthcare.

References

Barry, C. A. 2006. The role of evidence in alternative medicine: Contrasting biomedical and anthropological approaches. *Social Science & Medicine*, 62: 2646-2657.

Confortini, C. C. and Krong, B. 2015. Breast cancer in the global south and the limitations of a biomedical framing: a critical review of the literature. *Health Policy and Planning*, 30: 1350-1361.

Douglas, M. [1966] 2002. *Purity and Danger: An Analysis of Concepts of Pollution and Taboo.* London: Roultedge.

Foucault, M. 2003. *The Birth of the Clinic.* London: Routledge.

Klawiter, M. 2008. *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism.* Minneapolis: University of Minnesota Press.

Lazar, I. 2006. Taltos Healers, Neoshatnans and Multiple Medical Realities in Postsocialist Hungary. In H. Johannessen and I. Lazar (eds), *Multiple Medical Realities. Patients and Healers in Biomedical, Alternative and Traditional Medicine.* New York: Berghahn Books.

Livingston, J. 2012. *Improvising Medicine. An African Oncology Ward in an Emerging Cancer Epidemic.* Durham: Duke University Press.

Lochlann, J. S. 2013. *Malignant. How cancer becomes us.* London: University of California Press.

Mukherjee , S. 2011. *Emperor of All Maladies: A Biography of Cancer.* New York: SCRIBNER.

Pardo, I. 2000. Introduction–Morals of Legitimacy: Interplay Between Responsibility, Authority and Trust. In I. Pardo (ed.), *Morals of Legitimacy: Between Agency and System.* Oxford: Berghahn.

Pylypa, J. 1998. Power and Bodily Practice: Applying the work of Foucault to an anthropology of the body. *Arizona Anthropologist*, 13: 21-36.

Ross, A. I. 2012. *The Anthropology of Alternative Medicine.* London: Berg.

Sulik, G. A. and Eich-Krohm, A. 2008. No Longer a Patient: The Social Construction of the Medical Consumer. In M. S. Chambr and M. Goldner (eds), *Patient, Consumers and Civil Society.* Bingley: JAI Press.