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Alternative therapies in cancer treatment — hope or threat? (qualitative research)

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ABSTRACT

Introduction. Oncological patients, subject to strong emotions, may find it difficult to critically evaluate the information they receive on the effectiveness of the treatment offered, and therefore are susceptible to alternative methods, often abandoning the therapy recommended by a physician. The aim of this study was to analyze the way information is communicated to cancer patients by people promoting an alternative therapy, the use of intravenous infusions of vitamin C.

Material and methods. The research technique consisted of structured individual interviews conducted with Jerzy Zięba M.Eng. — author of the books: Hidden Therapies "What a doctor won't tell you" part. 1 and 2, and with Dr Agnieszka Jagiełło-Gruszfeld — a clinician from the Warsaw Oncology Centre. The study was expanded by a review of the scientific literature on vitamin C therapy and factors influencing the behavior of patients with diagnosed cancer, including the sources of information they use.

Results. There is a significant disproportion in the assessment of the effectiveness of vitamin C treatment made by people promoting alternative medicine and clinicians. Visible differences relate to the level of objectivity, legibility, as well as the frequency of information provided about unconventional cancer treatment methods.

Conclusions. The obtained results indicate the need to increase the availability of information provided directly by physicians about the dangers of inappropriate treatments for cancer patients. In diagnostic and treatment procedures it is important to be aware of the consequences of a specific method and the quality of the conversation between the physician and the patient about alternative therapies, as it may determine the patient's decision to choose a treatment.

Key words: alternative medicine, alternative therapies, vitamin C, oncology, cancer patients, health information quality, decision making, choice of treatment

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Introduction

In recent years increased activity has been observed in the media of social movements questioning the use of established methods of treating serious diseases, including cancer. The opponents stress the adverse effects of chemotherapy, accuse pharmaceutical firms of a businesslike approach to the drugs they sell and physicians of the lack of confidence in alternative methods of treatment and lack of familiarity with the results of clinical trials of unconventional treatment methods [1].

Oncological patients, subject to strong emotions because of their serious disease, may find it difficult to critically evaluate the information they receive. They often refuse the treatment recommended by the physicians [2]. Instead, they tend to use alternative methods [3–5] which are promoted by persons without a medical education; this can lead to the deterioration of the patients' health [6].

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Material and methods

Characteristics of cancer patients — psychological considerations

Patients with a diagnosis of cancer are subject to strong stress. Often the most difficult moment for the patients is not the moment of the diagnosis but a recurrence of the disease. Newly diagnosed patients hope that their treatment will be effective, but if it is not successful they are subject to a profound frustration [7]. Moreover, at that time the patients already feel the negative effects of the treatment (e.g. weight loss, weakness, hair loss). The patients must seriously face the fact that their plans for the future should be reassessed. Taking these aspects into consideration is seems understandable that cancer patients are not always capable of objectively evaluating the information that they receive about their state of health and the proposed treatment methods. Thus they can be manipulated more easily than healthy persons by presenting as true information which has limited support in the scientific literature. When people have strong emotions their rational thinking is limited, and cancer patients, as a rule, feel endangered [8].

Results

Sources of information for cancer patients about their disease

Patients with a cancer diagnosis can currently participate in the decision-making process related to their treatment; this is due to the increasing access to information about cancer and the available therapeutic options. This is particularly easy for younger and better-educated persons with higher incomes [9]. Persons giving advice related to health should be aware

of the fact that the patients can check the obtained information in the available sources of knowledge and that they will obtain information from all sources available to them. Published results of the ACCESS trial [9], conducted among cancer patients, indicate that 69% reported obtaining information from other sources than the medical personnel. Additionally, 60% admitted that at least one source other than the medical personnel affected their decision concerning the mode of treatment. Such sources affecting the therapeutic decision can for example be the family (42.7%) or the internet (31.9%). Detailed data about the sources of information and their effects on the decisions concerning the treatment of cancer patients is presented in Figure 1 below [9].

It is worth pointing out the effects of the internet on therapeutic decisions. Information obtained from the internet affected the decisions of 13.3% of patients — the percentage was higher in persons under 55 years old — 21%, with better education (24.8%) and who were more affluent (31.1%). In the same groups, scientific literature affected the therapeutic decisions in 13.8%, 23.1% and 23.4% of the cases.

According to the most recent scientific reports [10] 96% of cancer patients participating in phase I clinical trials rely on their physician as the main source of information and 89% of patients use the internet to obtain information on subjects related to their disease [10].

The quality of patient-physician communication is important for the choice of therapy by the cancer patient. Research has shown that criticizing patients for using alternative therapies or poor communication and lack of empathy may be the cause of a decision to use alternative therapies or even of refusing the treatment recommended by the physicians. On the other hand, good communication may lead to undergoing alternative therapy as a complementary method but not instead of conventional treatment [2, 11].

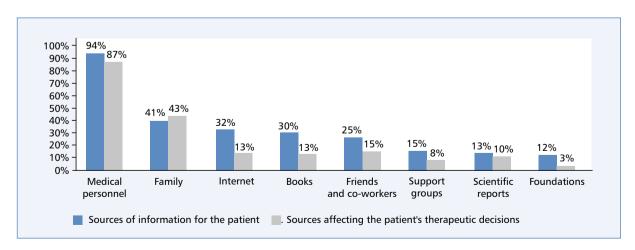


Figure 1. Sources of information for cancer patients and their effects on therapeutic decisions — ACCESS trial [9]

The information available on professional portals dedicated to cancer patients (e.g. https://www.cancer. gov/about-cancer/treatment/types http://www.nfz.gov. pl/dla-pacjenta/pakiet-onkologiczny/ http://www.sarcoma.pl/dla-chorych-i-opiekunow/abc-pacjenta-onkologicznego/ http://www.onkonet.pl/) is sufficient both with respect to quantity and quality. However, patients instead of using reliable www pages may obtain information from non-scientific portals (e.g. from youtube). Such dubious information can for example be found on the channel of Jerzy Zięba. He provides information about various types of alternative therapies od common diseases (including cancer). It should be noted that his channel has over 113 000 subscriptions whereas for comparison that of the Polish Oncological Society (PTO) does not have a single one. Moreover, Jerzy Zięba's films on anti-cancer treatment get 100,000 to 300,000 viewers while this is slightly over 500 persons for the PTO channel (by May 17, 2019).

Discussion

Alternative treatments — different viewpoints

According to the promoter of alternative therapies — Jerzy Zięba, author of the books: Ukryte Terapie "Czego ci lekarz nie powie" cz. 1 i 2. (Hidden therapies — what the doctor won't tell you — part 1 and 2) — the cause of cancer is the malfunctioning of the immune system. Therefore to cure cancer, its cause must be addressed – by increasing immunity. At the same time, Jerzy Zięba notes that chemo- and radiotherapy destroy the immune system which makes using natural therapies more difficult. According to Jerzy Zięba, anti-cancer treatment – especially in cases for which according to conventional medicine the chances of survival are small and only palliative care is used – should be based on intravenous infusions of vitamin C, which - according to him — should bring good results and allow to save the patients. In his statements, he refers to both scientific literature and reports from patients, who have described to him cases of curing a neoplasm by using vitamin C. However, he omits the fact that papers about the effectiveness of vitamin C are not unequivocal. According to the latest meta-analysis of clinical trials [12], no improvement in overall survival or in any other measurement of advanced cancer were observed in persons who received vitamin C infusions [12]. Jerzy Zieba is critical in respect to medical authorities, who doubt the treatment methods described by him: "(...) Polish physicians, including professors of medicine, who are my most frequent attackers, (...) do not understand the mechanisms of vitamin C action, and only comment on it because they are medical doctors or professors and that allows them to speak complete nonsense".

The fact that Jerzy Zięba refers to scientific research (a socio-technical method: a symbol of authority) [13], while at the same time undermining the knowledge of physicians often leads to patients abandoning conventional treatment for unconventional therapies.

Such cases have been observed by Dr Agnieszka Jagiełło-Gruszfeld M.D. Ph.D. from the Clinic of Breast Cancer and Reconstructive Surgery of the Oncology Center: "Patients often come to us at a moment when such therapy proved to be unsuccessful. The patient after his cancer diagnosis disappeared, for example for a year, and returned with much more advanced cancer. During that year he had used unconventional treatment methods. It makes the doctors angry and irritated. This should not be transferred to the patient, but one would like to say — you got what you wanted. We cannot do that, of course, but we have to deal with our feelings".

Dr Gruszfeld analyzed the literature concerning the effectiveness of alternative therapy in cancer patients. She states unequivocally: "I have become familiar with the literature concerning this form of therapy in order to be able to discuss it with patients. Of course, I am referring to typically medical literature, that is published in reliable, international journals. On the basis of this literature, I must, unfortunately, say that therapy with vitamin C is not a method whose effectiveness is in any way documented. Over a dozen trials have been performed with randomization of various groups of patients most of whom had advanced cancer. In some of these trials the patients received conventional therapy and additionally vitamin C or placebo. In some trials — even with patients with extremely advanced cancer — they received vitamin C or placebo. Practically, there were no statistically significant differences between these two groups".

The opinion of Dr Gruszfeld is confirmed by the most recent meta-analysis of clinical trials using vitamin C in cancer patients [12]. It encompassed 19 trials from the years 1974–2018. In most of them, vitamin C was not the main treatment but only an addition to other preparations. Eight trials used vitamin C intravenously. In another 8 oral supplementations was used simultaneously with intravenous administration or after it. In 3 trials only oral vitamin C was used. Publications about the trials concerned the effects of vitamin C on:

- Patient survival (10 papers);
- Response to treatment (9 papers);
- Quality of life (7 papers);
- Safety of the treatment (14 papers).

In none of the trials was the process of patient selection and randomization described in detail which negatively affects the evaluation of their quality. Of 10 trials evaluating patient survival only in one trial with randomization was a significant effect of intravenously administered vitamin C on patient survival observed. In 6 of 9 trials measuring the ef-

fects of vitamin C on the response to treatment, the observed effects were positive. However, the authors of the meta-analysis stress that the criteria of effect evaluation were highly subjective and with the exception of one trial not confirmed by pathomorphological analyses.

Conclusions

It is difficult for patients with a cancer diagnosis to objectively evaluate the soundness of the information appearing in the media on the safety and effectiveness of anti-cancer treatment. According to both Dr Agnieszka Jagiełło-Gruszfeld and Jerzy Zieba, M.Eng., cancer patients are subject to strong emotions which affect their decisions pertaining to the choice of therapy. Fundamental differences can, however, be observed in the evaluation of therapy effectiveness by the interviewed person. Dr Agnieszka Jagiełło-Gruszfeld bases her position on the results of clinical trial meta-analyses — scientific evidence of the highest level, whereas Jerzy Zięba bases his opinions on theoretical premises concerning the antioxidant activity of vitamin C described in the medical literature. He also supports his statements by citing patient testimonials. At the same time, he ignores reliable scientific evidence which does not confirm his assumptions. He draws far-reaching conclusions on the basis of dubious premises.

It is worthwhile to point out the existence of considerable asymmetry in the communication with cancer patients on the internet by medical professionals [6, 14] - in particular physicians and pharmacists — and by medical pseudoauthorities. The noted disproportions concern the level, objectivity of the information and the frequency and form of its transmission. Reliable reports from clinical trials (such as scientific papers) which could be easily understandable by people without a medical education are less accessible and less common. There is, however, easy access to information negating professional reports, and it is presented in simple, understandable words. An important step in the direction of increasing the awareness of patients about possible risks and consequences of inappropriate cancer therapies would be a more intensified transfer of information directly from the physicians. Otherwise, the number of people who decide to abandon therapy based on scientific data (EBM, evidence-based medicine) for treatment with unproven effectiveness may continue to grow.

In diagnostic and therapeutic procedures and education of physicians, attention should be paid to better awareness of the potential positive and negative effects of doctor-patient communication which in particular concerns the question of alternative therapies.

Conflict of interest

Authors declare that they have no conflict of interest.

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