



Opinion

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Aromatherapy and Cystic Fibrosis: Real-Life, but Many Questions Remain

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Abstract

Complementary and Alternative Medicine (CAM) usage in chronic illnesses, particularly chronic inflammatory diseases as cystic fibrosis (CF), has spurred extensive research. This opinion paper delves into the relatively unexplored realm of aromatherapy, specifically the use of essential oils (EO) in CF. Backed by a study funded by the French association "Vaincre la mucoviscidose" the research involved over 300 patients and parents participating in a detailed online questionnaire, supplemented by qualitative interviews with 20 individuals and therapists. The survey reveals that approximately a quarter of surveyed CF patients incorporate EO into their routines, primarily citing anti-infectious and mucolytic properties. Eucalyptus, ravintsara, lavender, and melaleuca were commonly used EO. Despite positive effects reported-such as preventing infections and reducing antibiotic use-communication between patients and medical professionals remains challenging. Many patients hesitate to discuss EO usage with doctors, fearing negative opinions or strained relationships. While patients desire recognition of EO use in medical records, doctors face difficulties in acknowledging therapies lacking robust clinical evidence. The study underscores the need for dialogue between patients and medical professionals, emphasizing the potential benefits of integrating EO into patient care. The contentious debate on combining EO with antibiotics prompts a call for transdisciplinary collaboration to ensure patient safety and explore the therapeutic potential of EO, especially in the context of antibiotic resistance. Overall, this study raises crucial questions about the integration of CAM into conventional medical practices, emphasizing the importance of understanding patient experiences, promoting dialogue, and exploring innovative avenues for clinical research.

Keywords: Complementary And Alternative Medicines, Phytotherapy, Aromatherapy, Herbal Natural Product, Real Life, Cystic Fibrosis, Infections

Abbreviations: CAM: Complementary and Alternative medicines; CF: Cystic Fibrosis; EBM: Evidence-Based Medicine; EO: Essential Oil

Introduction

The landscape of healthcare is evolving, with an increasing acknowledgment of the role of Complementary and Alternative Medicine (CAM) in managing chronic illnesses. This study delves into a relatively unexplored facet of CAM-aromatherapy, specifically the use of essential oils (EO)-within the context of cystic fibrosis (CF). While CAM has garnered attention in diseases like cancer and chronic inflammatory conditions, its application in CF remains a lesser-explored domain. The study, supported by the French association "Vaincre la mucoviscidose" represents a significant

effort to understand the prevalence, patterns, and motivations behind the use of aromatherapy. With a focus on both quantitative and qualitative data, the research unravels intriguing insights into the preferences and practices of CF patients regarding EO. The study not only outlines the types of essential oils commonly used, emphasizing their anti-infectious and fluidifying properties, but also delves into the socio-cultural aspects, including patient-provider dynamics and information-seeking behaviors. As the debate around the potential synergy or conflict between essential oils and antibiotics unfolds, this opinion article tries to clarify implications

not only for CF care but also for the broader context of antibiotic resistance and the quest for innovative therapeutic approaches. In exploring the intersection of patient-driven practices, medical perspectives, and the need for a transdisciplinary understanding, this research contributes to the ongoing dialogue on holistic healthcare. The following sections delve into the methodology, results, and implications, offering a comprehensive exploration of the intricate relationship between aromatherapy and CF care.

Opinion based on an exploration of health anthropology

In chronic illnesses, the use of Complementary and Alternative Medicine (CAM) is evident [1] and is the subject of a great deal of research [2, 3] especially in cancer but also in chronic inflammatory diseases [4-6]. The use of aromatherapy (therapy based in essentials oils-EO) in CF, justified by the anti-infectious [7] and mucolytic properties [8] attributed to EO (at least *in vitro*) is a quite unknown phenomenon that has been few studied to date, with only one communication presented in Denver in 2018 [9]. The French association “*Vaincre la mucoviscidose*”, whose missions are to fund research, support quality of life and raise awareness among the public and patients, has funded a large study on the topic. More than 300 patients or parents responded to a detailed online questionnaire, and around 15 took part in a qualitative interview conducted by health anthropologist. Five therapists (pharmacists and herbalists) who had advised patients were also interviewed. The results show that around a quarter of responding CF patients use EO episodically or regularly. The three quarters who do not use them, mainly cite the fact that they are not familiar with them, or more rarely that they do not trust a therapy that has not been validated by Evidence based medicine (EBM). Many of the respondents who do not use them seem eager to learn more about them, but do not dare to use them out of ignorance rather than lack of conviction.

The main EO used have unsurprisingly anti-infectious and fluidifying activities at least *in vitro*. They include various eucalyptus (*Eucalyptus globulus*, *E. radiata*, *E. polybractea*), ravintsara (*Cinammomum camphora*), lavender (*Lavandula officinalis*, *L. aspic*) and melaleuca (*Melaleuca quinquinervia*, *M. alternifolia*, *M. cajeputi*). More caustic EO's, such as clove (*Syzygium aromaticum*), cinnamon (*Cinammomum zeylanicum*), oregano (*Origanum compactum*) and savory (*Satureja montana*) are less frequently cited and seem to be more present in the arsenal of patients who already have some expertise. EO are also used to improve digestion. The cost of aromatherapy remains moderate for the patients who use it.

Patients are looking for quality advice and therapists who understand their illness. As a result, they tend to turn to dispensing pharmacists and the few trained doctors. Herbalists and naturopaths are consulted less frequently, as patients are looking for professionals who have mastered aromatherapy while understanding their illness and its conventional treatments. Above all, patients seek advice from their peers, either directly or via blogs and other media, sometimes using international exchange networks. Once they have tried EO and experienced the benefits, many develop expertise by reading books, consulting websites and sometimes even training. They then often become proselytizers,

encouraging other patients to draw inspiration from their positive experience. They are open to other CAMs, to trying different diets, to taking food supplements other than those prescribed.

Very few high-risk practices have been identified, and those that are can easily be the subject of simple advice (age-related contraindications, excessive doses, continuous treatments, undiluted caustic EO). Many positive effects have been described repeatedly and consistently: prevention of seasonal infections and limitation of superinfections, spacing out of antibiotic courses, disappearance, sometimes, of resistant germs, treatment of minor ailments without over-medicalization. These effects need to be confirmed, given what's at stake for patients and the reduction in the use of antibiotics.

Unfortunately, communication between patients and medical doctors, particularly hospital referrers, remains delicate. Most patients choose to avoid talking about their practices, fearing to be discouraged by a negative opinion, having doubts, or disturbing their relationship with their doctor, whom they trust. Some talk about it, but are rarely encouraged to do so, which favors the *status quo* and the development of self-expertise and self-medication in the absence of integration by the medical profession. However, all the users interviewed would like to see the use of EO recorded in their files and, ideally, for their referring doctor to be able to advise them, for good practice guidelines to exist and for their expertise to be taken into account.

Medical doctors, for their part, find it difficult to recognize a therapy with little or no clinical evidence, as the effects of EO are mainly documented *in vitro*, and as very few high-quality clinical studies have been carried out. Furthermore, the products used, like all phytotherapy in general, have variable compositions, which is always confusing for professionals used to handling single, standardized molecules, for which the method of evaluation is tailor-made. Finally, they are not at all trained in the practice of phytotherapy, which includes EO, which has a marginal status in France, although some doctors and many pharmacists recommend it.

In addition, the question of their association with antibiotics is the subject of a controversial expert debate. On one hand, some publications show the potentiation of certain antibiotics by certain EO, *in vitro* and sometimes even *in vivo* [10-12]. Others [13] suggest a reduction in the efficacy of antibiotics, particularly through the activation of efflux pumps, especially in *pyocyanin*. However, these studies were carried out on isolated active secondary metabolite and not on the totum of the EO, only *in vitro*, and at concentrations that are never reached *in vivo* (subtherapeutic). As a result, phytochemists and pharmacognosts familiar with EO tend to favor the combination of EO and antibiotics, while the researchers who carried out the studies cited warn of possible negative interactions, without however demonstrating them clinically. There has never yet been any dialogue between them, and a transdisciplinary approach seems more desirable than ever in this debate, which is of obvious benefit to patient care. It would be a shame to put patients at risk by making a problematic combination, but it would also be a shame to deprive them of a CAM that could help them manage

better their infections, without over-medicalizing them.

Finally, this real-life exploration raises several questions, some of which are general, concerning all chronic diseases, while others are specific to CF. First, the very good results reported by patients (and the rare problematic practices reported) suggest that conventional medicine may be depriving itself of an interesting anti-infectious treatment, at time of multi-resistance coupled to a better knowledge of antibiotics' side-effects, particularly on the microbiota. There is a disruption of the gut microbiota called dysbiosis in CF. However, the functional consequences of this dysbiosis are not well-known. However, there may be a link between dysbiosis and intestinal inflammation, which is present in CF. Taking antibiotics is one of the main causes of intestinal dysbiosis.

The question of potentiating or inhibiting conventional medicine activity by combining them with EO is also a major public health concern, far beyond CF, when innovation is running out of steam in infectiology, while bacterial resistance phenomena are exploding leaving medical doctors with fewer and fewer choices. Furthermore, this study also highlights the lack of dialogue that still prevails between medical doctors and patients about their use of CAMs, particularly in hospitals. In the specific case of CF, there are never alternative practices, because patients know what they owe to conventional medicine. Above all, they seek to optimize their care and reduce the frequency of antibiotherapies, but by no means exclude them. They are not questioning the skills of hospitals, but they would like to be heard and advised, because for them self-medication is a default choice.

Finally, the use of quantitative and qualitative methods makes it possible to document practices in real life, to raise issues and to explain them through illustrative interview data [14]. The reality of these practices can then be confronted with more theoretical debates involving the fundamental sciences, as illustrated by the point of antibiotic/EO association. This approach seems particularly fruitful in the case of CAMs, which evaluation is still problematic. The surprising results of this study demonstrating the use of EO, by often young CF patients, should push clinicians to clinically evaluate their results. The fact that a contemporary practice of patients outside medical accompaniment leads to a clinical study would be a *first* in clinical research strategy. The historical case of the discovery of morphine from poppies will be replayed?

Conclusion

In conclusion, this comprehensive study sheds light on the nuanced landscape of aromatherapy, specifically the use of EO in CF. The findings, based on a substantial sample size and a mixed-methods approach, reveal a significant but often unacknowledged integration of EOs into the lives of CF patients. The positive reported effects, including the prevention of infections and reduction in antibiotic dependency, underscore the potential of aromatherapy as a complementary approach in managing chronic illnesses. However, the study also exposes a communication gap between patients and medical professionals, with patients often hesitant to disclose their EO practices to healthcare providers. This reluctance stems from concerns about potential negative reactions

and a lack of validation from evidence-based medicine (EBM). The challenge for medical doctors lies in recognizing therapies with limited clinical evidence and variable compositions, characteristics inherent in phytotherapy and EO usage.

The contentious debate surrounding the combination of EO and antibiotics highlights the need for a transdisciplinary approach to better understand potential interactions and guide safe practices. The study prompts reflection on the broader implications for public health, especially in the context of rising antibiotic resistance and the search for innovative infection control strategies. Ultimately, this research underscores the importance of fostering open dialogue between patients and health professionals. Patients seek not to replace conventional medicine but to optimize their care, and their experiences warrant consideration and integration into holistic treatment plans. The study's call for clinical evaluation of EO use, initiated by patients outside traditional medical channels, challenges existing paradigms and invites a reevaluation of clinical research strategies. In embracing the potential benefits of CAM, particularly aromatherapy, healthcare providers can forge a path toward more patient-centered and integrated care, acknowledging the rich tapestry of practices that contribute to the well-being of individuals facing chronic illnesses like CF.

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Conflict of Interest

No conflict of interest exists.

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