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Expectations of Patients and Their Informal Caregivers from an Integrative Oncology Consultation

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Abstract

Integrative physicians (IPs) working in supportive and palliative care are often consulted about the use of herbal medicine for disease-related outcomes. We examined 150 electronic files of oncology patients referred to an IP consultation for demographic and cancer-related data; use of herbal medicine for disease-related outcomes; and narratives of patients and informal caregivers describing their expectations from the IP consultation. Over half (51.3%) of patients reported using herbal medicine for disease-related outcomes, more so among those adopting dietary changes for this goal ($P < .005$). Most (53.3%) were accompanied by an informal caregiver, especially those using herbal medicine (66.2%, $P = .002$) or adopting dietary changes (69.8%, $P < .001$). The majority of patients (84.4%) expected the IP to provide guidance on the use of herbal medicine for disease-related outcomes (e.g., "curing," "shrinking," "eradicating" and "cleansing"). Most caregivers (88.8%) expressed a similar expectation, with some having additional questions not mentioned by the patient. IPs need to identify and understand expectations of oncology patients and their informal caregivers, helping them make informed decisions on the effective and safe use of herbal medicine. The IP may need to "reframe" expectations regarding the ability of herbal medicine to treat cancer and immunity, to more realistic quality of life-focused goals.

Keywords

integrative oncology, integrative physician, herbal medicine, expectations, informal caregivers, reframing

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Introduction

The use of complementary medicine (CM) among oncology patients is widespread, with as many as half of these patients in the U.S. having used at least 1 CM modality during the previous year, 91% of them during conventional oncology treatments.[1-3] Patients seek out CM therapies for a number of reasons, which range from alleviating symptoms and improving quality of life (QoL); to disease-related outcomes such as "strengthening" the immune system and "fighting" their cancer.[4-6] One of the most popular CM modalities is the use of herbal and dietary supplements,[5] which are often perceived as "natural" and therefore considered as both safe and effective.[7] While some herbal products have been shown to be effective in reducing symptoms (e.g., ginger for chemotherapy-induced nausea/vomiting[8]), others are associated with toxic effects (e.g., cyanide toxicity with Laetrile, derived from apricot pits[9]) or with negative interactions with conventional anti-cancer drugs (e.g., inhibited absorption and increased metabolism with *Hypericum perforatum*[10]). Despite the potentially harmful effects of herbal medicine, most patients do not tell their oncologists that they are using herbal medicine, either because they are not asked or because of an anticipated negative and dismissive response.[1]

Informal caregivers such as family members, spouses or partners and friends frequently accompany oncology patients to doctor visits, diagnostic tests, and treatments. Caregivers may significantly influence a patient's decision to use CM for either QoL or disease-related outcomes, and may also have questions and expectations which are

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important to address for the patient they are accompanying, as well as for themselves. Limited qualitative research has shown that patients with advanced lung cancer and their family caregivers include complementary and alternative medicine among the main strategies being used for coping with their illness,[11] and that informal caregivers are interested in obtaining reliable information on lifestyle changes, including stress management, proper nutrition and relaxation techniques, for both the patient and for themselves.[12]

Many cancer centers offer Integrative Oncology services, in which non-conventional medical therapies are provided within the center's supportive and palliative cancer care setting.[13,14] These services are headed by medical doctors with training and experience in CM and who integrate these practices in their therapeutic repertoire, and are commonly referred to as "integrative physicians" (IPs).[15] During the consultation, the IP can identify the use of CM by the patient, including herbal medicine; present the findings of the research on the effectiveness and safety of these therapies, including the potential for toxicity and negative interactions with conventional medical treatments; and co-design an evidence-based and rational CM treatment plan for the relief of symptoms and improving QoL.[16,17]

A number of studies have examined the expectations of patients undergoing IP consultations, with most anticipating that they will be referred to CM treatments for relief of symptoms and improved QoL.[18,19] However, in a study of patients with breast cancer, 29.4% reported that they also expected the IP to provide guidance on the use of "alternative" therapies for disease-related outcomes. This expectation was significantly greater among patients who were currently using herbal medicine for disease-related outcomes (48.6%) when compared to those who were not (15.8%; $P = .001$).[20] Expectations of informal caregivers of adult oncology patients from CM have yet, to the best of our knowledge, to be explored. The present study set out to examine the use of herbal medicine by oncology patients referred to an IP consultation by their oncology healthcare professional, and to identify the expectations from the consultation of patients and their informal caregivers.

Methods

We undertook a retrospective chart review of 155 consecutive electronic files of patients referred to the Integrative Oncology Clinic, under the auspices of the Cancer Pain and Palliative Medicine Service, Department of Oncology, Shaare Zedek Medical Center, Jerusalem, Israel. The electronic files of consecutive oncology patients aged ≥ 18 years who had undergone an initial IP consultation (between May 2019 and April 2020) were included. All patients had been referred to the consultation by their oncology healthcare professionals (oncologists, nurses, social workers and psychologists). However, the patient files did not specify who initiated the discussion about this option.

The IP consultations lasted on average between 45 minutes to an hour. All consultations in the present study were performed by a single IP practitioner (NS) using a uniform structure:

1. Review of the patient's cancer-related diagnosis and treatment, as well as their non cancer-related medical history.
2. Review of the patient's symptoms and concerns related to their cancer and oncology treatments, as well as their impact on their QoL and function.
3. Review of the patient's current or planned use of CM, including herbal medicine and dietary changes, whether for QoL- or for disease-related outcomes (i.e., "strengthening" the immune system, "fighting" the cancer). Patients are also asked whether they had consulted with a physician or practitioner of non-conventional medicine.
4. Exploration of the expectations from the IP consultation and CM treatment from both the patient and the accompanying informal caregivers. Patient and caregiver narratives about these expectations were recorded by the IP as free text in the electronic patient file.
5. Addressing questions raised by the patient and/or caregiver, including those regarding specific herbal products and their effectiveness and safety (toxicity, herb-drug interactions).
6. Co-designing a CM treatment plan with the patient, and asking the patient to schedule a follow-up visit. This includes guidance on herbal and other evidence-based complementary medicine modalities which have been shown to relieve symptoms and improve quality of life and function.

The data from the patient files were collated and entered into a Microsoft Excel 2010 program, using a Fisher's exact and Student's *t*-test (both two-tailed) to analyze continuous variables. A *P*-value of .05 was considered to be statistically significant. The study was approved by the Ethics (Helsinki) Review Board of the Shaare Zedek Medical Center, Jerusalem, Israel (0155-20-SZMC).

Results

Characteristics of the Study Group

A total of 155 consecutive patient files were evaluated, with 5 files belonging to pediatric oncology patients (aged ≤ 18 years) excluded from the analysis. In the remaining 150 files, more than 3 quarters (78.7%) were female. The demographic and cancer-related characteristics of the study group

Table 1. Characteristics of the Study Cohort (n = 150), Comparing Patients Using/Planning to Use Herbal Medicine for Disease-Related Outcomes ("Users") with Those Who were Not ("Non-Users").

Demographic	Total	Users	Non-Users	*P*-value
N	150	77	73	
Female	118	64	54	
Male	32	13	19	.07
Age (mean ± SD)	58.9 ± 12.1	57.6 ± 12.2	60.2 ± 11.9	.189
Smoker?	18	7	11	.39
Exercise?	69	39	30	.156
Cancer-related				
Primary Tumor				
Breast	63	35	28	.237
Gastrointestinal tract	60	29	31	.332
Large Intestine	31	12	19	
Stomach	5	1	4	
Pancreas	16	12	4	
Other (GYN, CNS, Prostatic, etc.)	27	13	14	
Metastatic Disease	62	35	27	.188
Treatment Setting				
Adjuvant/Neoadjuvant	77	42	35	
Symptoms				
Gastrointestinal (upper/lower)	101	47	54	
Pain	78	40	38	
Peripheral Neuropathy	79	35	44	
Fatigue	119	56	63	
Anxiety and/or Depression	32	19	13	
Hot Flashes	43	18	25	
Sleep Disturbances	18	8	10	
CIM-related				
Modified Diet?	63	55	8	<.0001
Under Guidance?	68	56	2	<.0001
MD Practitioner	23	22	1	
Non-MD Practitioner	35	34	1	
Expectation from IP consultation				
Treat cancer/immune system	75	65	10	<.0001

are presented in Table 1. The mean age of the cohort was 58.9 years, with most patients diagnosed with breast cancer (42%) followed by gastrointestinal malignancy (large/small bowel, pancreas, other; 40%). The majority of patients had early stage disease, with 41.3% diagnosed with metastatic cancer at the time of the IP consultation. More than two-thirds (67.3%) reported gastrointestinal symptoms (upper, lower or taste-related), and more than half (52.7%) symptoms associated with chemotherapy-induced peripheral neuropathy.

Over half of the patients attending the IP consultation (n = 80; 53.3%) were accompanied by an informal caregiver: 46 with a spouse or partner; 21 with a son or daughter; 7 with a parent; and 6 with a sibling or friend. Caregiver accompaniment was slightly less common among female patients (50.8%) than males (62.5%), although the difference between genders for this outcome was not statistically significant ($P = .318$). A trend for a higher frequency of accompaniment by an informal caregiver was observed among patients with metastatic disease (62.9%) than localized disease (46.6%; $P = .067$). Herbal medicine users were significantly more likely to be accompanied by an informal caregiver (66.2%) when compared to non-users (39.7%; $P = .002$), as was the case for those adopting dietary changes for cancer-related goals (69.8%) when compared to those who did not (41.4%; $P < .001$).

Use of Herbal Medicine by Patients

More than half of the patients undergoing the IP consultation (51.3%) reported using or planning to use herbal medicine for disease-related consideration: that is, "curing" the cancer or preventing its recurrence; "strengthening" the body's immune system; or both. Among those using herbal medicine for this purpose, 54.2% were female and 40.6% male ($P = .07$).

The adoption of dietary changes and use of nutritional supplements, both with the goal of enhancing disease control, was common and both behaviors were commonly associated. A total of 63 patients (42%) of the cohort reported already using dietary changes for disease-related outcomes. This included removal of all products containing sugar (in some cases, including from fruit), dairy products and meat; preparing "green shakes"; eating only "organic" vegetables; and more. The majority (55/63, 87.3%) of patients who modified their diet for disease-related outcomes reported using herbal medicine for this goal as well. In contrast, only 11% non-users reported taking on dietary modifications for this purpose ($P < .005$). Nearly three-quarters of patients using herbal medicine for disease-related outcomes (72.7%) were doing so under the guidance of a non-conventional practitioner: 23 with physicians (MDs) and 35 with non-physician practitioners of non-conventional medicine. In a number of cases the IP recommended against the use of specific herbal products, either because of potentially toxic effects (e.g., Laetrile,[9] 2 patients), or negative herb-drug interactions (e.g., *Hypericum perforatum*,[10] 3 patients).

Expectations from the IP Consultation

The expectations of the referring oncology healthcare professional, patients and informal caregivers were recorded as described by the IP as free text in the electronic patient file.

Referring oncology staff. Patients attending the IP consultation had been referred by one of their oncology healthcare professionals to the IP consultation for the purpose of providing guidance on CM treatments that could reduce the symptom load and improve patient QoL; to advise them on the safe use of herbal and dietary supplements; and to prevent financial abuse of vulnerable patients and family members by unprincipled CM practitioners.

Patients. Among the patients using dietary modifications or herbal medicine at the time of the consultations, the majority (84.4%) came with the expectation that they would be receiving guidance on the use of non-conventional medicine for disease-related outcomes ("curing" the disease; "strengthening" the immune system). This expectation was held by only by a minority (13.7%) of those patients who were not using herbal medicine or dietary modifications for this goal at the time of the consultation ($P < .005$).

Informal caregivers. Among informal caregivers, nearly a third (31.1%) expressed an expectation that the IP consultation would address QoL-related issues, with more than two-thirds (68.8%) that it would address disease-related outcomes. Nearly half (48.8%) agreed with and had no additional questions or expectations beyond those of the patient regarding the goals of the IP consultation. Many of the caregivers (40.0%) had additional disease-related questions and expectations of improved likelihood of cure or prolonged survival most commonly regarding the use of herbal medicine for disease-related outcomes. Only 9 of the caregivers (11.3%) had QoL-related questions and expectations regarding the use of CM for the relief of cancer and treatment-related symptoms and concerns. The IP was expected to address the questions and concerns of both patients and caregivers.

Illustrative Patient and Caregiver Narratives

Patient and caregiver narratives were entered verbatim in the patient's electronic file during the IP consultation. These selected quotations illustrate some of the expectations regarding the ability of CM to control or even "cure" the patient's cancer, prolonging life without negatively impacting the conventional treatment regimen.

◊ "I want you to tell me what I need to do. . .maybe there's something to cure the disease. . .". *[From a 58 year-old female patient undergoing chemotherapy and endocrine treatment for metastatic breast cancer].*

◊ "I'm looking for a savior. . .I need the wonder-drug. . .". *[From a 57 year-old female patient undergoing adjuvant chemotherapy for localized breast cancer].*

◊ "I would like to hear about things that can shrink the tumor. . ." *[From a 78 year-old female patient undergoing chemotherapy for metastatic colon cancer].*

◊ ". . .in order to improve her medical condition. . .just like the conventional treatment makes her tumor smaller, so too the natural treatment can do the same thing, without clashing with each other. . ." *[From the daughter of a 74 year-old female patient undergoing chemotherapy for metastatic cecal carcinoma].*

◊ "Can you cure the disease through diet?" *[From the wife of a 58 year-old male patient undergoing chemo-radiation for localized lun0g cancer, asking about a "cleansing diet"].*

◊ ". . .near the end. . .I am willing to try anything, as long as it doesn't cause harm..". *[From the father of a 42 year-old female patient in hospice care for terminal metastatic breast cancer, on mechanical ventilation. The father had heard from a physician in the U.S. about an alternative therapy which combined intravenous vitamins with a ketogenic diet].*

◊ "Do you have anything for cancer?" Heard that fruits and vegetables "can remove the disease. . .". *[From the husband of a 65-year-old female patient undergoing chemotherapy for metastatic colon cancer].*

◊ ". . .something that can eradicate the cancer. . .". *[From the sister of the above patient].*

At the same time, patient and caregiver expectations addressed the ability of CM to reduce the symptom load, improving QoL and function.

◊ "I want to sleep at night without pain. . .so that my daughter can see that her mother is strong and functioning". *[From a 45 year-old mother of 3 on endocrine maintenance therapy following resection and adjuvant chemo-radiation for localized breast cancer]*.

◊ "I want to have control over my body. . .that I should have the strength to get up, to go upstairs. . .it's very frustrating for me not to have control over my body. . .what can I eat to get stronger?". *[From a 58 year-old female patient undergoing chemotherapy and endocrine treatment for metastatic breast cancer]*.

◊ "I would very much like him to have a series of treatments with acupuncture. I want him to be able to continue his life as usual, together with the disease, which with God's help we will overcome and get past. . ." *[From the wife of a 73 male patient undergoing chemotherapy for localized pancreatic cancer]*.

◊ "What can we give to make her stronger?" *[From the daughter of a 61 year-old female survivor of localized breast cancer]*.

◊ "I just want her to feel better. . .". *[From the daughter of a 72 year-old female patient undergoing chemotherapy for metastatic duodenal cancer]*.

Often, patients expressed frustration with their oncologist's skepticism, ignorance and unwillingness to engage in a discussion about CM, as well as dissatisfaction with the ability of conventional anti-cancer therapies to produce a desired result.

◊ "I'm extremely upset that the oncologists tell me that the herbal remedies are all nonsense. . .they're not willing to address the subject. . .it's very frustrating. . ." *[From a 58 year-old female patient undergoing adjuvant chemotherapy for non-metastatic cancer of the pancreas]*.

◊ "At this point I don't see any reason to continue with the (conventional – NS) treatment. . .". *[31 year-old female patient on a TDM-1 chemotherapy regimen for metastatic breast cancer]*.

Finally, in some cases the patient's expectations were not congruous with those of the caregiver. This was often related to the difficulty of the patient in taking large quantities of herbal products and adopting stringent dietary changes as prescribed by the caregiver.

◊ "Instead of swallowing all these pills (supplements given to her by her daughter; NS) maybe there's some type of food that can provide the same solution. . .to strengthen, to feel better. . .all day long I have to make sure to take all these pills. . .it takes away from my appetite. . .instead of eating fruits and vegetables. . ." *[From an 86-year-old female patient undergoing chemotherapy for metastatic pancreatic cancer, whose daughter and only child is insistent that she take a large number of supplements while avoiding all "sugar," including that from fruits]*.

◊ "I would like to try the Ephedra, but I already have too many things to take. . .I am trying to cut out sugar, but find it difficult. . .I know it's forbidden, everyone tells me that it makes the cancer grow. . .I need you to 'organize' the list. . .and if you have any other supplements I should take. . ." *[From a 57-year-old mother of 2 undergoing adjuvant chemotherapy for localized uterine cancer, whose husband insists that she take a number of capsules with herbal components, as well adopt a number of dietary changes in order to "cure" her cancer]*.

Discussion

To the best of our knowledge, this is the first study to examine the expectations of both oncology patients and their informal caregivers from an IP consultation. The unmonitored use of herbal medicine by these patients, especially when used in conjunction with conventional anti-cancer treatments, raises a number of safety-related concerns which require both a non-judgmental conversation and an evidence-based approach. In the present study, herbal medicine use for disease-related outcomes ("curing" the disease and/or "strengthening" the immune system) was reported by more than half of patients attending the IP consultation, more so among female patients and those adopting dietary modifications for this purpose. The high rate of herbal medicine use is characteristic of Middle Eastern countries, where there is a high affinity for traditional medical therapies among which the most prevalent is the use of herbal medicine.[20] Effective communication between patients and their oncology healthcare professionals can be facilitated by the IP who understands the "language" of both conventional and CM paradigms of care, and can thus serve as a "gatekeeper" for an effective and safe therapeutic environment (see Figure 1).

The research to date on the role of the IP working in the supportive and palliative cancer care setting has addressed the gap in expectations between those of the referring oncology healthcare professional, who are invariably interested in QoL-related concerns and evidence-based guidance on the safe use of non-conventional medicine; and those of their patients, many of whom are using herbal products and adopting dietary changes with the goal of "curing" their disease, "shrinking" their tumor, serving as a "wonder drug".[21,22]

In the present study, more than half of the patients were accompanied by a caregiver, and this was more likely if they were using herbal medicine and/or adopting dietary changes for disease-related outcomes. In many cases, these caregivers were found to play a central and important role in the patient's use of herbal medicine. And as seen with the patient narratives, many caregivers used terms such as "cure," "make the tumor smaller," "remove the disease" when asked by the IP about their expectations from the consultation.

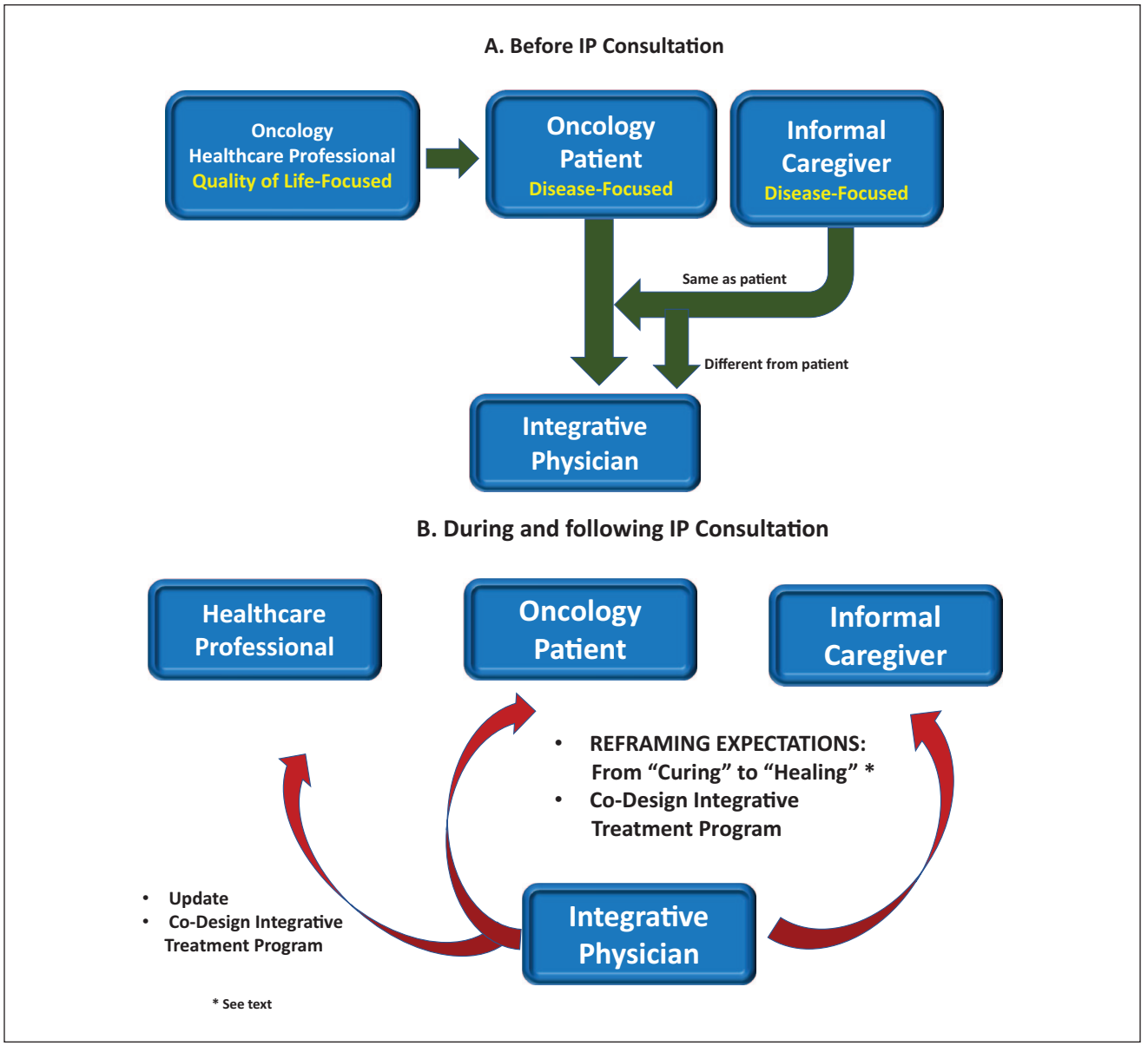

Figure 1. The integrative physician (IP) as "gatekeeper". (A) Identifying expectations from the IP consultation. (B) Updating the referring healthcare professional; "reframing" expectations; and co-designing an integrative treatment program (see text).

This study incorporates all of the limitations of being a small, single center, retrospective and exploratory evaluation. Other limitations include a potential researcher bias in the selection of the narratives and their contents; and the lack of grading the severity of symptoms and reduced function which may have influenced patient and caregivers' expectations. However, the findings support those of an earlier study examining the expectations of female patients with localized breast cancer from the IP consultation. This study took place in a large cancer center in central Israel, and though it did not examine caregivers it did find similarly high rates of herbal medicine use among patients, the majority for disease-related outcomes as well.[21] Future prospective studies are needed to better understand patient and caregivers' expectations regarding the use of herbal medicine during cancer care. This research should include both quantitative and qualitative methodologies, examining more extensively aspects such as symptom severity and asking questions such as: Who initiated the referral to the IP consultation? Were the goals and expectations of patients, informal caregivers and the referring oncology healthcare professionals regarding this practice adequately addressed?

In conclusion, over half of the patients attending an IP consultation in the present study reported using herbal

medicinal products for disease-related outcomes. Both patients and their informal caregivers frequently expressed an expectation that the IP would support this agenda and provide additional herbal products to "cure" the cancer. These findings emphasize the need for oncology healthcare professionals to ask patients about their use of herbal and other dietary supplements, as well as promoting knowledge among integrative physicians on the beneficial as well as potentially harmful effects of these products. The findings also highlight the challenging role of the IP in addressing the caregiver's perspective on the use of herbal medicine and dietary manipulation; and the need to address misconceptions and "reframe" expectations of CM, from disease-related outcomes to more realistic QoL-centered goals.

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