



Being in touch: narrative assessment of patients receiving online integrative oncology treatments during COVID-19

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Abstract

Objective We examined the qualitative impact of an online integrative oncology (IO) treatment program, designed in response to the restrictions created by the current COVID-19 pandemic.

Methods Patients undergoing chemotherapy were seen by an integrative physician (IP), together co-designing an IO treatment program of ≥ 6 weekly treatments to alleviate symptoms and improve quality of life (QoL). IO practitioners guided patients and their caregivers online in self-treatment with manual/touch, movement, and/or mind-body modalities. Narratives of both patients and IO practitioners were analyzed for systematic coding, identifying barriers and advantages of the online treatment program.

Results Narratives obtained from 30 patients and eight IO-trained practitioners were examined. The patients had undergone 169 online IO sessions with a total of 327 IO interventions during the 3-month study period. Patient narratives included reflections on both non-specific effects (e.g., less of a “sense of isolation”) and specific QoL-related outcomes with the online intervention. IO practitioner narratives focused on barriers to providing manual-movement and mind-body modalities, suggesting practical recommendations on how to address specific QoL-related outcomes using the online IO “toolbox.”

Conclusions Effective online IO practitioner-guided treatments are feasible and may induce both specific and non-specific QoL-related effects. Future research needs to explore online IO interventions for additional situations in which access to IO care is limited.

Keywords COVID-19 · Integrative oncology · Continuity of care · Telemedicine · Quality of life · Palliative care

Introduction

The current COVID-19 pandemic has significantly restricted access to supportive and palliative cancer care. In order to ensure continuity of care, many oncology healthcare practitioners (HCPs) are turning to online telemedicine for treatment of breast cancer patients, geriatric and gynecologic oncology, radiation oncology, urological and neurosurgical oncology, and survivorship [1–7]. Telemedicine offers a partial solution for the present restrictions, though it is limited with patient-centered integrative oncology (IO) and palliative care, where emotional and spiritual concerns are the focus of treatment [8, 9].

Most IO settings provide a wide range of complementary medicine modalities, particularly manual/touch, movement, and mind-body medicine provided by trained integrative medicine practitioners. Many of these treatments entail physical touch and/or a personal and mindful interaction with the patient, requiring IO services to examine alternatives which would allow them to continue treatments, improving patients’

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QoL with evidence-based, effective, and safe patient-centered therapies. Many centers are turning to online applications, which may be adequate for conducting HCP-patient conversations, but they have yet to be shown to be effective for “hands-on” IO practitioner-guided treatments. Evidence support can be found in randomized controlled trials examining the effectiveness of self-acupressure [10], self-acupuncture [11], and self-hypnosis [12], though these studies have not been conducted in an online treatment setting.

The present study examined the qualitative impact of an online treatment program developed by an IO service in northern Israel during the COVID-19 lockdown, with the goal of providing continuous weekly care. Narratives describing the online interaction were recorded for patients and IO practitioners, identifying barriers to the online approach while examining practical suggestions for overcoming these challenges.

Methods

Study design

This was a patient-preference, prospective, controlled, and non-randomized study, which took place from March to May 2020 at the Lin and Zebulun Medical Centers of the Haifa and Western Galilee District, Clalit Healthcare Services, Israel [13]. The study centers are part of the Integrative Oncology Program, providing IO therapies to patients undergoing chemotherapy by a multidisciplinary team of practitioners from conventional medical, paramedical, and non-medical fields, all trained in integrative and supportive oncology care. This entailed completion of a 270-h IO training course, followed by IO mentoring for a period of at least 3 years. Eligible patients were aged ≥ 18 years and undergoing chemotherapy in a neoadjuvant, adjuvant, or palliative care setting for solid tumors.

Integrative oncology setting

Patients were referred by their HCP (oncologist, gynecologist, nurse-oncologist, or social worker) to a consultation with an integrative physician (IP) dually trained in supportive cancer care and IO. The IP and patient co-design a comprehensive IO treatment program based on research regarding effectiveness and safety, indications given in the HCP referral, and patient expectations. Weekly IO treatments include herbal and dietary supplements, acupuncture and other manual/movement modalities (e.g., acupressure, reflexology), and mind-body-spirit therapies (e.g., guided imagery, spiritual care). All patients receive standard conventional supportive care: palliative/supportive care consultations and medications, nurse-provided care, and psycho-oncology interventions.

In March 2020, the government of Israel responded to the COVID-19 pandemic by stopping all non-conventional medical practices, except for those operating in a hospital setting. In response, the Integrative Oncology Program initiated online interactions for patients who were able to continue treatment at the centers. Most programs used commercial video applications and some a non-video phone call. Weekly sessions (30 min on average) began with an assessment of QOL, identifying specific symptoms and concerns, and a discussion regarding treatment goals. IO practitioners then guided patient on self-administration of IO treatments, such as self-acupressure on the PC-6 point to alleviate chemotherapy-induced nausea. When present, informal caregivers were asked to participate in the patient’s treatment.

During sessions IO practitioners assessed the quality and accuracy of the intervention, modifying the instruction accordingly. At the end of the session, patients were given instructions for the ensuing week, addressing safety-related concerns and scheduling the next session. All therapeutic interactions were documented in the patient’s electronic medical file. Patients continuing treatment at the study centers were offered to participate in online treatments, as either an alternative or an “add-on” to their current regimen. An IO practitioner was assigned as an integrative case manager for each patient to maintain continuity of care, either by participating in the treatments or else coordinating sessions between other IO practitioners.

Data and analysis

Samples from free-text patient comments and narratives were taken from electronic medical files, as were those of the IO practitioners. Comments and narratives were also derived from the Measure Yourself Concerns and Wellbeing (MYCAW) questionnaire [14], which asks patients the following at follow-up: “Reflecting on your time at the integrative medicine center, what were the most important aspects of the treatment for you?” Qualitative analysis systematically coded patient narratives using ATLAS.ti Scientific Software (V.8). A qualitative content analysis was performed inductively based on the participants manifest (rather than latent) narratives, using a conventional content analysis approach, precluding the need for pre-established categories for coding [15].

Ethical considerations

The Ethics Review Board (Helsinki Committee) at the Carmel Medical Center in Haifa, Israel, approved the study protocol, which was registered at [ClinicalTrials.gov](https://www.clinicaltrials.gov) (NCT01860365). Participation was voluntary for all patients, with no incentive offered such as payment or the like.

Results

Description of study group

Of the 56 patients seen by an IP during the 3-month study period, 30 (53.6%) chose to undergo online treatments. Patients undergoing online treatment were mostly female (27, 90%), with a mean age of 61 years; mostly likely to have been born in Israel (18, 60%); and presented with a wide range of cancer types (18 with breast cancer, 60%). All patients received chemotherapy, in either an adjuvant/neoadjuvant (19, 63%) or palliative care setting (11, 37%) for metastatic disease. The majority of patients reported having experienced complementary medicine for non-cancer (21, 70%) or cancer-related indications (14, 47%).

Characteristics of the online IO intervention

The 30 patients participating in online treatment group underwent 169 online sessions during the 3-month study period, with a total of 327 varied IO interventions guided by 8 IO-trained practitioners (2 MDs, one nurse, one registered dietitian, and 4 non-MD practitioners). For 10 patients, treatments were given by more than one IO practitioner, often together during the same session. IO practitioner-guided self-administered treatments included manual-touch therapies (20 patients, including 13 self-acupressure treatments), movement therapies (20 patients, including self-practice of Feldenkrais/Paula methods and/or Qi Gong), mind-body-spiritual approaches (11 patients), herbal medicine use (7 patients), and practitioner-guided self-acupuncture (1 patient).

Patient narratives

Many narratives contained core themes such as loneliness, isolation, inability to engage in daily and social activities, and fear of contracting COVID-19. Many patients expressed these feelings before the lockdown, but had since increased. Patients described the pandemic as an “insane reality” and a “significant change in my life.” Many felt “insecure to enter the oncology department.” When told they would have to reduce or stop treatment at the study centers, many expressed disappointment:

I can tell you your treatment is my favorite and when I knew there would be no touch treatments, I had a hard time accepting it. (37-year-old female patient undergoing palliative care for metastatic colon cancer)

Many patients were concerned that online technological aspects would be too difficult, especially those requiring work with a computer. Some were skeptical regarding their ability

to undergo online treatment while speculating that specific modalities may work:

I wasn't able to understand what else you have to offer. I guess that the online treatment with guided imagery might help... (65-year-old female patient undergoing adjuvant chemotherapy for ovarian cancer)

They were also worried about creating a quiet treatment setting in their home without distractions, or other factors preventing them from learning or performing the self-administered treatments (e.g., locating the instructed acupressure point). Unlike the hands-on experience of the previous interactions, the online experience was perceived as “remote” and lacking the impact of the face-to-face meeting:

I did not like it so much but I am ‘going with the flow’... and though I have no patience, I still continue to exercise my legs for the neuropathy (64-year-old female patient undergoing neoadjuvant chemotherapy for breast cancer)

Patients were also worried about not being able to discuss the treatment with the IO practitioner in person. Certain patients felt that the online-guided self-treatment was less effective than the in-person treatment at the oncology center and had a shorter duration:

The online acupressure treatment was clear to me, but it felt different, like something was missing... The ability of my hands is inadequate for the needles. (37-year-old female patient undergoing palliative care for metastatic colon cancer)

Despite the many challenges which online IO treatment presents, many patients reported a beneficial effect, including a number which are considered non-specific. These include a sense of caring, containment, support, calming, and empowerment.

It is important to me to that I can be in touch with you, talk to you... that we have not disconnected... that you remained with me despite what's happening all around with the Corona...The sense of support has been very important to me...that I am not alone. (62-year-old female patient undergoing palliative care for recurrent metastatic ovarian cancer)

...everything they do is from the heart, and it really helped me...the most was from acupuncture...they really gave me a lot of warmth and love, and that's really important when providing service to people... (63-year-old female patient undergoing neoadjuvant chemotherapy for localized pancreatic cancer)

You give me balance, you are there for me; and when we moved to the home setting because of the Corona it continues to harmonize me, providing confidence and serenity, with each Skype call. (a 32-year-old female patient undergoing neoadjuvant chemotherapy for breast cancer)

These non-specific effects of treatment became more apparent as patients became actively involved by learning and self-administering the treatments at home, as opposed to their less active role in the oncology department. The following narrative describes one patient's experience with the learning process:

You are an angel who treats me with care and love. I hope I'm a good student...I'm at least trying and believing. (a 68-year-old female patient undergoing adjuvant chemotherapy for localized ovarian cancer)

A unique narrative was reported by a 71-year-old female patient undergoing neoadjuvant chemotherapy for localized breast cancer. A retired nurse was being instructed online by her integrative physician in self-acupuncture at points on her calves and feet for the relief of taxane-induced peripheral neuropathy:

The online self-acupuncture treatment feels just as it did when I was being treated in your clinic. I do not see a difference, since in any case you accompany and guide me on the phone. I feel that it helps me a lot and gives me the confidence that I have an address for any problem... The fact that I have a listening ear and can pick up the phone, it's already three quarters of the cure.

Specific effects were also described, typically in connection to a specific feeling with a perceived "link" between the integrative intervention and the outcome:

The online treatments with you do matter...to repeat with you with the hand and the breathing exercises, and to focus myself and to focus the warmth in my hands... Do you remember when I first came to you with the beginning symptoms of neuropathy? And after you touched me with the oil...it may have been bay leaf oil...all of a sudden it disappeared? When you talked to me and explained about the acupressure points, even though it was through a screen, I could sense the flowing and the warmth in my hands, and then was able to implement treatment.... (37-year-old female patient undergoing palliative care for metastatic colon cancer)

Some of the specific sensations described were related to the "De-Qi," a sensation reported by patients during acupuncture and, to a lesser degree, acupressure:

First of all, something in the body changes. I feel the movement, the change, the calmness, I feel different. (a 68-year-old female patient undergoing adjuvant chemotherapy for localized ovarian cancer)

Patient narratives described a benefit with the online intervention for a wide range of quality of life-related concerns, including pain, cancer-related fatigue, gastro-intestinal concerns (e.g., mouth sores, constipation), insomnia, and emotional concerns. And though reduced anxiety and loneliness can be considered non-specific effects, other related elements can be seen as well:

The most significant for me was the acupuncture and Shiatsu (received in the treatment center, prior to the pandemic; EBA). They strengthened me for as long they were available. The breathing sessions (provided online; EBA) with the spiritual care provider helped me to view my situation from the side. (a 61-year-old male undergoing adjuvant chemotherapy following colon cancer surgery)

IO practitioner narratives

The narratives of IO practitioners addressed barriers to and challenges facing the provision of guidance during the online treatment process. These included difficulties faced by patients with the online setting; a practitioner concern that the online interaction would be "cold and distant," in contrast to the "warm and direct" in-person, "hands-on" intervention in the oncology department; and difficulties in providing IO modalities online, particularly manual and movement therapies. In one narrative, an IO practitioner trained in manual and movement therapies discusses her treating a 59-year-old female patient undergoing adjuvant chemotherapy for colon cancer:

This was the first time I encountered my own difficulty with providing online therapy, due to the fact that Shira (not her real name) was not familiar with therapeutic touch and my slow and soft way of working. Shira is a very energetic woman, always active. Many of my guided exercises seems to awaken her pain... I was not sure of my ability to convey the message of softness. I called her again the same afternoon to make sure she was not performing the exercise too rigidly. She was happy and said that the 'puppet exercise' helped her to 'let go'... she promised not to be too hard on herself.

Despite these difficulties, many IO practitioners described a sense of creativity in their ability to design what they referred to as a new "online integrative toolbox." Practitioners

appreciated the willingness of their patients to enable continuity of care via the online route. They therefore did their best to ensure the fidelity and quality of the IO techniques used to induce specific therapeutic effects. The following narrative describes an IO-trained family physician guiding a patient in self-acupressure at the LI-4 point, with the goal of relieving pain:

She found the acupressure point and felt the Qi. She said: there is a point that I feel... this is it... a sort of pain.

IO practitioners frequently provided additional teaching tools which included videos, diagrams, and photographs or other educational material to help the patient understand and implement the guided self-treatment:

I instructed the patient about how to massage the meridian along the forearm. This was followed by a short video demonstrating this manual maneuver on my arm. The patient was thankful for what she called the use of the ‘full toolbox.’

IO practitioners also described how patients unfamiliar with or wary of the online process eventually became interested, even enthusiastic, about the process. One practitioner, trained in traditional Chinese and mind-body medicine, described the process of treating a 70-year-old-male patient with localized breast cancer undergoing adjuvant chemotherapy. Treatments were conducted with the help of his wife, who was the primary informal caregiver:

At first, Joseph opposed the treatment... said that he felt great and that he did not need any more sessions with us. As time progressed, he began to trust us and to cooperate. During a video conference I explained to Joseph and his wife, Sarah, how to locate the acupuncture points ‘Yin-Tang’ and ‘PC-6.’ They then both leaned back on a sofa in their living room and began relaxation exercises, followed by an extensive ‘body screen’ which he could later use when he had difficulty falling asleep. I explained to Sarah that she could also gently press on the acupressure points, and remind him of how to implement the relaxation techniques. The couple released themselves into a state of relaxation; Joseph closed his eyes and submitted himself to the process, with Sarah opening her eyes every so often and looking into the camera.

One of the barriers identified by practitioners was the difficulty in moving treatments from the in-person clinical setting in the oncology department to the patients’ home. This move was felt by some to blur the therapeutic boundaries between

them and their patients. In order to maintain a structured therapeutic setting, online sessions were scheduled a week in advance, usually on the same day of the week and at the same time as the previous session. Patients were asked ahead of time to prepare a comfortable and quiet setting in their home “as if you were being treated by me in the department.” During treatments the practitioners tried their best to create a therapeutic setting with no interruptions, especially when the practitioner was working from home.

One of the most challenging settings for providing online IO consultations and treatments was home hospice care. Shelly was a 55-year-old female patient with metastatic ovarian cancer, who had been undergoing IO treatments at one of the study centers for more than 2 years. During the COVID-19 lockdown, her IO spiritual care provider continued their weekly meetings online, until she succumbed to her disease and died in her home:

We talked about rebirth, about non-birth, what can be done ... with what consciousness one needs before they die. I got the impression that she had learned to be more devoted to herself...more accepting... with less of a need to be in control.

Discussion

The present study explored narratives of patients and IO practitioners faced with the unexpected challenge of creating an online patient-centered and self-administered treatment methodology in response to the current COVID-19 lockdown in Israel. The move from “treating” to “guiding” is especially challenging in the integrative oncology setting, with manual modalities such as acupuncture and acupressure administered by skilled practitioners, though there is an increasing trend among integrative nurses to teach the self-administration of these modalities [10, 11]. The current pandemic has become an impetus for furthering this trend, shifting the treatment setting from the oncology department to the patient’s home.

The patient narratives presented indicate that the provision of IO practitioner-guided online treatments is feasible and may induce both specific as well as non-specific effects. The fear of infection with COVID-19 may have increased the intensity of the non-specific effects, with patients appreciative and reassured by the ability to continue weekly scheduled sessions with their IO practitioner. At the same time, patient willingness to participate in the online program may have itself generated certain non-specific effects. It is also possible that the IO intervention also facilitated specific treatment effects, described by patients as the “de Qi” sensation of dullness, pain, or tingling during self-acupuncture.

The design and development of the online IO treatment program are important, not only for the current pandemic with its restrictions but also for the post-COVID-19 era. The effectiveness (whether specific, non-specific or both), as well as issues related to safety and ethics, need to be addressed. These include ensuring confidentiality of the treatment with the use of non-secured popular online software; difficulties with assuring a high level of treatment when performed by untrained patients and their caregivers; and the possibility that patients will continue to self-treat without the guidance or supervision of a trained IO practitioner.

There is also a need to examine the “generalizability” of the current COVID-19 pandemic for other situations with restrictions of movement and accessibility to medical care, especially IO modalities. The online program should be tested under normal conditions as well, with the goal of incorporating it as an option for patients residing far from the treatment center, or else with limited mobility due to a highly toxic chemotherapy regimen.

The present study has a number of methodological limitations which need to be addressed in future research. The first is the potential selection bias resulting from IO practitioners encouraging participation by more “favorable” candidates, as opposed to more “challenging” ones who may require an extra effort and “out-of-the-box” approach to overcome potential barriers to online communication. It is important that other IO settings be explored, since the patients studied may not reflect the online program with other patient populations. Finally, the present study used a qualitative rather than quantitative methodology, precluding any conclusions regarding the effectiveness of the online treatment program.

Nevertheless, the findings presented suggest that online IO treatments are feasible and should therefore be explored. There is a need to create practice guidelines for the online format, with specific recommendations on how to perform effective and safe IO consultations and treatments. The combined potential of in-person and online IO treatments may present an important development toward the goal of improving patients’ QOL and reducing their symptom load.

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Author contribution EBA, OG, NS, and YT initiated the trial and collected the data analyzed this study. EBA, OG, and NS planned the study. EBA, YK, and NS carried out the analysis and wrote a draft manuscript. All authors participated in the revision of the manuscript.

Availability of data and material Available on request.

Code availability Available on request.

Declarations

Ethics approval The study was embedded in a prospective study protocol which was approved by the Ethics Review Board (Helsinki Committee) of the Carmel Medical Center in Haifa, Israel, and was registered at [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT01860365).

Consent to participate Participation in this study was voluntary and verified by participants’ consent.

Consent for publication N/A

Conflict of interests The authors declare no competing interests.

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