

# Giving voice to cancer patients: assessing non-specific effects of an integrative oncology therapeutic program via short patient narratives

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## Abstract

**Objective:** The aim of this study was to assess patient perspectives regarding non-specific effects of a complementary medicine (CM) consultation and intervention within an integrative oncology setting.

**Methods:** Patients undergoing chemotherapy in a community-based oncology service were referred by oncology healthcare providers to an integrative oncology physician trained in CM-oriented supportive care. Assessment of concerns and well-being was made using the Measure Yourself Concerns and Wellbeing questionnaire, at baseline and after 3 months of CM treatments, which were designed to improve quality of life (QoL) outcomes. Patients were asked to describe the most important aspects of the integrative treatment process. Free-text narratives were examined using content analysis with ATLAS.Ti software for systematic coding.

**Results:** Of 152 patients' narratives analyzed, 44% reported an experience of patient-centered care, including CM practitioners' approach of togetherness, uniqueness, and the invoking of an internal process. CM practitioner approach was experienced within a context of an enhanced sense of confidence; gaining a different perspective; and acquiring emotional resilience and empowerment.

**Conclusions:** Short patient narratives should be considered for patient-reported outcomes, expressing perspectives of both effects and experience of care. CM may promote patient QoL-related outcomes through non-specific effects, enhancing patient-centered care. The benefits of CM dependent on general therapeutic incidental aspects (i.e., common factors) warrant attention regarding non-specific components of treatment.

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## Background

The integration of complementary medicine (CM) into supportive oncology has emerged over the last decade, signifying a growing process of integration of CM practices within supportive cancer care in leading oncology centers worldwide [1,2], during both active oncology treatment and survivorship [3,4]. CM is becoming a significant factor in the arena of cancer care, owing to the high prevalence of its use among patients with cancer during active oncology treatment and throughout survivorship [3,4]. Research has shown that patients with cancer often use CM because they believe it will improve physical and emotional health, enhance quality of life (QoL) outcomes, strengthen the immune system, reduce symptoms, and positively impact outcomes [5–9]. Within the conceptual framework of 'The Great Psychotherapy

Debate', as described by Wampold, we may consider the benefits of CM as being derived from the specific ingredients contained in a given treatment (i.e., medical model), or else more of a factor which depends on general therapeutic effects (i.e., contextual model) (10). In Israel, about half of patients with cancer are using CM, integrating these therapies with conventional care, including during chemotherapy [10].

The objective of the present research was to explore patient perspectives as expressed in their narratives about experiences and assessment of CM-integrative treatments. The relationship between the benefits of CM (if any) on implicit common factors in diverse methods and treatment-specific ingredients were examined. CM treatments were provided in an integrative oncology setting, with patients referred by their oncology healthcare practitioner to a CM consultation provided by an integrative

medicine-trained physician. Qualitative patient-reported outcomes (PROs), which comprise a patient-centered approach in the assessment of treatment outcomes [11], were examined using short narratives, which were captured in electronic medical records. Patients were asked to write one to three sentences about what they considered to be the most important aspects of the CM treatments received. Examining patient perspectives demonstrated the usefulness of a PRO instrument of short narratives of patients included in electronic medical records.

## Methods

### Research setting

In 2008, an integrative oncology program (IOP) was established within the Clalit Oncology Service of the Haifa and Western Galilee district of Clalit Health Organization (CHO). The CHO is largest health maintenance organization in Israel [12]. The IOP at the Clalit Oncology Service of the CHO offers CM consultations and treatments to patients with local or advanced cancer. The IOP service is provided by a multidisciplinary team of healthcare professionals, which include an integrative physician (IP; i.e., an MD physician who has undergone extensive training in CM and specialized in supportive cancer care-oriented CM); family physicians; dual-trained practitioners in CM and conventional medicine (a social worker, an occupational therapist, a physiotherapist, a nutritional specialist, and nurses); a spiritual support therapist; and a number of practitioners from the various fields of CM practice. Patients are referred by oncology healthcare practitioners (i.e., oncologists, oncology nurses, and psycho-oncologists), with treatment goals and expectations discussed at the initial IP consultation. Symptoms and concerns are evaluated with the Edmonton Symptom Assessment Scale (ESAS) [13] and Measure Yourself Concerns and Wellbeing (MYCaW) [14]. Conclusions from the consultation regarding treatment goals and plan are sent to the referring healthcare practitioners and primary care physician.

The patient-tailored integrative treatment plan is administered in conjunction with conventional supportive care and is based on patients' concerns, expectations, and health-belief models. CM treatments address the patient's main concerns and QoL status and are based on efficacy of a specific CM modality for a certain symptom or distress (e.g., acupuncture for chemotherapy-induced nausea) [15], safety considerations, prior CM patient's experience, and preference. CM treatment modalities include one or more of the following: counseling on the use of herbs and supplements, and related nutritional advice and workshops; Chinese medicine (acupuncture, etc.); mind–body–spirit medicine (relaxation exercises, guided imagery, etc.); and touch therapies (e.g., reflexology). Cuisine workshops integrate nutritional and herbal counseling, with preparation of menus designed to alleviate gastrointestinal symptoms

and fatigue. Workshops are supervised by an IP and a psycho-oncologist.

Initial IP consultations are followed by weekly or bi-weekly CM treatment sessions over a 3- to 4-month period, concluding with a second IP assessment in which ESAS and MYCaW questionnaires are re-completed. Patients attending  $\geq 5$  consecutive integrative care sessions, with  $\leq 30$  days between sessions, are considered to be adherent to the integrative care process [16].

### Ethical approval

Patients participated in the study on a voluntary basis and provided informed consent. The study protocol was approved by the ethics (Helsinki) committee of the Carmel Medical Center and registered at ClinicalTrials.gov (NCT01860365).

### Data and analysis

Patient-reported-outcome measures are increasingly used in both daily clinical practice and trials [11] and are defined as 'any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else' [17]. Although clinicians can make objective observations of observable symptoms, only the patients themselves can report on their personal feelings, experiences, and QoL outcomes. Patient perspectives complement those of clinicians, providing unique information and insights into both the effectiveness of health care and the experience of care [18]. PRO instruments include questionnaires with information and documentation supporting their use [17,19]. Qualitative data influence healthcare and policy development, providing direct patient accounts of the experience of illness and impact on human suffering and related interventions [20]. Corner *et al.* [21] found that free-text comments complement formal PROs among cancer patients, suggesting that short comments complement quantitative results, highlighting issues of priority.

At the concluding IP assessment, patients were asked the following open-ended question: 'Reflecting on your time at the integrative medicine center, what were the most important aspects of the treatment for you?' All free-text comments narratives recorded from July 2009 to September 2012 were sampled with quantitative data: demographic information; cancer diagnosis and treatment; and referral patterns to the CM consultation. Clinical assessment data collected at the initial and concluding IP consultations were collected, with a detailed description of the CM interventions provided.

The present analysis of patient narratives employed quantitative and qualitative modes of content analysis. Narratives were coded systematically using the textual analysis computer package Atlas-Ti (V. 6.2.), in two stages: First, one of the authors (Y. K.) conducted qualitative content analysis with conventional content analysis

approach [22], pre-empting the need for preconceived categories and titles and allowing them to evolve from the data. Patient responses were read verbatim, to derive codes by marking words that captured key concepts. Second, all quotes related to the codes were gathered and sorted in categories on the basis of their relationship to each other. The conceptual framework proposed by Tordes *et al.* [23] was incorporated, categories were merged, and codes were grouped into meaningful clusters. Unlike content analysis, this approach enabled the direct extraction of information from records without imposing preconceived categories or theoretical perspectives.

The second stage of the study entailed quantitative content analysis of data using SPSS software (version 18; SPSS Inc., Chicago, IL). A *t*-test was performed for continuous variables when normality was assumed, and a Mann–Whitney *U* test for non-normal distribution, with *p* < 0.05 considered to be of statistical significance. Analysis of variance tests compared levels of effectiveness with patient assessments of CM outcomes: effective to very effective, moderately or partially effective, not/slightly effective, or neutral. The Fisher exact test and Pearson chi-square were used to check for differences in the prevalence of categorical variables.

## Results

The analysis of the short patient narratives revealed two main themes: the effect of the treatments and the experience of care. As such, we first present the data related to patient demographics, disease characteristics, and the sequence of treatment with CM modalities. Next, we discuss patient perspectives regarding the effects of the CM treatments on desired outcomes. Finally, we discuss patient narratives regarding the experience of care (Figure 1).

### Demography, disease characteristics, and treatment sequences

Of the 313 patients evaluated, 159 attended the follow-up IP assessment. Non-attendance was attributed to lack of mobility/distance constraints; clinical deterioration or hospitalization; reluctance to undergo CM treatment; dissatisfaction with CM treatment outcomes, or conversely, significant improvement felt to preclude follow-up; and transfer of patient care elsewhere. Patient demographics, disease characteristics, and CM-related data are presented in Table 1. Nearly all patients attending the concluding IP evaluation wrote narratives describing their perspectives of important aspects of CM treatments. Adherence to treatment ranged from 2 to 24 (mean  $9.14 \pm 3.94$ , median 8).

### Effects of integrative CM treatments

All the 152 patients who provided a narrative referred to the effects of the CM treatments themselves. They wrote about the effectiveness in treating specific symptoms,

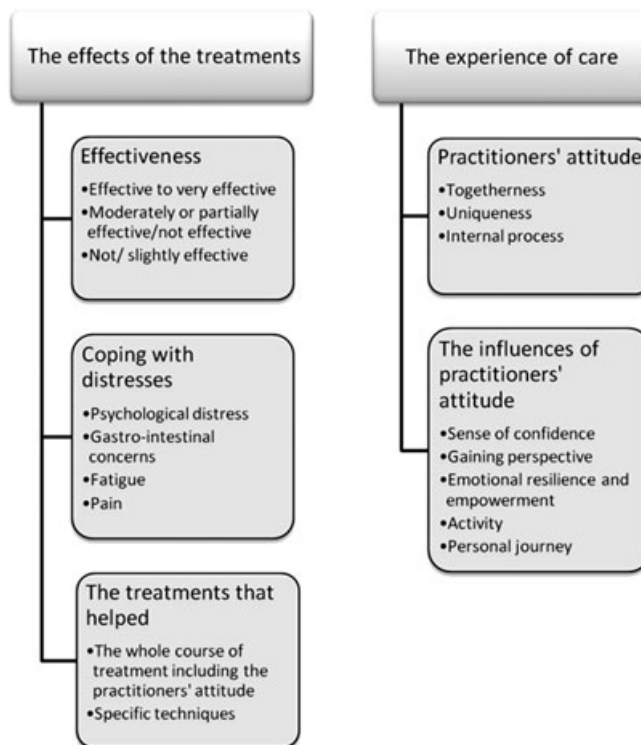


Figure 1. Thematic framework

Table 1. Characteristics and CM use (N = 159)

Characteristic		No. of patients (%)
Gender	Women	122 (76.7)
	Men	37 (23.3)
Spoken language	Hebrew	118 (74.7)
	Russian	25 (15.8)
Residence distance	Arabic	15 (9.5)
	Haifa	64 (40.3)
	Suburbs <sup>a</sup>	62 (39)
Type of cancer	Periphery <sup>a</sup>	33 (20.8)
	Breast	71 (44.7)
	Gynecologic	31 (19.5)
	Gastrointestinal	28 (17.6)
	Urological	10 (6.3)
	Lung	8 (5)
	Prostate	6 (3.8)
Recurrence	Other	5 (3.1)
	Primary cancer	120 (75.5)
Metastasis	Recurrent cancer	39 (24.5)
	Non-metastatic	91 (57.2)
Chemotherapy setting	Metastatic	68 (42.8)
	Palliative	48 (30.6)
Prior CM use for cancer-related outcomes	Neo-adjuvant or adjuvant	109 (69.4)
	Used CM	85 (53.5)
Prior CM use for non-cancer-related outcomes	Did not use CM	74 (46.5)
	Used CM	93 (58.5)
OCIC <sup>b</sup>	Did not use CM	66 (41.5)
	OCIC	141 (88.7)
	Non-OCIC	18 (11.3)

CM, complementary medicine; OCIC, optimal continuity of integrative care.

<sup>a</sup>See text.

<sup>b</sup>OCIC, attending  $\geq 5$  consecutive CM treatments, with intervals of  $\leq 30$  days.

chemotherapy side effects, or general QoL. Two examples are as follows: ‘All of the treatments helped me and improved the overall feeling after chemotherapy’ and ‘Acupuncture, nutrition and breathing techniques helped improve my general feeling. After each acupuncture treatment I felt much better for a day or two’.

Table 2 summarizes patients’ perceptions regarding CM effectiveness, with most patients believing CM treatments to have been helpful. We found no correlation between assessment of effectiveness and demographic data; medical-related parameters; prior CM use for cancer-related or non-cancer-related outcomes; adherence to CM treatments; optimal continuity of integrative care (OCIC) vs. non-OCIC; or the presence of specific concerns (gastrointestinal concerns, fatigue, pain, and emotional distress). Effectiveness of CM was rated from ‘effective’ to ‘very effective’ for the following concerns: emotional distress (70.6%), gastrointestinal and nutritional concerns (70.6%), fatigue (59%), and pain (59%). For example, ‘The treatments gave me a sense of hope... treatments did not help the hands, legs or weakness’. Nearly half of patients mentioned specific CM, which had helped:

Acupuncture was excellent for the chest pain and for breathing, and the pressure decreased. ... The addition of green salad and tahini, almond and nuts ... I was carefully following the hemoglobin level that was very important for me.

**Table 2.** Thematic framework (patient narratives) of effects and experience of CM treatments (N = 152)

Main themes	Themes	Sub-themes
The effects of treatments	Effectiveness	Effective to very effective (n = 98, 64.5%)
		Moderately or partially effective/not effective (n = 50, 32.9%)
		Not/slightly effective (n = 4, 2.6%)
	Distress	Psychological distress (n = 78, 51.3%)
Gastrointestinal concerns (n = 51, 33.6%)		
Fatigue (n = 39, 25.7%)		
Pain (n = 39, 25.7%)		
The entire course of treatment including the practitioners’ attitude (n = 130, 85.5%)		
The experience of care	Practitioners’ attitude	Specific technique (n = 83, 54.6%)
		Togetherness (n = 16, 10.5%)
		Uniqueness (n = 8, 5.3%)
	The impact of practitioners’ attitude	Internal process (n = 9, 5.9%)
		Sense of confidence (n = 8, 5.3%)
		Gaining perspective (n = 9, 5.9%)
		Emotional resilience and empowerment (n = 34, 22.4%)
		Activity (n = 18, 11.8%)
		Personal journey (n = 1, 0.7%)

### Qualitative theme analysis: the experience of care

No correlation between patients’ assessment of effectiveness of CM and demographic, cultural, and disease-related characteristics with adherence to treatment was found. Nearly half of patients (44.1%) mentioned the CM practitioners’ humanistic attitude and its effect:

...the meetings brought some energy... the supportive care helped me and gave me strength that I did not think I had. I cannot point to a specific treatment... the combination of relaxation and the warm and relaxing touch strengthened my spirit. I feel that I will find a way to cope with whatever challenges may come.

Patients wrote about how the CM practitioners contributed to their sense of not being alone in their battle with illness, a concept of ‘togetherness’. They described the warm, empathic, and encouraging attitude of the staff, which ‘... granted emotional support’. One patient mentioned an ‘attentive, sensitive ear’ and ‘a feeling like in a family, a place to be supported’.

The sense of ‘togetherness’ was also described by patients participating in the cuisine workshops:

The workshop gave me the opportunity to meet other women and spend time with them... to be exposed to the personal stories of other women in my situation, whom I had not met until then. This was very important... though not my goal when I decided to join the workshop.

Patients described feeling *being treated as a unique person* by the healthcare professionals at the integrative medicine service. ‘.... The most significant thing was the feeling that I’m being treated and even nurtured—they listened to me, I was no longer a patient, I was a flower’. ‘With time and patience they listened to me as a person with feelings and emotions, and not just as a number’. ‘They speak to me—not to the person standing over my head’.

The CM practitioners *invoked an internal process*, reflected by the use of CM-related terms such as ‘an improved inner feeling’; ‘a sense of confidence, of internal care’; ‘inner reflection’; and ‘internal connection’. One patient noted that ‘breathing training helped me to relax, to be aware of myself, to be more attentive to my body and work on it. I got to know myself better’. Another said, ‘Thanks to our meetings, I discovered the powerful forces that exist within me’.

Another theme that arose was *gaining a sense of confidence*. ‘Talks with the spirituality-trained practitioner, spiritual support and guided imagery were very helpful. It affected my mood, gave me more confidence. I became very strong’.

The CM practitioners also helped patients *gain perspective*, proportionality, and a sense of control of their

situation. The meetings gave 'a different perspective on my illness'; also, 'I think all the treatments I went through were necessary to make me feel proportionate'. One patient learned to take control over pain and emotions:

I must say that after the meetings I feel much more optimistic that I will get better and be healthy. I also learned to control pain through the way I look at pain. Guided imagery also improved my personal control of feelings. Actually I received training for life.

The word 'strengthen' featured prominently in the narratives, reflecting empowerment and transformation from passive to active role. Many patients used the terms 'strengthen' or 'gaining powers' in both a general sense and a physical sense.

... about acupuncture...there is something very comforting in knowing that the body is so weak and exhausted...and to know that there is something that strengthens the whole system, as well as the soul Treatment gave me a feeling that I am physically stronger, perhaps more power, faith and caring.

Patients described gaining *a sense of agency*: no longer seeing themselves as merely passive or controlled participants, but rather with some freedom of action, within the limits of their disease. For many, CM treatments helped improve them physically and to become more active in daily life and in treating symptoms. The CM treatments helped ameliorate patients' physical condition and enabled them to be more active, as in the case of the patient who wrote: 'you are helping me... I'm walking better... because of acupuncture. Kitchen workshops gave me independence; I run my hands, before I sat like a dummy in a wheelchair'.

Patient narratives did not refer to the past or the future, or express *a sense of continuity*, choosing instead to focus entirely on the present. The one patient to address his past and future wrote:

... I actually received training on how to look at life and I see that I did not have such a bad life. I had also moments that were not easy, but in general I love life.

## Discussion and conclusions

Our analysis of patient narratives, treated in an integrative oncology setting, advances an understanding of patient's experience of care. As Black and Jenkinson suggest, this enabled us to 'capture the patients' perspective' [18], providing unique information and insight into healthcare outcomes and the experience of humanistic care. Within theoretically competing models of contextual and medical

psychotherapy [24], our findings suggest that both specific effects (differential aspects that distinguish a particular treatment) and non-specific effects (common factors that underlie all psychotherapies) are important. Although PROs focus primarily on effectiveness, the dimension of experience should be considered as well. As Black has asserted, the impact of patients' experience of care, rendered with a human touch, is taken into account but still requires further investigation [25].

A dominant theme arising from patients' narratives was how CM treatments 'humanize' oncology care. In severe illness, patients tend to feel dehumanized and cut off by conventional medical culture, alien to a sense of everyday belonging [23]. The sense of togetherness in the complementary-integrative center; the experience of empathy and emotional support; an attentive, sensitive ear; and the advice and guidance given helped patients feel they were not alone in their struggle. To be human is to actualize a self that is unique and can never be reduced to a list of general attributes and characteristics [23]. Experiences of empathy, emotional support, togetherness, and being treated as a unique person may generate internal processes. Instead of viewing themselves as passive recipients of illness and treatment, patients gain a sense of participating in the healing process.

This study presents an opportunity to examine PROs assessment in the general medical setting. Short narratives can be collated in electronic medical records and analyzed for both clinical practice and outcome research. Assessment using short narratives has several advantages and disadvantages. Although they may not engender profound perspectives as extensive interviews or focus groups, short narratives are more manageable and can be integrated into electronic records, offering a broad perspective on select patient populations. Both quantitative and qualitative methods can be used for analysis, although the need to interpret the narratives presents certain challenges.

By highlighting issues that are important to patients, findings extracted from the analysis of short narratives can be used as a basis for developing study questionnaires. The study of Corner *et al.* [21] showed how emerging themes complement formal PROs, providing insight into QoL-related issues for cancer survivors. They found relationships explaining the significantly worse QoL-related outcomes in cancer patients. Information derived from PRO research can be useful for clinical decision making and improve health care [25].

The present research has several limitations. We analyzed only those narratives that were written by patients who attended the concluding IP evaluation. Our analysis is thus restricted to patients who remained throughout the integrative treatment program or who were able to attend the concluding IP assessment despite the challenges of their illness and treatment. It is therefore possible that although we found that the majority of patients felt that

CM treatments were helpful, a larger proportion of those who did not attend the session would have reported that they were not. And although we attempted to monitor perspectives of non-adherent patients using telephone interviews, the resulting qualitative data were poor. This may be resolved in future studies through the use of trained oncologists, nurses, or psycho-oncologists who can administer follow-up MYCaW questionnaires to patients at the time of treatment.

We were unable to reach an understanding of the relationship between patient experience and outcomes. Although our findings suggest a link, it is not clear whether a good experience increases the likelihood of reporting a good outcome, or vice versa. Understanding such a relationship is important for interpreting outcomes and experiences [18]. Future qualitative research will need to compare patients' satisfaction from CM addressing non-specific effects (e.g., the holistic attitude of the

CM practitioner) with assessment of specific effects of the intervention.

In conclusion, we examined the impact of a CM consultation and treatment program for cancer patients using short patient narratives with a validated PRO tool (the MYCaW). Our findings help advance an understanding of the effectiveness of CM on non-specific treatment outcomes and promotion of QoL-related parameters. Non-specific effects of integrative treatment are at the heart of supportive cancer care, enhancing patient-centered care and providing a holistic, bio-psycho-social-spiritual outlook. Clinical studies examining specific effects of CM can support these findings, and it is our hope that our findings will encourage further research within the broader psycho-oncology context. CM treatments, when administered within the context of integrative oncology, can present a meaningful modality enhancing QoL and encouraging collaboration between disciplines and promoting psycho-oncology care.

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