

Individualized Integrative Cancer Care in Anthroposophic Medicine: A Qualitative Study of the Concepts and Procedures of Expert Doctors

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Abstract

Background. Cancer patients widely seek integrative oncology which embraces a wide variety of treatments and system approaches. **Objective.** To investigate the concepts, therapeutic goals, procedures, and working conditions of integrative oncology doctors in the field of anthroposophic medicine. **Methods.** This qualitative study was based on in-depth interviews with 35 highly experienced doctors working in hospitals and office-based practices in Germany and other countries. Structured qualitative content analysis was applied to examine the data. **Results.** The doctors integrated conventional and holistic cancer concepts. Their treatments aimed at both tumor and symptom control and at strengthening the patient on different levels: living with the disease, overcoming the disease, enabling emotional and cognitive development, and addressing spiritual or transcendental issues according to the patient's wishes and initiatives. Therapeutic procedures were conventional anticancer and symptom-relieving treatments, herbal and mineral remedies, mistletoe therapy, art therapies, massages and other external applications, nutrition and lifestyle advice, psychological support, and multiple forms of empowerment. The approach emphasised good patient-doctor relationships and sufficient time for patient encounters and decision-making. Individualization appeared in several dimensions and was interwoven with standards and mindlines. The doctors often worked in teams and cooperated with other cancer care-related specialists. **Conclusion.** Integrative cancer care pursues an individualized and patient-centered approach, encompassing conventional and multimodal complementary interventions, and addressing, along with physical and functional needs, the emotional and spiritual needs of patients. This seems to be important for tumor and symptom control, and addresses major challenges and important goals of modern cancer care.

Keywords

integrated oncology, patient-centered care, clinical reasoning, qualitative study, doctors, individualized medicine, integrative medicine

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Introduction

The global burden of cancer is increasing and is now the leading cause of death in Western countries.¹ About half of all cancer patients in Europe and North America use integrative cancer care (ICC).²⁻⁶ This umbrella term encompasses the use of both conventional and complementary and alternative methods (CAM), integrating them with an emphasis on *the natural healing power of the organism* and on *whole person medicine*, which includes mental, emotional, spiritual, and social factors; on *lifestyle* factors, such as diet, physical activity, rest, sleep, relationships, and work; the *doctor-patient relation* as a partnership; and inter-professional collaboration.⁷⁻⁹

One health care approach to providing ICC is anthroposophic medicine (AM),^{10,11} practiced in about 80 countries worldwide, with the widest distribution in Europe and South America. AM cancer care is practiced in specialized cancer centers, hospitals, outpatient settings, and private practices.

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It integrates conventional cancer treatment with AM medications, such as mistletoe therapy (MT), art therapy, eurythmy therapy, body-based treatments, nursing care, intensive counseling, and psychotherapy. The approach is individualized and encompasses spiritual aspects.^{10,12}

ICC, particularly in AM, is a patient-centered approach.^{8,13} Patient-centered care is a widely recognized central goal in health care and evidence-based medicine (EBM),^{13,14} integrating clinical expertise and patient values along with best external evidence.¹⁵ Particularly with respect to chronic illnesses, patients have an increasing role in self-managing their disease, including symptoms, treatments, appointments, decision-making, problem-solving, lifestyle changes, and dealing with the social, psychosocial, and existential consequences.¹⁶⁻¹⁸ In recent decades, EBM has been dominated by the accumulation of experimental evidence, whereas clinical expertise and patients' values have received little attention in regard to research, guidelines, and policy-making. This has created a "crisis" in EBM.^{14,19} Accordingly, the research agenda should be broadened to cover patients' values and experiences, real-life clinical encounters, the various elements of good illness management, and the development of a better understanding of the less algorithmic components of clinical methods such as intuition and heuristic reasoning.¹⁴ Therefore, observational studies, qualitative research, and whole system research are recommended to complement the results of clinical trials.²⁰

Regarding ICC, a substantial body of research has been conducted in recent decades; about 7800 citations referring to randomized controlled trials on CAM in cancer are indexed in the major medical databases PubMed and Medline (accessed August 12, 2015). Conducted clinical trials focus mostly on single or a few interventions. AM health care and some of its components have also been assessed in clinical trials²¹⁻²⁵ and some global effectiveness studies.²⁶⁻³⁰ ICC and AM imply system approaches and interventions that are individually tailored to the patients' specific conditions and needs—a therapeutic landscape that is largely unknown to researchers and the general medical public.²⁰ In order to achieve transparent insights, we therefore designed a qualitative study to investigate the concepts and procedures of ICC as practiced by expert AM physicians. The study was part of a larger qualitative research program, and analyses of other parts of this program have been or will be published elsewhere (and are partly referenced in the Results section).

The research questions were the following:

1. How are cancer patients cared for within the integrative care setting?
2. What are the underlying concepts and therapeutic goals?
3. What are the procedures?
4. How do expert physicians approach and assess cancer patients and which issues are important?

5. In what way is this treatment approach individualized and what does this mean?
6. What are the organizational working conditions?

Methods

Design

We conducted a qualitative study, using semistructured, in-depth interviews with doctors highly experienced in AM and ICC, with the aim of assessing their concepts, procedures, experiences, and observations.³¹⁻³³ Data analysis was a multistep process, using a deductive-inductive categorizing system based on structured qualitative content analysis.^{33,34} The study was approved by the Ethics Committee of the University of Freiburg.

Recruitment and Setting

Participants were purposively sampled.^{35,36} We recruited doctors who worked in the field of AM and ICC. Participants were recommended by other physicians or were accessed via the literature. The criteria for selecting the interviewees were, for example, to cover a broad spectrum of different AM/ICC therapy approaches, to achieve this over varied areas of medical specializations within different treatment contexts (eg, hospital or office-based practice, palliative or curative patients, specialized vs primary care, etc), and to take into account physicians' ages and countries. Doctors were contacted and offered information about the study aims and interview duration, and they were asked to prepare a presentation of 1 or 2 examples of oncological treatment cases.

Interviews

Two different researchers (GSK and MM) interviewed the doctors between 2009 and 2012. GSK is a medical doctor and researcher and is well known in the field of AM cancer care; MM is a psychologist and researcher. All interviews were conducted face-to-face. Anonymity and confidentiality were ensured, enabling open communication. Most interviews took place in the work setting of the respective doctors; a few were conducted at the research institute or within the context of a congress. All doctors consented to digital audio recording, except one, whose interview was recorded as field notes.

All interviews started with a warm-up question. Subsequently, the doctors were asked to describe 1 or 2 case examples to give an uninfluenced account of their procedures, concepts, and observations. An interview guideline had been constructed with input from the literature and external experts and was used to follow-up on topics and give prompts.³⁷ The topics covered patient assessments, decision-making, treatment approaches, choosing MT and

other therapies, monitoring, individual adjustments, treatment goals, specific constellations, symptoms and complaints in cancer disease, psychological and spiritual issues, safety factors, and new insights. To differentiate between concepts, procedures, and observations, doctors were often asked to concretize their answers and to illustrate them with case examples throughout the interview. At the end, the interviewees were asked to fill out a form with their sociodemographic information. All interviews were transcribed by staff members of the research institute according to the approach of Kuckartz.³⁸ The interviews were finally sent to the participants for member validation.^{35,37}

Data collection was terminated after 35 interviews because no new areas of information could be disclosed and no new properties of categories were identified in respect to the research question.³⁵

Analysis

To analyze the data, we used structured qualitative content analysis,^{31,33} combined with techniques of thematic framework approach.³⁵ Structured content analysis combines deductive application of categories with an inductive open process to find new categories, themes, and interpretations. With this systematic and iterative, constant comparative method, concepts and procedures can be identified. Throughout this process, contextual influences are continuously taken into account.³⁹

Data analysis was predominantly done by GSK and MM, using MAXQDA computer software⁴⁰ as a support for data management. Two more researchers took part in team meetings to enhance validity (HK, researcher and medical doctor; DF, psychologist and experienced qualitative researcher). The analysis was done in close exchange between the researchers, and the steps of analysis were documented.

In the first step, we read the interviews and applied codes from the guideline categories, also noting new codes (open coding).³¹ Second, domains for data extraction and further analyses were defined and extracted for each doctor. Several of the interviewees had published articles or books, which served as an additional source of information (explication). The categories were further refined, reviewed, and discussed by at least 2 researchers. The following themes were isolated: patient assessment, the role of conventional therapies, use of further complementary medical or CAM treatments, psychological and emotional care, self-help, how doctors follow-up on treatment or cooperate with other doctors, and their sources of knowledge. When preparing the charts, original quotations of the participants were referred to and words and phrases from the participants' own language were used when summarizing the core meanings in order to ground the themes in the data.³⁵ Data analysis then focused on issues specifically related to the individualization of the treatment process. This included searching the data for the term

"individual" and related expressions, and analysis of the actual procedures carried out by of the doctors with respect to individualization. The emerging dimensions of the doctors' individualized approaches related to (1) disease, condition, treatment focus; (2) patient; (3) doctor; and (4) therapy. In the final analysis, the underlying concepts and treatment goals of the doctors were examined and discussed by the research team (triangulation of researchers) and were checked using the case examples from the interviews (data triangulation).

For triangulation, we undertook a number of measures: comparison of the interview data with all quantitative and qualitative studies investigating patients' perspectives on AM and MT, with a HTA report on AM^{23,24} and its included original investigations; reading patients charts, contacting patients, and attending physicians for publishing case reports; visiting working places and websites of the doctors; attending patient consultations with one doctor; discussing doctors' topics with colleagues and other health care providers; attended doctors' conferences and working groups. In rare instances, where parts of the interviews were contradicted by these additional sources, these conflicting data (dealing with a presumed tumor remission in certain patients) were then not presented.

To increase the validity, participating doctors received the interview transcripts and the final analysis results before publication. The results contained anonymized codes instead of names, so that the doctors could revise them. These codes were removed before publication.

Results

The Sample

Thirty-five doctors were interviewed, each for between 100 and 297 (mean 171) minutes. Their characteristics are shown in Table 1. Ten further interviews could not be conducted due to organizational problems (2), no response to invitation (4), illness (1), and unease with respect to presenting therapeutic intimacies in public (3). The doctors illustrated their procedures, observations, and experiences using 350 case examples, which were supplemented with publications.

Concepts of Cancer Disease and Treatment

The interviewed doctors perceived the human organism, cancer disease, and treatment simultaneously through 2 complementary concepts (see Figure 1), the first being common medical concepts in terms of tumor biology and cancer as a local disease, leading to the therapeutic concepts of tumor eradication; and the second comprising the complementary holistic concept of the organism, which was hierarchically structured into the physical, etherical, emotional,

Table 1. Sample Characteristics: Doctors Using Mistletoe Therapy and Integrative Cancer Care.

	Number	Years, Median (Range)
Doctors	35	
Men	30	
Women	5	
Age (years)		55 (40-84)
Specialty of doctor ^a		
Oncology, hematology	8	
Internal medicine, pulmonology, or gastroenterology	17	
General practitioner	12	
Pediatrician	3	
Gynecology	1	
Neurology	1	
Research doctor	1	
Work experience as a physician		26 (11-57)
Cancer patients treated with ME/year: median (range)	270 (13-1000)	
Setting		
Hospital or outpatient clinic	21	
Resident doctor	14	
Working in or collaborating with cancer centers	35	
Country of workplace		
Germany	22	
Switzerland	6	
England, France, Sweden, Italy, Czech Republic, Egypt, Peru	One from each country	

^aSome doctors have several specialties and are mentioned twice.

and cognitive levels and differentiated into 3 systems, namely, the nerve-sense, metabolic-limb, and rhythmical systems, which were then further differentiated into organ “processes” or “functions,” such as “liver function.” The doctors perceived the whole organism as affected by cancer and influencing cancer growth and control. Two mediating concepts were tumor immunology, with fever as a key therapeutic element, and mind-body interaction, whereby emotional and cognitive well-being support healing and cancer control at the physical level. Therefore, treatment on the emotional and cognitive levels was seen to not only provide a humane therapeutic background but was also considered essential for disease outcomes. Among these overall cancer concepts, the specific conceptual foci, scientific interests, and expertise varied between the doctors.

Therapeutic concepts such as tumor eradication and symptom control were extended by the goals of strengthening the different levels of vitality, emotion, and cognition.

These goals can be summarized by the overall concepts of living with the disease, overcoming disease physically and mentally, enabling emotional and cognitive development, and strengthening of the human being (if not possible physically, then emotionally and cognitively), which was considered of high value even if the patient ultimately dies. The inclusion of spiritual and/or transcendental issues was dependent on the patients’ wishes and initiatives. The doctors used methods of empowerment (eg, psychological support, thoroughly informing on disease and treatment, support of self-management and autonomy) and preferred activity-inducing treatments, natural medicines, nonpharmacological interventions, and self-help, and they drew on the patients’ resources and creativity using the medium of art.

Individualization Arises in Various Dimensions

Explicitly and implicitly, ICC was individualized in regard to its following dimensions.

Regarding Disease, Condition, Treatment Focus. Individualization of treatment depended on the condition and treatment focus. Specific diseases and symptoms, particularly when uncomplicated or when curable, were primarily treated according to standards; these could be standards of the medical society (eg, oncologists), the specific medical society (eg, AM doctors), specific groups (eg, AM doctors in hospitals), or individual doctors (mindlines). Incurable or resistant disease, increasing complexity, or concomitant diseases prompted individualization. Other reasons for individualization included the simultaneous interpretation of a disease with different pathophysiological concepts (eg, cancer biology, immunology, and organismic level), as well as addressing the whole situation of the patient with a consistent holistic treatment approach. In incurable cancer, the treatments were individualized and depended on the specific condition, symptoms, their evolution over time, and the goals of the patient. This referred not only to AM

For instance in CLL, there I have patients, the blood counts are completely stable, but fatigue is the problem. And then I do not orient my MT on stabilizing the blood . . . the treatment success in this case is that fatigue improves. (Oncologist)

but also to chemo- and radiotherapy (“ . . . these individual disease constellations and the questions arising from it cannot be answered by trial results at all. At least not in palliative oncology. This is highly individual . . .” [Oncologist]).

Positive therapeutic goals and strengthening healthy capacities were addressed individually, and so was the emotional, cognitive, and spiritual focus: “Together with the patient establish an individual health concept . . . strengthen their capacities, their inner resilience . . . a crucial concept” (Internist).

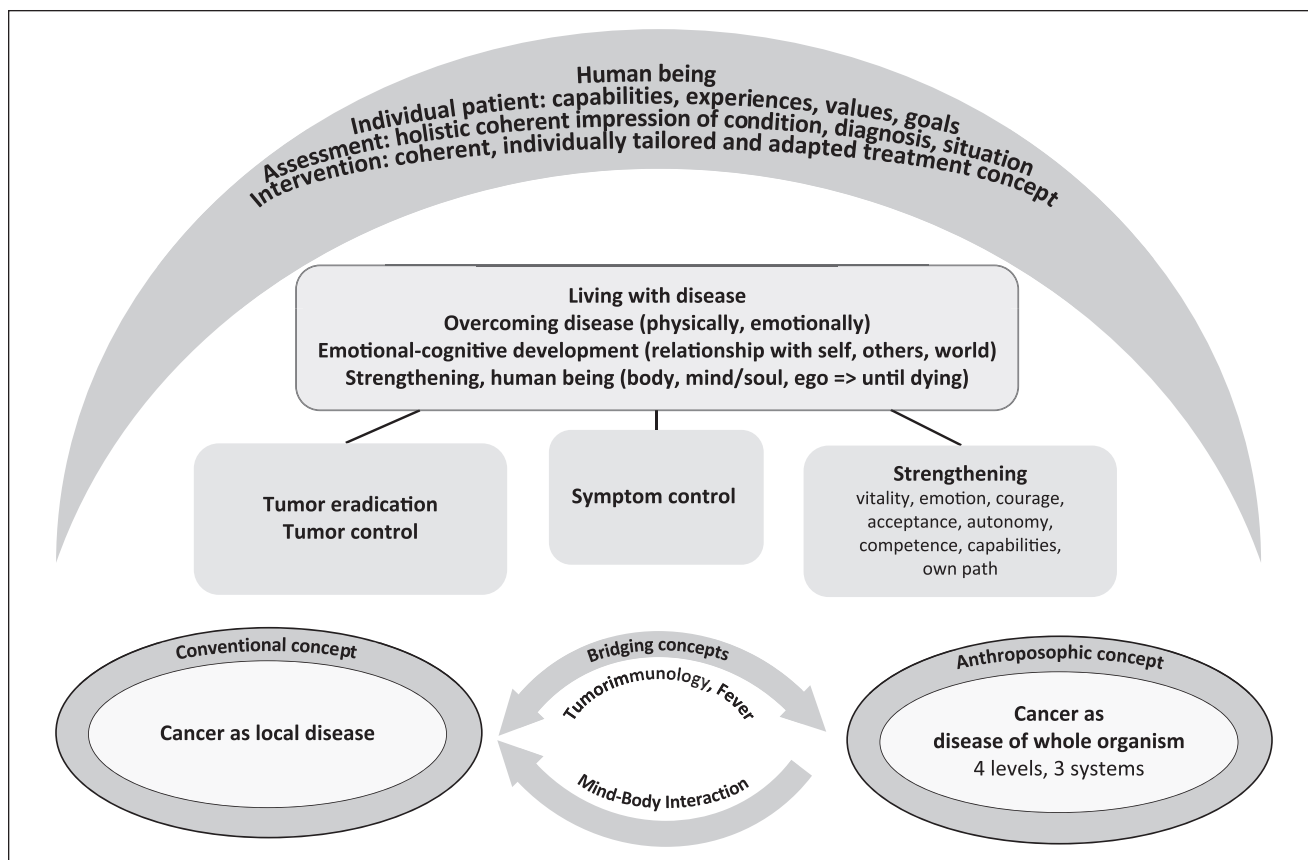


Figure 1. Concepts of cancer disease and treatment, and patient assessment determining the interviewed doctors’ integrative cancer care practice.

Regarding the Patients. The extent of individualization depended on the situation, goal, and activity of the patients. Doctors emphasized a patient-centered approach: “One has to start from the individual patient, individual parameters, needs; there is no standard program” (General practitioner). This approach was based on an in-depth knowledge of the patient (“That we recognize the patient in his individuality” [Oncologist]). It referred to informing and shared decision-making, to addressing the mental and spiritual level (“What individualizes and forms a human being are our mental and spiritual forces . . .” [Gastroenterologist]) and to tailoring the whole treatment concept to the patient’s condition, constitution, needs, and values:

There are many things that patients bring with them . . . what is their concept and to start from there, where the patient really stands . . . which ideas does the patient have about what is good for him/her and how can he/she build up his/her health further. (Internist)

While this still included standard anticancer treatments, some of the patients sought their own way beyond these standards. In order to prevent them from making decisions

they may later regret, to find their inner goals, and to find an individual solution, a trusting, face-level relationship and an engagement on a personal level was pursued, which may integrate discussions of issues that are important to the patient such as literature, history, politics, and so on. For instance, some patients were not afraid of death but rather of losing certain sensibilities or fine cognitive functions:

For instance a patient with advanced esophagus carcinoma wished to write several publications; he had a spiritual orientation and rejected chemotherapy because he feared cognitive impairments and emotional constraints; with regular intralesional mistletoe extract injections the esophageal stenosis reopened, the patient could eat and kept well for a substantial time with a good QoL and pursued his writing and publishing activities. (Gastroenterologist)

Other patients did not accept functional losses due to extensive resection (such as partial resection of the hard palate in an 88 year old man⁴¹), or did not accept the complete loss of sexual function.

Sometimes the patient even took over most of the treatment themselves: For example,

Mrs. . . . died a few weeks ago, from her advanced hepatocellular carcinoma. . . . About 15 years ago . . . in the morning of her scheduled liver transplantation she jumped out of bed and said: I won't do this. Since then she has more or less just injected mistletoe, except a pre-operative vasoligation. Summing it up, the tumor completely regressed . . . she lived her life . . . about four or five years ago she had a recurrence or a new HCC . . . With her, we have this aspect of individualized treatment, . . . it was difficult to capture this . . . I had asked her, when did you take ME? . . . She told: "yes, sometimes I do it regularly, but then I pause . . . If I awake in the morning and feel frightened. I am frightened that the world will collapse upon me, or the tumor will win again. Then I . . . take mistletoe and subsequently I feel tremendously good. . . . And when . . . I freeze. Sometimes I don't freeze at all for weeks and sometimes I freeze in the morning, at noon, in the evening. Then I inject my mistletoe." . . . The special feature was . . . and nobody had taught her . . ., pay attention to your inner voice and do this and that and then take this, but she made the experience herself . . . (Gastroenterologist)

Regarding the Doctors. Individualization also depended on the attitude, expertise, and clinical reasoning of the doctor and touched the core of the professional self-understanding. Doctors' decisions were usually based on standards and scientific data; knowing them was considered to be indispensable. In addition, the doctors developed their own standards in areas where official standards did not exist, where they were insufficient or incommensurate, or they observed good effectiveness or good practicability. At the beginning of a doctor's career, the focus on standards was stronger. As the doctors' experience and expertise grew, they developed their own standards, increased their individual decision-making capacity, and adapted more to the individual patient ("over time trust in the individual, the patient grows" [Oncologist]). Acting according to the specific situation was regarded as important, but to be more difficult, necessitating more expertise.

. . . guideline medicine is very easy. One just has to know the data and then you say: in your case this and that is recommended. This is very simple. The question is only, whether this is always true in every situation. (Gastroenterologist)

Guidelines would not "release from the obligation" to proceed individually.

Intuition was regarded as a crucial element for handling individual disease constellations.

At the moment, when it is individual, it is always intuitive. . . . Metastasized breast cancer . . . ten drugs available . . . which one to choose? . . . Matter of experience . . . look at your vis-à-vis . . . well, we then enter highly individual trade-off aspects. (Oncologist).

Good decision making was described as an interplay of theoretical concepts, empirical data, personal experience, and a "subjective medical competence":

I believe that I comply with a standard which I have arranged for me or discussed with my colleagues. And, on the other side, I do it to some extent irrational . . . sometimes I sit in front of a patient and . . . I don't really know what I should actually do . . . then I trust in some way on the sum of my subjective experiences. . . . And I could not really say what the ratio is. This is actually completely awful, terribly careless, yes? But there is something else in the game. When one can open oneself to this process, then one can evolve this process to a method, . . . actually the method of medicine. . . . I know good conventional doctors, who in principle do it exactly so, without being able to describe it, . . . my surgical colleague . . . on intensive care . . . shall I open this patient, shall I not . . .? Something else happens than a guideline of science-based medicine . . . something intuitive, not really sizable, something medical, where everything is condensed into a subjective competence of judgment, which, if it goes well, is the highest art, the center of good therapeutic art. (Gastroenterologist)

Regarding Therapy. The decisions for conventional anticancer treatments and the modes of their application were described as highly standardized, with individual adaptations in cases of increased risks of side effects, decreased expectations of benefits, or if applied for strictly symptom-relieving purposes. Regarding MT, the decision and their general mode of application were also standard in the sample of interviewed doctors, with additional apparent substandards. Depending on the treatment response, course of disease, and evolving therapeutic goal, MT was increasingly individualized. Some of the individually chosen treatments (eg, intravenous MT) did follow substandards. When the organismic response was a therapeutic intent, MT was adapted accordingly:

. . . I have to provoke a response, because it [MT] is a dual therapy that does not begin linearly, in order to generate a change in a target cell. Instead, the organism should respond and bring itself into a new form, in order to offer opposition to the disease . . . (Oncologist)

Furthermore, treatments were often varied over time to achieve organismic or emotional responsiveness: ". . . I generally tend not to treat nonstop . . . and to always keep the same dose. Like a plank in the wind. But rather . . . something permeable, something fluctuating . . ." (Gastroenterologist). Other treatments, such as medicines, creative therapies, eurythmy therapy, external medical applications, psychosocial help, and counseling, were considered the core of individualized medicine.

Integrative Cancer Care Procedures

Comprehensive Patient Assessment by the Doctors. Assessment was often comprehensive (Figure 2). The doctors strived to develop a holistic, coherent impression of the patients ("capturing and seeing the whole person" [Oncologist]). One

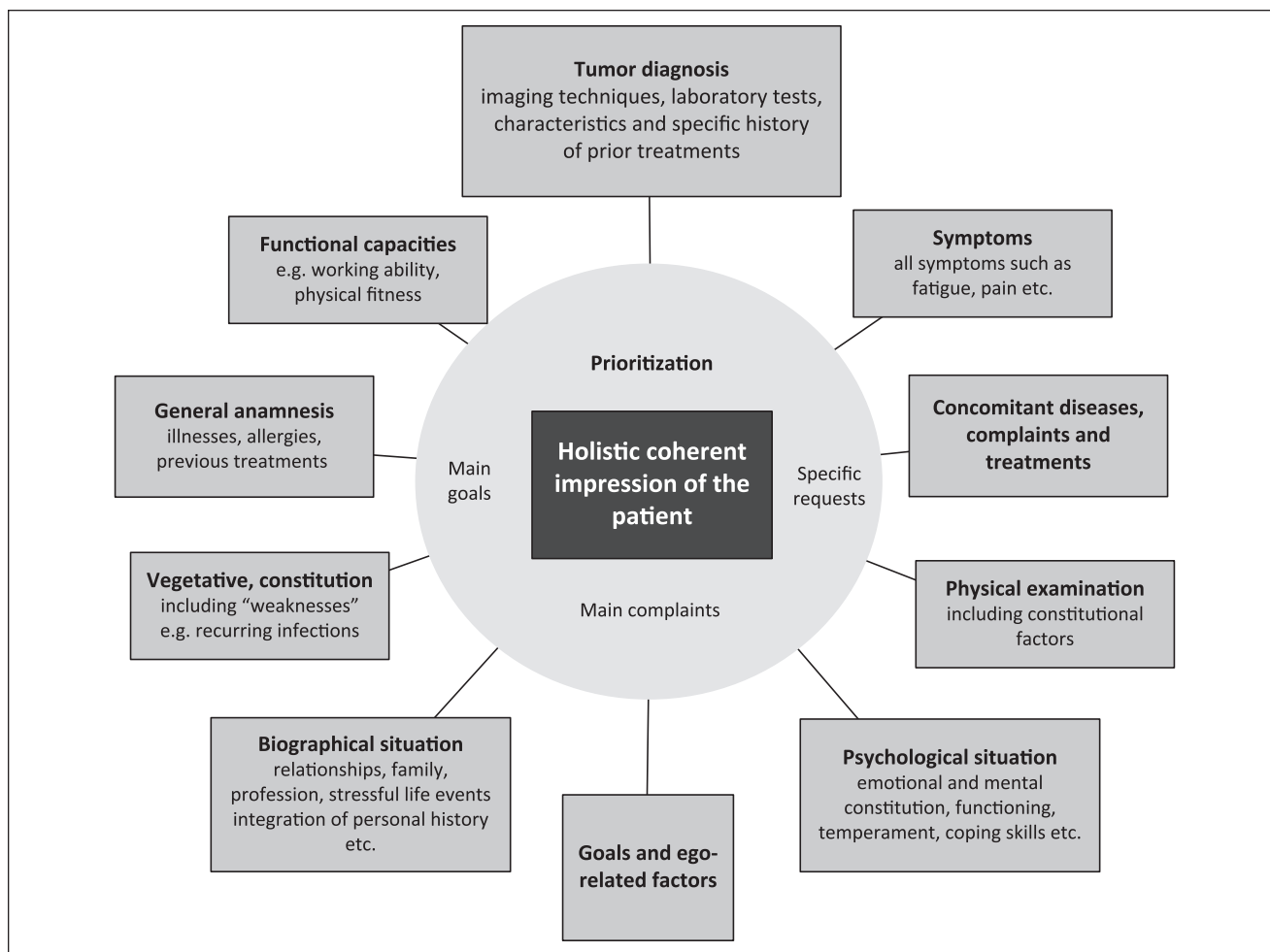


Figure 2. Patient assessment in the interviewed doctors' integrative cancer care practice.

doctor, for instance, stated that he carried out three 1-hour consultations with each patient: first assessing the present values and disease-specific information followed by a complete physical examination and perception of the patient's constitution, and finally a thorough examination of the original tumor histology and discussions with the pathologist. Some doctors stated that they had special team meetings with doctors, nurses, art therapists, and others, with all contributing information on the history and condition of the patient.

All doctors assessed the tumor diagnosis and its characteristics, including site (organ, growing centrally or peripherally, in gastrointestinal or neural organs, localized or disseminated, location of metastases), pathology, and stage. The primary diagnosis was either made by the interviewed doctors or had been made before. Previous cancer treatments, tumor response, and side effects were registered, along with the patient's well-being, symptoms, functional abilities, and other disease-related conditions.

The doctors also focused on general and vegetative anamnesis ("from birth until . . ." [Oncologist]) as well as

concomitant diseases, often differentiating diseases into "inflammatory" or "sclerotic," to get an impression of the patient's constitution, "What dominates in this patient" (Oncologist). Physical examinations included constitutional factors such as warmth, skin color, and turgor (eg, "rather delicate or rather with an emphasized metabolic side; delicate and permeable or vigorous . . ." [Oncologist]).

Emotional and biographic issues were also assessed, including social integration, emotional balance, resilience, feeling of exposure or protection, ability to set boundaries, important positive and negative life events ("darknesses in life"), sense of life, disease coping, and whether a religious orientation helps in coping and conveys a sense of safety and trust in life. Emotional anamnesis was correlated with disease and vegetative anamnesis. Also of importance were strengths, capabilities, values, interests, hobbies, and personality traits.

When cancer recurred or progressed after a long period of control, or when the therapeutic process did not bring the expected results, the extensive assessment would often be

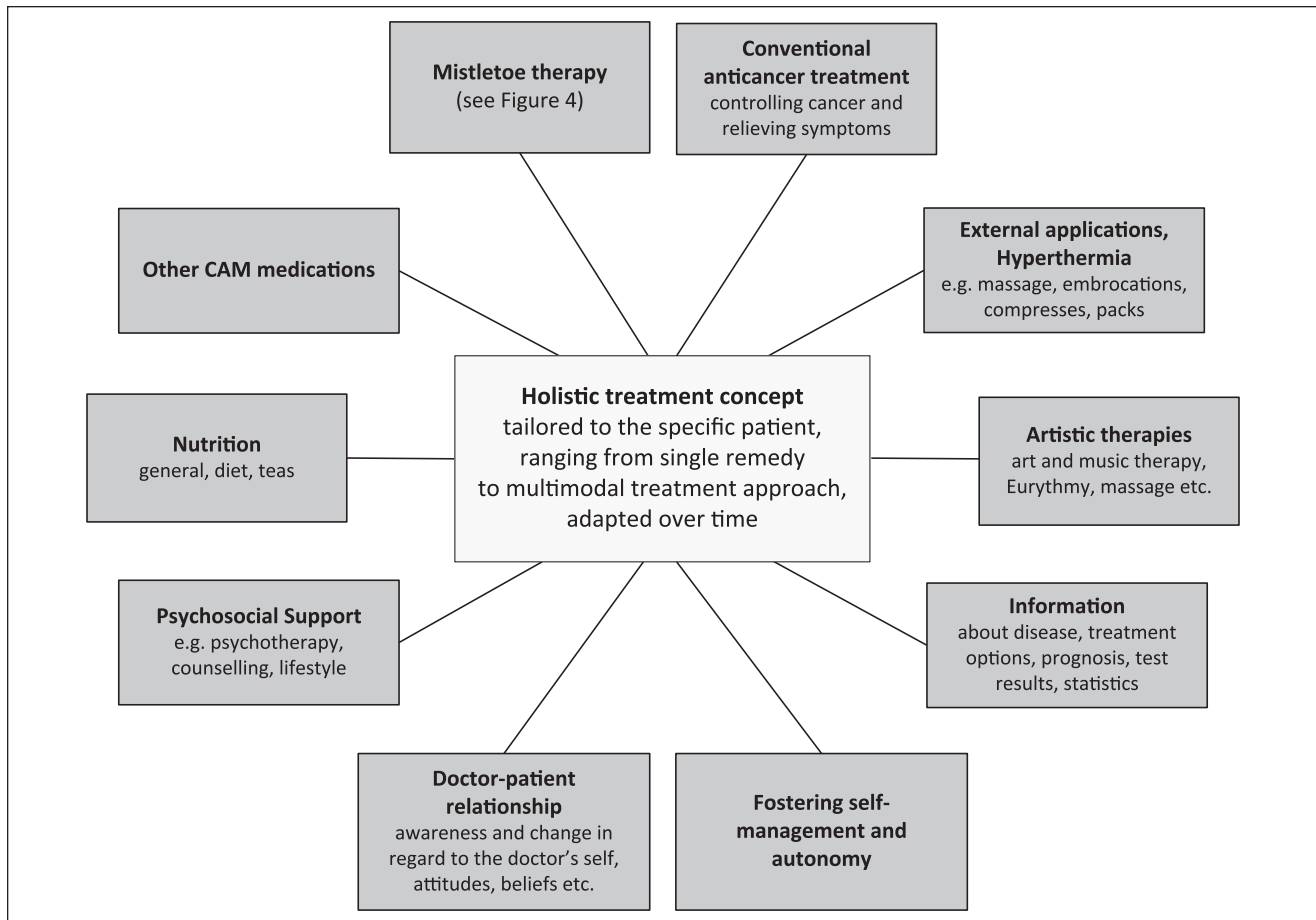


Figure 3. Integrative cancer care practiced by the interviewed doctors.

repeated. The intensity of the follow-up differed according to the situation. For instance,

The patient or family calls three times per week in the beginning, . . . every 2 weeks or monthly, or if he is well, every two or three months. . . . We always have to know, how does it go with our patients. (General practitioner, South America)

Multimodal Interventions Used for the Individual Holistic Treatment Approach. The primary intention was developing a good relationship with the patient: “If I would rank on a scale . . . of utmost importance . . . is tending the relationship. Yes, being clear, open, transparent, honest, empathic, etc” (Oncologist). A number of issues set the course for further decisions: the person as such, the diagnosis, a curative versus palliative situation, the patient’s specific request and whether the doctor is the primary treating doctor, the supplying of adjunct treatment, or the asking for advice. The complex assessment then developed into a holistic treatment concept, fitting this specific patient (Figure 3).

Conventional Anticancer Treatments. Patients, depending on the diagnosis, general condition, and therapeutic goal, were

primarily treated with conventional anticancer treatments, including surgery, chemotherapy, radiotherapy, endocrine therapies, and targeted therapies. The patient may already have finished, still be undergoing, approaching, or deciding on treatment. These treatments were integrated in the treatment concept and partly provided by the doctors or in their centers: “We are not alternative . . . we treat integratively . . . conventional successful treatments, complementing according to the individual situation of the patient” (Oncologist).

The necessity of these treatments was either obvious or assessed according to the individual case and discussed with the patients. For example, when their benefit was low, the toxicity high, or no standards existed (“There are cases, where no standard exists, . . . cases that were given up, or . . . just is no rational concept” [Pediatrician]), or when, in a palliative state, the tumor behavior was stable, the patients would often be treated with AM or CAM alone, with chemotherapy added only in rapidly progressing diseases or to control symptoms. For instance, a pulmonologist treated patients with stable pleura mesothelioma with ME and added chemotherapy when the disease progressed rapidly.

All of the doctors stated that they had been visited by patients refusing part or all of the standard treatment. If the expected benefits were high, the doctors mostly continued to advise them. If patients were emotionally upset, in a bad condition, or had unrealistic expectations of other approaches despite the available information, the doctors would attempt to stabilize them emotionally and strengthen them physically, postponing the decision on chemotherapy and potentially reaching a settlement. For instance,

A young man refused indicated surgery of his seminoma and insisted on sole MT; he agreed on a limited attempt of three months: if by then the tumor was not in clear remission, standard treatment would follow; he simply needed this time. (Oncologist)

Several patients were described as having improved in their physical and emotional condition with ICC, having built-up trust, confidence, and courage, and then accepting the standard treatment. On rare occasions, the doctors later regretted having pushed patients to receive chemotherapy. For example, for one patient with advanced lung cancer, chemotherapy had a substantial influence “on his inner emotional sensitivity, openness, transparency, affective and emotional resonance” (Pulmonologist). Alternatively, patients with unrealistic expectations of the CAM approaches, and who refused the standard anticancer treatments, were later sometimes highly upset when the cancer progressed.

In rare cases, well-informed patients clearly declined the standard treatment.

This has to be thoroughly discussed, one can do it with only a very few, who really want to go this way. Patients rarely have to sign something for me, but in this case they have to sign an informed consent. (Gynecologist)

Then it is an artistic act to find out: is it just aversion? . . . This is not a basis, not to use this treatment. Or is he so convinced that he says, I cannot look into the mirror, when I would accept this treatment; this does not fit me and I've thought about it well. I will do everything else, but this is out of question, I won't manage this. We have such patients . . . If this is well scrutinized, then one can go such an “alternative” way. (Oncologist)

For example, some older women with breast cancer who refused surgery, or who had severe concomitant diseases, received intratumoral MT often combined with endocrine treatment.

Mistletoe Treatment and AM Medications. Most patients received MT. The overall goal was tumor control, a stable condition, improvement of quality of life (QoL), symptom relief, and improved tolerability of conventional cancer treatment. The mode of application and adaption depended on a variety of factors (see Figure 4) and on the context of

the doctor. The individual adaptation was regarded as essential for its effectiveness: “And I believe this is how you can individually dose mistletoe treatment and apply it as individually indicated, with the greatest effectiveness possible” (Oncologist).

MT was usually applied subcutaneously. Other, mostly off-label applications were given for specific purposes. These included *intratumoural*, high-dose MT to stabilize the tumor disease and to induce tumor remission, for example, reopen a tumor-stenosis; *intravenous infusion* to increase effectiveness, to invigorate and strengthen patients in progressing disease, to support tumor control, to induce fever, to improve tolerability of chemotherapy, and to support recovery;⁴⁴ *intrapleural* to treat malignant effusion; in rare cases, *intraperitoneal* or *intrapericardial* (malignant effusion); *intravesical* (recurrent bladder cancer); *intrathecal* (brain tumor or metastases); *oral* (children, brain tumor, fear of injections); or as an *inhalation*.

MT was sometimes combined with hyperthermia to increase effectiveness,^{42,43} or combined or exchanged with Helleborus, for instance, in cases of severe B symptoms, tumor fever, excessive loss of body weight, exhaustion due to preceding chemotherapies, concentration difficulties after cranial irradiation, or lymphomas. Depending on the specific symptoms or conditions, or in order to support specific organ functions, a broad variety of other AM and CAM medications were added.

Art Therapies. Artistic creative activity was assumed to support development and learning processes better than words and to improve emotional and cognitive functions, such as finding meaning, purpose, and motivation; supporting emotional stabilization; and balancing the interplay of thinking, feeling, and willpower.

Painting with water colors, meeting colors and figures on an archaic level concerning intellect and willpower, but an intense basic experience regarding feeling. . . . Sculpturing with clay . . . bringing awareness of the willpower up to fingertips. (General practitioner)

Eurythmy therapy was also regarded as

rehabilitation in broad sense: it improves bodily problems, e.g. pains and stiffness after surgery or iatrogenic menopausal symptoms, and it improves the general well-being and self-awareness, the sense of courage and confidence, fights the feeling that body has betrayed me. (Oncologist)

Art therapies were also used to support other therapies, such as psychotherapy and MT, and to provide access to the spiritual side. Art was often taken up by the patients and continued at home, motivating and inspiring the patients by their newfound interest: “If patients take something along that they can develop—not just biologically, but in their

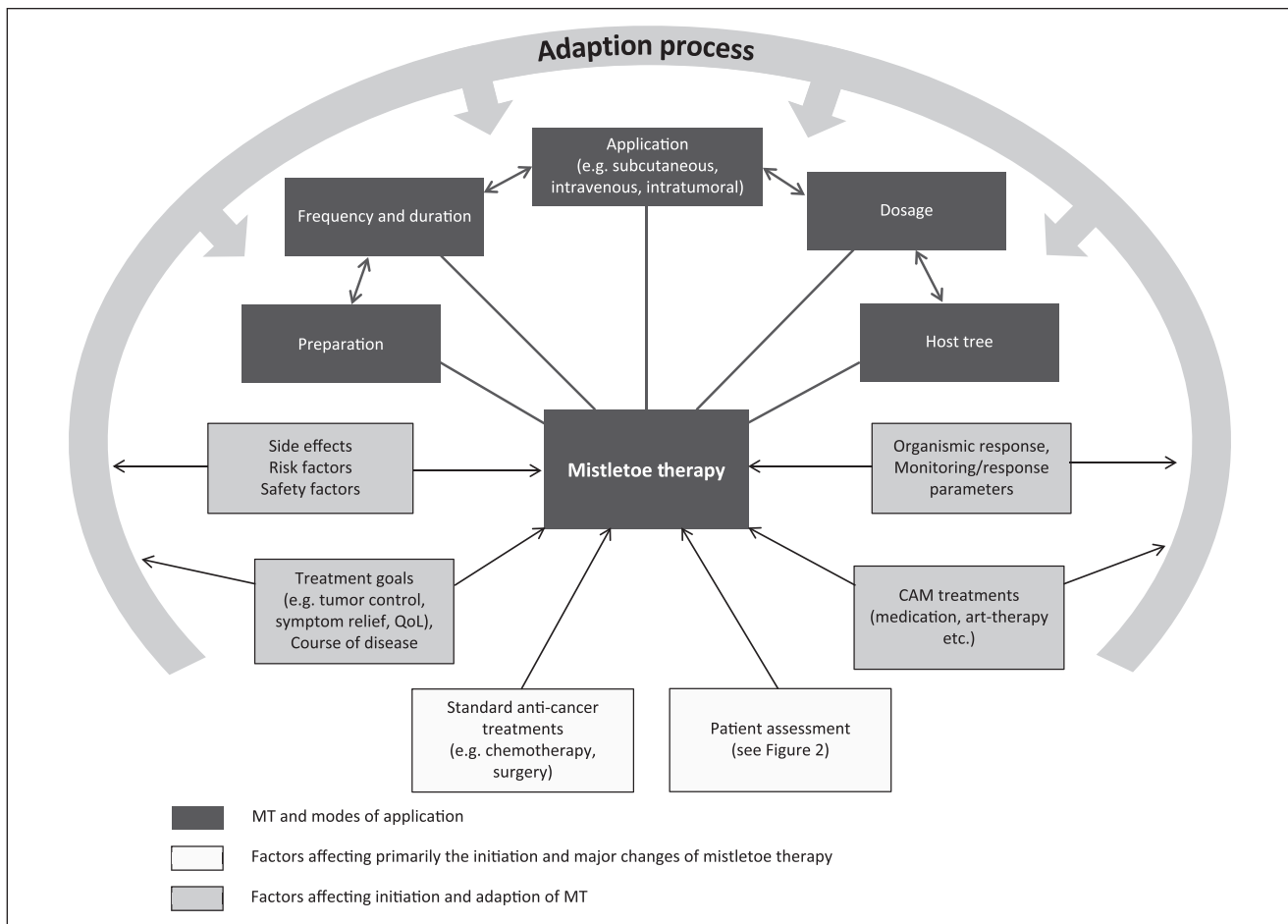


Figure 4. Factors affecting modes of mistletoe treatment.

personalities—and they are on their way, I believe this correlates with a better treatment response. That is my experience” (Oncologist).

External Medical Applications, Massages, Teas. Massages (rhythmical), embrocations, compresses, baths, and teas were applied by massage therapists, nurses, or by the patients at home. The intention was to improve QoL, relieve certain symptoms, support organ functions, and support cancer treatment. Therapies included support of liver function with yarrow liver compresses combined with yarrow tea or by liver *Einreibung* (embrocation) with Oxalis or Stannum; support of renal function with Equisetum compresses; and support of sleep with a footbath or a relaxing massage. Other indications for specific external applications were freezing, nausea, anasarca, thrombosis, neuropathic pain, cramp-like pain, anxiety, fever, and inflammatory breast cancer; or to gain contact, support relaxation and provide comfort to children and palliative patients: “So that they have some halt, not being so alone in the world . . . giving them ground under their feet” (General practitioner).

Nutrition, Diet. Most doctors advice on nutrition, suggesting it should improve QoL, strengthen the patient, and help them maintain their weight. The idea that a diet could fight cancer directly was dismissed. In most cases, a balanced diet was recommended, with a focus on fresh organic produce, rich in fruit and vegetables, high-quality oils, and eupeptic in nature, while simultaneously reducing the consumption of alcohol, red meat, sugar products, and white flour. Doctors took account of individual preferences while avoiding the dogmatic pursuit of rigorous dietary guidelines. Meals should be enjoyed and celebrated. For specific situations, dietary consultation was provided.

Psychological Support. Psychological care, such as talking to the patient, psychotherapy, and counseling, was a central part of treatment, particularly in cases of progressive disease: “I actually see my main focus primarily in talking with the patient . . .” (General practitioner). Doctors emphasized initiative and openness from the patient, while avoiding any imposition, “Meeting the patient where he or she is” (Oncologist).

Themes and goals centered on understanding “disease as a path/journey”; to “live as a human being” by participating in life despite the disease; to regain activity, control, and hope; to reduce depression and anxiety; to “choose a new life” by increasing autonomy, resilience, and courage; to reorient toward positive goals, not just “anticancer”, to gain “emotional freedom from cancer”; to come to terms with past trauma; and to pursue self-development, lifestyle changes, creativity, and reflecting on relationships with the self and others. Emphasis was put on relieving patients of feelings of guilt and the fear of death and dying. Art, music, literature, poetry, and metaphors from nature were used, along with body-oriented measures, relaxation, and mindfulness techniques.

Spiritual or transcendental issues were only discussed if the patients addressed them. Most doctors expressed a transcendent or spiritual life view themselves, with taking care of dying patients exhibiting a high level of significance in their descriptions. When a patient’s constitution weakened substantially, their therapeutic intentions transformed to relieving, supporting, and giving peace, but also enabling consciousness as much as possible. The doctors endeavored to support their patients “every minute” up to death, and to never “give up” on patients.

Communication and Information to Enable Patient Autonomy. Informing the patient was a prerequisite for his or her competence, independent judgment, disease coping, and therapeutic success:

Very important to inform patients about their tumor stage, . . . impact of stage, necessity for adjuvant treatments. I have somewhat made it my task, . . . that I, if necessary, talk extensively with the patients about their situation and about adequate treatments, also conventional; . . . supports disease coping . . . self-healing forces. (General practitioner)

Medical language had to be made understandable for patients:

Many patients do not understand the language of the doctors and many doctors do not understand the language of the patients. . . . They have to . . . understand the technical terms. . . . I tell them: translate it. . . . This is very, very important. (General practitioner)

The medical findings had to be illustrated (“How big is the tumor in fact”) and the statistical benefits and risks explained using absolute numbers rather than relative risks. Thorough comprehension was reported to reduce pressure and victimization. The partner or spouse was integral to this process, as he/she was also affected by the disease and enabled ongoing reflection at home.

Self-Management, Daily Activities, and Autonomy of the Patient. Self-competence and self-responsibility were major issues. Doctors promoted patient autonomy by informing,

but also by teaching their patients how to manage medical problems using easy measures such as embrocations, poultices, compresses, teas, and life-style changes:

Help for self-help is totally essential. . . . we train them with these measures. So that they have inner sense of security. . . . From one moment to the other one is suddenly sick to death and one is completely and utterly passively at the mercy of some modern, also partly highly effective therapies, but . . . this self activity seems paralyzed. That one can overcome this paralysis and tries to teach the patients things that are important for them. How they can free themselves from a difficult situation; by themselves, at home as well. (Internist)

Examples included borage-curd-poultice to relieve lymphedema; measures to handle constipation, stomach problems, dyspepsia, impaired sense of taste, oral mucositis, and sleep problems; but furthermore also emotional care, daily walks, creativity, self-care: “Do I do something good for myself, do I like myself, can I accept myself, do I love myself?” (Gastroenterologist).

Organizational Working Conditions, Self-Care, and Development of the Doctor

The hospital doctors worked in teams, and interdisciplinary tumor conferences and interprofessional team conferences were frequently mentioned.

. . . after surgery, when the complete case is discussed in the tumor conference and when we have the exact pathological reports and then decide together on an adequate treatment concept and this will be discussed with the patient extensively and treatments proposed. (Gastroenterologist)

Office-based doctors also worked in teams or discussed their patients with colleagues, specialists, or consulted a specialized AM hospital. They participated in specialized working groups focused on certain procedures and guidelines (eg, gynecologists or oncologically specialized pediatricians).

Some doctors worked in a cancer center (officially acknowledged and certified, for instance, by the German Cancer Society on the basis of their technical and medical qualifications; <http://www.krebsgesellschaft.de>), the others cooperated with oncologists, surgeons, radiotherapists, and other relevant specialists, often referring patients to each other. This cooperation was usually described as positive: “These centers know me all for long . . . they know that I know exactly what they do . . . it functions well” (Pediatrician). Good cooperation seemed significant for patient’s outcome: “The patient has to be at the center. . . . And the doctors have to be able to talk to each other” (General practitioner, oncologist). Some cooperation was described as more reserved or disparagingly, which was regarded as impairing the patient’s course of disease.

Regarding sources of knowledge, the doctors referred to colleagues in their direct working environment, to congresses and meetings (*Onkofortbildung*), including also discussions of experiences and presenting best and worst cases, to medical books and articles, case reports, guidelines, clinical trials and studies, to general conferences and, most important, to their experiences with patients and patient feedback.

Doctors also described the following sources and procedures for self-care and self-development: fostering a connection with nature, going for a walk in nature, being mindful of plants, and embracing the mood of nature. The doctors also described working on their own attitudes toward the patient: having respect, and seeing the side of the patient's personality that impressed them, being dedicated to the care of very advanced and severely ill patients, and always looking for possibilities for providing support and relieving suffering. Throughout, the doctors described experiencing a great sense of satisfaction with their profession: ". . . and this is what I experience as very satisfying in our treatment concept: this patient-centeredness" (Internist).

Discussion

The interviewed doctors integrated conventional and holistic concepts of cancer and bridged them with the transitional concepts of tumor immunology and mind-body interaction. From these concepts, they developed a holistic and individualized treatment approach to achieve tumor and symptom control and strengthen the patient on different levels such as living with the disease, overcoming the disease, and enabling emotional and cognitive development (Figures 1-3). The doctors pursued and emphasized patient-centered care. The organizational working structure was usually "interdisciplinary" and "integrative" in terms of Boon et al.⁴⁵

The concepts, procedures, and therapeutic goals of the interviewed doctors were consistent with patients' perceptions of AM investigated in prior qualitative studies and surveys. For instance, in a Swiss study on cancer patients, the features of AM inpatient cancer care were described as the support of emotional well-being in terms of balance, courage, and hope; physical well-being in terms of strength, recovery, reinforcement of life forces, and fitness for work; cognitive-spiritual issues in terms of the return to essentials, to oneself, to inner peace, self-confidence, the ability to decide, and disease coping; and the quality of human relations in the sense of patients appreciating friendly, attentive, caring personnel, who conveyed security, strength, support, the sense of being taken seriously, and being treated as a "whole being."²⁶ Similarly, in a British ethnographic study, the patients outlined the following as particularly favorable: the time given to consultations to discuss concerns; the calm and unrushed nature of the staff; the dialogue-like communication and the doctor's approachable and friendly manner;

the thoroughness in exploring medical and biographical histories; the levels of care, concern, and personal encouragement; the combination of conventional and AM care; the holistic nature of AM, and not just addressing symptoms; the use of natural treatments; the person-centered approach, tailored to individual needs; the achieving of a different outlook on life; and finally, support for empowerment, self-management, personal learning, and development.⁴⁶ Similar results were also reported in recent observational, qualitative, and survey studies in Sweden, Switzerland, Holland, and Germany.^{10,24,30,47-52} Clinical trials reported improvements in QoL through AM cancer care, MT, and art therapy.^{21,23,24} The individual nutritional support, as indicated in our interviews, has been outlined in detail in a report from an AM hospital.⁵³ The organizational working conditions, the interprofessional and interdisciplinary collaborations, were part of several studies and a Health-Technology Assessment Report on AM.^{23,24,26,27,30,48,29,50,52}

Many of the therapeutic goals of the interviewed doctors addressed the physical, social, emotional, and spiritual needs of cancer patients that often remain unmet in usual cancer care.⁵⁴⁻⁶¹ These unmet needs increase distress, morbidity, and mortality and are unfavorable for tumor control.⁶² Human understanding and empathy as part of "the good doctor's" tasks are deeply rooted in our culture, in patient's expectations, and doctors' self-understanding.^{63,64} A participatory health care style is associated with greater patient satisfaction,⁶⁵ better self-management,⁶⁶ QoL,⁶⁷ and reduced health care costs.^{68,69} Nonetheless, physicians rarely involve their patients in clinical decisions,⁷⁰⁻⁷³ and lack of respect, empathy, and communication are among the most common complaints made by patients.^{74,75} Doctors often focus on the technical and biomedical characteristics of a case, while losing sight of the dimensions of the patient's suffering, values, and feelings.⁷⁶ Thus, a more humanistic approach is generally demanded as a reaction to the prevailing impersonal and scientific approach.⁷⁷

To a considerable extent, our interviewees seemed to practice patient-centered care in a similar manner to that which was proclaimed by the *Institute of Medicine* as one of the 6 aims of high-quality health care in the 21st century and which was promoted as a "return to real evidence-based medicine."¹⁴ Patient-centered care is characterized by knowing the patient as a person, by exploring both the disease and the illness experience, and by ensuring that patient values and needs guide all clinical decisions. This includes sharing information and deliberation, tailored to the patient's concerns, beliefs, expectations, and literacy; allowing the patient to question medical assumptions and understandings of facts; promoting a listening, trustful, empathetic, and healing relationship; and involving family and friends. This approach goes beyond algorithms and individualizes evidence for the patient. It requires the commitment and

skills of practitioners, and a well-organized interdisciplinary patient-centered “community of care.”^{13,14,78,79}

Individualized health care delivery is regarded as the global approach of the future, supported by a “science of the individuality.”⁸⁰ Individualized medicine refers to different issues, such as adjustment to genetics,^{81,82} disease subclassifications and staging,⁸³⁻⁸⁵ clinical features or concomitant diseases,⁸⁶ and clinical responses.⁸⁷ In a more humanistic sense, this is what is meant by patient-centered care.^{78,79,88,89} Particularly for patients with advanced cancer, but also with chronic pain,⁹⁰ it is regarded as indispensable.^{14,91}

The individualized care described by our interviewed doctors was rooted in the holistic concept of the human being and appeared as multidimensional and interwoven with external and internal standards. Guidelines and scientific results were considered important and common ground; they were predominantly used in disease- and symptom-oriented management, in the curative area, in uncomplicated cases, at the beginning of the treatment, and by beginners. Individualization increased with a number of factors: disease complexity; suffering; palliative care; when addressing mental aspects or in terms of strengthening of capacities; with the increasing influence of patients’ goals, values, and autonomy; with growing expertise of the doctor; and when tailoring the treatment to specific responses such as symptom relief or organismic reaction. Sources for knowledge building and medical decision-making in our sample of interviewed doctors were similar to the procedures described in a British study on medical experts’ reasoning: The results from clinical trials and guidelines are only regarded as one source of information, whereas “mindlines,” “socially constituted knowledge,” tacit knowledge (a characteristic feature of expertise⁹²⁻⁹⁶), discussions with colleagues, and medical literature are seen as more decisive.^{97,98} Also, intuitive decision-making was appreciated. Intuition has been widely recognized for its central role in clinical reasoning and its meaning historically originated from the ideas of “direct perception . . . made intelligible through cognitive understanding” (from Plato to Descartes) and “logico-mathematical understanding” (Spinoza), and has only recently “fallen . . . to something unscientific and unverifiable—a form of common sense.”^{99,100}

Strengths and Weaknesses

The main strength of this study is the use of qualitative methods to generate rich insights into doctors’ concepts of and procedures in ICC, their approach to individualized care and methods for dealing with the multifaceted suffering of cancer patients, and the integration of conventional and CAM in the same institution. We used strategies to enhance the trustworthiness of our results, including multiple coders and respondent validation. They included partly reviewing charts; talking to some patients and collaborating

doctors; reading articles and case reports authored by the interviewed doctors, investigations on patients’ perspective, efficacy, effectiveness, safety, and costs of AM; visited doctors’ working sites and conferences; and publishing some of the case reports presented by the interviewees. Further strengths are the range of participants obtained through purposive sampling in regard to different specifications, countries, settings, and ages; the extensive interviews (up to 5 hours); the amount of information gathered, the trusting open atmosphere developed through confidentiality and the researchers’ reputation; and the high qualifications and expertise of the doctors.

The study has some limitations. First, it only presents the views of the doctors. The treatment process was not directly observed, and the patients’ and other health care providers’ perspectives were not evaluated. These approaches would have provided important sources of information to complement the doctors’ reports. Nonetheless, several other studies investigating the perspective of patients have been conducted at some of the same institutions, and some of the doctors participated in these studies. These studies confirm our doctors’ descriptions.^{10,23,24,26,27,29,30,46-52}

Another limitation is that our doctors present a highly experienced group, which may not be representative of the average caregiver. The doctors in our group are particularly skilled in complementary medicine and to varying extents also in conventional cancer care, and are deeply committed to high-quality care. However, as they were purposefully sampled and not randomly chosen, we do not know to what degree their procedures and concepts can be generalized. Even so, the extent of the exchanges in conferences, meetings, and publications point to some common grounds. Furthermore, it should be noted that the aforementioned descriptions are a summary of the interviews. Doctors vary in their approaches and they treat patients differently. Nonetheless, the concepts were comparable throughout, and we found no significant contradictions. Moreover, the time restrictions in health care do not always allow for such a comprehensive approach, or at least, not initially. The doctors reported cost cutting in health care, particularly the significant reductions in their days in hospitals, strongly affected and limited the application of ICC.

The findings of this study have implications for research and practice. ICC may contribute to the pursuit of a broadened patient-centeredness, which, although hampered in reality, is a meaningful goal in modern health care, and an important one for cancer patients. Its barriers and chances in health care policy, management, reimbursement, the medical profession, and education should be further investigated. Also patients’ satisfaction with ICC and the influence of interdisciplinary care and teamwork should be subjects of further research. Regarding AM care, the effectiveness, safety, and economic nature of single treatments and the whole system of cancer care should be further

investigated to enhance our understanding of which therapeutic strategies are successful and support the patient-centered approach in general.

Conclusion

Patients are cared for by interviewed AM and ICC doctors within an integrative holistic treatment concept that encompasses conventional and multimodal complementary interventions, tailored to the individual patient and addressing physical and functional issues alongside emotional and cognitive ones. This practice of patient-centered integrative care is interprofessional and interdisciplinary, may serve the unmet needs and the satisfaction of cancer patients, and be important for tumor and symptom control. It addresses major challenges and important goals of modern cancer care, focusing on the individual situation and condition, personality, values, and needs of a patient. Patient-centered, interdisciplinary, interprofessional, integrative care should be an issue for modern health care management and for further research.

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