

Great Expectations

What Do Patients Using Complementary and Alternative Medicine Hope For?

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Abstract

The aim of this review is to summarize the published evidence regarding the expectations of complementary and alternative medicine (CAM) users. We conducted electronic searches in MEDLINE and a hand search of our own files. Seventy-three articles met our inclusion criteria. A wide range of expectations emerged. In order of prevalence, they included hope to influence the natural history of the disease; disease prevention and health/general well-being promotion; fewer side effects; being in control over one's health; symptom relief; boosting the immune system; emotional support; holistic care; improving quality of life; relief of side effects of conventional medicine; good therapeutic relationship; obtaining information; coping better with illness; supporting the natural healing process; and availability of treatment. It is concluded that the expectations of CAM users are currently not rigorously investigated. Future studies should have a clear focus on specific aspects of this broad question.

Complementary and alternative medicine (CAM) has been defined as “diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine.”^[1] The range of modalities in CAM includes acupuncture, aromatherapy, chiropractic, herbal medicine, homeopathy, hypnotherapy, massage, osteopathy, reflexology, tai chi, yoga, and many more.^[2] CAM has become an important

issue, not least because a sizeable proportion of the public is using it.^[3] To many observers, the popularity of CAM seems puzzling in view of the enormous progress mainstream medicine has made during the last decades. Yet patients continue to be seduced by the many promises made in CAM.

In order to better understand this phenomenon, we aim to summarize the evidence regarding the expectations of CAM users as reported in the relevant literature.

1. Literature Search

1.1 Methods

Literature searches were conducted in order to locate studies researching the expectations of CAM users. MEDLINE (PubMed interface) was searched (in December 2009) using the following key words: 'expectation', 'motivation', 'reason', 'perceived benefit', 'attitude', 'CAM', 'complementary and alternative medicine', 'complementary and alternative therapies', 'patients', 'users', and 'participants'. No restrictions of language or time were applied. In addition, our own extensive files and the reference lists of the articles found through the electronic searches were hand searched.

All articles thus located were scanned for relevance to the subject at hand. Those that were considered relevant were studied in detail and key findings were extracted by both authors according to predefined criteria (table I);^[4-77] discrepancies between the authors were resolved through discussions.

1.2 Results

Five articles were found via the electronic searches and the rest, i.e. the vast majority, through hand searching. Most relevant articles had adopted survey methodologies, and most of the research originated from the US; other important contributors were the UK, Australia, and Canada. Thus, English-speaking countries clearly dominated (table I).

A wide range of recurring expectations emerged (table I and table II). Judging from the frequency by which each of the themes occurred, one can construct a rank order of expectations (table I). The six most frequently documented expectations were the hope of influencing the natural history of the disease; to prevent illness; to experience fewer side effects; of being in control of one's health; for symptom relief; and to boost the immune system (table II). These expectations were usually expressed by the majority of the study sample or by a sizable proportion thereof. The wording to express these hopes varied widely between investigations (table I).

There was a lack of uniformity regarding the research questions asked. Some investigators were interested in 'motivation' or 'motives', others in 'reasons' or 'intentions' for CAM use. Others again investigated 'attitudes' towards CAM or the 'rationale' or 'purpose' for CAM usage. Direct questions about 'expectations' or 'expectancies' were relatively infrequent. Validated questionnaires were not employed as, to the best of our knowledge, such instruments do not exist.

Many of the studies were conducted in cancer patients. When analyzing studies of cancer patients separately, we found the same rank order as for the full data set. The same applied when we extended our analysis to patients with any type of potentially life-threatening condition (table I). Such diseases included chronic obstructive pulmonary disease. Several investigations were conducted in healthy or general populations.

2. Discussion

Our analysis confirms what one might have intuitively suspected: users of CAM expect a very wide range of things. The expectations are likely to depend on numerous factors, such as type of disease, severity of condition, type of CAM, country of origin, age of patient, research methodology, and on the definition of CAM.

Expectations can affect clinical outcomes. Conditioned learning theory predicts that previous experiences shape expectations which, in turn, influence health. The mechanisms involved are similar to those underlying the conditioned placebo response.^[78-80] Direct evidence for this theory comes, for instance, from clinical trials in which initial patient expectations (partly) determined the eventual clinical result.^[81,82]

Our results are far from straightforward and not easy to interpret. A relatively safe assumption seems to be that all CAM users and at least two different subsets of CAM users tend to try CAM with the expectation of curing or at least positively affecting their condition, preventing disease, and taking treatments that are safe. This begs the question, to what degree are these expectations realistic? Generally speaking, CAM

Table I. Main themes emerging from primary studies researching the expectations of complementary and alternative medicine (CAM) users

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Adusumilli et al., ^[4] 2004, US (2186 pts undergoing surgery)	Self-administered questionnaire	Motives for herbal medicine use (surgical pts)	Being in control over one's health: pts were using herbal medicine for personal autonomy on health (26%) Availability of treatment: ease of availability (14%) Spiritual or religious support: for spiritual and religious beliefs (5%)
Astin, ^[5] 1998, US (1035 randomly selected individuals)	Postal survey	Perceived benefits of alternative medicine	Influence on natural history of condition: alternative medicine works better for my particular health problem than standard medicines Disease prevention, health/general well-being promotion: the treatment promotes health rather than just focusing on illness Symptom relief: significant predictors included desire for control over health matter
Barrett et al., ^[6] 2000, US (37 pts [mixed diagnoses])	Structured interviews	What were your reasons for seeking alternative treatments?	Disease prevention, health/general well-being promotion: healing and staying healthy in a proactive sense Being in control over one's health: alternative healers were characterized as relying on self-empowerment Holistic care: pts noted that they preferred to be treated as whole people rather than as composites of numerous biomedical attributes
Boon et al., ^[7] 2000, Canada (422 pts with breast cancer)	Postal survey	Reasons for using CAM (breast cancer survivors)	Influence on natural history of condition: treat breast cancer (27.9%), attempt to stabilize current condition (17.4%) Disease prevention, health/general well-being promotion: prevent a recurrence of cancer (42.5%) Being in control over one's health: provide a feeling of control over life (37.9%) Boost immune system: boost the immune system (63%) Improving quality of life: increase quality of life (53%) Relief of side effects of conventional medicine: treat side effects of conventional treatments (21%)
Corner et al., ^[8] 2009, UK (304 cancer pts)	Postal survey	Motivations for using CAM	Influence on natural history of condition: some pts adopted CAM as a strategy for improving the chance of cure from cancer Disease prevention, health/general well-being promotion: used CAM to be in control of the situation Being in control over one's health: to help with feeling in control of the situation Boost immune system: boosting the immune system Relief of side effects of conventional medicine: some had used CAM to assist in reducing the side effects of cancer treatments Cope better with illness: used CAM to help cope with the stress of having cancer, to help with feeling more relaxed

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Table I. Contd

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Ernst et al., ^[9] 1995, UK, Austria, Germany (211 pts [mixed diagnoses])	Questionnaire survey	Why do you think people seek treatment by alternative methods such as acupuncture, homeopathy, or chiropractic? (nine answers to choose from)	Fewer side effects: people seek treatment by alternative methods because they hope to be cured without side effects (47.9%) Emotional support: the alternative method is their last hope (37.9%) Good therapeutic relationship: they feel they will be better understood (28.9%)
Feldman and Laura, ^[10] 2004, Australia (518 university students)	Survey	Main reasons for using CAM practices	Disease prevention, health/general well-being promotion: emphasis on prevention (24.5%) and lifestyle (33.1%) Fewer side effects: fewer side effects (32.1%) Being in control over one's health: sense of control (22.1%) Holistic care: holistic approach (28.6%) Availability of treatment: availability (28.6%)
Gardiner et al., ^[11] 2007, US (31 044 pts [mixed diagnoses])	Survey	For which of the following reasons did you choose natural herbs (of five options)	Disease prevention, health/general well-being promotion: among herb users, 28% felt that herb use was very important in maintaining health and well-being
George et al., ^[12] 2004, Australia (71 pts with COPD)	Interview study	Intentions (reasons) for using CAM	Influence on natural history of condition: CAM was used by the study participants to help alleviate their disease condition Disease prevention, health/general well-being promotion: CAM was used by the study participants as a preventive measure Relief of side effects of conventional medicine: CAM was used by the study participants to counteract side effects of prescribed medications Obtain information: CAM practitioners were described as informative, thorough, available for longer discussions Compensate for dietary deficiencies: CAM was used by the study participants to compensate for dietary deficiencies due to restrictions or dislike of certain foods
Guethlin et al., ^[13] 2010, Germany (647 cancer pts using homeopathy)	Survey	Expectancies (what pts expect from homeopathic treatment)	Influence on natural history of condition: I expect the treatment to have a specific anti-tumor effect Disease prevention, health/general well-being promotion: I expect the treatment to enhance physical well-being Emotional support: I expect the treatment to enhance psychological well-being
Harnack et al., ^[14] 2001, US (752 individuals randomly selected from the general population)	Postal survey	Rationale for using specific herbs (why they had used the herb; a list of reasons for use was provided)	Influence on natural history of condition: Ginkgo biloba improves memory and treats heart disease Disease prevention, health/general well-being promotion: hawthorn prevents hardening of the arteries Boost immune system: Echinacea boosts immune system Emotional support: St John's wort to support a healthy mood

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Table I. Contd

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Holst et al., ^[15] 2009, UK (six pregnant women)	Focus group	Reasons for using herbal supplements and perception of herbal supplements	Fewer side effects: the women are aware of the fact that 'herbal' does not equal 'safe', but they state a belief in herbs being safer than pharmaceuticals Obtain information: the women did not believe that they were given all available information about a drug
Huber et al., ^[16] 2004, Germany (350 pts [mixed diagnoses])	Survey	Attitudes towards CAM and conventional medicine assessed by FAN	Influence on natural history of condition: I believe that the efficacy of CAM is equivalent to or better than conventional medicine in my disease Fewer side effects: I believe that CAM has less side effects than the therapies of conventional medicine Cope better with illness: I believe that CAM can help me to cope better with my disease Time to talk: I believe that CAM physicians have more time for their pts than conventional physicians
Marsh et al., ^[17] 2009, Canada (373 orthopedic pts)	Survey	Reasons for taking CAM Provide explanations for the results from the survey and mentions 'reasons for herb use' in discussion	Disease prevention, health/general well-being promotion: I want to prevent future illness (35.9%) Fewer side effects: Alternative therapies are less harmful to my body than prescription drugs (18.2%) Being in control over one's health: I want to have control over my own health (43.6%) Good therapeutic relationship: I have experienced dissatisfaction with conventional practitioners, i.e. physicians (3.9%)
Marstedt and Moebus, ^[18] 2002, Germany (5000 pts [mixed diagnoses])	Survey	Factors influencing the decision to use alternative medicine	Fewer side effects: the fear of side effects is an important determinant
Menniti-Ippolito et al., ^[19] 2002, Italy (30 000 Italian individuals)	Face-to-face interviews	Reasons for using unconventional medicine	Influence on natural history of condition: greater efficacy (20.5%) Fewer side effects: the most common reason given for using unconventional therapies was concern about side effects related to the use of standard pharmacological therapies (71%) Good therapeutic relationship: better doctor-pt interaction (13.2%)
Micke et al., ^[20] 2010, Germany (120 pts with lung cancer)	Survey	Reason for the use of CAM	Disease prevention, health/general well-being promotion: 27% had a better feeling using CAM
Molassiotis et al., ^[21] 2005, eight European countries (956 pts with various cancers)	Postal survey	Reasons for using CAM	Influence on natural history of condition: to directly fight the disease (16.4%) Disease prevention, health/general well-being promotion: to improve physical well-being (40.6%) Fewer side effects: might help, can't hurt (23.1%) Boost immune system: to increase body's ability to fight the cancer (50.7%) Emotional support: to improve emotional well-being, provide hope, and increase optimism (35.2%)

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Table I. Contd

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Molassiotis et al., ^[22] 2006, eight European countries (111 lung cancer pts)	Postal survey	Reasons for using CAM	Relief of side effects of conventional medicine: to counteract ill effects (24.8%)
Nayak et al., ^[23] 2003, US (11 600 MS pts)	Postal survey	Reasons for using CAM therapies in the past or present	Being in control over one's health: gives me more control over my healthcare (36.7% of those currently using or who have used CAM treatments) Symptom relief: the most common reason for using CAM [was] the desire to use holistic healthcare Holistic care: CAMs take into consideration the inter-relatedness of mind, body, and spirit (63.4% of those currently using or who have used CAM treatments)
Oldendick et al., ^[24] 2000, US (1584 adults)	Telephone interview	Reasons for CAM use (asked whether they used this treatment primarily to stay healthy or to treat some health problem)	Influence on natural history of condition: use was for treatment of allergies or other respiratory problems (17.7%) Disease prevention, health/general well-being promotion: 47% of reported CAM use was to maintain health
Palinkas and Kabongo, ^[25] 2000, US (542 pts [mixed diagnoses])	Survey	Reasons for using CAM	Fewer side effects: 25.9% used CAM to avoid side effects of conventional medicine Being in control over one's health: 14.7% used CAM because they preferred to deal with the problem themselves Good therapeutic relationship: 6% used CAM because they were unhappy with attitude of family physicians Make correct diagnosis: 12.1% used CAM because they believed that conventional medicine failed to correctly diagnose their problem
Patterson et al., ^[26] 2002, US (356 cancer pts)	Telephone survey	Pts were asked to identify reasons for using the alternative treatment and provider (of four options)	Influence on natural history of condition: to treat cancer (7.7–55.9%) Disease prevention, health/general well-being promotion: to treat non-cancer symptoms or prevent non-cancer diseases (47.1–97.4%) Symptom relief: 56% reported CAM use for treatment of cancer
Pedersen et al., ^[27] 2009, Denmark (3343 pts with breast cancer)	Survey	Do you believe that the alternative therapy you have received will have a positive effect upon the breast cancer illness itself? (of four options)	Influence on natural history of condition: approximately one-third of CAM users were certain or relatively certain that CAM would have a positive effect upon the cancer itself
Reid, ^[28] 2002, UK (75 pts using homeopathy)	Questionnaire survey	Reasons for using OTC homeopathy	Influence on natural history of condition: 61.2% agreed/strongly agreed that OTC homeopathy is more effective than prescribed medicines Fewer side effects: OTC homeopathy can cause no harm (74.6%) Support natural healing process: 95.8% agreed/strongly agreed that OTC homeopathy is a more natural treatment

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Table I. Contd

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Richardson, ^[29] 2004, UK (327 pts attending a CAM clinic [mixed diagnoses])	Questionnaire survey	Attitudes towards CAM and conventional medicine assessed by FAN Expectation: open-ended question, "What do you expect from the complementary therapy service?"	Fewer side effects: reduction of the risk of allopathic treatments Being in control over one's health: need for self-help advice Symptom relief: pts expected symptom relief Holistic care: desire for a therapeutic/holistic approach to treatment Improving quality of life: wish to improve quality of life Obtain information: provision of information by caregivers
Risberg et al., ^[30] 1997, Norway (630 cancer pts)	Survey	Reasons for starting, and expectations of, NPCTs	Influence on natural history of condition: ten pts (10%) believed NPCTs could cure their cancer Disease prevention, health/general well-being promotion: 41 pts (39%) believed that the use of NPCTs might improve physical resistance and/or their general condition Boost immune system: an attempt to strengthen their immunological defence
Rossi et al., ^[31] 2005, Italy (481 pts with migraine)	Structured interview	Reasons for use of CAM therapies for migraine	Fewer side effects: safer than conventional treatments/fewer side effects (26.5%) Symptom relief: the most common reason for deciding to try a CAM therapy was that it offered a potential improvement of headache
Salmenperä et al., ^[32] 2001, Finland (216 breast cancer pts)	Postal survey	Reasons for the use of complementary therapies	Fewer side effects: they are natural and 'soft' therapies (men 51%; women 64%) Emotional support: they offer hope for the future (men 72%; women 88%)
Shahrokh et al., ^[33] 2005, US (35 elderly users of herbal medicines)	Interviews	Expectation: open-ended question, "What do you expect from the complementary therapy service?"	Fewer side effects: herbal supplement users view supplement as safe
Shenfield et al., ^[34] 2002, Australia (174 children with asthma)	Pt interviews	Reasons for using CAM	Disease prevention, health/general well-being promotion: CAM was given to treat other problems such as improve the child's energy levels or behavior Fewer side effects: it does no harm Symptom relief: 17.5% were given CAM to treat or improve asthma symptoms Boost immune system: most of the CAMs were given for preventative reasons, such as boosting immunity Improving quality of life: most (71.2%) of the CAMs were given for preventative reasons Good therapeutic relationship: reasons given for deciding to use CAM included "the alternative practitioner was really supportive" Support natural healing process: reasons given for deciding to use CAM included 'it's more natural'

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Table I. Contd

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Simpson and Roman, ^[35] 2001, UK (1134 children)	Survey	Reasons for using CAM	Fewer side effects: 31.8% used CAM because of the fear of side effects of conventional medicines Holistic care: more personalized attention (13.2%)
Smith and Eckert, ^[36] 2006, Australia (911 children)	Survey	Why did the child use CAM?	Influence on natural history of condition: reason for CAM use was to treat a small range of health complaints Disease prevention, health/general well-being promotion: reason for CAM use was to prevent illness or to maintain health (39%)
Spigelblatt et al., ^[37] 1994, US (208 children using CAM)	Postal survey	Factors influencing choice to use alternative medicine	Fewer side effects: the main factor that persuaded parents to use alternative medicine was fear of the side effects of conventional remedies (21%) Holistic care: more personalized attention (9%)
Tilden et al., ^[38] 2004, US (family caregivers of pts who recently died)	Interviews	Motive for using CAM	Influence on natural history of condition: a minority (15.6%) used CAM specifically to slow their diseases and/or to prolong their lives. Only 5.5% used CAM with the hope or expectation of cure Symptom relief: the most frequent reason for using CAM was symptom relief
van Tonder et al., ^[39] 2009, South Africa (98 cancer pts)	Self-administered questionnaire survey	Reasons for CAM usage	Symptom relief: the main reason for using CAM was to improve quality of life Boost immune system: CAM therapies were mostly used in the hope of boosting the immune system (49% of cancer pts) Emotional support: pts used CAM for stress management Improving quality of life: CAM therapies were used to improve quality of life (34% of cancer pts)
Vardeny and Bromberg, ^[40] 2005, US (53 pts with ALS)	Survey	Expectations from their use of herbal supplements and alternative therapies	Influence on natural history of condition: hoping for a slowing of disease progression (44%) Disease prevention, health/general well-being promotion: pts stated they expected an improvement in well-being (54%) from the use of these agents
Verhoef et al., ^[41] 1998, Canada (14 pts with IBD)	In-depth qualitative interviews	Factors influencing the use of CAM	Fewer side effects: to avoid these serious side effects of conventional medicine was a major consideration when deciding whether to use CAM Being in control over one's health: pts need to be in control of their own care Emotional support: these comments reinforce the importance of psychological factors such as positive thinking Holistic care: pts expressed a strong desire to have individualized disease management

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Table I. Contd

Study, year, country (pts)	Study design	Question asked in the study	Key finding
Verhoef et al., ^[42] 1999, Canada (167 pts with brain tumor)	Survey	Reasons for alternative therapy use by brain tumor pts	Fewer side effects: all natural, no side effects Being in control over one's health: to do something, take charge of my health (23%) Boost immune system: do anything that might help and might boost my immune system Holistic care: desire for pt-focused treatment Relief of side effects of conventional medicine: side effects of conventional therapies (15%)
von Rohr et al., ^[43] 2000, Germany (221 pts with advanced cancers)	Structured interviews	Pts' view of anthroposophical treatments	Influence on natural history of condition: pts had quite high expectations regarding the effectiveness of anthroposophical treatment on the tumor itself Disease prevention, health/general well-being promotion: pts appreciate most the perceived positive influence on psychological as well as physical well-being Improving quality of life: pts had quite high expectations regarding the effectiveness of anthroposophical treatment on quality of life
Werneke et al., ^[44] 2004, UK (318 cancer pts)	Survey	Purpose of herbal medicines and supplement use	Symptom relief: half of all pts took CAMs in order to fight cancer Boost immune system: pts with hematological cancer aimed to boost their immune system with echinacea Relief of side effects of conventional medicine: milk thistle was taken, presumably to counter some side effects of chemotherapy Improving quality of life: half of all pts took CAMs for the nonspecific purpose of improving their health or in order to fight cancer
Wilkinson et al., ^[45] 2002, US (1099 pts with prostate cancer)	Postal survey	Perceived benefits that CAM may offer	Influence on natural history of condition: 47% expected it to cure the disease Being in control over one's health: 63% thought they had more control over the disease Symptom relief: 90% believed that it would help them to live longer and 47% expected to cure the disease Emotional support: 81% reported feeling more hopeful Improving quality of life: 90% believed that CAM would help them live longer and improve their quality of life
Winterholler et al., ^[46] 1997, Germany (129 pts with MS)	Postal survey	Factors influencing the decision to use alternative medicine	Fewer side effects: 29% expected fewer side effects Being in control over one's health: 57% expected active participation in therapy
Xue et al., ^[47] 2008, Australia (1067 Australian individuals)	Survey	Rationale for use	Influence on natural history of condition: treatment of a specific medical condition Disease prevention, health/general well-being promotion: general health and well-being Improve sporting performance: improving sporting performance
ALS =amyotrophic lateral sclerosis; COPD =chronic obstructive pulmonary disease; FAN =Freiburger Questionnaire on Attitudes on Naturopathy; IBD =inflammatory bowel disease; MS =multiple sclerosis; NPCTs =non-proven complementary therapies; OTC =over-the-counter; pts =patients.			

Table II. Six main expectations emerging from table I

Expectation	Comment
Influence on natural history of conditions	21 publications from various countries, diverse research methodologies. Most frequent diagnosis: cancer
Prevention/well-being	21 publications from various countries, diverse research methodologies. Most frequent diagnosis: cancer
Fewer side effects	20 publications from various countries, diverse research methodologies, mixed diagnoses
Being in control	13 publications (mostly from the US), diverse research methodologies. Most frequent diagnosis: cancer
Symptom relief	10 publications (mostly from the US), mostly surveys. Most frequent diagnosis: cancer
Boost immune system	9 publications from various countries, mostly surveys. Most frequent diagnosis: cancer

has not been shown to cure serious diseases.^[2] Offering false hope has recently been called a “cruel and fraudulent act.”^[83] Neither do we have strong evidence that many forms of CAM are effective in disease prevention.^[84] However, it is reasonable to assume that most types of CAM are safer than mainstream therapies.^[2]

Knowing about the most common expectations of patients might be valuable in several ways. Our findings lend themselves to formulating better defined hypotheses about patients' expectations that can subsequently be tested. Our data might also enable researchers conducting survey and interview studies to define their research question and analytical methods better than in some of the articles reviewed in table I.^[85] On a clinical level, it may be useful to know what patients expect; this can be relevant for dealing with patients who are CAM users, may tell us what type of information CAM users require, and it can deepen the therapeutic relationship with such patients.

Our analysis has important limitations. It relies mostly on survey data that can be criticized for being ‘soft’, full of contradictions, and dependent on a host of confounders.^[86] It is therefore not surprising to find inconsistencies in the reported results. For instance, some studies suggest that patients expect a cure (table I), but other

investigations clearly suggest the opposite.^[27] Similarly, some surveys suggest that patients expect therapeutic benefits (table I), while others demonstrate that this is not the case,^[87] and some studies imply that CAM users are disenchanted with mainstream medicine (table I), while others do not.^[88] One of the problems here is that CAM surveys and interview studies are often open to misinterpretation.^[85] In the present analysis, there often was a fine line between the reason for CAM use, experience of CAM, and expectation (table I).

3. Conclusion

Many investigations have addressed the expectations of CAM users. Despite this plethora of data, there is a lack of systematic research on the subject and the existing body of research does not generate a clear picture. Further studies should have a clearer focus and try to find answers to specific aspects of this broad question.

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