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USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE IN THE CONTEXT OF CANCER

Perspectives on exceptional
experiences

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ABSTRACT

Although little is known about the use of complementary and alternative medicine (CAM) among cancer patients in Sweden, European research which includes Sweden shows that an average of 39% of cancer patients report CAM use.

AIMS: The overall aim of this thesis is to explore perspectives on CAM use among individuals with cancer in connection to reported exceptional sickness trajectories. The specific objectives are: To explore patterns of CAM use among cancer patients with reported exceptional cancer trajectories (Paper I); To explore how different stakeholders—patients, their significant others, CAM providers and biomedical health care (BHC) providers—conceptualize and discuss exceptional cancer trajectories and possible explanations for them (Paper II); To explore *how* a personal narrative about CAM use is told, in addition to *what* is told, to see how the meaning of the negotiation between different therapies is created (Paper III); and To explore patients' perspectives on the use of biologically-based therapies in the context of cancer (Paper IV).

METHODS: Through invitations in mass media, a critical incident technique was used to recruit cases perceived as exceptionally positive or negative in relation to CAM use in the cancer context, without further definition by the researchers. Qualitative interviews were conducted with 38 patients, four significant others, five CAM providers and three BHC providers.

Analytical techniques utilized include latent and manifest content analysis (paper I, II), principal component analysis (paper I), narrative analysis (paper III), and framework analysis (paper IV).

RESULTS: All cases were framed as exceptionally positive by the person reporting the case. There was great diversity in CAM use with 38 patients using a total of 274 CAM therapies consisting of 148 different therapeutic modalities, with biologically-based therapies representing the most common and most diverse type of CAM. Two patterns of CAM use were identified: related to number of CAM therapies, and preference for different types of CAM. Current professional CAM categorizations did not fully cover descriptions of CAM use in this study. Patients, their significant others, and their CAM and BHC providers framed the reported sickness trajectories along a continuum between the exceptionally positive and the ordinary, with stakeholder groups varying in their focus on well-being and long-term survival. Patients described a wide range of benefits related to CAM use, including aspects of physical and psychological well-being, as well as disease-related benefits. Side-effects of biologically-based therapies could be interpreted by patients as positive or negative depending on the specific situation. Also, patients and their significant others emphasized the importance of a dialogue about CAM with BHC providers. From a lay perspective, communication with BHC providers described as positive was seen as indicative of a more collaborative rather than hierarchical relationship.

DISCUSSION: This study design allowed for generation of new knowledge about patients', significant others' and CAM providers' focus on exceptional well-being in addition to the BHC acknowledged endpoint of exceptionally long survival otherwise used for the study of exceptional cancer trajectories. The findings of this thesis are discussed in relation to the potentials and challenges that arise from the diversity of CAM. Patients' perceived sense of agency coupled to CAM use, discrepant views of CAM between patients and professionals are also discussed, as well as the importance of patient-provider communication. Implications of this research for clinical practice, policy, and future research are considered, with evidence of many types, including user perspectives, argued as necessary to improve safety and satisfaction for cancer patients using CAM. These findings also serve to refine future research questions to better reflect the ways in which CAM is used by individuals with cancer.

Keywords: complementary therapies, cancer, qualitative analysis, exceptional sickness trajectories

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LIST OF ABBREVIATIONS

BBT	Biologically-based therapies
BCS	Best Case Series
BHC	Biomedically-oriented health care
CIT	Critical incident technique
CAM	Complementary and alternative medicine
NCCAM	National Center for Complementary and Alternative Medicine
NCI	National Cancer Institute
NIH	National Institutes of Health
NAFKAM	Nasjonalt forskningscenter innen komplementær og alternative medisin
PCA	Principal Component Analysis
PC	Principal Component
TM	Traditional Medicine
WHO	The World Health Organization

1 PREFACE

I started studying pharmacy with an interest in finding chemical substances of natural origin that could lead to new discoveries of drugs for diseases we could not yet cure. My first project in line with this pursuit was a SIDA-financed Minor Field Study project in Sri Lanka that I conducted under the supervision of Dr Premila Perera in 1999. While the initial plan was to study chemical properties of plants used in Ayurvedic medicine, after a short time we decided to also conduct interviews with Ayurvedic doctors in order to find out about their views of the use of these plants. It was through these interviews that my interest in the ways herbal medicines were utilized within traditional systems of medicines, such as Ayurveda, was born. A couple of years later, I met Associate Professor Torkel Falkenberg who provided supervision in my Masters Thesis' project, where I pilot-tested a survey instrument to map policy guidelines for herbal medicines worldwide in collaboration with the World Health Organization. Through this study, I learnt about some of the difficulties and politics of documenting utilization of health care services outside the domain of formal health care. I was perplexed at the figures showing a widespread use of herbal medicines worldwide while very few governments had national policies addressing this issue. With this new information, I became curious to learn more about users' perceptions of herbal medicines and other methods used outside formal health care systems, i.e. complementary and alternative medicine (CAM). From an initial quest to find cures for diseases in nature, my interest had transformed into a desire to understand how herbal medicines and other forms of CAM may help individuals to cope with diseases for which we yet have no cure. Meeting Professor Carol Tishelman with expertise in research about lay experiences of cancer, I was introduced to the science of qualitative methods. Altogether, I had then found a research platform from which I could begin studying multiple perspectives on CAM use in the context of cancer. In 2003, with supervision from Associate Professor Torkel Falkenberg and Professor Carol Tishelman, I started working on the research plan that in 2004 received funding from the National Research School in Health Care Sciences, the Swedish Cancer Society and the Traffic & Cancer Injury Fund, and this thesis is the result.

This study is based on one large data set of interviews with patients, their significant others and providers, following an invitation in the Swedish media that called for people with experiences of exceptional cancer trajectories in connection with CAM use to contact me. In the study I have included concepts and methods originating from a wide variety of social sciences as well as nursing. Although my research has been influenced by these disciplines, I want to emphasize that I have had no ambition of becoming a specialist in these fields. Rather in this thesis, I have taken a pragmatic approach to utilizing methods and concepts I have found appropriate for facilitating improved understanding of the study participants' experiences.

The 38 individuals with cancer who participated in this study made a strong impression on me personally. The strength and wisdom many of them imparted are captured in the following words:

May I have the serenity to accept
the things I cannot change,
the courage to change the things I can,
and the wisdom to know the difference.

The Serenity Prayer

2 INTRODUCTION

Caregivers, services and products outside the formal health care system may be referred to as complementary and alternative medicine (CAM). Although not a new phenomenon, the use of CAM has increased dramatically during the last 15 years and is today widespread, with Molassiotis et al.¹ estimating that 39% of cancer patients in Europe use CAM. The reasons for the increase and popularity of CAM use among cancer patients are manifold. The rising consumer movement, the increased availability of health-related information on the internet, and the rising holistic health and self-help movements are some commonly discussed factors influencing the popularity of CAM². As a response to this increase of CAM utilization and the continued frequent utilization of traditional medicine (TM) throughout the world, the World Health Organization (WHO) calls for increased collaboration between health care sectors and the recognition of TM/CAM to address unmet health care needs worldwide³. Increased collaboration between health care sectors in cancer care may be particularly relevant, due to the popularity of CAM among this group of patients and the challenges of patient safety, e.g. including the risk of serious interactions between CAM and biomedical cancer treatments.

The WHO suggests that research on the efficacy, safety and quality of CAM is essential to facilitate increased collaboration between CAM and biomedically-oriented health care (BHC). However, while the body of research on CAM use and its influence on cancer patients has increased during the last 15 years, there is still notably little research that can confirm its effect. As Fønnebo et al.⁴ argue, there appears to be “*a gap between published studies showing little or no efficacy of CAM, and reports of substantial clinical benefit from patients and CAM practitioners.*” (p.1). As a researcher in this project, I myself take on the task to qualitatively explore individuals’ experiences of CAM use to improve the understanding of this gap between people’s reported experiences and the current body of research on efficacy.

3 AIMS

The overall aim of this thesis is to explore perspectives on complementary and alternative medicine use among individuals with cancer in connection to reported exceptional sickness trajectories.

The specific objectives are:

- To explore patterns of CAM use among cancer patients with reported exceptional cancer trajectories (Paper I);
- To explore how different stakeholders- patients, their significant others, CAM providers and BHC providers- conceptualize exceptional cancer trajectories (Paper II);
- To explore how different stakeholders- patients, their significant others, CAM providers and BHC providers- discuss possible explanations for the reported trajectories (Paper II);
- To explore *how* a personal narrative is told, in addition to *what* is told, in order to see how meaning of the negotiation between different therapies is created (Paper III);
- To explore patients' perspectives on the use of biologically-based therapies in the context of cancer (Paper IV).

4 BACKGROUND

CAM as a research field may be seen as related to many disciplinary fields. In this background I have included concepts to contextualize this research in relation to other fields and provide background information to facilitate understanding of the research findings.

4.1 HEALTH CARE SYSTEMS

Throughout history, people have found different ways to improve health and to prevent and manage disease. When signs or symptoms of disease emerge, individuals find ways to manage the situation themselves and/or seek help from others. Help may be provided from family and friends, from informal caregivers in the community or from formal health care systems.

With the growth of larger and more complex and culturally diverse societies, therapeutic options are also likely to increase in number, resulting in health care pluralism⁵. Helman emphasizes the importance of viewing a health care system as part of a society with two main inter-related aspects; a cultural aspect that entails certain common assumptions and normative practices; and a social aspect that involves the organization of human relationships⁵. In most high-income countries today, there is a formal health care system supported by law in both its social and cultural aspects. In addition, most societies have health care sub-cultures that differ from the formal health care system both in terms of social and cultural aspects⁵. Such health care sub-cultures may be indigenous to the culture where they exist and are then often referred to as Traditional Medicine (TM), while practices more recently introduced to a particular culture or society are often referred to as Complementary and Alternative Medicine (CAM). The use of the terms TM or CAM is thus context-dependent with the result that a particular practice, for example acupuncture, may be referred to as TM in China, while it is classified as CAM in Sweden.

In his now classic work the medical anthropologist Kleinman⁶ suggests a model that includes three main sectors from which health care is delivered, namely the bio-medically oriented *professional sector*, the *folk sector*, and the *popular sector*. The *professional sector* constitutes health care providers within the bio-medical tradition such as medical doctors, nurses, pharmacists, physiotherapists, etc. The *folk sector* comprises specialists, working with issues of health and sickness in paradigms outside the bio-medical tradition, thus including many CAM. The *popular sector* encompasses the largest part of any health care system and includes activities initiated and delivered by individuals, family and members of the community⁶. Although this model has been criticized for not taking into account the continuous interplay between these different sectors as well as social forces that act to diffuse these borders^(e.g. 7, 8), I found the model useful as a sensitizing concept when relating to the different stakeholder perspectives in this study. The aspects of Kleinman's model I found particularly useful for this work were primarily the acknowledgement of the important role played by patients and their significant others in treatment decisions as well as the clarification that there are two sectors in which health care specialists work, referred to by Kleinman as the professional and folk sector. I have used the terms the *BHC sector*, the *CAM sector* and the *popular sector* in this thesis.

The relationship between these different sectors of health care differs throughout the world. Using WHO terminology³, collaboration between health care sectors may be viewed as integrative, inclusive or tolerant. In *integrative health care systems*, health care sub-cultures (referred to as TM/CAM) are described to be acknowledged and utilized on all levels of the formal health care system including education, practice and financing. Such a situation has been identified in only a few Asian countries, e.g. China, Vietnam, and North and South Korea. *Inclusive health care systems* acknowledge and utilize some TM/CAM within their

formal systems of care, although not on all levels. Examples of such countries are USA, Germany, Nigeria, and Mali. *Tolerant health care systems* do not officially incorporate aspects of TM/CAM in their dominant health care system, although the practice of such care is tolerated³. According to this description, Sweden is an example of a country that would be considered having a tolerant attitude towards CAM. It should be noted that according to WHO, tolerant systems represent the lowest level of integration without any further specification of different degrees of tolerance.

4.2 COMPLEMENTARY AND ALTERNATIVE MEDICINE

In academic literature, the most commonly used term for health care practices used primarily outside the formal health care system in high-income countries is complementary and alternative medicine (CAM), which is also the term used in this thesis. The field of CAM is often characterized as sharing some core philosophical characteristics. Goldstein⁹ e.g., describes CAM as having characteristics such as an emphasis on holism, a focus on a vital force in humans (also called qi, prana and life force), a focus on spirituality, a positive definition of health, and a distinctive view of the health process and relationship. However, representing a wide variety of systems, practices and professions, the CAM field also shows heterogeneity in philosophies on which practice is based. Many attempts have been made to reach a working definition of CAM^(e.g. 10-14), without consensus being reached. Instead, attempts to define CAM have been criticized as either being based on ad hoc lists of CAM practices for use in utilization surveys, or categorical descriptions that rapidly change¹⁵. Moreover, the use of CAM as a concept has been criticized, since by definition it is a complement or alternative to a formal health care system. According to Achilles¹⁶, this may be problematic since the boundaries between CAM and the formal BHC systems are dynamic. Examples of influences leading to indistinct borders between CAM and BHC include the increasing utilization of some CAM services within BHC systems¹⁷, the legitimization of some CAM professions such as chiropractors, the increased interest in CAM among BHC professionals¹⁸, as well as the transitions in BHC with an increased incorporation of patient-centered care and holistic care (characteristics often associated with CAM)^{16, 19}.

Despite an awareness of the heterogeneity within both CAM and BHC and the increased flexibility of the boundaries between them, the practice of dividing health care practices into CAM and BHC may still serve practical purposes since the majority of CAM modalities are practiced under different structural constraints than BHC. As Eskinazi¹² argues, CAM is practiced outside formal health care systems “...because they [CAM] pose challenges to diverse societal beliefs and practices...”^(p. 1622). He specifies such societal beliefs and practices as being of cultural, economic, scientific, medical, and educational nature¹². Although aware of the limits of all definitions, Kelner and Welman¹⁵ assert that CAM classifications should be chosen in accordance with the particular aim for which they are used. In line with this, I have used Cochrane Collaboration’s¹⁴ definition and the NCCAM categorization system¹⁰ in this thesis. The definition of the Cochrane Collaboration was chosen because it reflects the context-dependent, flexible relationship between CAM and BHC, and acknowledges the heterogeneity of CAM by specifying that CAM may refer to entire health systems or individual modalities and practices with or without accompanying theories and beliefs¹⁴:

“Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities and practices, and their accompanying theories and beliefs, other than those intrinsic to the politically dominated health systems of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health or well-being. Boundaries between CAM and within the CAM domain

and that of the dominant health care system are not always sharp or fixed” (p. 693).

The NCCAM classification was found pragmatically useful. It classifies all CAM into five categories (see Table 1): 1) Alternative medical systems; 2) Mind-body interventions; 3) Biologically-based therapies; 4) Manipulative and Body-based methods; and 5) Energy therapies.

Table 1. Categorization of CAM practices as described by NCCAM¹⁰.

Alternative Medical Systems	Alternative medical systems are built upon complete systems of theory and practice. Often, these systems have evolved apart from and earlier than the conventional medical approach [used in US]. Examples of alternative medical systems that have developed in Western cultures include homeopathic medicine and naturopathic medicine. Examples of systems that have developed in non-western cultures include traditional Chinese medicine and Ayurveda.
Mind-body interventions	Mind-body medicine uses a variety of techniques designed to enhance the mind’s capacity to affect bodily function and symptoms, including meditation, prayer, mental health and therapies that use creative outlets such as art, music or dance.
Biologically-based therapies	Biologically-based therapies in CAM use substances found in nature, such as herbs, foods and vitamins. Some examples include dietary supplements, herbal products and the use of other so-called natural therapies (for example, using shark cartilage to treat cancer).
Manipulative and body-based methods	Manipulative and body-based methods in CAM are based on manipulation and/or movement of one or more parts of the body. Some examples include chiropractic or osteopathic manipulation, and massage.
Energy therapies	Energy therapies involve the use of energy fields. They are of two types: 1) <i>Biofield therapies</i> are intended to affect energy fields that purportedly surround and penetrate the human body. The existence of such fields has not yet been scientifically proven. Some forms of energy therapy manipulate biofields by applying pressure and/or manipulating the body by placing the hands in, or through these fields. Examples include qi gong, reiki and therapeutic touch. 2) <i>Bioelectromagnetic-based therapies</i> involve the unconventional use of electromagnetic fields, such as pulsed fields, magnetic fields, or alternating current or direct-current fields.

The concept of CAM also includes a distinction between *complementary* medicine, defined as practices used along with BHC, and *alternative* medicine, which are practices used instead of BHC^(e.g. 10). With the increasing utilization of some CAM within BHC, the concept of *integrative medicine* has emerged, signaling different degrees of collaboration between CAM and BHC^{20, 21}. From a BHC standpoint, the distinction between the use of CAM as an alternative or complement to BHC may be particularly relevant in relation to potentially life-threatening conditions such as cancer with Norwegian oncologists e.g., reporting being more positive towards CAM use when it is used as a complement rather than as an alternative to BHC cancer care²².

4.3 CANCER

In the year 2000, the WHO estimated that 22.4 million people were living with cancer and that cancer caused 12.6% of all deaths making it a leading cause of death globally²³. The WHO also estimates that due to frequent smoking, the adoption of unhealthy lifestyles and an increasingly older population, cancer cases will increase by 50% to 15.7 million by the year 2020²³. Recent improvements in BHC treatments and diagnostic tools have improved the prognosis and survival rates for many types of cancer. In high-income countries, cancer is currently the second most common cause of death and, in low-income countries it is the third most common cause of death. Cancer represents a diverse class of diseases, the five most

common types worldwide being cancer of the lungs, stomach, colorectal area, liver and breast²⁴.

With its high prevalence throughout the world, most people will experience cancer at some point in their lives, either by having the disease themselves or knowing someone who has cancer. Corner²⁵ refers to cancer as part of our culture “*understood as a dreaded disease, feared perhaps more than any other disease, associated with inevitable death, and a death that is painful and unpleasant*”^(p.9). Sontag²⁶ further suggests that cancer has become a metaphor for war and a vehicle for the large insufficiencies of growth and consumption in this society. In light of the use of such metaphors for cancer, Corner²⁵ means that “*The cancer metaphor has developed a meaning within our culture that is both part and not part of cancer the disease; it developed a life of its own, and may or may not in the end reflect the disease in any direct way.*”^(p.10).

My interest in cancer in this thesis is not in cancer as a disease but rather in aspects of the individual experience of cancer as an illness existing in relation to particular cultural understandings as described by Corner²⁵, and cancer as a sickness within the context of a particular society as suggested by Sontag²⁶.

4.4 THE SWEDISH CONTEXT

Although there is a paucity of research studies on CAM use in Sweden, existing reports show similar trends to findings from other European and North American countries, in the widespread popularity in CAM use, which has increased since the middle of the 1980s²⁷. A report from the Stockholm county suggests that the number of individuals with experiences of CAM in 2000 had doubled from the middle of the 1980s²⁸. Twenty percent of the individuals (n=1001) interviewed for this report had seen a CAM provider during the past year, and 23% reported using natural remedies, so called “*naturläkemedel*”. i.e. herbals with a particular legal status in Sweden, in the last year. The most commonly consulted CAM providers were massage therapists, naprapaths and chiropractors²⁸. In line with international studies on CAM use, women with middle- to high-incomes and with higher levels of education were most likely to use CAM. To my knowledge, the European study by Molassiotis et al.¹ is the only utilization survey including CAM use among Swedish cancer patients. They found that 18 (31%) of the 59 cancer patients included reported utilizing some type of CAM.

Formal cancer care in Sweden is dominated by the BHC with national health insurance generally covering cost of care and treatment provision within BHC. In general the national health insurance does not cover CAM, although there are some notable exceptions, see below. Eklöf and Kullberg²⁹ report that CAM provision in Sweden is provided in at least four different ways in relation to the formal health care system:

- Provision of CAM by non-licensed CAM providers, i.e. the provision of CAM care, is outside the jurisdiction of the Swedish Board of Health & Welfare.
- Formalized collaboration between individual providers (both licensed and non-licensed) and institutions providing CAM within the formal BHC health care system. The anthroposophic hospital Vidarkliniken is an example of such collaboration in terms of cancer care.
- Provision of certain CAM by licensed BHC providers within the formal BHC health care system. The provision of acupuncture or lymph massage by e.g., physiotherapists or nurses are examples of such care available at some clinics in Sweden.
- Close collaboration between licensed providers and non-licensed providers providing CAM within a particular health care setting.

In line with the Swedish Health Care Act³⁰, BHC providers are legally required to practice based on “science and tested experience”. Although the term “science and tested experience” is somewhat ambiguous, it basically prohibits BHC providers from recommending or providing CAM with a few exceptions regarding situations when a patient initiates the request for CAM or when no BHC treatment is available. These exceptions also require that no risks are associated with the particular CAM therapy. Also, the Swedish Health Care Act³⁰ prohibits all non-licensed health care providers from treating certain conditions, including cancer. However, since the law does not define the difference between treatment of cancer and treatment of a person with cancer, the role of non-licensed professionals providing CAM to cancer patients with the aim of improving well-being remains largely unclear.

4.5 RESEARCH ON CAM USE AMONG INDIVIDUALS WITH CANCER

While many CAM methods have been used for thousands of years (e.g., in the case of TM/CAM such as Ayurveda), many TM/CAM have not been evaluated scientifically³. However, with the increasing popularity of CAM, scientific investigations on CAM have increased. The increased interest in investigating CAM according to scientific principles, which rose during the 1990’s, is for example indicated by the increase in number of academic journals specifically dedicated to such inquires¹⁵.

I have categorized research on CAM use among individuals with cancer broadly as related to four areas: 1) Utilization studies addressing questions like *What CAM methods are used, how are they used, and by whom?* 2) Studies of reasons underlying people’s use of CAM, addressing the question *Why do people use CAM?* 3) Studies of CAM efficacy asking questions such as *Does it work?* 4) Studies of potential risks with CAM use examining issues like *Is CAM safe?*

4.5.1 Utilization of CAM

Research indicates that CAM use among individuals with cancer is widespread. Molassiotis et al.¹ found that CAM use occurred among 39% of the 956 cancer patients, included in a survey in 14 European countries. Similar estimates of the extent of CAM utilization were found in other surveys, e.g., in Japan with Hyodo et al.³¹ finding that 45% of surveyed cancer patients reported using CAM. Data on CAM utilization among cancer patients presented by Boon et al.³² also suggest that the reported use of CAM has increased from 1998 to 2005. Cancer patients, along with other patient groups with chronic symptomatic illnesses, report using more CAM than other groups in society^(e.g. 33, 34). Studies also vary in their estimates of CAM use among cancer patients, as exemplified in the review by Ernst and Cassileth³⁵, who found that reported CAM utilization rates varied between 7-64%. Besides reflecting actual differences in CAM utilization in different contexts, this variation in estimates is also likely to reflect differences in defining CAM³⁵.

Reports suggest that a majority of individuals with cancer who use CAM, use these therapies to complement their BHC treatment and/or to help cope with treatment or its side effects^{1, 36, 37}. Findings from several countries indicate that the most commonly used types of CAM used among cancer patients can be categorized in the NCCAM category *Biologically-based therapies* (BBTs)^{1, 36, 37}, with choice of therapy often specific to geographical location, e.g., mistletoe in Switzerland, olive leaf paste in Greece and particular kinds of mushrooms in Japan^{1, 31}. Other popular single CAM methods among cancer patients have been found to include spiritual therapies, healing and relaxation techniques^{1, 36, 37}.

In parallel with studies of the gender distribution of CAM users in the general population, women with cancer have been found to be more likely to use CAM than are men with cancer^{1, 37}. In addition, several studies have found that age and educational levels are predictors of CAM use, in that younger people and people with higher educational levels tend to use CAM more^{1, 31}. Nagel et al.³⁸ also report that patients who rated their own prognosis as “unfavorable” were more likely to use CAM than those who rated their prognosis as more “favorable”. Moreover, they suggest that patients with more pain are more likely to use CAM³⁸.

The literature presents somewhat contradictory results regarding the influence of disease stage on CAM use. In their study from Germany, Nagel et al.³⁸ found that cancer stage seemed to influence the extent of CAM use such that patients with advanced cancer were found to be more likely to use CAM than patients with earlier stages of cancer. In contrast, Anker³⁷ reports that in the survey of 250 Danish cancer patients, no correlation was found between disease stage and reported CAM use.

4.5.2 Reasons for CAM use

It is likely that individuals resort to CAM for a variety of reasons. Reasons for using CAM have by large been described to depend on either a positive choice towards CAM or a negative choice away from BHC³⁹. Astin⁴⁰ e.g., suggests that people may be pulled towards using CAM because they perceive these therapies to be congruent with their own values, beliefs and philosophical orientations toward health and life. Positive qualities coupled with CAM have been reported to include taking personal control over one’s health and illness, and being treated in a “holistic” way where body, mind and spirit are considered^{15, 41, 42}. Thorne et al.⁴³ also suggest that CAM may be seen as part of self-care management used to increase personal responsibility for one’s own health. Moreover, it has been suggested that in an early stage of cancer, individuals use CAM to complement BHC treatments in promoting wellness or to relieve symptoms or adverse effects of BHC treatment⁴⁴⁻⁴⁶. Kronenberg et al.⁴⁴ report that it is predominantly in the case of advanced illness or recurrence, that users seek CAM to directly effect the cancer disease or tumor burden, i.e. search for a cure. Along the same line, Boon et al.⁴⁵ argue that “pull factors”, such as those mentioned above, are the main reason for CAM use among people with cancer, which also explains why most people report using CAM as a complement to BHC care rather as an alternative.

Some cancer patients may however turn to CAM as a result of being dissatisfied with BHC care^{39, 41}. Sirios and Gick⁴¹ report that such “push factors” may include ineffectiveness of BHC, concern about adverse effects, or bad experiences of patient-doctor communication. However, Thorne et al.⁴³ have carefully pointed out that the use of CAM among chronically ill patients does not “automatically signify an ideological opposition to BHC, although it can indicate a healthy skepticism for BHC as the exclusive basis for self-care and health promotion decisions.”^(p. 681)

It is debatable whether beliefs about health and sickness also influence people’s use of CAM in the context of cancer. Based on their qualitative interview study with women with breast cancer, Truant and Bottorff⁴² postulated that women’s choice of CAM in some cases depended on their conceptualization of the cause of the cancer. In contrast, however, Balneaves et al.³⁶ found no statistically significant association between CAM use and beliefs about cancer or treatment options among a group of women with breast cancer.

4.5.3 Studies of CAM efficacy

While few would disagree that it is important that evidence used to inform health care policy and practice is subjected to scrutiny, what counts as evidence is still a matter of debate. In this thesis I have viewed evidence in line with the proposition by Rycroft-Malone et al.⁴⁷ who argue that, given the centrality of the patient-provider relationship in professions within BHC for example nursing, evidence should be seen as something broader than that derived from research on efficacy. She argues that the recent political and financial focus on research evidence in relation to the efficacy of specific treatments has been at the expense of our understanding of other types of evidence. In addition to evidence on treatment efficacy, she suggests that evidence from clinical experience, patients and providers, and the local context and environment is also important⁴⁷. While the focus of this thesis is to explore aspects of evidence from patients and providers, I will here briefly summarize some of the evidence of CAM efficacy in the cancer context because of its impact on health policy decisions today.

The efficacy of an increasing number of CAM therapies has been tested in randomized clinical trials resulting in 53 CAM-related Cochrane Reviews⁴⁸. Although research evaluating CAM in the context of cancer is still scarce, studies have been conducted both in relation to effects on disease progression and survival, as well as effects on symptom relief and well-being.

The majority of studies on CAM efficacy in the context of cancer have focused on symptom management, reduction of complications from BHC treatment and palliative cancer care^{49, 50}. For example, in a Cochrane review, Ezzo et al.⁵¹ concludes that acupuncture-point stimulation is effective for post-operative nausea and vomiting among cancer patients. Based on their review, Wilkinson et al.⁵² also suggest that CAM in the form of massage is helpful for reducing anxiety and physical symptoms among cancer patients. Moreover, Smith et al.⁵³ suggest that mindfulness-based stress reduction is helpful for cancer patients in improving mood, sleep quality and reducing stress.

Few benefits related to disease progression and survival have been confirmed through randomized clinical trials. However, other types of data suggest promising therapies, including some dietary regimens, herbal remedies, and mind-body therapies^(e.g. 1, 54, 55). Mistletoe therapy is one of the most extensively researched herbal remedies used in the cancer context. Different researchers reviewing current research seem to agree that there is evidence of the efficacy of mistletoe to improve quality of life among cancer patients and to reduce adverse effects from BHC cancer treatments (e.g. chemotherapy, radiation)^{56, 57}. However, the same researchers disagree as to whether current research supports survival benefits from mistletoe therapy, suggesting the need for more high-quality, independent clinical research addressing this issue.

While the authors of some Cochrane Reviews on CAM^(e.g. 57) call for more efficacy studies in the form of high-quality randomized controlled trials, Fønnebo and Launsø⁵⁸ argue for the need to reassess the questions we ask about CAM use in order to improve the external validity of CAM research. The research presented in this thesis has been motivated by the need for improved external validity in CAM research with the long-term goal of refining future research questions to better reflect the ways in which CAM is used by individuals with cancer.

4.5.4 Risks of CAM use

The unregulated nature of many CAM products as well as CAM providers in many countries⁵⁹, presents challenges both to patients and health care providers who want to assure the safe use of CAM. In the absence of formalized educational standards for CAM providers, the risks associated with the practice of unqualified providers may increase. Moreover,

Zollman and Vickers¹⁴ suggest that an indirect risk in CAM use is the refusal of effective BHC treatment, delay of diagnosis, or use of ineffective but expensive CAM.

Some herbal products have also been found to be contaminated with heavy metals or adulterated with pharmaceutical substances⁶⁰. Risks associated with the use of BBTs including e.g. herbal products and dietary supplements, in the context of cancer include potential negative interactions with pharmaceuticals. Some herbal remedies may alter blood levels of pharmaceuticals, and antioxidants might diminish the anti-tumor effect of radiation therapy^{61,62}. Werneke et al.⁶³ found that warnings were issued about possible interactions or contraindications for 12% of patients using dietary supplements or herbal products as a treatment complement at a cancer center.

4.6 EXCEPTIONAL CASES

To bridge the gap between reported CAM user satisfaction and the lack of efficacy evidence, Fønnebo and Launsø⁵⁸ suggest systematically collecting successful case histories, also commonly referred to as “exceptional cases” or “best cases”. In this thesis, the data collection method has been inspired by approaches investigating best cases. Therefore, relevant efforts in this area are described here.

In 1991, the National Cancer Institute (NCI) in the United States initiated the still on-going Best Case Series (BCS) program, in which CAM providers who treat cancer patients, are invited to report 5-10 of their most successful cases⁶⁴. The NCI then assesses the reported therapeutic approaches through retrospective analysis. An ultimate best case series in the context of this BCS program consists of “*clear evidence of tumor regression in association with a CAM treatment that could not be attributed to other treatment or be expected from the known natural history of the disease itself.*”^{65(p. 553)}. The aim with the BCS program is to provide guidance on which CAM techniques merit further study in randomized clinical trials⁶⁴. As noted by Fønnebo and Launsø⁵⁸, similar initiatives have been conducted both in Germany and Denmark for limited periods of time.

The BCS at NCI has resulted in a number of hypotheses tested in clinical trials⁶⁶. For example, phase II trials have evaluated a special dietary regime for lung-cancer patients and a pancreatic proteolytic enzyme treatment for adenocarcinoma of the pancreas. Nahin's review⁶⁵ of 24 best case series based on the use of CAM in North America however, found that only six of these best case series fulfilled adequate standards of documentation. He therefore recommends additional rigor in the standard of best case series documentation to successfully impact on the research agenda⁶⁵.

In 2002, Fønnebo and colleagues at Nasjonalt Forskningscenter innen komplementær og alternativ medisin (NAFKAM) at Tromsø University, Norway established a “Best and worst case registry” for CAM use⁶⁷. As noted by the name, the NAFKAM approach aimed to document both what they refer to as best cases and worst cases. NAFKAM defines such cases as unexpected disease (i.e. not only cancer) trajectories in the context of CAM use in relation to symptoms, medical treatment, clinical findings, laboratory or diagnostic tests⁶⁷. They further specify worst cases as including for example serious adverse effects following CAM use. Although inspired by the NCI approach, which uses the endpoint of tumor reduction, the NAFKAM registry thus uses a broader definition of best and worst cases compared to NCI with a range of biomedical and subjective measures. Moreover, the NAFKAM approach differs from that of the NCI in that it also includes cases in which both CAM and BHC treatment have been utilized.

This thesis project originated as a part of the NAFKAM Best and Worst Case Series initiative. However, the design of this project differs from the NAFKAM Best and Worst Case Series registry in that it uses an open definition of what constitutes Best and Worst Cases, thereby inviting cases perceived as exceptional not only from the BHC perspective, but also from the perspective of the person reporting the case. In contrast to previous focus on the effect of certain CAM treatments in relation to exceptional sickness trajectories, the focus of this project is on patients' experiences in connection with the use of CAM.

5 DESIGN & DATA COLLECTION METHODS

The four papers in this thesis are based on data collected through qualitative interviews with patients, their significant others, CAM providers and BHC providers in 2004 and 2005. In this section, aspects of the study design common to all papers are presented. In Sections 5-8, I present the specific objectives and methods of analysis for each paper in conjunction with the findings from that paper.

Because I have explored multiple stakeholder perspectives in this thesis, I refer to participants with cancer using the terms *participants*, *individuals with cancer* or *patients* interchangeably. I would argue that the term *patient* is not appropriate in this thesis in part because this term assumes a particular role in relation to the BHC system, in part because some individuals interviewed did not report being a patient within the BHC system at the time of interview, and because some of the participants presented themselves as having multiple roles, e.g. being both a patient and a provider. Despite this, I have often used the term *patient* in this thesis as a shorthand term to easily distinguish the position of the individuals with cancer from other stakeholders.

5.1 QUALITATIVE DESIGN

Since there is a lack of previous research addressing CAM use among people with cancer in the Swedish context, in this thesis, I aim to explore CAM use through qualitative inquiry. According to Creswell⁶⁸, a qualitative study design is appropriate when a topic needs to be explored, i.e. when variables of interest cannot easily be identified or where theories that explain individuals' behavior or other phenomena are lacking.

The methodological design of this research was inspired by interpretive description described by Thorne et al.^{69,70} as a pragmatic approach that utilizes existing evidence of all kinds as a starting point for inquiry striving to further understand clinically relevant phenomena. According to Thorne⁷⁰ an inquiry is interpretive in that it may explore associations, relationships and patterns within a described phenomena going "*beyond the self-evident-including both the assumed knowledge and what has already been established- to see what else might be there.*" (p. 35).

This research utilizes qualitative interviews as the method of data collection. In this context, interviews are viewed as situations where various meanings of experiences are constructed and negotiated by participants. Mishler⁷¹ states that when telling about their experiences, people relate both to the events and their meanings. Moreover, the meanings of experiences are placed in particular social and cultural contexts^{72,73}. In this context, participants' accounts during an interview are viewed as products of an interrelationship of the interviewers and the interviewees. Mishler⁷¹ points out that during an interview situation, interviewers and respondents "*strive to arrive at meanings together that both can understand*" (p. 65).

This thesis utilized what Sandelowski⁷⁴ terms a mixed-methods approach in that both qualitative and quantitative analysis techniques have been applied. For each paper in this thesis, the specific research objectives guided the sampling of data from the larger data set, and the analysis techniques applied. Table 2 shows an overview of the samples and analytical techniques that are described more in detail in sections 6-9.

Table 2. General characteristics of papers I-IV.

Paper	Sample	Analytical technique
I	All participants with cancer (n= 38).	Manifest content analysis & Principal component analysis
II	Five cases with data from multiple stakeholders: patients (n=5), significant others (n=3), CAM providers (n=4), BHC providers (n=3).	Latent content analysis
III	One significant other.	Narrative analysis
IV	Twelve participants with cancer reporting BBT use (n=12).	Framework analysis

5.2 SAMPLING & DATA COLLECTION

The data sampling method for this project was inspired by the best and worst case series registry at NAFKAM. Flanagan⁷⁵ has termed the sampling of “exceptional” or “extreme” incidents critical incident technique (CIT). He argues for the study of extreme incidents as a way of also understanding that which occurs more commonly. While Flanagan describes his techniques of sampling with a focus on objective variables for what is considered critical incidents, Norman et al.⁷⁶ have further developed this sampling technique to include personal experiences of critical incidents. The aim of such approaches is to understand the meaning of the critical incidents as perceived by the respondents⁷⁶. In line with this aim the most appropriate unit of analysis is what Norman calls “happenings” revealed by critical incidents rather than the incidents themselves. As a sampling technique, Norman et al.⁷⁶ argues that CIT “seems capable of capitalizing on respondents own stories and avoids the loss of information which occurs when complex narratives are reduced to descriptive categories”^(p. 591).

In contrast to previous studies of best (and worst) cases, this study utilized an open definition for what was considered an exceptional trajectory (i.e. a best or worst case) and what was CAM. Swedish print media were used to invite reports with the question: “Do you have experiences of an exceptional course of cancer in connection to CAM use?”. In this request, an exceptional sickness trajectory was described as a trajectory perceived as related to “unexpected or unusual improvements or deteriorations of the health of people with cancer” (see Appendix 1). An open definition was also used for CAM, only specifying such use as outside the formal Swedish health care system and with a few examples given, indicating that CAM may include different kinds of medicines, modalities, self-care practices and prayer.

One advertisement was placed in the cost-free daily paper Metro. Three additional invitations were formulated in combination with longer articles about the research project in Dagens Nyheter, one of Sweden’s major daily newspapers, Tidningen Dagen, a Christian newspaper issued four days a week, and in Amazona, a magazine published by the breast cancer patient organization. In addition, I personally invited case reports in presenting the project at two oncology clinics, one CAM clinic and one patient organization.

In response to our concerted efforts to locate cases of exceptional cancer trajectories, we received 52 reports through phone calls, e-mails and letters from patients (38 reports), significant others (4 reports) and CAM providers (10 reports). Of the initial 52 case reports, we were able to follow up 38 cases with patient interviews (see Figure 1). There were various

reasons why we could not follow up the remaining 14 cases. Although reporting their cases to the project, some patients also said they did not have any time, while others said they were too sick, and one report was provided after the death of the patient. Reports concerning the 38 cancer patients included in the interview study came either from the patients themselves (n=28) or from CAM providers (n=10). No BHC providers reported cases to the study.

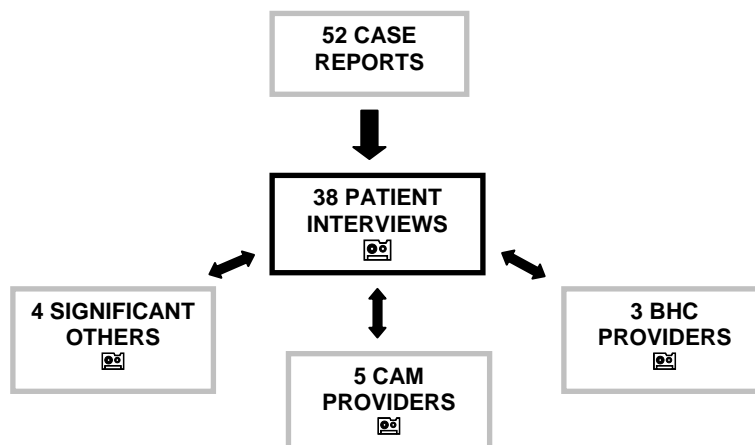


Figure 1. Overview of data collection.

The study comprised 31 women and 7 men with cancer, 36-85 years old (median= 55 years old, IQR^a= 48-63 years old), half of which reported living with a partner at the time of the interview. Various malignant diagnosis were reported although the majority of participants (n=24) reported primary breast or gynecologic tumors. Fifteen participants reported having metastasized cancer. Reported time between first diagnosis of cancer and time of interview ranged from 1-32 years (median= 5 years, IQR= 1-13 years) (see Table 3 & Table 4).

While the purpose of our recruitment was to locate both exceptionally positive and negative accounts in conjunction with cancer and CAM use, we only received reports of cancer trajectories framed as positive. Although we received no reports in which the cancer trajectory was framed as negative, some specific individual experiences were framed as negative.

Between April 2004 and November 2005, I interviewed 24 patients who were included in the study and Dr Anette Forss interviewed an additional 14 patients. The interviews with patients were of open character and generally lasted between one and two hours. At the beginning of the interviews, I gave a brief description of the project followed by one or several initial guiding questions or remarks such as “*Where did it all start for you?*” or “*Please tell me what happened to you*”. The interviews took place at a location chosen by the respondents, either in their homes, at the research unit or elsewhere. Thirty-six participants consented to the interview being audio-recorded and later transcribed verbatim. Detailed interview notes were taken after consent from two participants who were uncomfortable with audio-recording. All patients were given fictitious names.

^a The inter-quartile range (IQR) indicates data values within the 25% - 75% interval of the total range of data.

Table 3. Reported characteristics of patients.

	Frequency (n=38)
Age	
≤40 years	3
41-50 years	9
51-60 years	13
61-70 years	6
>70 years	5
Age unknown	2
Sex	
Female	31
Male	7
Marital status	
Married or common-law	19
Divorced//Widowed/Single	15
Unknown	4
Occupational Status	
Working full-time	7
Working part-time	2
On sick-leave	7
Retired	9
Unknown	13
Education	
College education	20
Elementary school + High School	4
Unknown	14

Table 4. Reported disease characteristics.

Primary Cancer	Frequency (n=38)
Breast	17
Gynecological	7
Stomach, Colon and Rectum	4
Lymphatic leukemia	2
Lung	2
Prostate	2
Other sites	4
Metastasized disease	15
Median time since 1st cancer diagnosis (years)	5 years

Other stakeholders involved in the 38 patient cases were pragmatically selected based on consent from patients and accessibility. In total, interviews were conducted with four significant others, five CAM providers and three BHC providers. These interviews differed from the interviews with patients in that an individual interview guide was used for each specific situation. I constructed these guides through reviewing the patient interview and noting the areas I was most interested in discussing. The location for these interviews as chosen by the respondents was either at their work/home or at the research unit. All but one of these interviews were audio-recorded and later transcribed verbatim. Detailed notes were taken after consent from one CAM provider who was uncomfortable with audio-recording. These stakeholders were also assigned fictitious names.

Interviews were transcribed verbatim either by me or by two research assistants. Transcription rules regarding how to handle pauses, false starts, emotional expressions etc., were agreed upon to assure conformity between different interview transcriptions as well as different transcribers⁷⁷.

5.3 ETHICAL CONSIDERATIONS

As standard practice for all research involving people, this study has been conducted in accordance with the ethical principles defined in the World Medical Association Declaration of Helsinki⁷⁸. As part of the study design, predictable risks and burdens for the individual

participants were assessed. Ethical approval was received from the Karolinska Institutet Regional Research Ethics Committee (Dnr 03-610).

The voluntary participation in this project was emphasized by the researchers from the start as well as participants' ability to withdraw participation at any time. Following participants' initial presentation of interest in the study, the researchers provided information about the study aim and the research procedures, including information about the interview and that all information shared with the researcher would be confidential. On this occasion, participants were also informed that the researcher would also want to record the interview, so that they could consider that before they consented to doing the interview. While most participants consented to having the interview be recorded, three participants declined. In these particular cases, the researcher took detailed notes instead, having obtained the participants' consent. Participants chose the interview place of their preference, either at home, in a public place, or at a centrally-located research unit. After the interviews were conducted, the participants signed a formal written consent form.

Although it was beyond the scope of this study to collect and analyze data from medical records, we nevertheless asked for participants' consent to obtain such records in the same written consent form at the time of interview for the purpose of data gathering to the Scandinavian Best and Worst case registry at NAFKAM, Tromsø University.

In cases where a report was not filed by the individual with cancer him/herself but rather by another stakeholder, researchers always established initial contact with the individual with cancer via telephone, e-mail or letter, providing information about the study as well as informing that participation was voluntary. This was also the procedure when other stakeholders- significant others, CAM providers and BHC providers- were contacted after receiving patients' consent. The interview procedure with all stakeholders followed the same ethical practice as stated above.

Since, in some cases, this research involved interviews about one patient from different stakeholder perspectives, it was clearly stated both in the oral and written information, that information from each stakeholder would also be held confidential in relation to other stakeholders involved in the same case.

Another ethical concern in this study involved legal issues in relation to the Swedish law that prohibits non-biomedical health care providers to treat cancer diseases³⁰. There was a possibility that this study would reveal cases in violation of this law, which could potentially prevent CAM providers (and patients) from reporting their cases to the study. We decided we would not initiate legal proceedings around any cases of possible violation of this law. Worst cases would be published in accordance with scientific principles allowing for confidentiality of the involved participants, while at the same time allowing for disclosure of a problem.

6 PAPER I: MAPPING PATTERNS OF CAM USE IN CANCER: AN EXPLORATIVE CROSS-SECTIONAL STUDY OF INDIVIDUALS WITH REPORTED POSITIVE “EXCEPTIONAL EXPERIENCES”

The paucity of research on CAM use in the Swedish context justified an open definition of CAM, allowing study participants to report any therapy they considered to be CAM. This approach to documenting CAM use also complemented previous international surveys on CAM use that primarily have used questionnaires with pre-defined definitions of CAM. The specific objective of paper I is:

- To explore patterns of CAM use among cancer patients with reported exceptional cancer trajectories.

Reports of CAM use by all 38 study participants were explored using two methods of analysis. Manifest content analysis was used to describe CAM use in relation to one current categorization system, while principal component analysis was used to statistically explore patterns of CAM use.

6.1 STEP 1: MANIFEST CONTENT ANALYSIS

6.1.1 Analysis

Therapies, practices and systems reported by the 38 participants as being used outside the formal BHC health care system were coded using the qualitative data analysis program NVivo⁷⁹. To describe these CAM, the widely used CAM categorization system by National Center for Complementary and Alternative Medicine (NCCAM), National Institutes of Health, U.S., was used. Manifest content analysis was used to categorize CAM into the following five categories of the NCCAM system with focus on the obvious, visible components of the described CAM without interpretation of its underlying meaning⁸⁰: *Alternative Medical Systems*; *Mind and Body Interventions*; *Biologically-Based Therapies*; *Manipulative and Body-Based Therapies*; and *Energy Therapies*, which are further distinguished into the subcategories *Biofield therapies* and *Bioelectromagnetic-based therapies*.

6.1.2 Findings

These 38 participants described using a total of 274 CAM representing 148 different therapeutic modalities (see Table 5 and Figure 2). The participants reported using 1-26 therapies each (median=4, IQR=1-8). The majority of participants reported being in contact with a CAM provider (n=32), although 6 participants reported self-care use only. Most of the 274 reported therapies could be classified according to the system of NCCAM. However, 50 CAM were not consistent with this categorization system and we therefore introduced two additional categories- *Spiritual/health literature* and *Treatment centers*- resulting in a system of seven CAM categories.

6.1.2.1 New empirically-derived CAM categories

The categories *Spiritual/health literature* and *Treatment centers* were empirically derived, based on participants' descriptions of such modalities as therapeutic. These categories were reported by 15 participants each. Participants described literature as therapeutic, both in the sense of providing pragmatic recommendations on how to improve health or combat disease and/or as a source of emotional and spiritual support. Daniella for example, described how a

pamphlet about special diet for cancer patients gave her pragmatic recommendations on diet, referring to this in religious terms: "And then I received a pamphlet, it turned out to become like a Bible to me, it has the title 'Diet list for people with tumor disease' ...". Ofelia described how a book gave her emotional support and comfort, acting as inspiration rather than practical advice:

"Instead of reading about breast cancer I read a book by Bernie Siegel, Love, Medicine & Miracles. And it gave me everything! I didn't read anything else. /.../ he argued that each one should take an active role in one's improvement. /.../ I experienced comfort there [through the book]."

In descriptions of *Treatment centers*, participants emphasized the environment of these centers as well as their encounters with staff and other patients, rather than the specific therapeutic modalities utilized there. For example, Victor and his spouse described their feeling on arrival at such a center as "coming home", with the sense of being "one big family" with the other patients and staff at the center. The reported treatment centers could be placed on a continuum with varying levels of integration of different therapies, from use of psychosocial interventions in a BHC setting, to integration of BHC and CAM treatments.

6.1.2.2 CAM utilized by category

Overall, therapies within the category *Biologically-based therapies* (BBTs) were the most common type of CAM described within this study, reportedly utilized by 27 of 38 participants. This category also comprised the greatest variety of therapies, with 77 different modalities described. *Mind-body interventions* and *Energy therapies* were also commonly reported by 23 versus 21 individuals. The majority of therapies reported to this study were only utilized by one or two participants (see Table 5). Eight CAM, however, were reported by six or more participants: art therapy (painting) (n=6), counseling (n=6), mental practice (n=6), meditation (n=9), mistletoe therapy (n=16), healing (n=10), the book *Love, Medicine and Miracles* by Bernie Siegel (n=6) and, the anthroposophic treatment center Vidarkliniken (n=10).

The need for expansion of the NCCAM categories with two empirically derived categories, suggest a discrepancy between user and professional conceptualizations of CAM use. The seven category system presented here suggests a less technical and therapy-specific view of CAM compared to the NCCAM categorization.

Table 5. CAM therapies as described by participants sorted into seven CAM categories. Five categories have been defined by NCCAM while two categories are empirically derived (underlined). Number of participants reporting a certain CAM is indicated in parenthesis (if more than one).

NCCAM CATEGORIES	Total number of therapies reported	Number of individuals reporting therapies
ALTERNATIVE MEDICAL SYSTEMS antroposophic medicine (6), homeopathy (3), traditional Chinese medicine	10	10
MIND-BODY INTERVENTIONS painting (6), music, dance, sculpturing, counselling (6), support groups, mental practice (6), relaxation techniques (2), eurythmy (3), gestalt therapy, bonitology (2), kinesiology, prayer (3), meditation-various types (9), family constellations, visualization (3), rehabilitation program, rosen method body work	50	23
BIOLOGICALLY-BASED THERAPIES aloe vera (2), angelica, antioxidants (5), apis, ayurvedic preparations, birch ash (2), blutsaft, cayenne pepper, cetraria, chalk, charchole, chinese herbal medicine, cypress, coffee enema, dendrite cell treatment (2), ecomer, edta, enzymes (2), field horsetail, fish oil, garlic (2), geranium, ginger, ginseng, helixor (2), iceland lichen, inhalation mixture- chamomile, peppermint and lemon balm, iscador (14), juniperberry, kan yang, lactase enzyme, lavender, lemon concentrate (2) lemon grass, lemon balm, linseed bandage, lycine, magnesium (2), marjoram, micro-algae, mung bean sprouts (2), new castle virus (2), nouni (2), olibanum, ozone therapy (2) quercetin, pankreon, probion, proline, proteas, radish, raw food diet, rosemary, sage (2), sandal wood, saw palmetto, selen (2), shark liver oil, silica, silymarin, silver, sodium ascorbate, sodiumselen respond selen, sulfur, supergreens, THX, valerian root, vegan diet, vitamin A, vitamin b, vitamin C (3), vitamin D, vitamin e (5), walnut supplements, wheat grass juice, yarrow, zinc (2)	115	27
MANIPULATIVE AND BODY BASED THERAPIES acupuncture (3), chiropractic care, feldenkreis, fever baths, herbal baths, local and whole body hyperthermia (2), stretching, lymph massage (2), alternative surgical procedure, soft tissue massage	14	12
ENERGY THERAPIES Biofield therapies: healing (10), qi gong (4), tai chi (2), yoga (3), reflexology, color therapy, homeopathic remedies (gold, arsenic, barium-iodate, viscum/mesenchym comp, conium maculato)rn) Bioelectromagnetic-based therapies: ECT-laser (3), frequency medicine (2), magnetic field therapy (3), plasma lamp therapy	35	21
EMPIRICALLY DERIVED CATEGORIES		
<u>SPIRITUAL/HEALTH LITERATURE</u> <i>A Course in Miracles</i> - author unspecified, Bays Brandon- <i>The Journey</i> (2), Chopra Deepak- <i>Perfect Health</i> , Ehdin, Sanna- <i>The Self-Healing Human</i> (4), Gawler Ian- <i>You can conquer cancer</i> , Hamer Gerhard- <i>The New Medicine</i> (3), Pollak Kay- <i>Att välja glädje</i> [only in Swedish], Hayes Louise- no specific book, Alexander Marcus- <i>Kvantmänniskan</i> [in Swedish], Preben Maria- no specific book, Moss Ralph- <i>Cancer & CAM information</i> , Shine Betty- <i>Mind to Mind</i> , Siegel Bernie- <i>Love, Medicine and Miracles</i> (6), Sai Baba- no specific book, Simonton, Carl- <i>Getting Well Again</i> , Stern Bengt- <i>Feeling bad is a good start</i> (3), Walsch Donald- <i>Conversations with God</i>	31	15
<u>TREATMENT CENTERS</u> <i>Centro Antroposofico</i> - Antroposophic center, Spain; <i>Furusjön</i> - Health retreat, Sweden (2); <i>Humlegården</i> - Alternative Clinic for cancer patients, Denmark (2); <i>Lustgården</i> - Rehabilitation unit for cancer patients, Sweden, <i>Mösseberg</i> -rehabilitation for cancer patients, Sweden (2), <i>Vidarkliniken</i> - Antroposophic hospital, Sweden (10), TCM hospital combining TCM and BHC, Germany	19	15

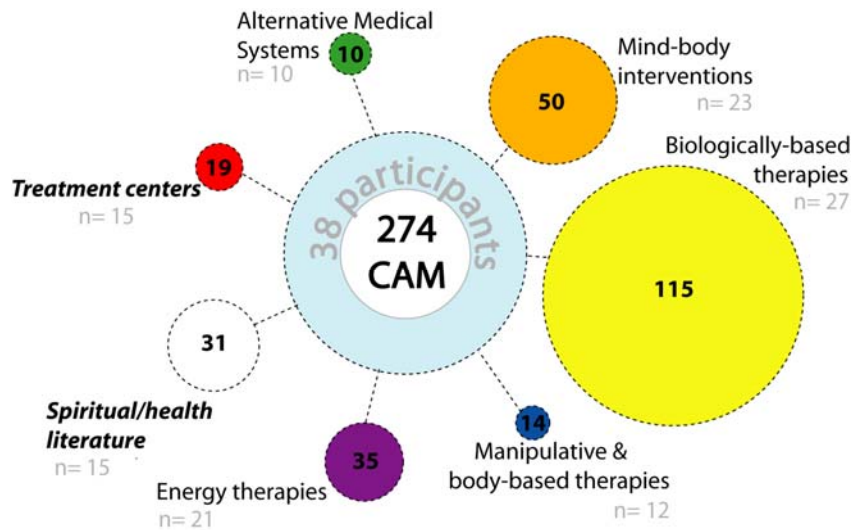


Figure 2. Overview of the reported CAM therapies in seven categories. Empirically-derived categories are presented in bold. The figures in the circles represent number of therapies reported for each category. The grey figures indicate number of participants (n) reporting use of the categories.

6.2 STEP 2: PRINCIPAL COMPONENT ANALYSIS

We were unable to qualitatively identify patterns of CAM use with the level of sophistication desired. Therefore, our next step was to attempt to disentangle this variability by exploring patterns of CAM use with the statistical explorative technique, principal component analysis.

6.2.1 Analysis

To further explore patterns of CAM use, we used Principal Component Analysis (PCA). PCA serves to reduce dimensionality of data while retaining as much possible of the variation of the original variables. Participants' use of therapies within each of the seven CAM categories were listed with the numbers 1-26 depending on the number of therapies utilized. From this data, a 7x7 matrix was created, from which listing of the co-occurrence of therapies from the seven categories was made (e.g. listing how many times therapies from the category *Biologically-based therapies* were utilized together with therapies from therapies within the category *Mind-body interventions*). From these original data, the principal components (PCs) and the proportion of variance explained by each of them were calculated in the program R using mathematical formulas standard for PCA⁸¹. Principal components one and two were selected for further analysis, representing 63% of variability of the original data. The relationships between the categories were first displayed as vectors (i.e. PC loadings, see figure 3) indicating that all categories have positive scores on the loadings of PC1, while PC2 loadings are both positive and negative. We interpreted this as indicative of PC1 representing the number of therapies used and PC2 the preference for type of CAM therapy used (on a continuum with *Alternative medical systems* and *Treatment centers* opposite from *Energy therapies*). Based on the number of therapies used within each category, the scores of the first two PCs were then calculated for each user, giving an indication of each user in relation to the first two PCs (see PC scores in figure 4) where we interpret the x-axis as representing the number of therapies used by each individual and the y-axis as the category preference.

6.2.2 Findings

The PCA resulted in a graphical approximation of correlations between the seven CAM categories. In Figure 2, CAM categories are shown as vectors. A small angle between vectors

represents a strong correlation between the category use and an orthogonal angle between categories represents independence between category use. Based on correlations between use of certain categories, the seven CAM categories were grouped into three pairs and one singleton: a) *Energy therapies and Spiritual/Health literature*, b) *Manipulative and body-based therapies with Mind-body interventions*, and c) *Alternative medical systems with Treatment centers* and d) *Biologically-based therapies* standing on its own. This suggests that for example *Energy therapies* are in this sample often utilized in combination with *Spiritual/Health literature* while therapies from both these categories are less frequently used together with therapies from *Alternative medical systems* or *Treatment centers* (orthogonal angle between categories representing opposition).

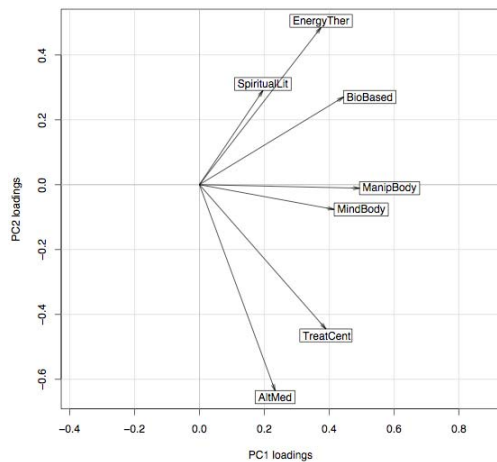


Figure 3. A display of the first two principal components indicating relationship between CAM categories.

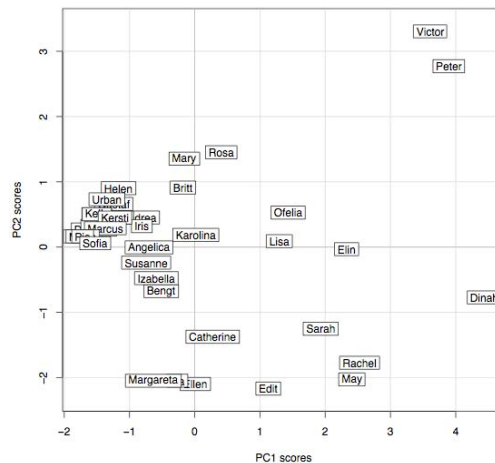


Figure 4. User profiles of study participants presented with their scores along the first two principal components indicating number of therapies reported (x-axis) and type of category preference (y-axis).

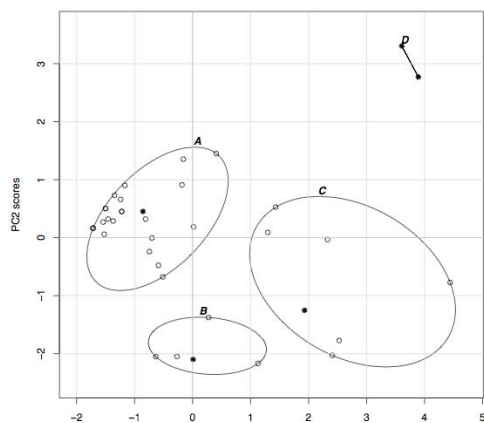


Figure 5. A four-cluster grouping of the participant profiles shown in figure 4.

The two factors explaining the largest proportion of variation in CAM use among the study participants were a) number of CAM therapies used and; b) a category preference for *Energy therapies* over the categories *Alternative Medical Systems* and *Treatment centers* or vice versa. Based on this variation in CAM use, individual user profiles were created for each of the 38 individuals. Figure 4 displays these user profiles with the x-axis representing the number of therapies used and the y-axis representing the CAM category preference.

Individuals with high scores on the x-axis have a reported use of a large number of CAM therapies and individuals with high positive scores on the y-axis indicate a preference towards therapies from the

categories *Energy therapies* and *Alternative Medical Systems*. A cluster analysis of the individual user profiles suggests a grouping into four clusters (see Figure 5) with 63% of participants in one dominant cluster, characterized by a preference towards the *Energy therapies*' end of the spectrum and use of less than average number of CAM therapies. Beyond the large number and wide variety of CAM therapies reported in this study, this analysis thus suggests some patterns in these participants' CAM use. Two main factors as

differentiating CAM use in this group were identified; the number of CAM utilized and the type of CAM utilized. In line with this, CAM users' preference for different CAM categories may exist along a spectrum, raising the hypothesis that use of therapies from one CAM category may be interrelated with use (or non-use) of therapies from another CAM category.

7 PAPER II: WHAT IS AN EXCEPTIONAL TRAJECTORY? MULTIPLE STAKEHOLDER PERSPECTIVES ON CANCER TRAJECTORIES IN RELATION TO CAM USE

In line with the idea behind critical incidents as described by Flanagan⁷⁵ and Norman⁷⁶, and the open definition of exceptional trajectories used in this thesis, paper II explores different stakeholder perspectives of cancer trajectories reported as exceptionally positive. The specific objectives of paper II are:

- To explore how different stakeholders- patients, their significant others, CAM providers, BHC providers- conceptualize exceptional cancer trajectories and;
- To explore how these stakeholders discuss possible explanations for the reported trajectories.

7.1 ANALYSIS

This paper is based on an analysis of different stakeholder perspectives of five cases reported as exceptional. The perspectives used for the analysis were those indicated by patients, i.e. who was regarded as a CAM provider, a BHC providers etc. The data consist of 16 interviews with patients, their significant others, CAM providers and BHC providers (see Table 6). The five cases in focus in this analysis were pragmatically selected, based on the availability of data from multiple stakeholder perspectives and represented the four different user profiles suggested in paper I (see Figure 5).

After reading the interviews in their entirety, interview excerpts of relevance for the research objectives were selected. These excerpts were then divided into meaning units consisting of one or more sentences, centered around a cohesive topic⁸⁰. These meaning units were then condensed into more abstract terms and labeled with codes.

7.2 FINDINGS

All stakeholders in this paper framed the reported cancer trajectories along a continuum between the exceptionally positive and the ordinary with varying emphasis on well-being and/or long-term survival. Regardless of whether patients' trajectories were described as exceptional or not, all stakeholders discussed possible explanations for these positive trajectories as either related to agency and responsibility or BHC and/or CAM treatments.

7.2.1 Exceptional well-being

Exceptional well-being was similarly described by patients, significant others and CAM providers both as related to unexpected long-term survival and as an outcome independent of disease progression and/or an unknown future. Andrea exemplifies how well-being could be described in direct relation to improvements in disease: her "*test results improved*", she was "*feeling better*" and that she was happy "*life [was] becoming normal again*". In contrast, others described well-being as a quality experienced despite advanced disease. Victor's spouse for example said: "*This large tumor, like, oh my goodness, how can he go around with that and still feel as GOOD as he does?*". Regardless of its described relation to disease state, well-being was often described as a feature of that which was considered "*normal*". Moreover, well-being was described by patients in terms of physical strength and the lack of experienced side effects of BHC treatments. BHC providers did discuss patients' well-being, but did not refer to well-being in relation to the exceptional sickness trajectory.

Table 6. Overview of collected data. Patient characteristics and information about the representation of stakeholder perspectives for each case.

PATIENT CASE	Approx. age	Sex	Site of primary cancer	Survival time (years) since diagnosis of recurrence or metastasis, at time of interview	Survival time (years) since recurrence or metastasis, as noted 2008	BHC	CAM	SIGNIFICANT OTHER
Andrea	53	Woman	Cervix (recurrence)	3	7 [#]	x	x	x
Catherine	58	Woman	Uterus (metastasized)	4	> 7	x	x*	-
Dinah	58	Woman	Breast (metastasized)	2	> 5	x	x*	-
Victor	48	Man	Lung (initial diagnosis with metastasis)	3	4 [#]	-	x*	x
Peter	63	Man	Prostate (recurrence)	3	> 6	-	x**	x

Deceased after interview.

* CAM provider is also a licensed BHC physician.

** CAM provider is also the patient in this case.

7.2.2 Exceptional long-term survival

All stakeholders mentioned aspects of long-term survival in relation to the reported sickness trajectories. Patients and significant others tended to relate their length of survival to their own or their BHC/CAM providers' expectations. Victor for example, referred to his CAM providers' words: *"Once when we got there [to the CAM provider], he looked at me and said: 'What the hell are you doing here? You should be dead' [laughter]"*.

CAM and BHC providers normalized the reported trajectories, although the forms for this differed between provider groups. CAM providers referred to long-term survival as on the one hand being a common occurrence within their practice, but on the other hand, as being an exceptional occurrence in a context outside their own clinic. Victor's CAM provider for example, described Victor's case as one among many *"good cancer stories"* in his clinic's *"long row of cases"*. In contrast, Dinah's CAM provider framed Dinah's long-term survival as clearly exceptional also within his own frame of reference:

"For me, this is a best case /.../ and I have had a number of patients... let's say 20-30 patients over the years, who have consulted me with metastasized cancer diseases /.../ I have never [otherwise] seen liver metastasis in regression."

In contrast to CAM providers, BHC providers described patients' long-term survival as within the normal limits of disease and treatment response, as for example illustrated by Catherine's BHC provider: *"It [Catherine's type of cancer] often has a very serious course, but in this case it's a slowly growing tumor and you can live with it for many years, and she [Catherine] has done that, it's almost 20 years now."* In line with this, BHC providers could describe patients' trajectories as representing successful, but not exceptional, tumor control.

7.2.3 Agency and responsibility

Patients, significant others and CAM providers shared the view that having an active role and taking responsibility for their illness had positive effects on their sickness trajectories. Peter for example said: *"As I believe, the trajectory has been influenced by the fact that I've taken responsibility /.../ I'm convinced of that"*. Taking an active role in one's sickness was explained both as a personal characteristic and an approach determined by the patient. Patients, significant others and CAM providers in this study emphasized that agency involved a job and that it was important to be active in treatment decision making, to find out about the causes of disease to enable change and to recognize the need for and accept help from others.

BHC providers spoke about the importance of patients' involvement in their treatment and disease as having a psychological benefit rather than as something that could affect the sickness trajectory per se. Andrea's BHC provider for example, said that it was important that Andrea felt that she *"had done what she can"*.

7.2.4 Treatment-related attributions

Stakeholders attributed exceptional trajectories to both specific therapies as well as to combinations of therapies. Patients and their significant others explained the reported exceptional trajectories referring both to specific treatments and to the result of the combined use of BHC and CAM. Andrea for example, described one particular CAM therapy as *"a life line"* but also attributed her recovery to a combination of BHC and CAM treatments saying:

"...you could say I have put a lot of trust into X [CAM therapy] /.../ it has felt like a very important source of security /.../when I started. Yes, that's perhaps the most important thing [for my recovery] but it is hard to say, because it is also a combination of different things... it is really hard to say what is what, what would have happened if I hadn't taken that last course of chemotherapy and what would have happened if I had not done X [CAM therapy]..."

In contrast to patients and their significant others, BHC and CAM providers primarily explained patients' improvements as related to one or several treatments within their own sphere of practice. Dinah's BHC provider for example attributed Dinah's improved state of disease to an anti-hormonal treatment:

"Well, I have more patients than [Dinah] who have had the same, what we call tumor burden /.../ who have responded well to anti-hormonal treatment only, or this endocrine therapy. So even if it doesn't work for everyone, it works for sufficient number [of patients] for this effect to come only from this anti-hormonal treatment."

Similarly, but with reference to a combination of several therapies, Dinah's CAM provider referred Dinah's improvements: *"I see X [a manipulative and body-based therapy] as most important, in addition to her changes in diet and the dietary supplements"*.

8 PAPER III: USING NARRATIVE ANALYSIS TO UNDERSTAND THE COMBINED USE OF CAM AND BHC

Both paper I and II indicate discrepancies in views of CAM between the health care sectors that may be of clinical relevance, possibly impeding communication between sectors. Findings from paper I suggest that the definition of CAM may be broader and less technical from a patient perspective than in current professional definitions. In paper II, discrepancies between patients' and providers' (both BHC and CAM) attributions of sickness improvements are described. Patients' tended to relate improvements to a wide range of therapies as well as their own active role while providers primarily related improvements to treatments within their own sector of health care. This indicated a lack of common ground for discussing experiences of CAM in relation to cancer, which is of particular interest in relation to the third study exploring a significant other's perspective on using CAM in conjunction with BHC treatment. The specific objective of paper III is:

- To explore *how* a personal narrative is told, in addition to *what* is told, in order to see how the meaning of the negotiation between different therapies is created.

8.1 ANALYSIS

For this analysis, an interview with a significant other was selected based on its' rich descriptions of negotiations between different CAM and BHC therapies. This interview transcript was viewed as a long narrative about how "Christian", the narrator, experienced his deceased partners' use of an herbal tea in conjunction with their encounters with BHC professionals. Interpretations were based on analysis of both narrative content and structure⁸²⁻⁸⁴. The interview was first divided into 14 narrative acts that had different and distinct subplots, each with clear beginnings and ends⁷¹. The meanings of all these narrative acts were interpreted, and based on the relevance for the research objective, two narrative acts were selected for detailed structural analysis. These two acts were broken down into narrative stanzas to facilitate closer attention to structural and linguistic features of the narrative such as the narrator's use of pronouns, verb forms and his use of other actors' voices (see Figure 6).

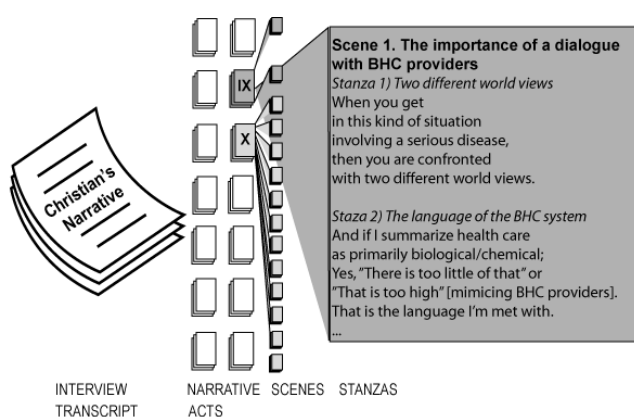


Figure 6. Overview of the structural narrative analysis process.

8.2 FINDINGS

Although the narrator describes BHC and CAM as representing two different world views, he is able to negotiate a story in which these are combined. This analysis suggests that the BHC may remain in a vital role as a frame of reference for the use of certain CAM modalities. The detailed instructions for how the tea is supposed to be taken and the cause-and-effect reasoning suggest that the tea is taken just like other medications. The herbal tea and BHC medications were thus interpreted within the same frame of reference, although the herbal tea is not an accepted part of the BHC system. Through this analysis, it also becomes evident that one individual may have several simultaneous purposes for using one CAM as illustrated here by an herbal tea, which is initially viewed as used for symptom relief while later in the narrative it is described as being used as a potential cure for cancer.

The importance of the BHC sector in relation to self-care CAM use is illustrated through the presence of BHC providers throughout the narrative. The narrator describes the dialogue with BHC as very important although problematic, describing his own position as “*vulnerable*” in relation to BHC professionals, saying that he and the BHC professionals had two different “*worldviews*”, speaking two different “*languages*”. Through the detailed analysis of two narrative acts, a variation of perspectives of CAM within the BHC sector becomes evident with examples both of what are perceived as good and bad examples of communication about CAM with BHC providers. Negative experiences of communication with a BHC provider are described in relation to a lack of interest in the herbal tea. Aspects of loneliness in relation to the use of BBTs without this BHC provider’s interest become evident through the narrator’s use of the pronouns “*I*” and “*nobody*”. While the narrator describes himself as open both to the possibility that the tea has no effect and that it actually has an effect, the attitude of the BHC physician is described as “*unscientific*”. The BHC physician is given the name “the Joker” as to indicate his antipathetic role. The narrator has, through his attitude towards the herbal tea, positioned himself as an advocate of scientific rationality while the BHC provider is identified as unwilling to apply his belief system in practice, denying visible empirical evidence. In the end of the narrative act, the narrator’s attitude towards this BHC physician expands to encompass the entire BHC system.

In the second act, the narrator describes a contrasting positive experience of a BHC physician who showed interest in the herbal tea. While the narrator does not describe this physician as believing in the potentiality of the tea, there is no conflict between the physician and the narrator who believes in the potential effect of the herbal tea. In his perceptions of the dialogue between himself and this physician, the narrator makes room for opposing views. This physician is given the nickname “*Dr Oncology Clinic*” in contrast to “*the Joker*”. The narrator’s perceived sense of collaboration with this physician is viewed through his use of the pronoun “*we*” in descriptions of how they cared for his spouse. A perceived reconciliation takes place between the narrator and the BHC system; hierarchical roles diminish as the “*I*” versus “*they*” become the collaborative “*we*”.

9 PAPER IV: LAY PERSPECTIVES ON THE USE OF BIOLOGICALLY-BASED THERAPIES IN THE CONTEXT OF CANCER: A QUALITATIVE STUDY FROM SWEDEN

The focus on the use of Biologically-based therapies (BBT) in paper IV was driven by findings in paper I as well as in previous research suggesting that BBTs represent the most commonly type of CAM used by cancer patients (see description of reported BBTs in Table 5)¹. As indicated by paper III, negative experiences of communication about CAM and BBTs between BHC providers and patients/significant others may influence the overall perception of the BHC system. With previous research also indicating that patient- provider communication about BBT is poor^{85, 86}, and that physicians may underestimate how many of their patients are using BBTs⁸⁷, an increased understanding of lay perspectives on BBT use is justified. The specific objective of this paper was therefore:

- To explore lay perspectives on the use of biologically-based therapies in conjunction with cancer.

9.1 ANALYSIS

Patient interviews with 10 women and 2 men reporting BBT use were selected for qualitative analysis. With the intention to achieve a sample representing a variation of BBT use, these interviews were selected on the basis of the analysis in paper I and with attention to variation in: number of BBTs reported by each participant; use of BBTs as alternative or complementary to BHC care; different ways of combining BBTs with other types of CAM and; the use of BBTs with varying regulatory status. Selected participants represented all four user profiles as indicated in paper I, Figure 5. Of the 12 participants, 8 reported having metastatic or recurrent disease.

The analysis was inspired by the qualitative approaches of framework analysis⁸⁸ and interpretive description^{69, 70} that share the common goal of generating results that are relevant both for clinical practice and policy. Four categories derived from extant literature in the field were used to guide the initial analysis: CAM is safe; Belief in efficacy; Sense of control and; Disadvantages of the BHC. As the analysis progressed we revised these categories into six categories relevant for patients' continued BBT use.

9.2 FINDINGS

The 12 participants reported using a total of 45 different BBTs with the majority (40 BBTs) of these regulated as dietary supplements, three as natural remedies, two as pharmaceuticals with temporary legal exemption, and two BBTs used without national authorization.

The qualitative findings suggest that certain manners of reasoning could function to facilitate continued BBT use, whereas other kinds of reasoning could either facilitate or prevent continued BBT use, depending on the situation (see figure 7). Reasoning which stimulated continued use involved perceptions of: *BBTs as harmless*; *BBTs as contributing to improved physical and psychological well-being*; *BBT use playing a role in cancer-related benefits* and; *Negative experiences of or expectations on BHC treatments*. Reasoning that could either facilitate or prevent continued used, depending on the situation, included: *Perceived side effects ascribed to BBT use* and; *Self-administration of BBTs*.

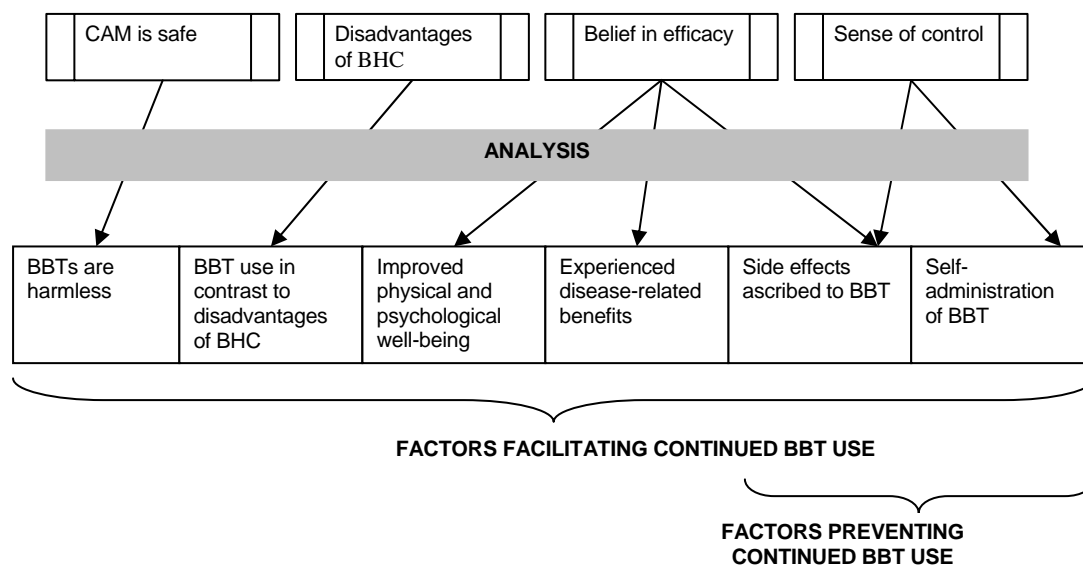


Figure 7. Factors facilitating or preventing continued BBT use.

9.2.1 Facilitators for continued BBT use

9.2.1.1 BBTs as harmless

Participants described experiencing BBTs as causing no harm with the only negative feature being the possibility that these therapies would have no effect at all, as illustrated in the following quote: *“Feels good not to have any foreign poison running around in my body. Worse case scenario would be that nothing happened.”*

Views of BBTs as harmless were common across different legal classifications. Participants also spoke of their BHC providers as either uninterested in or passively supportive of their BBT use.

9.2.1.2 Improved physical and psychological well-being

Participants described a wide range of improvements perceived as related to BBT use. This was most commonly described in general terms such as becoming *“healthier”* or specified as improved physical function and/or psychological well-being. For example, one participant described improved physical function: *“I felt the effects of the enzymes, the cell nutrition and the lactoplus. Right away I felt things settling down in my body somewhere. My sleep was more relaxed, I felt /.../ much more alert physically.”* Other participants spoke of perceived improvements in terms of physical well-being as interrelated with psychological well-being:

“Taking some Vitamin C is enough. That gives you a bit more vitality. It’s not coffee even if that makes you more alert, that’s a kind a vitality that’s wrong. In the spring you get vitality. And when you feel vitality your soul usually feels better too.”

9.2.1.3 Cancer-related benefits

Positive features related to BBT use were also expressed in terms of an experience of a reduced tumor burden, symptom relief or prevention of recurrent disease. Benefits related to tumor burden were often framed in terms of improved BHC measures:

“It [BBT] was very good at first. When I started, my tumor markers were at 520 and they went down to 100.”. Symptom relief was framed in relation to one’s own experiences: “I woke up at two o’clock in the morning. My lymph glands felt like balloons fit to burst. There’s no doubt about it. These two drops [BBT] under my tongue and I get much less trouble.”.

9.2.1.4 BBTs in contrast to disadvantages of BHC

Participants commonly described positive experiences of BBTs by contrasting them with experienced or expected negative side effects of BHC treatments. Side effects from BHC treatments were explained as having a negative effect on one’s whole person, while side effects from BBTs were generally experienced as fewer in number and milder:

“However strong the reaction (side effect) they have had from their [BBT], that reaction is nowhere near the one [side effect] you have to endure with chemotherapy drugs. /.../ So I don’t feel motivated for the side effects (of the chemotherapy drugs) at all. I feel motivated for the side effects of this [BBT]. There are very few of those.”

9.2.2 Factors acting as either facilitators or obstacles for continued BBT use

Experiences of side effects perceived as related to BBT use as well as self-administration of BBT use, seemed to trigger either continued or stopped use of BBTs, depending on individual circumstances.

9.2.2.1 Self-administration of BBTs

Self-administration of BBTs was described by participants as facilitating continued use when they experienced circumstances that allowed them to manage and control the situation by themselves:

“I started injecting mistletoe /.../ I did it myself, didn’t want to burden anybody. And then I started injecting myself in my armpit, you see you can do that with your left hand by using a mirror, so injecting oneself, you can bloody well do lots. Stuff you wouldn’t think you could do.”

In contrast, self-administration of BBTs was at other times described as placing participants in a vulnerable situation that could potentially lead to termination of use due to the lack of help and support from BHC:

“And I get injections [of BBT] there, empty injections, [I said] ‘Then you [BHC provider] have to help me, how am I supposed to take this [mistletoe] myself, cos’ I’ve never put a needle in an arm before’. That really frightened me. But I really wanted to. And so then she just said [BHC provider] ‘Don’t bring that here, we’re not going to help you with that’ ”.

9.2.2.2 Side effects ascribed to BBT use

Although side effects from BBTs were rarely described in this material, when they were, it was in both positive and negative terms. When described as positive, these side effects were experienced as mild and/or taken for granted and often with a dose-response logic explained as linearly related to effect:

“My dose, I wish it was more concentrated [of BBT]. So that I got a proper reaction. The people in country x must have had a stronger reaction because they were given so incredibly much more (higher dose). They’ve also had incredibly much stronger effects.”

When explained in a negative sense, side effects were described as disturbing symptoms in relation to a perceived lack of effect of the treatment overall: *“The levels [tumor markers] doubled, went through the roof/.../ Of course, even before that I felt that I shouldn’t continue with this [BBT] since I wasn’t feeling well, stomach pain.”* .

10 DISCUSSION

The aim of this thesis is to explore perspectives on CAM use among individuals with cancer in connection to reported exceptional sickness trajectories. All cases reported to this study were framed as exceptionally positive. The findings of paper I suggest great diversity in CAM use with 38 patients using a total of 274 CAM therapies consisting of 148 different therapeutic modalities, with BBTs representing the most common and most diverse type of CAM. Two patterns of CAM use were identified: related to number of CAM therapies, and preference for different types of CAM. Current professional CAM categorizations did not fully cover descriptions of CAM use in this study. Patients, their significant others, and their CAM and BHC providers framed the reported sickness trajectories along a continuum between the exceptionally positive and the ordinary, with stakeholder groups varying in their focus on well-being and long-term survival (Paper II). Patients described a wide range of benefits related to CAM use, including aspects of physical and psychological well-being, as well as disease-related benefits (Paper II, IV). Side-effects of BBTs could be interpreted by patients as positive or negative depending on the specific situation (Paper IV). In paper III and II patients and significant other emphasized the importance of a dialogue about CAM with BHC providers. The findings from paper III suggest that from a lay perspective, communication about CAM perceived as positive may be indicative of a shift from a hierarchical to a more collaborative relationship.

In this Section, I will discuss different contexts in which these findings may be understood and applied. I will discuss the findings in an integrated manner, followed by methodological considerations. Finally, I will discuss implications of this research on the levels of practice, policy and research.

10.1 DISCUSSION OF FINDINGS

Below, I discuss findings that are central to several of the papers in this thesis in relation to four main areas: Diversity of CAM use; The focus on well-being in relation to exceptional experiences; Sense of agency; and Discrepancies in patient-professional views on CAM and the importance of the patient-provider relationship.

10.1.1 Diversity of CAM use

While paper I suggests diversity in the number and types of CAM utilized by this group of participants, papers II and IV suggest yet another type of diversity, i.e. in terms of the perceived benefits following CAM use. These benefits were said to range from disease-related benefits to well-being. In general, both types of diversity are in line with previous research on CAM utilization (e.g.1, 36, 89) and the acknowledged difficulties of defining the field of CAM¹⁵. While in paper I, we attempted to disentangle some of this diversity through the exploration of patterns of CAM use, I here discuss diversity as a phenomenon in itself.

Although the findings of this thesis are not statistically generalizable, the CAM use suggested is strikingly similar to the findings of both Balneaves et al.³⁶ and Molassiotis et al.¹ with regard to the diversity of CAM modalities reported, the high proportion of women in the sample and BBTs as the most commonly reported type of CAM. Boon et al.⁴⁵ suggest that the diversity of CAM use is part of users' perception of BHC and CAM cancer treatment options as a "smorgasbord" from which they "pick and choose". With little previous knowledge about CAM use in the cancer context in Sweden, it is impossible to know how CAM use described in this group of patients relates to the use of CAM among cancer patients in Sweden in general. However, given the similarities to other studies, these findings give no indication that

CAM use among this group is significantly different from CAM use in other groups of cancer patients using CAM with regard to these factors.

The 38 study participants in this thesis were hypothesised to represent what Balneaves et al.³⁶ refer to as committed CAM users. This assumption was based on the recruitment strategy employed in this study, the level of initiative demanded for participants to actively contact the researchers, and the high commitment to CAM suggested in the qualitative analyses here (papers II and IV). However, the variation in CAM use with regard to number and types of CAM, suggests difficulties characterizing committed CAM use in terms of number of therapies, which is one of several defining characteristics Balneaves et al.³⁶ proposed. The findings from papers I and III suggest that commitment rather might be characterized either by the loyal use of a limited number of therapeutic modalities or by the use of a large number of different CAM therapies. This suggests two different types of commitment, either to one or several specific CAM modalities, or commitment to CAM in a broad sense that may be attributed to a lifestyle. This suggestion is, however, somewhat limited, since it is based on findings from a relatively small group. Other variables suggested to characterize commitment to CAM use by Balneaves et al.³⁶, such as frequency of CAM use, effort associated with this use and expenditure, have not been explored. Despite this, these findings raise the hypothesis that it may be difficult to quantify commitment to CAM use, suggesting diversity in patterns of CAM use even among committed users.

The findings in papers II and IV resemble those of previous studies suggesting a diversity of reasons for CAM use^(e.g. 89, 90). The findings from paper III also reflect this diversity on an individual level, indicating that one CAM method may be used for multiple purposes simultaneously. Interestingly, our expectation that experiences of different types of CAM would differ was not fulfilled. Instead, we found no difference in descriptions of experiences of BBTs (paper IV) and other types of CAM (paper II), nor do these descriptions differ notably from those in the literature. However, due to the cross-sectional nature of this study, these findings share the limitations of many other studies of users' reasoning about CAM use in that they cannot be used as a basis for distinguishing between individuals' motives for initiating CAM use, and reasons for continuing to utilize CAM.

Goldstein⁹ describes some aspects of this diversity in his definition of holism as a core characteristic of CAM, expressing a belief that "*the whole is greater than the sum of the parts*" with an emphasis on the "*uniqueness of the factors that produce health or illness for each individual*"^(p. 4). He also points out that "*what will work for one individual may not work for someone else*". This description of holism seems to resonate well with the described diversity of CAM in papers I, II and IV. Through these analyses, we noted that participants described the importance of their individual approach to the cancer sickness, attributing improvements to their own active role as well as to CAM and BHC treatments. The emphasis on individual strategies of dealing with cancer has also been reported by both Berland⁹¹ and Egeland⁹² in the qualitative explorations of people surviving cancer with poor odds. Egeland⁹² for example, describes that patients were resistant to giving other patients specific advice, instead emphasizing the importance that treatments made sense to the individual him/herself. Similarly, Berland⁹¹ states that:

"The findings here clearly suggest that there is no 'right way' to heal. Some participants, the 'determined fighters', focused their attention on fighting to survive. Others prayed, visualized, changed their attitudes about themselves, and altered how they lived their lives. Still others believed their healing derived from a transformational shift that deepened their sense of meaning and purpose."^(p. 17)

The diversity of approaches represented by CAM may thus be seen as a repertoire of healing resources. Along this line, Harrington⁹³, in her historical review of the mind-body therapies suggests that these need “*to be appreciated as a set of narratives that offer people a diverse set of cultural resources to make sense of their experiences.*” (p. 245)

With support from previous research, the findings of this thesis thus suggest that the diversity of CAM may, from a patient perspective, be seen as an asset. This potentiality of the diversity in CAM use should therefore be accounted for in various efforts that strive to gain more specificity about CAM use, such as efforts to categorize and evaluate CAM use. For example, the findings of paper I suggest a possible limitation of the NCCAM categorization system from the views of CAM users. Future research needs to explore the value of the two categories *Treatment centers* and *Spiritual/health literature* described in Paper I, to better accommodate CAM users’ views in CAM categorization systems. In the context of implementing evidence-based health care where evidence, according to e.g. Rycroft-Malone⁴⁷ includes patients’ experiences, the appreciation of the diversity of CAM by patients, should also be accounted for as important evidence in conjunction with other kinds of evidence, e.g. the efficacy of specific CAM modalities.

10.1.2 The focus on well-being in relation to exceptional experiences

Experiences related to CAM use in connection to the exceptional trajectories reported here (paper II, IV) ranged from specific disease-related benefits to a sense of agency related to one’s role in the treatment process. Due to this wide range of experiences, I find it appropriate to use the term exceptional *experiences* instead of *trajectories* to emphasize participants’ focus on their experiences of sickness as opposed to a focus on cancer disease and its progression. This is also to emphasize that it was beyond the scope of this thesis to assess objective variables of cancer trajectories.

Findings from papers II and IV suggest that patients’ and significant others’ accounts related to the reported exceptional trajectories and CAM use cover a variety of experiences ranging from disease-related benefits to general well-being. Many of these characteristics resemble those found in previous research on patients’ experience of CAM use⁹⁴⁻⁹⁶, that also suggest a wide range of experiences related to well-being, while aspects related to disease specific improvements are less pronounced. Moreover, findings from paper II suggest that while some patients conceptualize well-being as related to disease state, others expressed well-being irrespective of this. This resembles the way Goldstein⁹ describes another of five key characteristics of the CAM field, namely the positive definition of health. He argues that “*The lesson CAM offers is to seek the meaning of health independently of symptoms and disease*”^(p.8).

These different ways of conceptualizing the relationship between the cancer disease and well-being, resemble two different kinds of illness narratives termed by Frank⁹⁷ *restitution narratives* and *quest narratives*. Restitution narratives, according to Frank⁹⁷, have a basic plot that reads along the lines of “*Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again*”^(p.77). It is thus a narrative focused on cure and life becoming normal again. Frank further states that “*Medicine’s [here referred to as BHC] hope for restitution crowds out any other stories*”^{97(p. 83)}. Quest narratives on the other hand, he means are told by individuals “*in search for alternative ways of being ill*”^{97(p. 117)}. Essential for a quest narrative is to undergo some kind of transformation during the “*illness journey*”. These stories imply that “*the teller has been given something by the experience, usually some insight that must be passed on to others*”^{97(p. 118)}. Paper II shows examples similar to both kinds of narratives. For example, Andrea’s own description of her situation resembles a restitution narrative in the way

she focuses on being free from cancer at the time of interview. Catherine's reported experiences on the other hand, are reminiscent of a quest narrative in her emphasis on well-being despite advanced disease, referring to how "*one can live a good life anyway*".

While the conceptualizations of exceptional trajectories formulated by patients, significant others and CAM providers show characteristics of both restitution and quest narratives (paper II, III and IV), the same conceptualizations of BHC providers were primarily related to characteristics of restitution (paper II). This mirrors the common use of the term "exceptional cancer trajectories" portrayed in research^(e.g. 65, 98) as well as popular literature⁹⁹ in relation to survival or cure from cancer, i.e. characteristics of the restitution narrative.

The presence of quest narratives in the findings of this thesis is particularly interesting, considering the data collection method, using the term "exceptional trajectories", which to my knowledge has previously been reported only in association with restitution types of narratives, i.e. where an exceptionally positive trajectory is characterized by cure of disease. This is likely to be a feature of our data collection method in which we did not define the term "exceptional sickness trajectories" (as has been done in other research).

Differences in conceptualizations of exceptional experiences as well as explanations of perceived effects of CAM may thus be understood in the light of illness narratives of restitution and quest. The wide range of perceived benefits of CAM related to well-being (paper II and IV) resemble characteristics of quest narratives, where the focus is on the *process* of care rather than the *outcome*. This emphasis on the process of care as opposed to its outcomes is also reminiscent of what Muir Grey¹⁰⁰ suggests as one characteristic of post-modern medicine, which incorporates current social concerns and trends in health care practice. In clinical practice, the focus on process versus outcome may be important in relation to understanding different kinds of hope among patients. As Ezzy¹⁰¹ suggests, the hope of recovery in restitution narratives is very different from the "transcendent hope" that may be expressed through quest narratives where the goal is rather to find new ways of experiencing time and reality.

Patients', significant others' and CAM providers' focus on exceptional well-being in the findings of paper II may also be viewed in the context of the larger health care system as possibly reflecting Swedish legislation³⁰ that prohibits non-licensed providers to treat cancer and limits cancer treatment by licensed BHC providers to the principles of "science and tested experience". This legislation may in part explain why the interviewed CAM providers, three of whom were also licensed BHC physicians, tended to emphasize their patients' exceptional well-being.

The focus on well-being may also be seen in light of most CAM therapies not being part of the publically-financed health care system in Sweden. CAM providers may thus have a greater need for legitimization compared to providers within BHC^{102, 103}. Tovey¹⁰⁴ distinguish between formal and professional legitimization processes in his discussion of U.K. alternative practitioners and inter-sectoral acceptance. He describes professional legitimacy as "*the acceptance or denial of the occupational validity of practitioners or groups by another*" and formal legitimacy as "*a matter of political inclusion and exclusion*"¹⁰⁴. In these findings professional legitimacy may have been a factor in the interviews with CAM providers, as the study was based at a medical university. Patients reporting exceptionally positive experiences of CAM use in combination with BHC may have a need for formal legitimization considering their extensive use of CAM as self-care therapies. The hypothesized desire for different forms of legitimization of CAM use may thus have attracted both patients and CAM providers to report cases to this study. However, it is possible that the limits of the Swedish health care act

may have influenced others in the opposite direction, i.e. not to report cases to this study due to the legal restrictions.

The findings from this analysis thus suggest the importance of understanding the contexts in which different stakeholders conceptualize exceptional sickness trajectories. These findings may also be understood in relation to the lack of a public sphere for discussing experiences related to CAM use in the cancer context in Sweden.

10.1.3 Sense of agency

The findings of this thesis suggest that participants experienced a sense of agency facilitated by CAM use (paper III, IV), which was also said to contribute to exceptional experiences (paper II). I suggest that the sense of agency in these findings was related to a variety of interrelated features that included engagement in treatment decisions (paper II, IV), support from others (paper II, IV), finding explanations of possible psychological causes for cancer (paper II), and dealing with a sense of vulnerability (paper II, IV).

Previous research has also emphasized that CAM users report a sense of agency and/or personal responsibility in relation to treatments and treatment decisions^{45 42, 105}. Boon et al.⁴⁵ suggest that this sense of agency among CAM users may be based on the perception, as mentioned earlier, of BHC and CAM cancer treatment options as a “*smorgasbord*” from which they “*pick and choose*”. They further argue that CAM use may be more common among people who are comfortable with personalized decision-making rather than among those who primarily follow recommendations from an authority figure. In line with this proposal, it is interesting to note that the findings from paper III suggest that engagement in CAM also involves engagement in BHC treatment decision-making.

In papers III and IV, a sense of agency is shown to be a double-edged sword with potentially both negative and positive aspects. A sense of agency is most commonly described in the research literature in relation to positive characteristics. The study by Balneaves et al.¹⁰⁶ is however an exception, the findings of which resemble those of papers III and IV, suggesting that in their study, women with breast cancer experienced what they termed a role conflict in relation to CAM and the decision-making process. They describe this role conflict in relation to the various roles taken on by these women including “...*being an information gatherer and evaluator, a liaison between conventional and CAM health professionals, and a decision-maker.*” (p.978). In light of dealing with this vulnerable position, it is interesting to note that neither Verhoef et al.⁹⁵ nor Koitan et al.⁹⁶ mention similar issues in the qualitative explorations of patient experiences of integrative health care. This may have several reasons; one may hypothesize that such experiences are there but were not revealed in these studies. Given the discrepancies between patient and professional views on CAM in this thesis, it may however be more likely that integrative health care, where providers are given the role to inform about and provide both CAM and BHC, do eliminate these aspects of experiencing vulnerability.

One may hypothesize that it is to avoid such vulnerability that patients also described the need for support from others as another aspect related to a sense of agency (papers II and IV). Along the same lines, Verhoef et al.⁹⁵ and Young¹⁰⁷ suggest that one part of the CAM experience is to feel connected to a larger group. This suggestion is mirrored in descriptions of the CAM category *Treatment centers* in Paper I where patients expressed feeling like “*one big family*” and “*coming home*”. Findings from paper II also suggest that patients valued the meetings with other patients at treatment centers, describing being strengthened by other patients that could act as positive role models.

The emphasis on a sense of agency in the findings of this thesis as well as in previous literature on CAM use may also be seen in relation to a wider cultural context where the WHO in its definition of health also underscores individuals' own responsibility for health¹⁰⁸. Goldstein¹⁰⁹ also points out similarities between CAM and the fitness movement with regard to the emphasis on personal responsibility. Similarly, individual responsibility is also emphasized in health promotion¹¹⁰. Along this line, Al Windi¹¹¹ found in a cross-sectional survey from Swedish primary health, that those who used certain CAM modalities (i.e. manipulative and body-based therapies) also exercised more regularly than those who did not use these CAM therapies. Although this may be a feature of the specific type of CAM use investigated in his study, it supports the notion that CAM use may not be an isolated phenomenon.

Goldner¹¹² further suggests that the personal responsibility emphasized by many CAM users and providers serves as a "slogan" for what she conceptualizes as a consumer movement. Viewing CAM use in certain situations as a kind of social activism acknowledges the impact of CAM users on the political, not just the medical agenda¹¹² and provides an additional way of understanding the sense of agency coupled with CAM use and the reports of exceptional experiences in this thesis.

10.1.4 Discrepant views on CAM between patients and professionals and the importance of the patient-provider relationship

All of the papers in this thesis indicate some degree of discrepancy between patient and professionals views of CAM. In paper I, we suggest that there are differences between users' and professionals' categorizations of CAM. In paper IV, we note that side effects perceived as related to BBT use can be interpreted by users as a positive sign of the treatment effect. Both these findings appear to contribute new knowledge to the literature. The analysis of paper II suggests there are also discrepancies in the way in which patients and providers (BHC and CAM) explained treatment-related improvements. While patients explained their own improvements as related to their own engagement as well as BHC and CAM treatments, BHC and CAM providers explained improvements as a consequence of treatments within their own sphere of practice only.

The discrepancies suggested by the findings in this thesis are particularly important in the light of the findings by Richardson et al.¹¹³ who propose that discrepancies in views on CAM between patients and their BHC providers may be one of the barriers to communication about CAM. Communication about CAM is important both in relation to patient safety and in relation to the perceived importance of such communication by patients and significant others themselves, as suggested by the findings of paper III.

Although some researchers suggest that communication about CAM use may have increased as the cultural acceptance and information about CAM has improved⁸⁹, other reports still suggest that many cancer patients do not talk to their BHC physician about their CAM use^{85,86,114}. Kao et al.⁸⁷ propose that physicians are also likely to underestimate the use of CAM by their patients.

In line with other research^(e.g. 115), Christian's narrative in paper III suggests that a perceived attitude of indifference or lack of interest may be a barrier to communication about CAM. It is interesting to consider these findings in light of the results of Koithan et al.⁹⁶ who found that the positive experience of the provider-patient relationship was one of the reported benefits from an integrative medicine facility providing both BHC and CAM. Koithan et al.⁹⁶ also found that while the patient-provider relationship in some cases was perceived as one of the

most beneficial aspects of integrative medicine, when it was dysfunctional, it was perceived as the most disturbing aspect of all. These findings are well supported by the findings in paper III in the examples of “*The Joker*” and “*Dr Oncology Clinic*”. These findings are also interesting in relation to the findings of Tishelman et al.¹¹⁶ who found that over one quarter of their sample of 400 lung cancer patients report that some aspects of their contact with the BHC health care system was the cause of the most distress experienced at one or several points in time during the first year after diagnosis.

The suggested importance of a dialogue about CAM with BHC providers is also interesting in light of the importance of the patient-provider relationship in CAM practices according to Goldstein⁹. Sharma¹¹⁷ points out that in CAM, the patient and provider are partners in a cooperative process aimed at healing. Moerman¹¹⁸ suggests that providers are one of the most important sources for patients’ knowledge and meaning and therefore the providers’ conviction regarding the power of their treatments is essential to treatment outcome. He thereby refers to one aspect contributing to the phenomenon of placebo or the meaning response, which I find to be a preferable term, as important to all health care practices provided by practitioners, both BHC and CAM. Kaptchuk¹¹⁹ argues that for a number of reasons, the meaning response may be enhanced in patients’ consultations with CAM providers compared to consultations with BHC providers. Kaptchuk¹¹⁹ means that one aspect contributing to this difference may be that a diagnosis by a CAM provider is more likely to resemble patients’ own perceptions compared to a diagnosis by a BHC provider. Along the same line, Moerman¹¹⁸ suggests that a meaning response may be more pronounced in patients meeting with some CAM providers, since CAM providers may have experienced the benefits of their own treatment themselves more often than BHC providers. CAM providers may therefore be more “convincing” about the usefulness of their treatments¹¹⁸. These aspects of the meaning response are interesting in relation to the findings from paper II that propose discrepancies in views between patients and BHC providers regarding their views on well-being in relation to the cancer disease while the same discrepancies were not found between patients and CAM providers in this regard. However, it should be noted that the findings of paper II also suggest that comparisons between the views of different stakeholders should be made with caution, given the difficulties in classifying stakeholders. Two CAM providers were also BHC providers and one patient was also a CAM provider himself.

The findings related to the patient-provider relationship of this thesis coupled with the extant literature in the area thus emphasize CAM users’ perceived importance of the patient-provider relationship both with regard to their contacts with BHC providers and CAM providers.

10.2 METHODOLOGICAL CONSIDERATIONS

In line with the aims of this thesis, these results should be discussed in terms of analytical generalizability rather than statistical generalizability. Analytical generalizability is described by Kvale¹²⁰ as a “*reasoned judgement about the extent to which the findings from one study can be used as a guide to what might occur in another situation*” (p. 233). Rather than trying to identify the most common experiences of CAM use, this thesis has explored situations perceived as exceptionally positive by those involved. Such inquiries are directed toward envisioning new possibilities of thought and action¹²⁰.

10.2.1 The lack of reports of exceptionally negative trajectories

As mentioned earlier, we only received reports framed as positive despite our initial call and later efforts to recruit both positive and negative cases. Interestingly this is reflected in the literature on CAM users’ experiences, which primarily involves positive experiences of CAM. Reports of cases regarding cancer to the Scandinavian Best and worst case registry at

NAFKAM, Norway are also only framed by those reporting as positive, with 58 received positive reports as of April 2009¹²¹.

Although the reports to this study were all framed as positive, some negative experiences coupled to CAM use were reported, such as the side effects as presented in paper IV. Reasons for the lack of negative reports in this study may be related to a number of other factors. One possible explanation may be related to the phrasing in our invitation of case reports: “*Do you have any experiences of exceptional sickness trajectories?*” The findings in paper I suggest that several participants had read popular literature^(e.g. 99) where the term exceptional trajectories is associated with positive rather than negative trajectories. If this term is associated primarily with positive trajectories, negative reports may have been deterred by this heading, despite the fact that the more detailed text of the invitation specified both positive and negative reports.

Moreover, individuals who have had negative experiences of CAM may have experienced deterioration in their health, which may have prevented them from reporting to this study. Given that CAM use is often initiated by individuals themselves, and that most CAM is used outside formal cancer care, issues of shame and blame may also have prevented people from reporting such experiences to the researchers, who are based at a well-known medical university.

The findings from paper IV also point to another possible reason for the lack of negative reports, namely the way CAM users conceptualized experiences related to CAM, for example side effects perceived as related to the use of BBTs, may be perceived as positive if interpreted as sign of effect.

10.2.2 Trustworthiness

Issues of trustworthiness have been addressed throughout the research process. While trustworthiness in quantitative research is often said to rely on the concepts of validity, reliability and generalizability, the terminology of trustworthiness in qualitative inquiry varies depending on the tradition in which the research is conducted⁷³. In this study, I have related issues of trustworthiness to four areas identified by Thorne⁷⁰: *Epistemological integrity*; *Representative credibility*; *Analytical logic*; and *Interpretive authority*.

10.2.2.1 Epistemological integrity

Thorne⁷⁰ refers to *epistemological integrity* as the coherence between the assumptions of the nature of knowledge and the design of the research. In this research, my standpoint has been to acknowledge multiple co-existing perspectives on a reality that is contextually constructed, rather than striving to reveal an “objective view” of reality. I agree with Kvale¹²⁰ who describes such a stance: “*Today- with a delegitimation of global systems of thought- there is no longer a stable foundation to support a universal and objective reality*”^(p. 41).

In this thesis, I utilize both quantitative and qualitative analysis techniques. The explorative statistical method principal component analysis was utilized in paper I to explore patterns of CAM use. Due to the large number of therapies reported to the study, we found it desirable to quantify the reported therapies in order to explore patterns of CAM use, that we had not been able to identify through qualitative exploration⁷⁴. This analysis provided useful information on variations in CAM use that was also used for the sampling of individuals for the qualitative analyses in papers II and IV. While some researchers argue that qualitative and quantitative methods cannot be mixed because they represent different paradigms, Sandelowski⁷⁴ reasoned that these different techniques of analysis are not paradigm-linked in themselves. Rather, it is

the way they are utilized that determines whether they can be used with epistemological integrity or not.

10.2.2.2 *Representative credibility*

According to Thorne⁷⁰, research in which the theoretical claims are consistent with their sampling strategy shows *representative credibility*. Factors influencing representative credibility include the variation in study sample in relation to the focus of the study, the time and engagement in the phenomenon under study, and the triangulation of data sources⁷⁰. The sampling of participants for this study was pragmatic based on both time and economic constraints. Accepting the sample size of 38 individual cases was based on the amount of data that we considered reasonable to handle within the scope of the study aims, methods and time frame. Despite this pragmatic sampling approach, our sample has considerable variation with regard to characteristics identified as important by previous research. For example, our sample includes participants who both used CAM as a complement to BHC and as an alternative to BHC treatment. Also, the type of CAM reported as utilized was shown by paper I to be distributed in all NCCAM categories. Participants also reported different stages of cancer disease with some describing total absence of disease at the time of interview while others described having an advanced metastasized disease. The number of men participating in the study (n=7) may be seen as a limitation, although women are also over-represented among CAM users in general¹.

The analysis of paper I enabled sampling of participants for papers II and IV, based on variation in participants' reported use of number and type of CAM. While this facilitated variation in the samples on the level of CAM characteristics, the single data collection limited our ability to draw on analytical insights for further sampling. For example, while the findings in paper I suggested an importance of CAM within the empirically derived category *Spiritual/health literature* there was a lack of rich descriptions on this issue in our data. This indicates a need for particular awareness of aspects related to spirituality in future studies in this area. Besides this, we found that the sample of 38 individuals was large enough to incorporate aspects that proved significant during the course of our analysis.

Since this sample of individuals is self-selected through mass media without contact with a treatment center, the sample is likely to reflect CAM use during different stages of the cancer trajectory. This is a difference from many other studies of CAM use that recruit participants through hospitals while patients are undergoing BHC treatment. Like many other studies of CAM use, a limitation of this study is its cross-sectional nature, making it impossible to explore CAM use over time.

10.2.2.3 *Analytical logic*

The third aspect of trustworthiness described by Thorne (2008) is an *analytical logic* that “*makes explicit the reasoning of the researcher from the inevitable forestructure through the interpretations and knowledge claims made on the basis of what was learned in the research.*”^(p 224).

As a researcher engaged in this project, I have strived to keep an open mind in relation to the issues appearing relevant in the analysis of the interviews while simultaneously addressing the findings of international research in this field which pointed towards issues of particular clinical relevance. This balance act between my own pre-understanding of clinically pertinent issues and what appeared to be important and new issues appearing during the research process influenced all levels of the research process. For example, the use of previous research

varied with papers I and IV using analytical frameworks based on previous research to guide the analysis, while in papers II and III, we used a more open analysis.

10.2.2.4 Interpretive authority

The fourth criteria for trustworthiness described by Thorne⁷⁰ is *Interpretive authority*, which serves to assure the reader that the findings presented by a researcher do not just reconfirm the researcher's preconceived ideas. This requires for example that the reader needs to be able to get a grasp of the researcher's background, intentions and interests in the area of study. In the early phases of this research, being a novice to qualitative research, I strove to approach the study participants with what Patton⁷³ terms *empathic neutrality*. This is described as the researcher approaching respondents with interest and understanding, albeit taking a stance that is nonjudgmental and neutral towards the respondents' thoughts, emotions and behaviors⁷³. During the course of this research, I have found it difficult to be 'neutral' in meetings with participants, since I noticed that the information that was shared became much more nuanced when I, as the researcher, also responded to participants' concerns. In some instances, this meant that I shared my own experiences, however usually I tended to respond to participants by formulating further questions. For example, some tension between the fields of BHC and CAM was obvious in some of the interviews. In these cases, I found it helpful to relate and reflect on my own experiences both related to my role as a licensed pharmacist and from my participation in an educational program in the oriental body therapy modality Shiatsu.

During the analysis processes for the different papers, a diversity of interpretations and reassessments were encouraged by the involvement of our entire research team with experiences from different research and clinical fields.

10.3 IMPLICATIONS

“We desperately need new knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience- not so that we can advance theorizing, but so that we have sufficient contextual understanding to guide future decisions that will apply evidence to the lives of real people”^{70(p 36)}.

The findings of this thesis add to a further understanding of a number of aspects of CAM use in the context of cancer. As the first study of CAM use among cancer patients in Sweden that explores multiple types of CAM, I however also view this thesis as a starting point to inform and inspire further initiatives in this area on practice, policy and research levels, as discussed below.

10.3.1 Implications for education and clinical practice

In line with previous research^(see e.g. 115, 122), the findings of this thesis point to the importance of patient-provider communication about CAM in several ways. For example, the diversity of CAM use (paper I), showing a large portion of unregulated BBTs (paper IV), and the documented safety risks, both with regard to the quality of CAM⁶⁰ and the risks for interactions between BHC cancer treatments and BBTs, indicate the importance of a patient-provider dialogue about CAM. Importantly, it has also become clear that patients and significant others perceive a dialogue about CAM as important, and that such a dialogue may influence the patient-provider relationship (paper III).

Given the findings of this thesis coupled with previous research, it seems imperative to urge all health care providers within BHC to actively initiate a discussion about CAM use with their

patients. Nurses and pharmacists are two professions for whom this issue may be particularly relevant. Nurses' role in communication about CAM may be particularly important in the light of the greater amount of time they often spend with cancer patients compared to physicians, and that they may therefore have more opportunities to discuss CAM. As the only licensed health care providers with compulsory basic education in BBTs, pharmacists are well suited to help assure safe and effective use of BBTs by guiding patients to evidence-based information and addressing risks of interactions with BHC treatment^{123, 124}. Since research suggests that both nurses and pharmacists may hold uninformed views about CAM¹²⁵, educational initiatives about CAM for these and other BHC groups are important. Given the wide spectrum of benefits users ascribe to CAM use (papers II and IV) and with reference to the findings of Tasaki et al.¹¹⁵ that patients perceived BHC providers' focus on scientific evidence to be a potential barrier to communication about CAM, it is important that future educational initiatives include aspects both related to users' motivations and experiences of CAM, and aspects related to the quality, safety and efficacy.

Resembling the definition of evidence as proposed by Rycroft-Malone et al.⁴⁷ the Swedish Council on Technology Assessment in Health Care¹²⁶ states that the implementation of evidence-based health care should include the acknowledgement of patients' needs and preferences. The findings of this thesis points towards a number of patient preferences regarding CAM, e.g. the diversity of CAM, the patient-provider relationship, sense of agency, and a wide range of experiences of well-being. These aspects need be considered, in conjunction with other types of evidence, in the implementation of guidelines as to how BHC providers should relate to their patients' CAM use.

10.3.2 Implications for policy

The importance of a patient-provider dialogue about CAM and the discrepant views about CAM between patient and professional stakeholders described in the findings of this thesis, suggest tensions between the three health care sectors. The lack of formal discussion about CAM in cancer care is also apparent in the absence of any discussion about CAM in the new Swedish cancer strategy¹²⁷ and other important policy documents^(e.g. 128). In light of the suggested frequent use of CAM among cancer patients and the influence of this use on patient satisfaction and safety, this lack of formal acknowledgement of CAM use is notable.

From a global perspective, formal acknowledgement of a need for increased collaboration between health care sectors has however increased during the last 15 years with an increasing number of countries addressing such collaboration in policy documents as well as laws with Norway being one notable example¹²⁹⁻¹³¹. The development towards increased collaboration between health care sectors is in line with the suggestions that CAM use is not a isolated phenomenon but rather something that affects and shapes health care systems and ways of dealing with health and illness in their entirety^{16, 132}.

Although the results of this thesis point to specific needs in the area of cancer care, Tovey, Chatwin and Broom¹³³ argue that due to the particular popularity of CAM among cancer patients, the study of CAM in the cancer context may make particular issues underlying the biomedical/CAM dynamic more visible. The extent to which the results of this thesis are relevant even for other patient groups should therefore be considered.

As suggested by the findings of paper IV and previous research¹, BBTs represent the most common and heterogeneous type of CAM. Therefore it is notable that only a small portion of the BBTs reported to this study are regulated with regard to quality and safety. This implies obvious risks for patient safety. While some systems for BBT surveillance are in place^(e.g. 134),

adverse effects and interactions involving BBT use are still likely to be underreported¹³⁵. The results of paper IV lead to the hypothesis that users may not report side effects of BBTs if they view these effects as being positive, an issue important for further consideration in the design of effective surveillance systems.

As Cassileth and Deng¹³⁶ point out, the popularity of BBTs is also notable in light of their particular risks regarding both quality and safety (e.g., herb-drug interactions). This is in contrast to other types of CAM with more supportive evidence, which are also sometimes advocated by BHC, e.g., mind-body therapies. This is an important issue to consider in the creation of health care services integrating CAM and BHC treatments, as mind-body therapies are frequently included but BBTs less often addressed.

10.3.3 Implications for future research

In this thesis, multiple perspectives of exceptional experiences in relation to CAM use in the cancer context have been explored. Based on these findings, future research should:

- Include aspects related to patient well-being in addition to long-term survival in the evaluation of best case series.
- Explore a less technical CAM categorization to better accommodate the views of CAM users.
- Explore the relationships between the use of different CAM categories.
- Explore the relationships between stage of disease and type of CAM use.
- Explore risks with CAM use and how such risks may be assessed and documented
- Include longitudinal studies of CAM use, e.g., exploring how initial motives for CAM use relate to motives for continued use.
- Explore outcome variables for CAM evaluation research that take into consideration the wide spectrum of benefits reported by CAM users.

11 FINAL REMARKS

The design of this thesis allowed for generation of new knowledge about patients', significant others' and CAM providers' focus on exceptional well-being in addition to the otherwise acknowledged endpoint of exceptionally long survival in the study of exceptional cancer trajectories. Future research on exceptional cancer trajectories should therefore consider aspects of well-being in addition to long-term survival.

Since these findings suggest that frequently used categorization systems may not fully cover the diversity of CAM as appreciated by its users, further exploration of a less technical view of CAM categorization that may better accommodate users' views is needed. The wide range of benefits perceived as related to CAM use described here also suggests a need for multiple research methods in the evaluation of CAM use.

The findings of this thesis provide argument for the use of multiple types of evidence in clinical practice, including user perspectives, to improve safety and satisfaction for cancer patients using CAM. Based on the reported frequent use of CAM among cancer patients and the findings of this thesis, increased communication and collaboration between health care sectors is recommended.

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13 SAMMANFATTNING [IN SWEDISH]

Studier visar att användningen av komplementär och alternativ medicin (KAM) bland cancerpatienter är utbredd. I en Europeisk studie rapporterade i genomsnitt 39% av cancerpatienter att de använde sig av någon form av KAM.

SYFTE: I den här avhandlingen undersöks KAM-användande hos cancerpatienter i samband med sjukdomsförlopp som rapporterats som exceptionella. De ingående fyra delstudierna fokuserar på: mönster i KAM-användning hos individer med rapporterade exceptionella sjukdomsförlopp, hur patienter, deras anhöriga samt KAM-vårdgivare och biomedicinskt inriktade (BM) vårdgivare resonerar kring exceptionella sjukdomsförlopp i samband med cancersjukdomar, hur kommunikation om KAM upplevs av patienter och deras anhöriga, och hur patienter med cancersjukdomar resonerar kring användningen av naturpreparat.

METOD: Personer med erfarenheter av sjukdomsförlopp som upplevts som exceptionellt positiva eller negativa i samband med cancersjukdomar och KAM användning söktes via massmedia. Varken KAM eller exceptionella sjukdomsförlopp definierades av forskarna. Kvalitativa intervjuer genomfördes med 38 patienter, fyra av deras anhöriga, fem KAM-vårdgivare, samt tre BM-vårdgivare. Flera olika tekniker användes för analys av data.

RESULTAT: Alla 38 fall i studien beskrevs som exceptionellt positiva av dem som rapporterade dessa. Analysen visar stor diversitet i KAM-användningen bland de 38 cancerpatienterna med totalt 274 rapporterade KAM-terapierna bestående av 148 olika KAM-modaliteter. Användning av naturpreparat var mest vanligt förekommande. Två mönster identifierades i relation till antal och typ av KAM som användes. Befintliga kategoriseringssystem av KAM täckte inte alla terapierna rapporterade som KAM av dessa användare. Patienter, deras anhöriga, KAM-vårdgivare samt BM-vårdgivare beskrev de rapporterade sjukdomsförloppen på en skala mellan exceptionellt positiva och vanliga. Välmående och överlevnadstid i relation till dessa förlopp betonades i olika grad av olika aktörer. Patienter beskrev en mängd olika upplevda effekter av KAM-användandet inklusive aspekter av fysiskt och psykiskt välmående samt förbättringar i relation till cancersjukdomen. Patienter och deras anhöriga betonade vikten av en dialog om KAM med BM-vårdgivare. Från ett patient- och anhörigperspektiv beskrevs positiva erfarenheter av kommunikation om KAM i samband med ett upplevt ökat samarbete med BM-vårdgivare och en mindre hierarkisk patient/vårdgivarrelation.

DISKUSSION: Studiedesignen i denna avhandling möjliggjorde att ny kunskap genererats kring patienters, anhörigas och KAM-vårdgivares fokus på exceptionellt välmående i tillägg till det fokus på exceptionellt lång överlevnad som i tidigare litteratur förknippats med exceptionella sjukdomsförlopp. Fynden diskuteras utifrån möjligheter och utmaningar till följd av den funna diversiteten i KAM-användning. Även patienters upplevelse av sin egna aktiva roll, diskrepansen mellan patient- och professionella perspektiv på KAM, samt vikten av patient-vårdgivar-kommunikation om KAM diskuteras. Avhandlingens fynd har implikationer för klinisk verksamhet, policy utveckling samt fortsatt forskning. Fynden styrker argumenten för att använda olika typer av evidens, inklusive patienters perspektiv, för att förbättra patienttillfredsställelse och säkerhet inom cancervården. Dessa fynd bidrar även till att nyansera framtida forskningsfrågor för att bättre reflektera brukares användning av KAM vid cancersjukdomar.

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