Complementary and Alternative Medicine Decision Making by Cancer Patients: An Integrative Literature Review

Running Head: Integrative Decision Making Review

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ABSTRACT
Background: Cancer patients consistently report conflict and anxiety when making complementary and alternative medicine (CAM) treatment decisions. In order to design evidence-informed decision-support strategies, a better understanding is needed of how the decision-making process unfolds during the cancer trajectory. Our objective was to review the research literature regarding CAM decision making within the context of cancer treatment, survivorship and palliation and summarize the emergent concepts within a preliminary conceptual framework.
Methods: Following the methods of an integrative literature review, we searched 12 electronic databases for English language articles that describe studies of CAM decision making related to cancer. Descriptive data and original result statements were analyzed with the goal to identify distinct concepts and their relationships.
Results: 35 articles were included. Seven unique concepts related to CAM and cancer decision making emerged: 1) decision-making phases; 2) information seeking and evaluation; 3) decision-making roles; 4) beliefs; 5) contextual factors; 6) outcomes; and 7) relationship between CAM and conventional medical decision making. CAM decision making begins with a cancer diagnosis and encompasses three distinct phases, each marked by unique aims for CAM treatment and distinct patterns of information seeking and evaluation. Phase transitions correspond to a change in health status or other milestones within the cancer trajectory. An emergent conceptual framework that illustrates the relationship between the seven central concepts is presented.
Interpretation: CAM and cancer decision making occurs as a non-linear, complex and dynamic process. The conceptual framework presented here identifies influential factors within that process as well as unique needs during different phases. The framework can guide the

development and evaluation of theory-based decision-support programs that are responsive to patients' beliefs and preferences.

Keywords: complementary medicine, decision making, decision support, cancer, integrative literature review

INTRODUCTION

It is well established that at least half of all cancer patients use some form of complementary and alternative medicine (CAM) , for example acupuncture, massage and natural health products, as part of their cancer care (1-5). Many factors contribute to the high prevalence of CAM use, including an increasing amount of high-quality research evidence, improved regulation of qualified practitioners, availability of cancer-specific practitioner training programs and cultural trends that privilege more 'natural' therapies and individual involvement in self-care (6-8).

While CAM use has become common within cancer care, it remains a controversial issue. Many CAM practices originate within philosophical traditions that deviate from Western medicine, leading some individuals to view them skeptically. Further, there is a history of a smaller and often lower quality body of research evidence as compared to conventional medical therapies. Existing CAM research evidence is also often difficult to find, synthesize and share with appropriate knowledge users. Finally, the potential for interactions with standard conventional cancer therapies is yet another common concern.

The controversies that surround CAM use contribute to an increased level of conflict and anxiety for patients who contemplate using CAM as part of their cancer care. For this reason, researchers have begun to explore how and in what context cancer patients make decisions about CAM use, primarily in an effort to design supportive interventions. Many different perspectives have been explored, including those of people with a range of cancer types (6;9;10), those who have declined standard care (11;12), and those who identify with a specific ethnic group (13;14). It has become clear that CAM and cancer decision making is a complex, dynamic, non-linear and often unpredictable process. In order to design evidence-informed decision-support strategies, a better understanding is needed regarding how the decision-making process related to CAM use unfolds during the cancer trajectory and what the relevant concepts and relationships are.

The purpose of this study was to review and summarize the research literature regarding CAM decision making within the context of cancer treatment, survivorship and palliation. Specifically, we were interested in the process, context and outcomes of CAM decision making and how the decision-making process related to CAM differs from that associated with conventional medical treatments. We aim to summarize the literature and synthesize its critical elements into a preliminary conceptual framework and make recommendations for future research.

METHODS

We conducted an integrative literature review (15) of English language research articles published since 1998 that describe CAM decision making related to cancer treatment, survivorship or palliation. Integrative literature reviews follow many of the same methods as systematic reviews, but the purpose is broader in scope. The intent is to synthesize a broad range of literature on an emerging topic to develop an initial or preliminary model or framework (16). Through this review, we intend to propose a more comprehensive, holistic understanding of CAM and cancer decision making than has been possible through any primary research study.

Our search strategy included both subject headings and keywords related to cancer, decision making and CAM or integrative medicine (Appendix 1). The following electronic databases were searched through September 2011: Academic Onefile, AltHealth Watch, Allied and Complementary Medicine Database, CINAHL, EBSCO, EMBASE, Medline, Omnifile, PsycInfo, PubMed, SocIndex and Sociological Abstracts. We included articles that describe the process or context of CAM decision making relevant to cancer treatment, survivorship or palliation, as well as the outcomes of the decision-making process. We defined process as a

series of actions, changes or reactions that happen over time as an individual contemplates CAM treatment options. We defined context as the set of circumstances within which decision making takes place. Outcomes were defined as the result of the decision-making process (and not cancer). We excluded articles that focused exclusively on CAM use or the context of CAM use, but included articles that describe the context of CAM decision making. Articles that described decision making related to cancer prevention were also excluded. Two reviewers independently screened identified article titles and abstracts for eligibility. For articles where it was difficult to determine eligibility based on the title and abstract alone, full-text of the article was retrieved before eligibility was determined. Once a list of included articles was developed, we reviewed each reference list for other potentially eligible articles missed in our initial search.

Descriptive data and results of the included studies were extracted from each article by one reviewer (LW). Descriptive data included such items as author(s), article title, research purpose, sample size and study design. In addition, we extracted verbatim result statements from each of the included studies. We did not conduct a quality assessment as this is outside the scope of an integrative literature review. Descriptive data were analyzed by calculating frequencies for relevant categories within each variable. Result statements were analyzed through an iterative process, with the goal to identify distinct concepts relevant to CAM decision making. We began with reading each article to ensure a comprehensive understanding of the content. Next, individual result statements were extracted and organized within Altas.ti qualitative software. As result statements were extracted, each statement was compared to all others and a code was applied to describe a concept within CAM decision making that the statement represents. Throughout this process, a set of seven unique analytic categories emerged that reflects a range

of concepts relevant to CAM and cancer decision making. The final step was to synthesize result statements within each category and propose a preliminary conceptual framework. Regular teleconferences with the research team helped to confer authenticity within the emerging analytic categories.

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RESULTS

We identified 425 articles through the electronic database searches and reference list scans. Of these, 35 articles were included in the review (see Figure 1).

Descriptive Analysis

Over half of the included articles (n=19, 54%) describe studies that were conducted in Canada. The majority (n=31, 89%) included participants with any stage of cancer, while over half (n=19, 54%) describe studies that focused on all cancer types. One-third (n=12, 34%) of the included articles describe studies that explored CAM and cancer decision making from the perspective of a special population, including those who declined some form of conventional treatment (n=5, 14%), different ethnic groups (n=5, 14%), significant others (n=1, 3%) and Phase I clinical trial participants (n=1, 3%). The majority of these articles (n=25, 71%) describe qualitative research studies, while the others reported on cross-sectional surveys (n=5, 14%), mixed methods studies (n=3, 9%) or synthesis research (n=2, 6%). See Table 1 for a summary of the descriptive results.

Emerging concepts in the CAM and cancer decision-making literature

Seven unique concepts related to CAM and cancer decision making emerged through our analysis: 1) Decision-making phases; 2) Information seeking and evaluation; 3) Decision-making roles; 4) Beliefs; 5) Contextual factors; 6) Outcomes; and 7) Relationship between CAM and conventional medical decision making. See Table 2 for a guide to which articles include data related to specific concepts. A brief synthesis of the results within each category follows.

1. *Decision-making phases*

The reviewed studies illustrate that CAM decisions are not made at any finite point in time but occur as a non-linear, complex and dynamic process, of which therapy choices are the outcome (10;17-21). While each person follows their own unique CAM decision-making process, there are different phases that correspond to different events across the cancer trajectory, and involve different aims and patterns of information seeking and evaluation (22). Three distinct phases are described in the literature, which we have labeled as early-, mid- and late-phase.

The early-phase of CAM decision making begins with the diagnosis or a recurrence of cancer (10;23;24). It is characterized by feelings of fear and a sense of loss of control (23). A wide range of CAM therapies are typically contemplated (25) during this phase and the process involves seeking and evaluating information regarding the pros and cons and reaching a decision regarding whether or not to use CAM, and if so, which type (19;25-27). Some people seem to move through this phase quickly and to spend little time researching CAM options, if at all (10). Those with past CAM experience seem to fall into this category as they tend to be less overwhelmed with the amount of available and conflicting information (10;28). Others spend

more time consulting a range of information sources to help evaluate the potential of CAM use (26).

The mid-phase is best viewed as a maintenance phase, with the aim being to develop a personalized regimen of CAM therapies that fits within an individual's beliefs and needs. Individuals seem to transition to this phase of decision making when they encounter some sort of positive change in their personal context; for example, once they have adapted to their cancer diagnosis or completed their cancer treatment. CAM therapies used during this phase are directed towards maintaining well-being, controlling the spread of cancer cells, managing treatment side effects, boosting the immune system, or preventing or delaying recurrence (10;29).

The late-phase of decision making includes the same iterative information gathering and evaluation apparent during the early-phase, but there is less urgency, a stronger awareness of CAM and more comfort with a variety of information sources (25). People seem to transition to this late-phase when their conventional treatment ends and they move into survivorship or palliative care (24;25;25). In the late phase, CAM therapies are considered that help address a variety of aims, including overcoming a sense of loss and abandonment after discharge, maintaining health, prolonging life, or coming to terms with impending death (24). In palliative situations, CAM regimens that were previously perceived to require significant time, money, and effort may be re-evaluated (30).

Transitioning between phases seems to correspond to a crisis or change within the cancer experience (22) that modifies perceived consequences or expectancies of CAM therapies within

cancer treatment (31). These changes seem to motivate people to revisit their CAM decisions and initiate a renewed process of gathering and evaluating information to help adapt to a new circumstance (10;24;25;32). This transitioning does not appear to be a desperate move on the part of patients but, instead, a reasoned approach to critically examine their situation and available options (20).

2. *Information Seeking and Evaluation*

Information seeking and evaluation is an integral component of decision making, with distinct patterns during each phase. For some people, this is a process that begins at diagnosis and continues throughout their cancer journey. Other people begin to seek and evaluate information when they transition between decision-making phases and need to revisit their CAM decisions. People tend to rely on a wide range of information sources, including books, the Internet, mass media, CAM and conventional practitioners, friends and family and other cancer patients (9;10;10;12;18;19;24-26;33;34). Preferred information sources differ depending on the decision-making phase, with the broadest range of information sources used in early-phase decision making when individuals are exploring their treatment options and learning what types of CAM are available. In subsequent phases, individuals tend to rely on personal experience and medical tests to evaluate whether or not CAM is working for their intended purpose (12;19;33-35).

The process of information evaluation has largely been studied by examining the meaning of evidence when cancer patients make CAM decisions. It is clear from this literature that what constitutes high-quality evidence for the safety and effectiveness of CAM seems to vary greatly among individuals (28) and also to diverge from the standard applied within evidence-based medicine (18;25;31;34). Information evaluation can play either a major or minor role in CAM

decision making. The greater attention an individual affords to a given content area and their beliefs regarding the potential for CAM use to modify their condition, the greater role for information evaluation (31). The type and source of information that individuals accept as evidence seems to depend mostly on underlying beliefs and values, perceived credibility of information, experience with CAM and the stage of disease (10;18;21;24;26;28;32). Anxiety, ethnicity and social support might also play a role (10;25;36).

3. Decision-making Role

Individuals tend to take either an active or passive role in decision making, and the role they chose may differ at different points during the decision-making process (18;22;25;26;31;37). People who take an active role appear more self-motivated (22), have more self-confidence (25), and are more likely to have used CAM before their cancer diagnosis (18;28) than those who take a passive role. The active group also embrace a wider range of CAM than the more passive group (18). Taking an active or passive role is associated with cancer type and state of illness: those with rare cancer, faster growing tumors or advance disease are more likely to take an active role (18). Regardless of whether their role is active or passive, cancer patients appear to experience CAM decision making as problematic. Taking an active role often requires going against the socially sanctioned expertise of medical doctors and assuming responsibility for one's own decisions, while taking a passive role conflicts with the ideal of individual responsibility for health (37).

4. Beliefs

A range of beliefs influence CAM and cancer decision making, including beliefs about the causes of cancer (9;11;33;35); treatment mechanisms (12;18;35); risks and benefits of CAM use (6;9;11;12;14;19;22;22;23;25-28;33-35;38;39); risks and benefits of conventional care (6;9-

12;19;22;23;28;32-35;39); available evidence (10;10;21;28); and disease status (10;22;25;31;39). While it is possible to categorize beliefs in this way, it is more likely that an individual's entire belief system influences the CAM decision-making process such that decisions are generally congruent with the complexity of the belief system. Depending on an individual's particular context at any given time, they will prioritize some beliefs over others when making decisions. For example, during active treatment, patients may prioritize their beliefs about treatment mechanisms and risks and benefits of care over their beliefs about the causes of their cancer. It is clear, however, that not everyone with cancer explicitly aware of his or her beliefs, which are not static. Current beliefs are informed by a range of factors, including past experiences of the individual (23) or their significant others (14), ethnocultural values (19;36), faith in God (14;22) and education (36).

5. *Contextual Factors*

Several contextual factors influence the experience of making CAM decisions, including demographic and disease-related factors, social factors and cultural norms. Relevant demographic and disease-related factors include age (20;29), geography (26;29), disease status and active treatment (20;23;25;28;32), past experience with CAM use and (11;19;23;32;33) income and ability to pay (13;19;26;29;32). Social factors centre on an individual's interactions with others, including friends and family, health care practitioners and other patients. Finding validation and support from others appears to be of great value to patients and to offer them the confidence to move forward with decisions that feel right for them (9;11;19;25;27;40;41). In some cases, however, support and recommendations from members of a support network can result in feelings of pressure and uncertainty (19;40). Cultural norms have a strong influence on decision making and appear to reflect a conflict between CAM and biomedicine (20;25), the

limits of biomedicine (6;9;18;19;23;24;26) and a perceived harmlessness of many CAM therapies (23;26).

6. Decision-making outcomes

The CAM decision-making process contributes to a range of outcomes, including a decision whether or not to use CAM, but also several others. The process of making a decision has been documented to empower individuals through more active participation in decision making (33), which can help increase a sense of control and thus reduce anxiety and fear (10;11;22;24;25;33;34;40;41). CAM decision making also introduces individuals to different philosophies of healing, healthy lifestyle behaviours and personal development (28). CAM decision making, however, is not always without difficulties. A common outcome of CAM decision making is conflict and resistance from clinicians, which can contribute to feelings of frustration and anxiety about making the "right" decision (21;25;41). Further, individuals describe feeling uncomfortable with the added responsibility and self-accountability that CAM use can bring (27;30;37).

7. *Relationship between CAM and conventional medical decision making*

Making decisions about CAM cannot be separated from making decisions about conventional medicine (6;23;27). These seem to be similar processes that occur concurrently (28) but, depending on the situation, either CAM or conventional medical decision making will take priority (10). Further, the goals of both CAM and conventional decision making appear to be the same, but an individual's beliefs and values lead them to choose either a CAM or conventional treatment (or both) to achieve their treatment goals (6).

Synthesis

An emergent conceptual framework that illustrates the relationship between the seven central concepts is presented in Figure 2. In this framework, CAM decision making begins with a diagnosis of cancer. The process encompasses three distinct phases, each marked by unique patterns of information seeking and evaluation: early- mid- and late-phase decision making. Transitions between phases correspond to a change in health status, a crisis, or other milestones within the cancer trajectory. All decision-making phases are influenced by a myriad of contextual factors, including demographic and disease-related factors, social factors, cultural norms and personal beliefs about cancer, its causes and its treatments. Outcomes of the decision-making process include CAM decisions (potentially multiple, over time) but also shifts in perceived sense of control, anxiety and fear and conflict over whether the "right" decision was made.

INTERPRETATION

Through this integrative literature review, we present a conceptual framework for CAM and cancer decision making that can be used to guide the development of decision-support programs as well as future research in this field. The inclusion of diverse studies that collectively represent diverse populations ensures the framework is comprehensive and therefore broadly applicable to cancer patients who are contemplating treatment options. It illustrates three distinct phases within CAM and cancer decision making, each characterized by different patterns of information seeking and evaluation. It is also clear that CAM decision making should not be considered a separate process from decision making related to conventional medical care. Beliefs, values and other social and cultural norms guide all treatment choices and some patients will require support to articulate and prioritize these factors when making treatment decisions.

The inclusion of diverse study designs within integrative literature reviews means that such reviews, for example as compared to systematic reviews, are more susceptible to lack of rigour (16). For example, while our search was extensive, it is possible we missed some primary studies, especially published in languages other than English. Searching multiple databases, coupled with reference list scans for eligible articles, suggests we included most of the published literature in this field. Further, the reliability of our sampling strategy is enhanced by using pre-specified inclusion and exclusion criteria and by using two reviewers to screen potentially relevant articles. Data extraction within integrative literature reviews can be especially problematic due to the wide range of variables, theories and populations studied within diverse primary studies. To provide focus and delineate boundaries for the review process, our team met frequently to formulate a clear research purpose and related data extraction strategy as well as to discuss the analysis as it was emerging (16). Finally, our data analysis strategy is compatible with strategies used to combine diverse data within mixed-methods studies (42), further supporting the rigour of our review process.

We expect the results of this review, including the conceptual framework and descriptions of relevant concepts within CAM and cancer decision making, will be instructive for health professionals providing support to patients moving through this complex process. Of note, decision-support programs should include different strategies to support patients within different decision-making phases. Further, they must acknowledge the variability and complexity of individuals' personal contexts, including beliefs, values and social roles, which will influence when and how people make treatment decisions. Decision support programs must also be flexible and adaptive to account for both active and passive decision-making roles, diversity in

preferred information sources and changing needs and goals throughout the cancer experience. Finally, given CAM decisions are intertwined with decision making related to conventional medical treatments, it seems reasonable that CAM decision-support programs are integrated with other programs offered within standard care.

To date, the majority of the research in the field of CAM and cancer decision making has been conceptual and exploratory. This perspective has been crucial to better understanding the complexity within CAM decision making. This integrative review, however, provides a comprehensive understanding of the CAM and cancer decision-making process, including the distinct decision-making phases, roles and contextual influences. It is thus time to move forward with the development and evaluation of theory-based decision-support programs to provide evidence-informed support for cancer patients in making CAM and conventional medical treatment decisions. The proposed conceptual framework is a guide to ensure decision support programs are responsive to patients' beliefs and preferences and appropriate to the unique needs that exist at different points throughout the cancer trajectory.

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CONTRIBUTOR STATEMENT

Marja Verhoef, Charlotte Paterson and Lynda Balneaves conceived the project, and collectively with Laura Weeks finalized the study methodology. Laura Weeks conducted the database search, and all authors helped to screen studies for inclusion in the review. Laura Weeks collected the data and led the data analysis, with regular input via team meetings with Marja Verhoef, Charlotte Paterson and Lynda Balneaves. Laura Weeks wrote the first draft of this manuscript, and Marja Verhoef, Charlotte Paterson and Lynda Balneaves reviewed and edited a series of manuscript drafts. Marja Verhoef is the guarantor and maintains responsibility for the integrity of the work. All of the authors approved the final version of this manuscript.

REFERENCES

(1) Table 1: Descriptive information of 35 articles describing the decision-making process by cancer patients

(2) Author (3) (Year published)	(4) Purpose	(5) Use of theory	(6) Cancer Type, Special Population	(7) Country	(8) Method/ Type of analysis	(9) Sample Size
(10) Balneaves LG (1999)	(11)To provide a preliminary description of complementary therapy use by women living with breast cancer and the predisposing factors associated with the decision to use complementary therapies.	(12)	(13) Breast	(14) Canada	(15) Cross-sectional survey	(16) 64
(17) Balneaves LG (2007)	(18) To explore the personal and social processes engaged in by women with early-stage breast cancer when making decisions about CAM during the time period after diagnosis to survivorship.	(19) Emergent, author developed: Bridging the	(20) Stage I and II Breast	(21) Canada	(22) Grounded theory	(23) 20

		Gap				
(24) Bishop FL (2004)	(25) To explore the positioning of people within accounts of treatment decisions precisely in order to explicate strategies used to manage ideological conflict within the context of orthodox and complementary medicine in cancer.	(26) Positioning theory	(27) All	(28) United Kingdom	(29) Discourse analysis	(30) 43
(31) Boon H (1999)	(32) To examine breast cancer patients' perceptions of, approaches to, and experiences with CAM.	(33) Push/Pull factors - Furnham & Smith (1988)	(34) Breast	(35) Canada	(36) Content analysis	(37) 36
(38) Boon H (2003)	(39) To explore prostate cancer patients' perceptions, feelings, ideas, and experiences regarding making decisions to use (or not	(40) Push/Pull factors -	(41) Prostate	(42) Canada	(43) Content analysis	(44) 29

	use) CAM.	Furnham & Smith (1988)				
(45) Boon H (2005)	(46) To investigate the question: are users of CAM more autonomous than non-users with respect to problem-solving and decision-making preferences?	(47) Deber-Kraestchmer problem-solving decision-making (PSDM) scale	(48) All	(49) Canada	(50) Cross-sectional survey	(51) 489

(52) Brazier A (2008)	(53) To evaluate the impact of participating in an integrative cancer care program at the Centre for Integrated Healing in Vancouver, British Columbia, on patients' lifestyle, quality of life, and overall well-being.	(54)	(55) All	(56) Canada	(57) Interpretive description	(58) 28
(59) Broom A (2007)	(60) To provide an examination of cancer patients' perspectives on the nature of evidence and the degree to which different understandings of evidence inform decision making about CAM and biomedicine.	(61) Social theory (post-modernity, reflexivity, technologies of the self,	(62) All	(63) Canada	(64) Interpretive qualitative research	(65) 80

		dialectic)				
(66) Broom A (2009)	(67) To 1) understand how individuals with cancer go about making decisions regarding the legitimacy of ideas, expertise, treatments, and regimens in the context of their cancer, and 2) to develop a conceptualization of therapeutic decision making, utilizing the notion of bricolage as a key point of departure.	(68)	(69) All, intensive CAM users	(70) Australia	(71) Interpretive qualitative research	(72) 20
(73) Broom A (2008)	(74) To examine individual cancer patients' temporal experiences of CAM including (a) the disciplining of the self demanded by certain CAM therapeutics and the impact of that on the experience of having cancer,	(75)	(76) All, intensive CAM users	(77) United Kingdom	(78) Interpretive qualitative research /	(79) 8

	(b) the role of CAM healing therapists in reconceptualizing disease and filling perceived gaps in biomedical cancer care, and (c) the complex interplay between CAM-derived notions, self-healing, and nearing death.				solicited diary-unstructured interview	
(80) Brown JB (2002)	(81) To further elucidate common themes across three studies of women's decision making and examine the process that women undergo in making an important decision about their health and well-being including: where and how they acquire the necessary information to make a decision; what factors influence their decision; who supports them in the decision-making process;	(82) Emergent, author developed	(83) Breast	(84) Canada	(85) Constant comparison	(86) 36

	and how they reconcile confusing or conflicting information.					
(87) Chiu L (2006)	(88) To explore in a sample of Chinese cancer patients: (1) the general conceptualization of CAM use; (2) the meaning of CAM use in relation to cancer; (3) the patterns of CAM use prior and after cancer diagnosis; (4) the reasons for CAM use; and (5) the socio-cultural process in making decision about CAM use.	(89) Emergent, author developed	(90) Stage I, II and III cancer, Chinese	(91) Canada	(92) Constant comparison	(93) 14
(94) Evans M (2007)	(95) To explore the processes shaping men's decision making about CAM, and the rationales they provide for their views and behaviour.	(96)	(97) All	(98) United Kingdom	(99) Constant comparison	(100) 34
(101) Evans MA	(102) To explore the use and evaluation of CAM related information by male cancer	(103)	(104) Male cancer,	(105) United Kin	(106) Not specific;	(107) 34

(2007)	patients.		any type	gdom	thematic	
(108) Gray RE (1997)	(109) To explore cancer patients' motivations for seeking information about unconventional therapies, their decision-making processes, their experiences with such therapies, their attempts to communicate with conventional health care practitioners, and their perceptions of family members and friends' reactions to their interest in unconventional therapies	(110)	(111) All	(112) Canada	(113) Not specific; thematic	(114) 32
(115) Hlubocky FJ (2007)	(116) To describe the general usage rates of biologically based CAM among participants in phase I trials. Secondary objectives were to explore social and demographic factors associated with CAM use,	(117)	(118) Advanced cancer, Phase I trial particip	(119) United States	(120) Cross-sectional survey	(121) 212

	describe potential differences in treatment decision-making preferences among CAM users and nonusers, and to investigate associations of CAM use with awareness of prognosis and quality of life.		ants			
(122) Jones RA (2007)	(123) To explore the beliefs and attitudes of African American survivors of prostate cancer regarding the use of CAM.	(124)	(125) Prostate, African American	(126) United States	(127) Cross-sectional survey and Phenomenology	(128) 14
(129) Kakai H (2003)	(130) To investigate ethnic differences in health information-seeking behaviors among cancer patients of diverse ethnicity in Hawaii. In addition, to explore a	(131)	(132) All, different ethnic	(133) United States	(134) Correspondence analysis	(135) 140

	possible association between patients' education and ethnicity and choice of health information.		groups			
(136) Kimby CK (2003)	(137) To examine the relationships between user profiles (sociodemographic factors, treatment orientations, cancer status), and the users' choice of various unconventional types of treatment (individualized versus standardized unconventional treatments).	(138)	(139) All	(140) Denmark	(141) Cross-sectional survey	(142) 441
(143) Markovic M (2006)	(144) To explore the impact of specific social and cultural factors influencing health care decision making.	(145)	(146) Gynaecologic	(147) Australia	(148) Grounded theory	(149) 53
(150) Montbriand M	(151) To recreate a model reflecting the health decision realities of patients diagnosed with	(152) Naturalistic and	(153) Respiratory and	(154) Canada	(155) Ethnography	(156) 48 Phase I;

(1995)	cancer of the respiratory or digestive systems.	rationalistic research; Phenomenology; Heuristics; Tversky's elimination-by-aspects theory; and	digestive		(following phenomenology)	252 Phase II

		emergent, author developed				
(157) Oh HS (2004)	(158) To explore how cancer patients choose a therapy after they are diagnosed with cancer, the decision-making strategies used by cancer patients when they visit a doctor or when they use alternative therapies.	(159)	(160) All	(161) Korea	(162) cognitive ethnographic decision tree model	(163) 29 Phase I; 165 Phase II
(164) Ohlen J (2006)	(165) To explore how significant others were involved in cancer patients' decision-making processes related to CAM.	(166)	(167) Early and advanced breast and prostat	(168) Canada (169)	(170) Grounded theory	(171) 40 early; 21 advanced; 31 signi

			e, significant others			fica nt othe rs
(172) Owens B (2007)	(173) To describe the self-help theoretical framework with CAM and to delineate relationships in Braden's Self-Help Model of side-effect burden to uncertainty, CAM self-care, and QOL in Hispanic women undergoing breast cancer treatment.	(174) Braden's Self Help Theory	(175) Breast, Hispanic	(176) United States	(177) Cross-sectional survey	(178) 144
(179) Ritvo P (1999)	(180) To apply a theoretical model, the Risk Adaptation Model, to further the clinical understanding of the motivations of cancer patients in seeking complementary therapies.	(181) Risk Adaptation Model	(182) All	(183) Not original research	(184) Not original research	(185) Not original research
(186) Shumay	(187) To examine cancer patients' reasons for declining all or	(188) Montbrian	(189) All,	(190) United	(191) Thematic	(192) 14

DM (2001)	part of recommended cancer treatment and choosing complementary and alternative medicine (CAM).	d's decisi on-tree model	differe nt ethnic groups and decline rs	Stat es		
(193) Singh H (2005)	(194) To compare the perceptions, beliefs, ideas, and experiences that contribute to the decision of prostate cancer patients to use or not to use CAM.	(195)	(196) Prostate, differe nt ethnic groups	(197) United Stat es	(198) T hematic	(199) 27
(200) Truant T (1999)	(201) To examine the complementary therapy decision-making process from the perspective of women with breast cancer in the context of the cancer trajectory.	(202) Emergent, author develo ped	(203) Breast	(204) Canada	(205) G rounded theory	(206) 16
(207)	(208) To summarize and review	(209)	(210)	(211)	(212) S	(213)

Verhoef MJ (2005)	the reasons for CAM use as well as the sociodemographic and disease characteristics associated with CAM use among cancer patients.		All, but focus on breast and prostate	International	ystematic Review	52 articles
(214) Verhoef MJ (2007)	(215) To (1) describe the type of information about CAM that cancer patients use in their decision making, (2) understand why certain types of information about CAM are accepted as evidence by cancer patients, and (3) explore the role of scientific evidence in treatment decision making.	(216)	(217) All	(218) Canada	(219) Content analysis	(220) 27
(221) Verhoef MJ	(222) To explore why and how patients with cancer decide to forgo conventional treatments in favor of	(223)	(224) All, decline	(225) Canada	(226) Content Analysis	(227) 31

(2002)	alternative treatments as well as which factors influence this decision.		rs			
(228) Verhoef MJ (1999)	(229) To explore cancer patients' experiences with and expectations of the role of family physicians in discussing complementary therapies.	(230)	(231) All	(232) Canada	(233) Content analysis	(234) 14
(235) White M (2006)	(236) To further explore the role of spirituality in cancer management and decision making for men with prostate cancer who declined conventional treatment.	(237)	(238) Prostate, decliners	(239) Canada	(240) Thematic	(241) 10
(242) White MA (2003)	(243) To explore in depth how sense of control was related to the decision to forgo conventional treatment for prostate cancer and to use CAM therapies for their cancer.	(244)	(245) Prostate, decliners	(246) Canada	(247) Content analysis	(248) 8
(249) White	(250) To 1) explore why men decline conventional prostate	(251)	(252) Prostate,	(253) Canada	(254) Content	(255) 29

MA (2008)	cancer treatment and use CAM 2) understand the role of holistic healing in their care, and 3) document their recommendations for health care providers.		decliners		analysis	

(256)

(257)

(258) Table 2: Concepts related to CAM and cancer decision making described within included articles

(259)

(260) Author (Year published)	(261) Decision-making Phases	(262) Decision-making Role	(263) Contextual Factors	(264) Beliefs	(265) Information Sources	(266) Outcomes of Decision making	(267) Relationship with Conventional Medical Decision making
(268) Balneaves LG (1999)	(269)	(270) x	(271)	(272) x	(273)	(274)	(275)
(276) Balneaves LG (2007)	(277) x	(278) x	(279) x	(280) x	(281) x	(282) x	(283) x
(284) Bishop FL	(285)	(286) x	(287) x	(288)	(289)	(290) x	(291)

(2004)							
(292) B oon H (1999)	(293) x	(294) x	(295) x	(296) x	(297) x	(298) x	(299)
(300) B oon H (2003)	(301) x	(302)	(303) x	(304) x	(305) x	(306) x	(307) x
(308) B oon H (2005)	(309)	(310) x	(311)	(312)	(313)	(314)	(315)
(316) B razier A (2008)	(317)	(318)	(319) x	(320)	(321) x	(322) x	(323)
(324) B room A (2007)	(325) x	(326)	(327) x	(328) x	(329) x	(330) x	(331) x
(332) B room A (2009)	(333) x	(334)	(335) x	(336)	(337)	(338)	(339)
(340) B room A (2008)	(341)	(342)	(343) x	(344) x	(345)	(346) x	(347)

(348) Brown JB (2002)	(349) x	(350)	(351) x	(352) x	(353) x	(354) x	(355) x
(356) Chiu L (2006)	(357) x	(358)	(359) x	(360) x	(361) x	(362) x	(363)
(364) Evans M (2007a)	(365) x	(366) x	(367) x	(368) x	(369) x	(370) x	(371)
(372) Evans MA (2007b)	(373) x	(374)	(375) x	(376) x	(377) x	(378) x	(379) x
(380) Gray RE (1997)	(381) x	(382)	(383) x	(384) x	(385) x	(386) x	(387)
(388) Hlubocky FJ (2007)	(389)	(390)	(391)	(392)	(393)	(394)	(395)
(396) Jones RA (2007)	(397)	(398)	(399) x	(400) x	(401) x	(402) x	(403)
(404) K	(405)	(406)	(407)	(408)	(409)	(410)	(411)

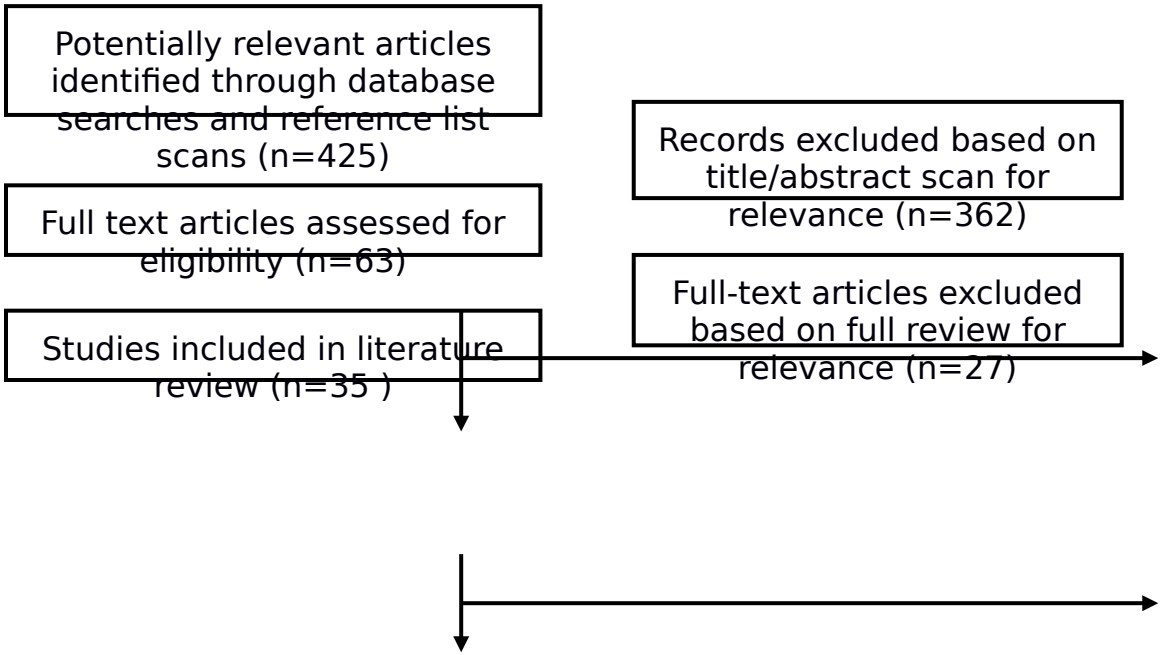
akai H (2003)			x	x	x		
(412) K imby CK (2003)	(413)	(414)	(415) x	(416)	(417)	(418) x	(419)
(420) M arkovic M (2006)	(421)	(422)	(423) x	(424) x	(425) x	(426) x	(427)
(428) M ontbriand M (1995)	(429) x	(430) x	(431) x	(432) x	(433) x	(434) x	(435)
(436) O h HS (2004)	(437)	(438)	(439) x	(440) x	(441) x	(442)	(443)
(444) O hlen J (2006)	(445) x	(446) x	(447) x	(448)	(449)	(450) x	(451)
(452) O wens B (2007)	(453)	(454)	(455) x	(456)	(457)	(458) x	(459)
(460) R itvo P	(461) x	(462) x	(463)	(464) x	(465) x	(466) x	(467)

(1999)							
(468) Shumay DM (2001)	(469)	(470)	(471)	(472) x	(473) x	(474)	(475)
(476) Singh H (2005)	(477)	(478)	(479) x	(480) x	(481)	(482) x	(483) x
(484) Truant T (1999)	(485) x	(486)	(487) x	(488) x	(489) x	(490) x	(491) x
(492) Verhoef MJ (2005)	(493)	(494)	(495) x	(496)	(497)	(498) x	(499)
(500) Verhoef MJ (2007)	(501) x	(502) x	(503) x	(504) x	(505) x	(506) x	(507) x
(508) Verhoef	(509)	(510)	(511) x	(512) x	(513)	(514) x	(515)

MJ (2002)							
(516) Verhoef MJ (1999)	(517)	(518) x	(519) x	(520) x	(521)	(522)	(523)
(524) White M (2006)	(525)	(526)	(527) x	(528) x	(529) x	(530) x	(531)
(532) White MA (2003)	(533)	(534) x	(535) x	(536) x	(537) x	(538) x	(539)
(540) White MA (2008)	(541) x	(542) x	(543) x	(544) x	(545) x	(546) x	(547)

(548) Figure 1: Results of Search Strategy and Process of Identifying Articles Related to CAM and Cancer Decision making

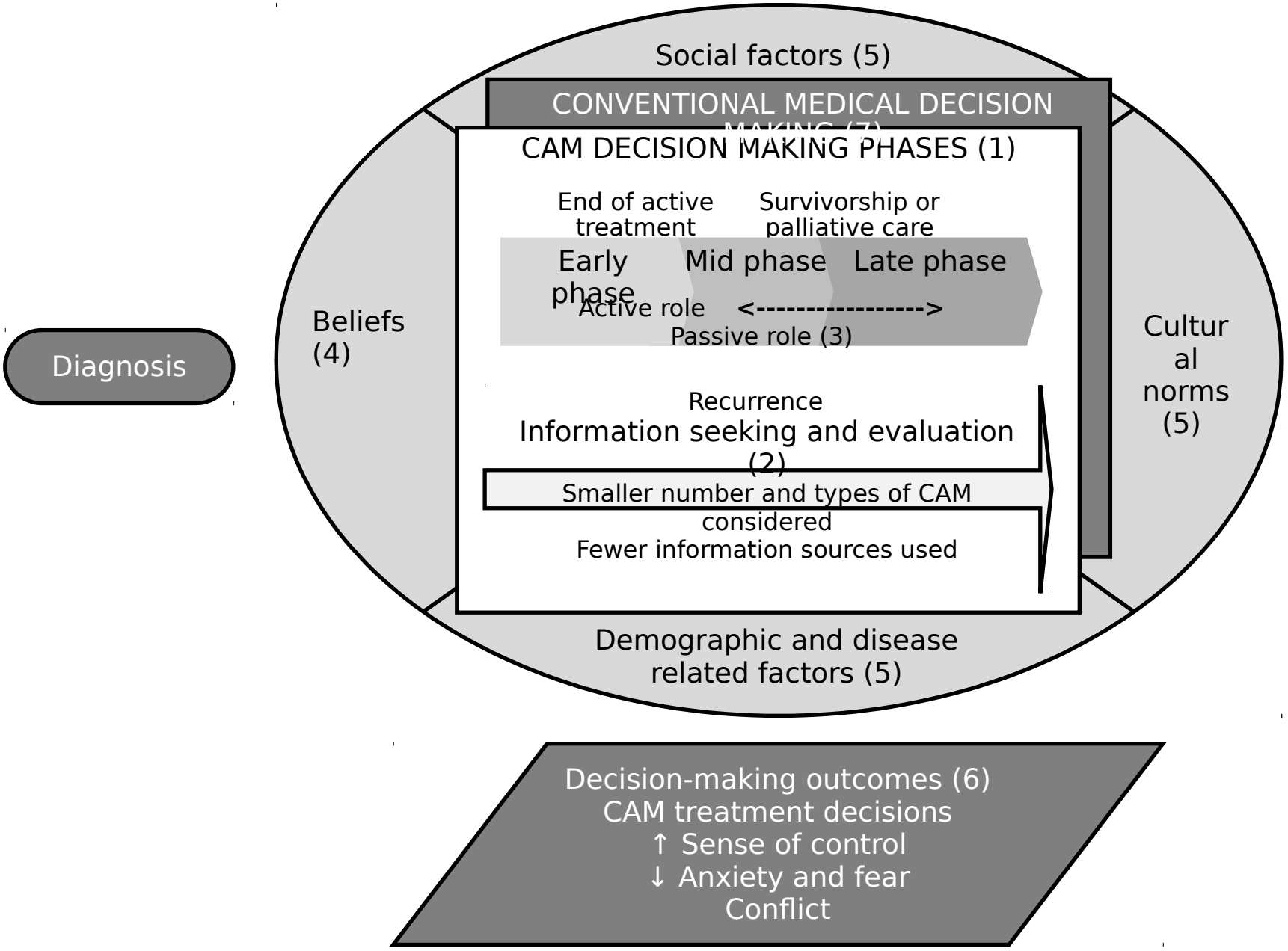
(549)


Potentially relevant articles identified through database searches and reference list scans (n=425)
Records excluded based on title/abstract scan for relevance (n=362)
Full text articles assessed for eligibility (n=63)
Full-text articles excluded based on full review for relevance (n=27)
Studies included in literature review (n=35)

(550) Figure 2: Conceptual framework of the CAM and cancer decision-making process

(551)

(552) Note: The numbers 1-7 in this framework correspond to descriptions of relevant concepts within the manuscript text


Diagnosis
Social factors (5)
CONVENTIONAL MEDICAL DECISION MAKING (7)
CAM DECISION MAKING PHASES (1)
End of active treatment
Survivorship or palliative care
Early phase
Mid phase
Late phase
Active role <----------> Passive role (3)
Beliefs (4)
Cultural norms (5)
Recurrence
Information seeking and evaluation (2)
Smaller number and types of CAM considered
Fewer information sources used
Demographic and disease related factors (5)
Decision-making outcomes (6)
CAM treatment decisions
↑ Sense of control
↓ Anxiety and fear
Conflict

(553) Appendix 1: Search Strategy for MEDLINE

(554)

(555) Ovid MEDLINE(R) 1998 to September Week 3 2011

(556) 1. exp Complementary Therapies/

(557) 2. (alternative medicine or alternative therap* or alternative treat* or complementary medicine or complementary therap* or complementary treat* or 'complementary and alternative medicine' or unconventional medicine or unconventional therap* or unconventional treat* or integrative medicine).tw.

(558) 3. 1 or 2

(559) 4. exp Neoplasms/

(560) 5. (cancer or carcinoma or Oncolog* or Tumor* or tumour* or Malignan* or Neoplasm).tw.

(561) 6. 4 or 5

(562) 7. exp Decision-making/

(563) 8. decision-making.tw.

(564) 9. 7 or 8

(565) 10. 3 and 6 and 9

(566) 11. (bibliography or classical article or congresses or corrected and republished article or government publications or journal article or review).pt

(567) 12. 10 and 11

(568) 13. human/

(569) 14. 12 and 13

(570)

(571)