The Complementary Medicine Education and Outcomes (CAMEO) program: A foundation for patient and health professional education and decision support programs

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ABSTRACT

Objective: This paper describes the background, design and evaluation of a theory-informed education and decision support program for cancer patients considering complementary medicine (CM).

Methods: The program was informed by the Shared Decision Making theory, the Ottawa Decision Support Framework and the Supportive Care Framework. Previous empirical evidence and baseline research were used to identify patients’ and health professionals’ (HPs) information and decision support needs related to CM.

Results: To address the continuum of CM needs, a variety of education and decision support interventions were developed, including basic CM information and resources for patients and HPs, a group education program and one-on-one decision support coaching for patients, and an on-line education module for HPs. Evaluation of the program and individual interventions is underway.

Conclusions: This education and decision support program addresses a significant gap in care and offers an evidence-informed framework in which to translate CM evidence to conventional care settings and promote communication about CM.

Practice implications: Evidence-informed CM education and decision support interventions are needed to shift the culture around CM within conventional care settings and promote open communication that will lead to CM therapies being safely integrated into care.

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1. Introduction

Up to 80% of Canadian cancer patients use complementary medicine (CM), yet most do not receive adequate information and decision support to assist them in safely integrating CM into their cancer treatment and care [1–3]. Whilst many CM therapies are safe and beneficial, others may pose risk to some individuals, particularly during active cancer treatment when the risk of interactions is increased [4,5]. Alarmingly, up to 60% of cancer patients report not discussing their CM decisions with health professionals (HPs) [3,6,7], citing concerns about the level of knowledge and interest in CM by HPs, as well as fears about jeopardizing the patient-HP relationship [8–10]. Surveys of HPs validate this lack of knowledge and interest, as well as other barriers to open communication about CM [11–17]. These barriers include lack of time, belief that CM is not their responsibility, and a perception that there is insufficient evidence to discuss CM. Open communication is needed between patients and HPs, as well as access to evidence-informed information about CM, to support patients in making informed decisions about the safe integration of CM into care [8,18].

Leading cancer care organizations in the US (e.g., Memorial Sloan-Kettering and MD Anderson), the United Kingdom (e.g., Macmillan Cancer Relief) and Australia (e.g., Cancer Council North South Wales) have also developed CM education and information resources for patients and HPs. These programs, however, have not focused on the development of decision support services, which are essential in assisting patients to understand the CM evidence they receive within the context of their illness as well as their beliefs, values, and goals. In addition, there has been a lack of evaluation of the impact of these programs on patients’ decisions about CM and patient-HP communication.

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In 2008, the Complementary Medicine Education and Outcomes (CAMEO) program was established at the Vancouver Centre of the British Columbia Cancer Agency (BCCA), the largest tertiary cancer treatment centre in British Columbia, Canada. The goal of the CAMEO program, a collaborative initiative of the University of British Columbia and the BCCA, is to not only address the education needs of cancer patients and HPs related to CM, but also support and evaluate informed decision making about CM within a formal research program. The specific objectives of the CAMEO program are to: (1) determine the best ways to support patients and families to make safe and informed decisions about CM and cancer; (2) evaluate how to improve HPs’ knowledge and decision support skills related to CM; and (3) facilitate the development of new CM and cancer research knowledge. The overarching mission of CAMEO is to raise the bar of clinical practice, at the point of care, so that all patients experiencing cancer are assessed for CM use and provided appropriate CM information and decision support that meets their needs, in an open, unbiased, and evidence-informed manner.

This paper will outline the empirical and theoretical foundations of the CAMEO program, including the baseline research required to tailor the education and decision support interventions to the unique context and CM needs that existed within the host cancer care agency. The interventions will be described along with the outcomes, measures used to evaluate the impact of the interventions and overall program on patients, HPs and the institution. Implications for integrating CM education and decision support programs into practice will also be discussed.

2. Methods

2.1. Empirical foundation of the CAMEO program

A series of research studies examining the CM information needs and decision-making process of patients across the cancer trajectory stimulated the development of the CAMEO program [1-2,18-21]. This research highlighted the numerous unmet CM needs held by cancer patients, including inadequate information, lack of open communication with HPs, and insufficient support in making CM decisions. Many patients also perceived a “gap” between CM and conventional medicine and struggled to integrate CM therapies into their cancer care plan in the face of conflicting advice and information [18]. Although a small number of individuals were able to bridge this gap, most described significant challenges in doing so. An ambulatory care survey conducted at the BCCA in 2005–2006 further highlighted the difficulties faced by cancer patients in communication with HPs about CM, with only half feeling “comfortable” discussing CM decisions with their HPs [22]. Patients at this institution identified the establishment of an accessible CM information and decision support resource within the conventional cancer care setting as one way to address these challenges [18].

2.2. Theoretical foundations of the CAMEO program

The CAMEO program has used two decision-making theories to inform how CM education and decision support can be effectively delivered in a patient-centred manner – the model of Shared Decision Making (SDM) [23] and the Ottawa Decision Support Framework (ODSF) [24]. The SDM model focuses on engaging patients in the decision-making process to develop patient-centred, preference-sensitive decisions that improve knowledge, produce realistic expectations, lower decision conflict, and increase congruence between values and choices [23]. The SDM process ensures patients’ values, beliefs and goals are considered, as well as clinician expertise and research evidence that may inform the decision. Similarly, the ODSF purports that decision quality is improved when patients with unmet needs have their values clarified, relevant information provided, and are offered values-based choices through coaching. As a result, patients will experience less decision regret and conflict and may take actions that positively affect their health outcomes [24]. The ODSF takes the tenets of SDM a step further by suggesting practical decision support tools, such as decision aids [25,26].

The SDM and the ODSF highlight the importance of engaging the patient in the decision-making process and ensuring their preference and goals are central to the decision. These models also acknowledge clinicians’ important role in interpreting the relevance of scientific evidence to a patient’s unique clinical context. It is hypothesized that the strategies developed within the CAMEO program, based on the ODSF and SDM, will lead to more open, unbiased and patient-centred dialogue between patients and HPs that will address CM information and decision support needs.

The final theoretical model that informed the structure of the CAMEO program is the Supportive Care Framework (SCF) [27]. Originally developed to identify and organize supportive care needs for cancer patients and families, it has been a useful framework to tailor information and decision support strategies across the continuum of basic to complex CM needs that exist within conventional cancer care settings. The SCF proposes that all cancer patients have basic needs that can be addressed with access to information and support by knowledgeable HPs. As the complexity of patients’ needs increase, the strategy to address needs must also change [27]. Based on the SCF, the CAMEO program’s interventions are organized in a hierarchical manner, ranging from basic CM information available to everyone, to specialized, tailored information and decision support strategies targeting those patients considering CM, to highly individualized decision support coaching provided to patients making complex CM decisions (see Fig. 1).

2.3. Baseline research informing the CAMEO program

An environmental scan and patient and HP needs assessments were conducted in 2008 to provide initial data regarding the current context, needs, and resources related to CM that existed in the practice setting where the CAMEO program was to be located. This research was integral to ensure the CAMEO program would have optimal relevance, application and uptake within the BCCA and did not duplicate services that already existed. In addition, the data collected provided a “baseline” that will allow the impact of the CAMEO program on patients, HPs, and the practice environment to be evaluated in the future.

The environmental scan identified existing policies, services, clinical tools, educational opportunities and research related to CM. This scan revealed few institutional policies and guidelines related to CM, limited services and up-to-date CM information resources, and minimal visibility and coordination amongst existing CM-related services. During the same period, two needs assessments were conducted with over 400 cancer patients and close to 100 HPs to determine the unmet CM information and decision support needs, as well as the support strategies that would have the best uptake. The needs assessments were also essential in demonstrating to key stakeholders the extent of need related to CM as well as the value of a CM decision support program in a conventional cancer care setting. Whilst a thorough discussion of the results of the needs assessments is beyond the scope of this overview of the CAMEO program, the surveys generally identified that the majority of cancer patients were either using or considering CM, but did not have their information or decision support needs met by HPs. In turn, the HPs reported significant gaps in knowledge related to CM and their decision support skills.
Both patients and HPs expressed an interest and willingness to engage in CM education and decision support interventions. The environment scan and the needs assessments have been invaluable not only in providing a mandate for the CAMEO program but have also given direction to the interventions developed.

2.4. Research team

The CAMEO research team is a diverse group of health researchers, clinicians and patient advocates with knowledge and experience in cancer. The researchers are drawn from the health disciplines of nursing, epidemiology, and CM and have had a long standing interest in treatment decision making within the context of CM. As a knowledge translation research program, it is essential that the CAMEO program has a strong link to the clinical setting to ensure the program remains relevant to the needs of cancer patients and HPs. To this end, a steering group was formed comprised of HPs and staff representing medical oncology, pharmacy, nutrition, psychosocial oncology and library science. In addition, a patient representative was included on the steering group to inform CAMEO’s programs from a patient perspective. Together, the investigative team and steering group identify priorities related to CM in the clinical setting, develop appropriate interventions, and plan for optimum uptake of interventions within patient and HP populations.

3. Results

3.1. Information and decision support interventions

For all patients living with cancer, the CAMEO program has identified a basic need for accessible, evidence-informed information about CM. To meet this need, a website (www.bccancer.bc.ca/cameo) was developed with links to credible and evidence-based CM information resources including national and international CM websites, a CAMEO-developed patient booklet with tailored CM information specific to British Columbia, and other clinical tools, such as an adverse reaction reporting form for natural health products. We hypothesized that access to this information will address the basic CM information needs for the majority of cancer patients.

To further support patients with basic CM needs, continuing CM education for HPs is required. Advancing HPs’ knowledge of CM is essential for decision support to occur in clinical care and to encourage open dialogue about CM. An on-line education program has been developed and will be offered through an established continuing education website that is available to all HPs within British Columbia. The program is comprised of three modules that review basic CM information, how to communicate with cancer patients about CM, and how to support patients in making informed decisions about CM. Strategies are presented that are easily translated into the clinical setting and reinforced through case studies that prompt HPs to consider how CM assessment and decision support can be part of their clinical practice.

A smaller number of cancer patients require more than just basic CM information; instead, these individuals are seeking more specialized information about CM as well as decision support in making informed treatment choices. To address these additional needs, the CAMEO program has implemented a group patient education seminar. This seminar provides more detailed information about CM, including potential risks and benefits of popular CM therapies, as well as decision-making strategies that can empower patients and families to make safe and informed CM decisions. A variety of tools have been specifically developed for use within this group patient education program, including decision-making workbooks and a CM use diary for monitoring the effects of CM therapies.

Finally, a small group of patients have highly complex needs related to CM (i.e., using multiple therapies, using CM concurrently with conventional treatments, considering CM as an alternative to conventional care) and require more specific support and intervention. CAMEO has addressed these needs through a one-on-one decision support coaching service. Patients and families with complex CM needs are contacted by telephone by an
experienced oncology nurse trained in CM information and decision support strategies. In this initial interview, patients' CM needs, beliefs and goals related to CM and clinical background are assessed. This interview is guided by a structured decision tool informed by the SCODEP decision aid [28]. The nurse then researches the efficacy and safety of the CM therapies in the context of the patient's clinical situation, as well as their beliefs and goals, and develops a written summary. Patients are then invited to either meet in person or by telephone to review the summary and to determine if their CM needs have been met. Referrals to other clinical services, such as patient and family counseling, nutrition, pharmacy or symptom management, may also be made based on the CM needs expressed.

3.2. Evaluation of the CAMEO program

A comprehensive evaluation plan is required to assess the impact of the CAMEO program not only at a patient, HP, and institutional level, but also across the different levels of CM education and decision support need (i.e., basic, specialized and complex), as illustrated in Fig. 1. Overall, a pre- and post-test design is being implemented to evaluate the effect of the CAMEO program and its unique interventions. The outcome measures utilized within the evaluation plan were selected based on the SDM theory and the ODSF, as well as consultation with experts in decision making and CM.

3.2.1. Basic level

To assess the impact of the basic information resources (e.g., website, brochure) as well as the HP continuing education program, the patient and HP needs assessments will be repeated at the end of the 4-year funding period, as well as the environmental scan. From a patient perspective, this will allow shifts in CM use, CM education and decision support needs, interactions with HPs about CM, and use and awareness of the CAMEO program to be assessed. From an HP perspective, changes in clinical practices related to CM (i.e., assessing, discussing, and monitoring CM use, reviewing CM information, patient referral to CM information resources) and awareness and referrals to the CAMEO program will be assessed (see Table 1). In addition, shifts in HPs' CM knowledge and perception of their preparedness to address patients' CM needs will be measured. The environment scan will be repeated to determine if a shift in culture has occurred at the BCCA since the CAMEO program was established. The environmental scan will identify new policies, standards, services and resources specific to CM that have been developed over the past 4 years.

3.2.2. Specialized

At the specialized level, the focus of evaluation will be on the impact of the group patient education seminars, which includes the implementation of the CM decision workbook and CM use diary. Table 1 outlines the unique set of investigator-developed and established outcome measures that will be used in a pre- and post-test design. Given the nascent research on CM education and decision support, it was necessary to develop several measures that assessed CM use, knowledge, and awareness of CM resources that was specific to British Columbia and the clinical institution at which CAMEO is situated. These measures were developed based on previous research conducted by the CAMEO investigative team [18,21,29,30] and others [31,32]. Specific patient-centred outcomes include CM use, knowledge about CM, and the CM information resources utilized (see Table 1). Decision quality is assessed using two tools drawn from O'Connor's work, including a modified Decision Self-Efficacy Scale [33] and the Decision Conflict Scale [34] (see Table 1). Communication between patients and HPs about CM and distress related to the CM decision are also measured using investigator-developed tools.

The decision aids identified in Fig. 1 are still under development and will not be formally introduced to the CAMEO program until they have been piloted and tested within a separate research trial.

3.2.3. Complex

The one-on-one decision support coaching intervention will be assessed using the same outcome measures that were employed in the evaluation of the group patient education seminar, with the addition of the Preparation for Decision Making Scale [35] (see Table 1). As well, an investigator-developed satisfaction scale will be implemented to gain feedback on the coaching intervention for future revisions.

In addition to the above evaluation, all consenting patients, family members, and HPs who contact the CAMEO program for

Table 1
Evaluation of patient and health professional interventions.*

<table>
<thead>
<tr>
<th>Level</th>
<th>Outcome variable</th>
<th>Measure used</th>
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<tbody>
<tr>
<td>Basic</td>
<td>CM knowledge</td>
<td>Investigator-developed check list</td>
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<tr>
<td></td>
<td>Attitudes towards CM</td>
<td>Investigator-developed check list</td>
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<tr>
<td></td>
<td>Practices related to supporting CM decisions</td>
<td>Investigator-developed check list</td>
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<tr>
<td></td>
<td>Current practices related to CM</td>
<td>Investigator-developed check list</td>
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<tr>
<td></td>
<td>CM information resources used</td>
<td>Investigator-developed check list</td>
</tr>
<tr>
<td>Specialized</td>
<td>CM used since diagnosis</td>
<td>Investigator-developed check list</td>
</tr>
<tr>
<td>Group patient education seminar (includes CM workbook and diary)</td>
<td>CM information resources used</td>
<td>Investigator-developed check list</td>
</tr>
<tr>
<td></td>
<td>HP consulted about CM</td>
<td>Investigator-developed check list</td>
</tr>
<tr>
<td></td>
<td>Knowledge about CM/CM information resources</td>
<td>Investigator-developed scale</td>
</tr>
<tr>
<td></td>
<td>Self-Efficacy in CM decision</td>
<td>Modified Decision Self-Efficacy Scale [33]</td>
</tr>
<tr>
<td></td>
<td>Decision conflict related to CM decision</td>
<td>Decision Conflict Scale [34]</td>
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<tr>
<td></td>
<td>Distress related to CM decision</td>
<td>Investigator-developed Decision Distress Thermometer</td>
</tr>
<tr>
<td>Complex</td>
<td>CM used since diagnosis</td>
<td>Investigator-developed check list</td>
</tr>
<tr>
<td>One-on-one decision support coaching</td>
<td>CM information resources used</td>
<td>Investigator-developed check list</td>
</tr>
<tr>
<td></td>
<td>HP consulted about CM</td>
<td>Investigator-developed scale</td>
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<td>Modified Decision Self-Efficacy Scale [33]</td>
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<td></td>
<td>Self-Efficacy in CM decision</td>
<td>Decision Conflict Scale [34]</td>
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<td></td>
<td>Decision conflict related to CM decision</td>
<td>Preparation for Decision Scale [35]</td>
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<tr>
<td></td>
<td>Distress related to CM decision</td>
<td>Investigator-developed Decision Distress Thermometer</td>
</tr>
</tbody>
</table>

* Evaluation of the CAMEO Website and the CM in British Columbia Brochure will be included in the post-program environmental scan.
information or to participate in the program are entered into a database that collects demographic and clinical information, CM use, information resources desired, and decision support needs. The database will allow better understanding of the general CM information and decision support needs of patients and HPs, as well as the opportunity to follow up on the long term impact of the CAMEO program and its interventions.

4. Discussion and conclusions

4.1. Discussion

The development and implementation of the CAMEO program mirrors the growing attention to the importance of shared decision making (SDM) that has occurred internationally within cancer care [36–39]. There has been a plethora of decision support tools developed and evaluated that address a multitude of cancer-related decisions, including screening, risk reduction, surgical options and adjuvant treatment [40–45]. Limited tools have been developed, however, that address CM and the complexity of CM decisions in the face of limited and uncertain evidence. The CAMEO program is filling this gap, as well as addressing the underlying assumption that both patients and HPs have the knowledge, skills, and desire to participate in shared decision making. Through our education programs and one-on-one coaching, patients and HPs learn how to communicate about CM and engage in an evidence-informed SDM process.

It is essential when developing a program, such as CAMEO, that thoughtful attention be paid to the theoretical, as well as the empirical, foundations upon which the program and its interventions will be developed. The use of the SDM and the OSDF led the CAMEO investigative team to develop education and decision support interventions that acknowledge more than just evidence related to CM, but also the clinical context of the patient and their beliefs, values, and goals that influence treatment decisions. This approach is anticipated to lead to better quality and safer CM decisions that are tailored to each patient’s unique situation and leads them to experience less regret in the future.

The CAMEO program is unique in its integration of research with clinical practice. As a knowledge translation program, the CAMEO program is not only translating the latest CM evidence to patients and HPs, and building capacity related to decision support, but is also continually evaluating the impact of these interventions on patients, HPs, and the larger clinical institution. This research agenda will be a valuable contribution to the growing body of knowledge related to CM education and how information can be best translated and decision support provided across diverse conventional care settings. This type of knowledge translation research is not without its challenges as tensions can exist between service provision and research. Communication between the clinical and academic collaborators is essential to ensure the education and decision support interventions developed are feasible and accessible within a clinical setting and effectively meet the needs of both patients and HPs.

The CAMEO program is a model for other CM education and decision support programs regarding how resources and interventions can be allocated to meet the continuum of needs that exist within a clinical setting. In the current climate of limited resources within health care systems, it is important that programs allocate resources in a manner that efficiently and effectively address the most pressing CM needs (e.g., therapies with an increase risk of interaction with conventional care). The interventions currently being evaluated by the CAMEO program not only address basic CM information needs, but provide patients and HPs with the skills needed to work together in making safe and informed CM decisions. Empowering patients and HPs in this manner allows the CAMEO program to build capacity within the institution related to CM decision support and ensure that it becomes a part of everyday clinical care.

4.2. Conclusion

As the first CM education and decision support program in Canada to be embedded within a conventional cancer care setting, the CAMEO program offers an evidence-informed framework in which to rapidly translate CM evidence through education and decision support interventions to patients, families and HPs. The theoretical foundations upon which the CAMEO program was developed ensure that its interventions foster open communication, support CM decision-making that is patient-centred, values-based, and preference-sensitive, and consider the patient’s clinical context. Further, the CAMEO program offers other conventional health care settings a roadmap to embed CM education and decision support services within conventional care in a manner that is fiscally responsible and addresses priority CM needs across patient populations.

4.3. Practice implications

Most cancer patients in North America are either using or thinking about using CM [1–3], yet few engage and discuss their decision making with HPs. Accessible evidence-informed education and decision support interventions, such as those developed by the CAMEO program, will offer both patients and HPs the necessary knowledge, skills and resources to safely and effectively meet CM information and decision-support needs. Through the consistent use of evidence-informed CM education and decision support interventions, it is anticipated that the culture around CM will shift within organizations. With more open and unbiased communication about CM comes the possibility that evidence-based CM therapies may one day be safely embedded into the everyday care of people experiencing cancer.

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Conflict of interest

The authors have no conflict of interests to report.

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