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From the conventional to the alternative: exploring patients' pathways of cancer treatment and care

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Abstract

Background: Complementary and alternative medicine (CAM) use is widespread and on the increase among cancer patients. Most research to date has involved a cross-sectional snapshot of CAM use rather than an exploration into the longitudinal, nonlinear treatment trajectories that cancer patients develop. Our aim is to explore and describe different treatment and decision-making pathways that individuals develop after receipt of a diagnosis of either breast, colorectal, or prostate cancer.

Methods: The study was part of a larger mixed-methods pilot project to explore the feasibility of conducting a five-year international study to assess cancer patients' treatment pathways, including health care use and the perceived impact of different patterns of use on health outcomes over the course of one year. The results presented in this paper are based on the analysis of personal interviews that were conducted over the course of 12 months with 30 participants.

Results: Five pathways emerged from the data: passive conventional, self-directed conventional, cautious integrative, aggressive integrative, and aggressive alternative. Factors that shaped each pathway included health beliefs, decision-making role, illness characteristics, and the patient-practitioner relationship.

Conclusions: The results of this examination of the longitudinal treatment and decision-making trajectory provide important information to support health care professionals in their quest for individualized, targeted support at each stage of the patient pathway.

Keywords: cancer, complementary/alternative medicine, conventional cancer treatment, decision making, integrative medicine, treatment pathways, typology

Introduction

Complementary and alternative medicine (CAM) use in cancer patients has been steadily rising over the past decade [1–3] and as evidence surrounding CAM treatments in cancer care has increased, a movement toward integrative medicine (IM) is underway [4]. As defined by the National Center for Complementary and Alternative Medicine at the National Institutes of Health [5], IM “combines mainstream medical therapies and CAM therapies for which there is some high-quality scientific evidence of safety and effectiveness.” Reasons for use include the improvement of general well being, immune system enhancement, seeking or regaining control, a focus on holistic healing, and reduction of psychological distress and conventional treatment side effects [6–10]. Many cross-sectional surveys have assessed CAM use in cancer patients, but only recently has research started to examine the complex regimen of conventional and CAM treatments some individuals develop over time [3, 11]. Treatment decision making is a complex, ongoing process, in which decisions are re-evaluated, often in a nonlinear and convoluted fashion [12–14]. Existing treatment decision-making theories have identified gaps in care and provided insight into how patients' treatment choices can be supported with evidence-based information [15–17]. Treatment decision making is an integral component in the conceptualization of individual treatment pathways. Treatment pathways are shaped by a range of similar variables, such as a person's values and beliefs, cancer story, treatment options, relationships with health care providers, social relationships and roles [18].

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The purpose of this paper is to explore and describe a range of cancer treatment trajectories or “pathways” (including self-care, conventional, and CAM treatments) that individuals develop over the course of their illness as well as to identify the factors impacting these pathways. Patient pathways are understood as cultural, socially constructed life courses, where cancer and the way the patient relates to it (including health care utilization and decision making) are “part of the journey” and based on patient perspectives. Pathways include the motivating factors behind treatment plans, utilization patterns and all conventional, CAM, and self-care treatment decisions. Understanding different types of treatment pathways can offer health care providers an enhanced understanding of patients’ treatment preferences and decision-making choices along the cancer trajectory. Documenting these pathways may lead to more effective communication with patients, resulting in targeted treatment and care and improved outcomes including quality of life.

This study was part of a larger international multi-site and mixed-methods pilot project to explore the feasibility of conducting a 5-year international study to assess cancer patients’ treatment pathways, including health care utilization (conventional, CAM, and self-care) and the impact of different patterns of use on health outcomes over a 12-month period of time. In our sample, pathways were retrospectively documented beginning at pre-diagnosis and continued through various phases of treatment to survivorship. The results we present in this paper are based on the qualitative data collected in this pilot study.

Materials and methods

A cohort of individuals living in Western Canada and Norway was followed for one year. The inclusion criteria of the study targeted participants who were 18 years of age or older, able to speak and read English and who had a first diagnosis of either stage I–III breast cancer, stage I–III prostate cancer, or stage I–II colorectal cancer within the past year. Patient characteristics, treatment decisions (conventional, CAM, and self-care), and salient life events impacting on treatment decisions were followed over time. A variety of recruitment strategies were used at the Canadian and Norwegian sites, including active patient recruitment at conventional and complementary cancer clinics through physician letter of invitation; advertisements and recruitment materials posted in cancer centers, oncology offices, and other clinical settings; advertisements in wellness magazines, as well as breast and prostate cancer support group publications. Baseline and follow-up interviews were conducted with 16 men and 14 women who used CAM or conventional treatments, or a combination thereof. Twenty-one participants were from Canada and nine from Norway.

Data were collected in semi-structured, qualitative baseline interviews of one hour minimum and monthly interviews which ranged in length from 20 to 60 min. Data were collected from July 2009 to July 2012, with Norwegian data collection beginning later than the Canadian portion of the study. The baseline interviews were designed to gather information related to pre-diagnosis health behaviors, the diagnostic experience, treatments recommended and chosen, information-seeking behavior and evaluation, and treatments used to date. Follow-up interviews were designed to elicit information related to treatment goals and decisions since the last interview, as well as any treatments under consideration. Health monitoring behaviors and the impact of life events on treatment decisions were assessed, as well as personal, contextual, process and illness-related factors that impacted decision making throughout the cancer treatment pathway. All interviews were digitally recorded and transcribed verbatim (Appendixes A, B and C). The Norwegian interviews were translated into English.

Ethical approval for the study was obtained from the appropriate institutional Ethics Review Boards in the cities in which recruitment occurred. All participants provided written, informed consent. Pseudonyms have been used to protect the identities of participants.

Data analysis

Qualitative content analysis was used to analyze the data [19, 20].

The process of data collection and analysis occurred simultaneously in accordance with qualitative research methods [21, 22]. Data were first analyzed manually, which involved reading the data repeatedly to achieve immersion and a sense of the whole [23]. Then, the interviews were read line-by-line to derive codes [24, 25] by first highlighting the exact words from the text that appeared to capture key thoughts or concepts. Next, the team approached the text by making notes of first impressions. As this process continued, labels for codes emerged that were reflective of more than one key thought. These were often taken directly from the text and became the initial coding scheme. These emergent categories were used to organize and group codes into meaningful themes [26]. Definitions for each category, subcategory, and code were developed. Exemplars for each code and category were identified from the data. Coding was conducted by three members of the research team (AM, LB, and EM) to improve the rigor of the data analysis and an audit trail of all coding decisions was created. To verify credibility, one aspect of trustworthiness, we conducted peer debriefing and member checks [27]. Once coded, all transcripts were entered into the qualitative software management program, NVivo 9.0 [28], which was used to code and organize the data. A typological analysis was conducted to further search for patterns and themes emerging from the analysis [29].

Results

Five pathways emerged from the data, which included Passive Conventional, Self-directed Conventional, Cautious Integrative, Aggressive Integrative, and Aggressive

Alternative. The typology label serves a dual purpose: the first word denotes the participant’s outlook toward and extent of involvement in decision making (i.e. “passive”) and the second word refers to the nature of the treatments used (i.e., “conventional”). Descriptive models for each of the five pathways are illustrated in Figures 1 – 5.

Individuals following a passive conventional pathway (Figure 1) are characterized by their preference to only use conventional therapies and no CAM. Their goal is to cure their illness by completing their physician-recommended course of treatment. Their preferred role in

the decision-making process is passive, with little time spent researching proposed treatment options. This approach is largely due to participants’ high regard for, and trust in, their physicians and the conventional care system, a sense of urgency about managing their cancer, and a belief that the treatment plan is straightforward.

A self-directed conventional pathway (Figure 2) is one in which an individual uses only conventional therapies, but plays an active and independent role in all aspects of their pathway, from seeking information

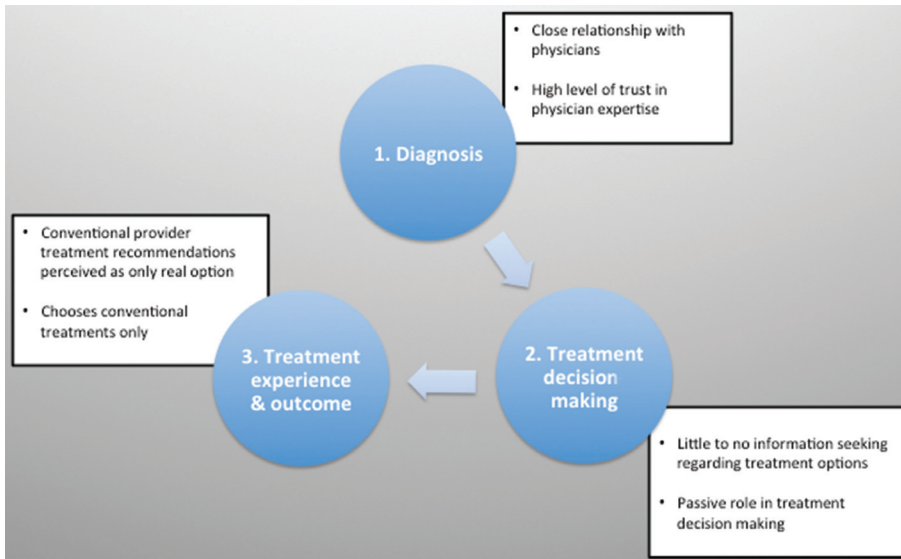


Figure 1: Passive conventional pathway.

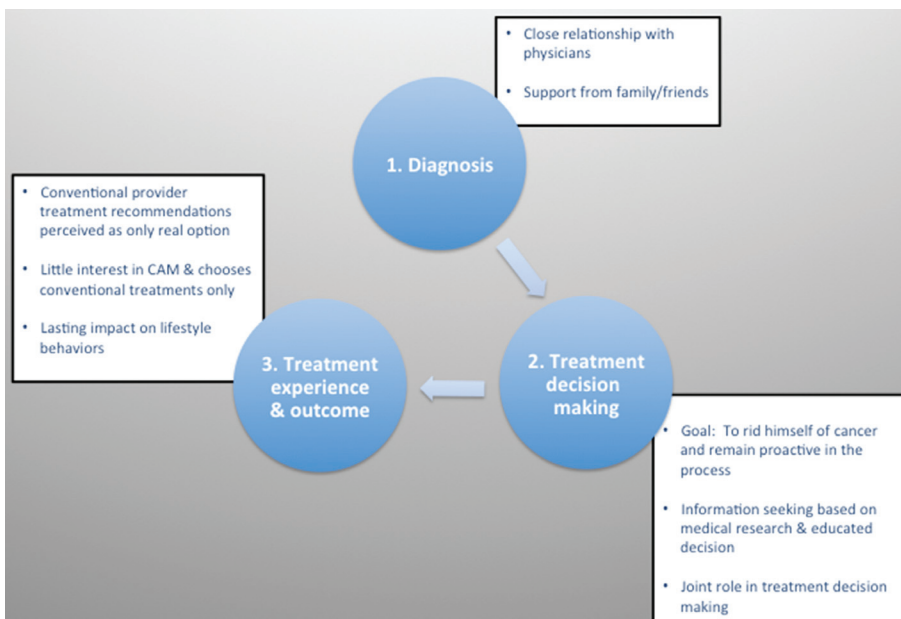


Figure 2: Self-directed conventional pathway.

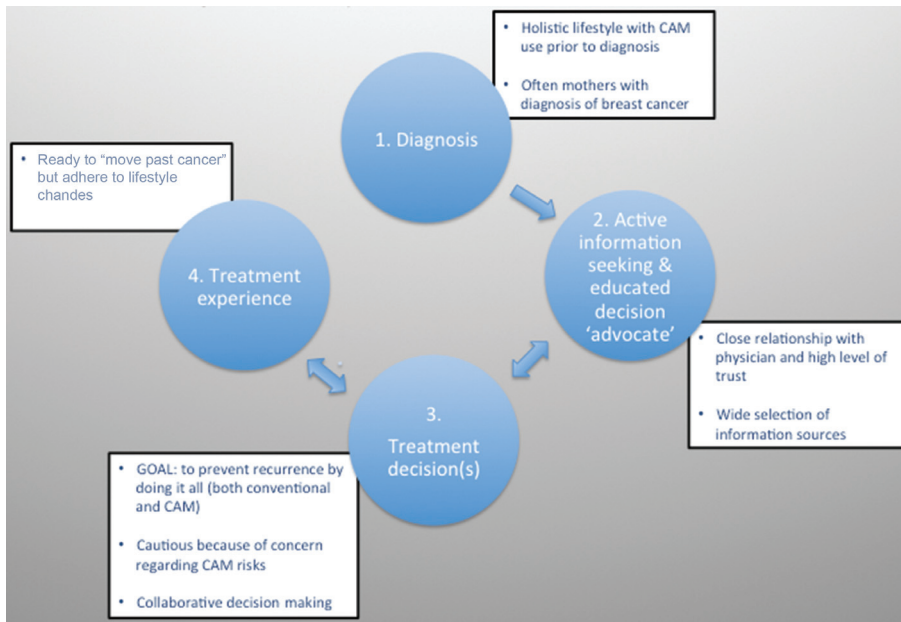


Figure 3: Cautious integrative pathway.

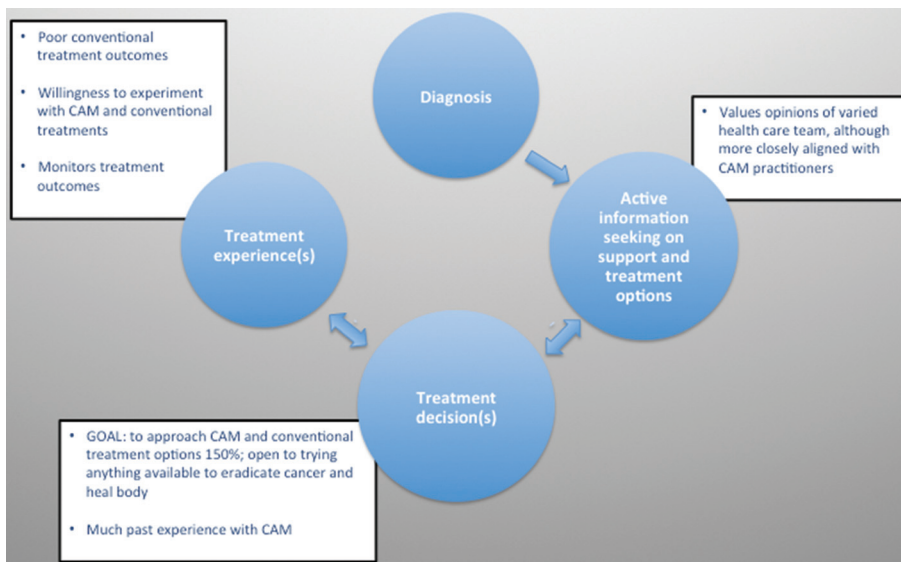


Figure 4: Aggressive integrative pathway.

through to evaluating treatment decisions. Health care providers play a consulting role but information seeking is driven by the individual and the final decision is largely made on their own. Cancer has minimal impact on their life, generally stemming from the belief that illness will not recur and satisfaction with conventional treatment choices.

Individuals following a cautious integrative pathway (Figure 3) opt for a conventional treatment protocol but manage side effects with CAM therapies. They prefer to make an educated collaborative decision with their

physician and gradually shift throughout their illness experience to taking on the role as their own advocate. The primary goal for the majority of individuals following this pathway is to do everything possible to prevent a recurrence. Heavily influencing their pathway is the individual's close relationship with their physician and their history of using CAM prior to their diagnosis. Their physicians tend to act as sounding boards for all treatment decisions and they remain cautious in their CAM choices, mainly due to conflicting information about CAM therapies.

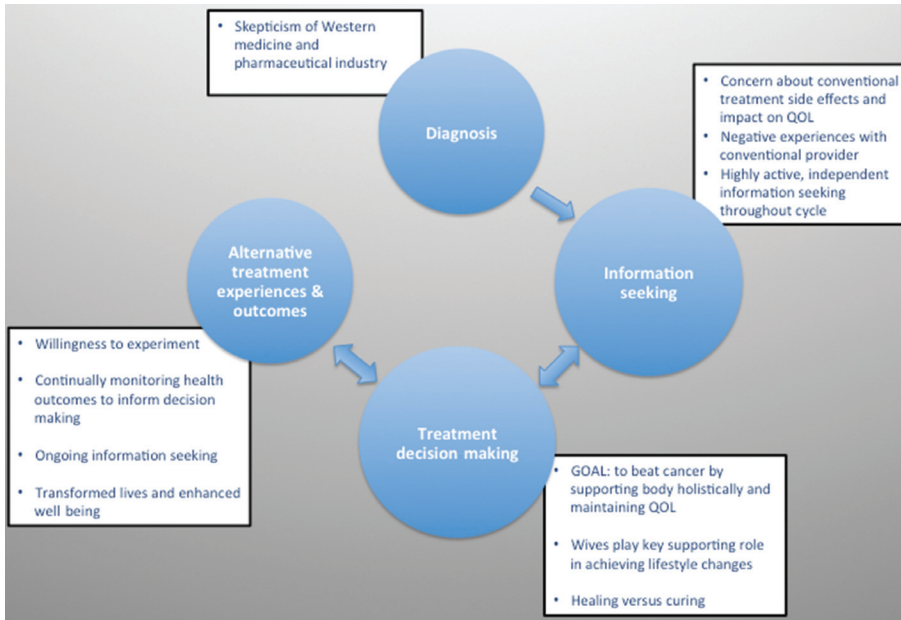


Figure 5: Aggressive alternative pathway.

An aggressive integrative pathway (Figure 4) is one in which individuals determinedly access CAM and conventional treatment options and are highly committed to their approach. They are open to trying anything available to eradicate cancer while supporting their body’s healing power. Opinions of their varied health care providers are valued and as such, little time is spent making treatment decisions. They prefer to defer to their health care team as they are considered the “experts.” Their pathway is often shaped by poor conventional treatment outcomes and a desire to be proactive once conventional treatment is complete.

The final pathway, Aggressive Alternative (Figure 5), is one in which an individual declines all conventional treatments with the goal of beating cancer by supporting

the body holistically while maintaining quality of life. Individuals on this path are constantly seeking information on alternative options and play a very active role in decision making. Health outcomes are closely monitored and used to inform treatment decisions. Aggressive alternative pathways are influenced by skepticism of Western medicine and the pharmaceutical industry, past encounters with conventional physicians that were negative and one-sided, healthy rapport and equitable relationships with alternative health care providers and concern with the risks and side effects of conventional treatment and impact on their QOL.

Each pathway has its own unique set of influencing factors, which will be described in further detail. The factors that most commonly influenced individuals’

Table 1: Common influencing factors.

Health Beliefs	Beliefs about treatment, health and wellbeing and the health care system. Includes cultural, spiritual and religious beliefs
Beliefs about Risk/Benefits of treatment	Beliefs about the risks and benefits associated with individual treatments or therapies
Preferred Decision-Making Role	Degree to which individual wants to be involved in making treatment decisions
Illness Characteristics	Influenced by illness type, stage, progression and available treatment options
Social Relationships, Roles and Responsibilities	Obligations to family and work, and is related to social roles and stage of life (includes encouragement/discouragement from social network)
Patient-Practitioner Relationship	How one’s relationship with health care providers (including notions of trust/credibility and satisfaction with care) influence decisions about conventional treatments, CAM therapies and lifestyle behaviors
Treatment Outcomes	Perceived/actual outcomes of care. Including cancer regression, cure, progress, symptom management, supporting body during treatment and overall well being and quality of life

decisions about treatments and pathways of care are listed in Table 1 and include health beliefs, beliefs about risks and benefits of a treatment, preferred decision-making role, illness characteristics, social relationships, roles and responsibilities, patient–practitioner relationships and treatment outcomes.

Five pathways: case illustrations

To better understand our proposed pathways, examples of each follow.

1. Passive conventional

The first case, Amanda, is a 53-year-old single mother of two from Canada. She was diagnosed with stage I breast cancer and accepted all recommended conventional treatments without hesitation. Her treatment options and plan were *extremely straightforward* given the cancer was discovered at an early stage and there was no lymph node involvement. Amanda's goal was to cure her cancer by completion of radiation and hormone therapy after her lumpectomy.

Aside from conversations with her physicians, she did not access information sources. She described herself as having put her *head in the sand a little bit* in regards to seeking information because there was *too much out there*. Instead, she placed her trust, and her treatment decision making, in her physicians' hands.

I felt like I was in good hands... Everything was being looked after. Her test results were clear-cut, her physicians agreed on her treatment, and there were no surprises along the way. With the help of her radiation oncologist, a personal acquaintance, Amanda progressed smoothly through the treatment system. She played a passive, permissive role in decision-making and did not use CAM therapies during the course of her treatment.

2. Self-directed conventional

The second case, Peter, is a married 53-year-old Norwegian father who works as a physician. He was diagnosed with stage II colorectal cancer and constructed a self-directed conventional pathway. The recommended course of treatment was radiation and chemotherapy as preparation for surgery. Two surgical alternatives were presented – the first to remove the entire rectum and have a permanent stoma and the other was to remove the tumor and mend the intestine back together.

Peter consulted his network of colleagues and medical team to gather information on which to base his decision. After a *catastrophic* diagnosis, he credits a

close group of family, friends, and colleagues with getting him *going in the right direction* immediately after his diagnosis. *I had a network of colleagues who have a lot more insight into the field and I have used them. And I have had input both from family and friends, from people who have some insight.* Peter decided to start radiation immediately but needed time to consider his surgical options and reconcile what he felt was a drastic surgery for a *small tumor without much infiltration*.

Peter's goal was to rid himself of cancer and he decided upon the recommended course of treatment. Peter's decision was influenced by Norway's recent development of national guidelines for the specific regime that his physicians were proposing to use with him:

It was explained that there is actually national guidelines for this treatment regime and they have good experiences with prognoses and results of treatment methods.

Always one to stay involved in decisions about his health care, once he opted for surgery, it was important to Peter that he share his feelings with his surgical team prior to his operation:

It was important for me to have talked to the surgeons ahead of time, so that they knew what I was thinking in relation to the one or the other choice. And I felt the need to tell them myself so that there wouldn't be a factor that would cause them to wonder unnecessarily.

3. Cautious integrative

The third case is Joan, a married 62-year-old Canadian mother with stage II breast cancer who developed a cautious integrative pathway. The course of treatment that Joan's surgeon recommended was either a lumpectomy or mastectomy followed by chemotherapy and radiation. Upon diagnosis, she actively sought information on both conventional and CAM treatment options. Joan was very thorough in her research on treatment options, while at the same time aware of the limited time she had to make a decision about conventional treatment. She consulted a wide range of books, websites, friends, colleagues, cancer survivors, and health care providers. One of her most trusted resources throughout the study was her family physician, whom she referred to *as her rock* and who she felt was key in making the *educated decision* collaboratively. Joan's goal was *to do everything possible to prevent a recurrence* and she opted to have a lumpectomy seven weeks after diagnosis, followed by the recommended course of chemotherapy and radiation. Once she made up her mind about the conventional treatments, she did not waver in her decision. The only decisions

that remained were how to manage the side effects of those treatments and support her mind and body using CAM. Prior to her cancer diagnosis, Joan eschewed conventional medicine in favor of a more holistic route in the form of healing foods, continuing to seek relief from such therapies was an expected course of action.

Joan described her approach to treatment as: *trying to treat it actively by being involved and by gathering as much information as possible and using methods that I feel fit with my convictions*. One of the major influencing factors in her decision to try everything to prevent a recurrence was her role as a mother to three children in their early twenties, including a daughter with mental illness and drug addiction who had recently attempted suicide. Her daughter's illness shifted her focus from her own illness to helping her daughter survive. Additionally, having lost her parents to cancer at a young age, Joan recognized that her children would need their mother for many years to come and wanted to do everything in her power to make that happen.

My oldest daughter has a very serious mental illness and she's at the hospital right now after a major suicide attempt. I'm looking after her. I don't really think of the cancer. I'm not worried about myself. That's not really that dominating in my life... I remember during that first dose of Docitaxil back when I was really quite ill, I remember lying on the couch and thinking I can't really count on my daughter who is really ill. I can't really count on her support like when I'm sick because every time she came home, I was the one who cooked. I was the one who did everything for her. And that was kind of a hard realization. That I will always be the caregiver for her.

Over the course of the study, Joan became her own *advocate* and spoke often about the critical role of seeking information about her health and treatments and judging its credibility. Joan was cautious in her CAM use and frequently consulted physicians and pharmacists about safety when combining CAM and conventional therapy. She stopped using all natural health supplements throughout chemotherapy for fear of lessening its effects but continued to receive acupuncture and use herbs from her garden to address some side effects. Throughout the study, Joan expressed great frustration with the conflicting information that she had encountered regarding natural health supplements. Joan was taking multivitamins but discontinued taking them for fear of contraindication. For her, this conflict reflected negatively on CAM therapies and caused her to continually question the safety of all current CAM therapies she was using.

You get very different information depending on who you speak. For example, the acupuncturist I saw says, 'Oh, some of the

doctors here prescribe way too many supplements. Just go the food route, get a juicer.' So it's quite inconsistent... I did go to a nutritionist at the Cancer Agency too. And even there you get conflicting information... When you are in a stress situation and you're trying to make decisions about your life, it is hard.

Regular acupuncture treatments to boost energy, lymph massage, exercise rehabilitation, nutrition seminars, and group meditation became an integral part of Joan's overall wellness program. Once active treatment concluded and she returned to work, Joan felt like she was ready to move on with her life. Unless her cancer returned, she commented that her work as a "patient advocate" was finished.

4. Aggressive integrative

The fourth case, Sarah, is a 48-year-old married Canadian diagnosed with stage IIa breast cancer, who developed an aggressive integrative pathway. Her physician recommended that she begin chemotherapy immediately, given that the large lump *appeared overnight*. The initial goal was to reduce the size of Sarah's lump prior to surgery, which depending on the results of the chemotherapy, would either involve a lumpectomy or a mastectomy. Sarah approached her cancer treatments (both conventional and CAM) with a "150% attitude" and was open to trying everything available to achieve her goal to eradicate the cancer and heal her body. Immediately post-diagnosis, Sarah began searching for support and treatment options. Information sources included her oncologist, the Canadian Cancer Society, anti-cancer books, the Internet and a group called "Best Doctors", which provided guidance on her breast reconstructive surgery plan. Although her doctors had said the decisions were up to her, Sarah believed her physicians were the experts and that it would have taken her *too long to thoroughly research treatment options*. She deliberately chose to *not* examine the risks associated with chemotherapy and mastectomy, for fear of being overwhelmed.

She started chemotherapy two weeks post-diagnosis and finished three months later. She spent very little time making this decision and deferred to her oncologist:

Never once did I ever think that chemotherapy wasn't an option... I was shocked to find out that there are people that do. I didn't even know that that option was available to say, 'No, I don't want chemotherapy.'

Given her tumor grew in between each of the rounds of chemotherapy, her physician put her on Herceptin. In addition, Sarah began taking a clinical trial drug, Zomata, to reduce her chances of recurrence. She

suffered side effects, including severe anxiety and depression. She stopped taking the drug halfway through the recommended course after her physician updated her about unfavorable interim trial results, including the potential for kidney damage.

Sarah joined an Integrative Cancer Care clinic to explore non-conventional options and was an avid user of their programs and services. She began seeing a naturopath, who prescribed several antioxidants and supplements to enhance immune function. To help heal from her reconstructive surgery, she incorporated regular massage, Reiki healing, and acupuncture treatments. Sarah aimed to *stay grounded* with a regular routine of mindful practices, including meditation, relaxation, and daily yoga. She refined her diet, attended a workshop to learn how to heal with herbs and registered in an 8-month long medicinal herb course. Sarah's quest for health and well being was tireless and at the end of the study continued regular visits to the Integrative Clinic and was completely immersed in the study of medicinal herbs.

5. Aggressive alternative

The last case, Tom, is a 64-year-old married Canadian. He declined all conventional treatments and pursued a highly aggressive alternative route. Tom's conventional treatment options included a radical prostatectomy, hormone therapy, chemotherapy, and/or radiation therapy (either beam or brachytherapy). His primary concern with conventional treatments was the possibility of damage to tissue. He was not prepared to accept the risks of incontinence, bladder infections, or erectile dysfunction; his quality of life was of paramount concern. He also expressed a commitment to being comfortable with his treatment choices and felt it was important he take responsibility for his decision to decline conventional treatments:

If I die sooner... then so be it, but at least, you know, life will be an enjoyable quality of life in terms of my standards... It's my life. I am the one that has got everything to lose and everything to gain. If I advocate that responsibility to someone else I am not doing myself any favors. If I make the wrong choice, ultimately I have to look in the mirror.

Tom's goal was to beat cancer by supporting his body holistically and maintaining his quality of life. He aimed to create an inhospitable environment for cancer to flourish. Immediately post-diagnosis he changed his diet dramatically, from being a *McDonald's and meat and potatoes kind of guy*, to one who ate cruciferous vegetables; avoiding dairy and meat. While he recognized the value of conventional medicine and physicians' abilities

within the context of some ailments, he had broad reservations about their understanding of prostate cancer, as well as the role of the pharmaceutical industry in North America.

They are very good at fixing bones and stitching you up and that type of thing, but I don't think the industry itself fully understands what cancer is and don't have any definitive answers as to what treatment works and what treatment doesn't work. I think they establish certain parameters that try to make their treatment look good. Europe has a different attitude towards alternative medicine, I guess, and it's one of the things that bothers me about the pharmaceutical industry in North America that has such a fairly dramatic hold on any serious diseases whether they be, you know, heart disease, cancer, whatever. They certainly limit the availability of a more natural approach.

Tom valued open and respectful communication with his health care providers. He worked in a business in which he dealt with *human beings and relationships, and those are the things that are important*. He enjoyed his rapport with his alternative practitioners and described feeling "pulled" toward their ideas about healing. He described the communication with his general practitioner (GP) as *fear-based and paternalistic*.

Over the course of his participation in the study, he became highly knowledgeable regarding alternative treatments options, closely monitored his outcomes, and used results to guide his treatment decisions. Tom was proactive in researching a variety of treatment options, continually exploring experimental cutting-edge therapies, some yet to be approved by Health Canada. He was an informed participant who played a highly active role in the treatment decision-making process. Tom incorporated a variety of treatments in direct response to treatment side effects and unsatisfactory test results. He used many and varied information sources including websites, Ted Talks, University researchers, fellow cancer survivors as well as his urologist and naturopath.

Toward the end of the study, Tom developed an enlarged prostate gland and stress incontinence. In consultation with his naturopath, he made the decision to stop monitoring his PSA scores because he believed they were too sensitive to outside influences. Instead, he focused on circulating tumor cell test scores, which involved having blood samples sent to Germany. In consultation with his naturopath, he began taking dichloroacetate (DCA), an experimental drug that was being tested by a University researcher. His tumor cell test score dropped drastically, which he attributed to DCA. However, a side effect of DCA was intense anxiety that seemed to pervade *all aspects of life*; therefore, he stopped taking it but remained committed to his quest to conquer his illness.

Crossovers

The cases described above provide an overall representation of the participants in the sample as no discrepant cases were identified. The major difference, however, is how individuals shifted between typologies as they moved through their cancer journey, which we referred to as a “Crossover”. Because of the dynamic nature of the treatment pathways, in some cases, participants changed pathways as a result of disease progression, treatment side effects, dissatisfaction with the conventional care system, and/or changes in health outcomes. Most common was the shift from Passive Conventional to Cautious Integrative. For example, a participant with aggressive stage IIa breast cancer had completed multiple conventional treatments including a mastectomy, chemotherapy, radiation, reconstructive surgery, and Tamoxifen. She endured significant treatment side effects, including lymphedema and long-term pain. Her goal was to start healing her body with acupuncture, physiotherapy, ion cleanses, yoga, multiple herbal remedies, Reiki, and yoga. After completion of the entire conventional treatment package, she described her healing approach as follows: *I am willing to try anything to feel better that is not involving chemicals.*

Discussion

Theory and clinical practice suggest that decision-making processes regarding CAM use differ from decision-making processes of those used in conventional medicine [13, 15, 30]. Our results are similar to other studies that have explored cancer decision making. Balneaves [15] identified three decision-making styles that overlap with these typologies as did Caspi et al. [13], who identified three distinct paths, suggesting the possibility of “alternative patients,” not just “alternative treatments.” Shumay et al. [30] found that increased CAM use was related to being female, Caucasian, increased education, breast cancer, increased side effects, low satisfaction with health care providers, and an increased perception of disease severity.

Understanding these differences in decision-making processes could improve patient–provider communication about treatment options. We chose to look beyond the scope of initial treatment decision making and explore the entire healing journey. In this study, no single influencing factor was solely responsible for a patients’ pathway. Instead, multiple factors woven

together led patients on different pathways. Garnering knowledge of the decision-making intricacies throughout the treatment pathway, together with a thorough understanding of the patient’s treatment goals and motivations, may help health care professionals initiate respectful dialogue and provide targeted support to individuals at each stage of their treatment pathway.

As demonstrated in Table 1, pathways are shaped by a range of variables that warrant mention.

Illness characteristics

The pathways that participants develop are influenced by both the illness type and the stage of disease. As a person’s prognosis worsens and the threat to one’s mortality grows, so does the desire to pursue therapies that are aggressive and have a higher likelihood of addressing the cancer. When the threat is minimal, it appears that individuals believe there is time and room for some error. Similar findings were also identified in a systematic review by Truant et al. [31] who synthesized knowledge about CAM use and advanced cancer patients. Findings demonstrate that advanced cancer patients who are younger, female, have higher education, had a longer duration of the disease and previous experience with CAM are more likely to use CAM during this stage of illness. As an example, prostate cancer is unique in the respect that for some individuals, active surveillance is an option to conventional treatment. Generally speaking, men with an early-stage diagnosis of prostate cancer tended to embark upon their path with less urgency and more time to explore potential CAM treatments than do men with early-stage rectal cancer. Similarly, women with early-stage breast cancer diagnoses (for example, Amanda with stage I breast cancer) pursued less-intensive conventional routes than those with stage II or III diagnoses (for example, Sarah with stage IIa breast cancer).

Desire to experiment with treatments

Some participants were more open to experiment with treatment options. This finding is similar to the patients in several other studies of CAM users [32, 33] who exhibited the willingness to engage with a variety of ideas about the body and illness. Broom described these individuals as undergoing “bricolage” or the iterative process of the collection of a variety of forms of expertise, practices, and technologies in an attempt to create their own

therapeutic trajectory. Laypeople, in their differential engagement with biomedical knowledge, seek to adopt, mimic, critique, or rewrite experts' positions [34]. Health care users search for knowledge that is meaningful in their everyday life with their disease, and often share "the alternative paradigm" [12, 32, 33]. This notion is certainly applicable to participants in both the aggressive integrative and aggressive alternative pathways. While it is not entirely clear whether this is a facet of their personality or rather more as a result of their specific illness characteristics, in some cases the phenomenon was pronounced.

Patient–practitioner relationship

This study and other recent studies have revealed that patient–practitioner relationships include notions of trust, credibility and satisfaction with care and, thus, directly impact decisions about conventional and CAM treatments [35, 36]. Closely linked to the preferred decision-making role is the degree that cancer patients' trust their physician [14, 37]. This complex concept embodies the technical, expertise aspect, as well as the interpersonal, communication element. Some patients place complete trust in their physician's expertise, as was exemplified in our participant, Amanda, and her permissive conventional pathway. Trust in the conventional health care system and health care professional can be perceived as embodied in many Canadian and Norwegian citizens, although these trust relations and the traditional evidence-based culture of health care delivery are being challenged by active "expert" patients in a post-modern culture of health care [38].

Decision-making preference

In this study, the level at which patients wished to participate in decisions about treatment largely influenced their treatment pathways. Passive conventional participants preferred their physicians to control their decisions while Cautious Integrative participants preferred shared decision making with their health care providers and the Aggressive Alternative participants preferred total control. Balneaves et al. [39] similarly found that women using CAM preferred a more active or collaborative role in treatment decision making than women only using conventional treatments. In Hack et al. study [40], patients who desired an active role in treatment decision making also sought or wanted detailed information.

Relative to passive patients, active patients desired significantly more detailed explanations of their diagnosis, treatment alternatives, and treatment procedures, which is also echoed in our findings. Lupton et al. [41] argues that patients may pursue both the ideal-type "consumerist" and "the passive patient" subject position simultaneously or variously, depending on the context. This illness behavior can be connected to "the reflexive self" acting in a calculated, pragmatic manner to engage in self-improvement and being skeptical about expert knowledge (Lupton 1997). Evans et al. [42] confirms the importance of gauging patients' preferences for participating in decision making. They found that patients' decision-making styles were contingent on identifiable communication strategies in the information sharing process with health care providers.

Health beliefs and outlook on risk/benefit

A range of beliefs influenced treatment pathways in this study including beliefs about the causes of cancer, treatment mechanisms, risks and benefits of CAM use, risks and benefits of conventional care, and available evidence. Although it is possible to categorize beliefs in this way, it is more likely that an individual's entire belief system influences the treatment decision-making process, where decisions are generally congruent with their belief system. Current beliefs are informed by a range of factors, including past experiences of the individual or his or her significant others, ethnocultural values, faith in God, and education [43].

Pathways are dynamic processes that may change over time due to a number of factors that include available conventional treatments, dealing with side effects from conventional cancer treatments, stage of cancer, stages of shock, surviving cancer versus living with cancer and relationship/interaction with providers/health care system.

Strengths and weaknesses of the study

A thorough understanding of key variables, such as those discussed here, highlights the inherent challenges in the development of complex and dynamic pathway typologies.

This is the only study of this kind to gather information about individuals' treatment pathways, documenting

experiences from pre-diagnosis onward. Individuals respond differently to a diagnosis and an exploration of the rationale for these responses and actions has been, to date, almost nonexistent. This research provides insight into this and may provide guidance in this area of research. This perspective is crucial to understanding the complexities that exist within decision making. It is our hope that with this information, we can move forward with development of theory-based decision support programs to better provide evidence-based support for cancer patients in making decisions about CAM and conventional cancer treatment.

However, we are limited in our ability to generalize these findings across types of cancer as the experiences captured in this explorative research are not representative of all individuals living with cancer using conventional and CAM therapies. Another shortfall is that we only followed individuals for one year. This research has established the initial groundwork needed to understand how patients' decisions and treatment experiences can fit within a particular trajectory. However, further research is required to validate these proposed treatment pathways.

Conclusions

To better understand how treatment pathways unfold for different patients and how health care providers may recognize and relate to these differences, additional research across a range of illnesses and geographical scope must be conducted. This research is needed to help health care providers understand the evolution of individuals' treatment pathways, to better assess and monitor their CAM use, and to offer more patient-centered care. It is our hope that a larger international study of treatment pathways and their influencing factors would lead to the development of a theory that can more accurately determine the type of health care interventions that people seek and ultimately the care pathways that hold the most promise.

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Appendix A. Baseline Interview Guide

1. Before we begin to talk about the cancer care pathway you have been on since being diagnosed with cancer, could you tell me a little bit about what you did for your health and wellbeing before you were diagnosed with cancer?
2. Can you describe how you reacted to the diagnosis?
3. How has the diagnosis impacted your life?
4. We're now going to talk about what has happened in terms of the treatment decisions and choices that you have had to make since being diagnosed with cancer.
 - a. What treatments did your doctor recommend following your diagnosis?
 - i. What treatments did you decide to have?
 - ii. When did you receive these treatments?
 - iii. What did you hope to achieve from these treatments?

- iv. How did you make your decision about these treatments?
 - v. What was the XX treatment like for you? (probe for each treatment received physical, emotional, etc.)
 - b. Some people with cancer also receive care from other cancer care professionals, like psychologists, dietitians/nutritionists, and counselors. After you were diagnosed with cancer, did you receive support from any of these individuals?
 - i. What treatments did you decide to have?
 - ii. When did you receive these treatments?
 - iii. What did you hope to achieve from these treatments?
 - iv. How did you make your decision about these treatments?
 - v. What was the XX treatment like for you? (probe for each treatment received physical, emotional, etc.)
 - c. What other treatments did you consider using following your diagnosis? (probe CAM therapies and practitioners)
 - i. What treatments did you decide to have?
 - ii. When did you receive these treatments?
 - iii. What did you hope to achieve from these treatments?
 - iv. How did you make your decision about these treatments?
 - v. What was the XX treatment like for you? (probe for each treatment received physical, emotional, etc.)
 - d. After you were diagnosed with cancer, what other things did you do to take care of yourself? (probe diet changes, exercise, stress reduction, smoking cessation)
 - i. What treatments did you decide to have?
 - ii. When did you receive these treatments?
 - iii. What did you hope to achieve from these treatments?
 - iv. How did you make your decision about these treatments?
 - v. What was the XX treatment like for you? (probe for each treatment received physical, emotional, etc.)
5. Now take a few moments and review the therapy survey you completed before the interview to see if there are any other therapies we haven't talked about that you would like to share?
 6. What kind/source of information did you use in making your decisions about treatments?
 - a. How was this information helpful/not helpful?
 - b. What information was missing?
 - c. How did your relationship with health care providers affect your decisions?
 7. Looking back at your cancer care pathway, would you make the same treatment/care decisions? If yes, why? If no, what why and what would you change?
 8. Out of all of the things that you have done since being diagnosed with cancer, what do you consider to be most important? Why?
 9. Many people with cancer have other important things happen in their lives after being diagnosed with cancer, such as getting married, losing a job, moving to a new place. What other important things have happened to you and/or your family during this time?
 - a. How do you feel XX (life event) has impacted you?
 - b. How do you feel XX (life event) impacted your treatment/care?
 - c. How do you feel XX (life event) impacted your response to treatment/care?
 10. Family and friends are often involved in people with cancer's experiences. Who, if anyone, has been important in your journey with cancer?
 - a. How have they been important?
 11. For those with children living at home ask: Have your children affected your decisions about care? Probes: How? Can you provide specific information or examples?
 12. For you, what in your life has been the most influential in how you have made decisions about your care? Probe: The treatments you have chosen? Beliefs, values? Life events? Other people?
 13. Looking back, what are the most important outcomes/goals of your cancer care pathway (treatments)?
 14. You've talked about a variety of treatments today. How do you see your treatments working together to help you achieve your goals?
 - a. What challenges, if any, have you experienced in combining your treatments?
 15. What do you use to cope with your treatments and/or your diagnosis of cancer? Probes: Can you identify some of the ways you help decrease stress or burdens? Can you identify what specifically works and what you do that doesn't work so well?
 16. I would describe my personal cancer care approach as _____.
 17. What else about your cancer care would you like to tell me?

Appendix B. Monthly Interview

- Using your completed calendar, I would like to talk with you about your use of new treatments *in the past month*. I would also like to talk to you about any treatments you stopped using *in the past month*, and the events that impacted what you did for your cancer care *in the past month*. Please refer to your calendar and outline these for me.

Assess whether new or stopped treatments.

- Please tell me more about the [new treatment #1] that you mentioned (if applicable).

→ Treatment; example, went to spiritual healer

What did you want to accomplish with this?

→ Treatment characteristic; example, wanted to lessen pain

Where did you learn about it?

→ Treatment characteristic; example, my sister told me

How often did you go (or how much did you take)?

→ Treatment characteristic; example, two times; example, one bottle of pills

Would you try this again? Do you think it worked?

→ Treatment characteristic; positive, negative, ambiguous

- What else did you do for your cancer care this month?

(Loop until done all NEW treatments)

- Are 'X', 'Y', and 'Z' all of your new treatments?

- Did you *consider* any other kinds of cancer care that you ultimately decided against?

→ Treatment considered

Why did you decide against using this?

- Was there anything else you considered?

(Loop until done all CONSIDERED treatments)

People may also have stopped using treatments or seeing practitioners.

- Please tell me more about the treatment(s) [#1] that you stopped using or doing (if applicable).

→ Treatment stopped: example, taking black cohosh

Why did you stop using this?

→ Treatment characteristic; example, it cost too much

- What else did you stop using or doing for your cancer care this month?

(Loop until done all STOPPED treatments)

- Are 'X', 'Y', and 'Z' all of your stopped treatments?

- Did you *consider* stopping any other kinds of cancer treatments or care that you are currently using?

→ Treatment considered stopping

Why did you consider stopping your use of this?

- Was there anything else you considered stopping?

(Loop until done all CONSIDERED STOPPING treatments)

- Now thinking about [event/situation #1], did that impact what you are using or doing for your cancer care? If yes, how? Now thinking about [event/situation #2]....

→ Life event

→ Event characteristic (absolutely anything)

- And did [event/situation #1] impact on what you *stopped* using? If yes, how? Now thinking about [event/situation#2].

Final questions:

- Is there anything we missed (treatments started, treatments stopped, and related events)?

- Is there anything else you would like add?

Appendix C. Concluding Questions

- Compared to last year when you started to take part in this study – where are you now in terms of health/wellbeing, cancer treatments, relationships, returning to work etc. (other relevant prompts)?
- Looking back on the journey you have been on over the past year, how would you describe your global experience?
- In ten words or less, how would you describe your approach to health and wellness this past year?
- How do you feel about the treatment decisions you made?
- How satisfied are you with your cancer treatment? Why?
- What have you learned? Positive? Negative?
- What has been the biggest worry for you?
- Has anything created distress and anxiety for you? What?
- Do you have any regrets?
- Is there anything that you would do differently?
- What advice do you have for your health care providers? And for the cancer care system?
- Are you interested in receiving a report about this study?