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Exploring patient-related contextual factors and personal reflections about patient engagement in the Managing Cancer and Living Meaningfully (CALM) intervention: A mixed methods study among adults with advanced cancer in Southern Alberta

Sears, Carly Sherrington

UNIVERSITY OF CALGARY

Exploring patient-related contextual factors and personal reflections about patient engagement in the Managing Cancer and Living Meaningfully (CALM) intervention: A mixed methods study among adults with advanced cancer in Southern Alberta

by

Carly Sherrington Sears

A THESIS
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Abstract

Background: The evidence-based Managing Cancer and Living Meaningfully (CALM) psychotherapeutic intervention was designed to address the complex needs of those with advanced cancer. Ample evidence supports the efficacy of CALM therapy; less is known about the patient-specific factors that influence initiation and continuation of CALM sessions.

Objective: This study aimed to enhance our understanding of the impacts of patient-specific factors, referral routes, and timing of referral on engagement in CALM therapy, with particular attention to the integration of patient voices through in-depth interviews.

Methods: This study used a concurrent triangulation mixed methods design involving analysis of baseline questionnaire data and referral details from participants in the CALM Implementation study (n = 69). Participants who consented to follow-up (n = 24) were invited to participate in brief, virtual interviews after completion of CALM therapy. Thematic analysis, within an Interpretive Description framework, was used to analyze interview responses (n = 10).

Results: Triangulation of quantitative and qualitative results suggests that initiation and continuation of CALM sessions is affected by multiple, complex factors including mood symptoms, referral route, need for support outside of family/friends, and decline in health status. Patients directly referred to CALM by healthcare providers (HCP) and those who self-referred (total n = 32) engaged in more CALM sessions (M = 4.97, SD = 3.51) versus those first referred to general Psychosocial Oncology (i.e., indirect referral; M = 3.19, SD = 2.26, $p < 0.05$). Stratified analysis found this effect was significant among younger participants (<65 years) and those with longer life expectancy (>10 months). Some participants suggested automatic referral to CALM following an advanced cancer diagnosis. Provision of comprehensive intervention

information, highlighting benefits while being sensitive to mortality fears, was deemed valuable to allow for informed decision-making.

Conclusion: Findings suggest that timing and referral route are important to our understanding of participation in CALM. Greater patient engagement in the CALM intervention following direct referral from a HCP may be based on trust in the HCP-patient relationship. Future health systems research may evaluate an automatic referral system in which CALM is offered to all patients following an advanced cancer diagnosis.

Keywords: advanced cancer, psychosocial oncology, early palliative care, referral routes, psychological intervention

Preface

Chapter three of this thesis, titled "Exploring patient-related contextual factors and personal reflections about the Managing Cancer and Living Meaningfully (CALM) intervention for adults with advanced cancer in metropolitan and non-metropolitan Southern Alberta: A mixed methods study," comprises the manuscript that will be submitted to *Psycho-Oncology*. Study conception, design, statistical analysis, interpretation of results, and drafting/editing this manuscript was completed by first author, Carly Sears, with guidance and input from Dr. Janet de Groot, Dr. Jessica Simon, Dr. Andrea Feldstain, Dr. Fay Strohschein, and Dr. Scott Patten.

Interpretation of results and planning for knowledge translation was guided by patient and family advisors within Cancer Care Alberta, who generously volunteered their time and perspectives to the project.

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Table of Contents

List of Tables

List of Figures

List of Abbreviations and Symbols

AbSPORU	Alberta's Strategy for Patient Oriented Research Support Unit
ASCO	American Society of Clinical Oncology
CALM	Managing Cancer and Living Meaningfully
CALM-N	CALM-Nurses
CGS-M	Canada Graduate Scholarship-Master's
CIHR	Canadian Institutes of Health Research (CIHR)
DADDS	Death and Dying Distress Scale
ECR-M-16	Experiences in close relationships – modified
HCP	Health care provider
HREBA-CC	Health Research Ethics Board of Alberta – Cancer Committee
ID	Interpretive Description
MCP	Meaning-centered psychotherapy
MCGP	Meaning-centered group psychotherapy
PaCES	Palliative Care Early and Systematic
PAN	Patient Advisors Network
PHQ-9	Patient health questionnaire, version 9
PPF	Putting Patients First
QUAL-EC	Quality of life at the end of life – cancer scale
RCT	Randomized controlled trial
SEGT	Supportive-expressive group therapy
SPCS	Southwest Palliative Care Service

TBCC	Tom Baker Cancer Centre
TNM	Tumor, node, metastasis classification
>	Greater than
<	Less than
≥	Greater than or equal to
≤	Less than or equal to

CHAPTER ONE: INTRODUCTION

1.1 Advanced Cancer

Advanced, incurable cancer encompasses diverse cancer diagnoses but, ultimately, denotes a cancer that cannot be controlled with treatment and is thus considered terminal (National Institutes of Health, National Cancer Institute, 2024).[1] Cancer staging is complex and depends on characteristics such as tumour type, location and size, invasion of lymph nodes, and spread to other parts of the body.[2] Although there are particular staging specificities associated with different cancer types and staging systems (e.g. tumor, node, metastasis classification, or TNM), in general, more advanced, recurrent, or incurable cancers are represented by higher stages (e.g., stage III or IV).[2] Given the ubiquity of cancer around the world, the number of people affected by advanced cancer is staggering. In Canada, alone, the estimated number of new cancer cases in 2023 was 239,100 (approximately 0.6% of the Canadian population) and cancer deaths was 86,700 (approximately 0.2% of the Canadian population).[3] In the United States, an estimated 623,405 people were living with metastatic breast, prostate, lung, bladder, colorectal cancer or melanoma as of February 2024 (approximately 0.2% of the population).[4] There is, therefore, an urgent need to develop, implement, and assess supportive care programming to best meet the needs of the individuals who are diagnosed with advanced cancer and their close others.

1.2 Living with advanced cancer: challenges and needs

The physical, psychosocial, spiritual, and financial implications of advanced cancer are complex and numerous. Progressive, life-limiting cancer diagnoses impose upon personal relationships, identity, life goals, and sense of meaning and purpose.[5–7] Inherent in the management of life-limiting illness, individuals diagnosed with advanced cancer are faced with concerns about mortality and unrelenting uncertainty.[8] Frequently, a diagnosis of advanced

cancer leads to significant distress, which may be experienced as depressive symptoms, death anxiety, loss of dignity, and/or demoralization.[5,9] Often associated with a limited prognosis and higher burden of physical symptoms, demoralization is characterized by hopelessness, loss of meaning, poor self-esteem, and the inability to cope with disease progression and looming mortality.[6,9,10] Along these lines, the physical manifestations of metastatic cancer (e.g., pain) are inextricably linked with elevations in death anxiety and depression.[7,10–14] Among people with advanced cancer, rates of depression are reportedly as high as 56%.[12,15] Given the high prevalence of depression and demoralization in people living with advanced cancer, it is essential to offer specialized psychosocial programming that helps to promote post-traumatic growth,[16,17] spiritual well-being,[18,19(p2)] a sense of meaning and hope,[17,20,21] psychological growth and resilience,[5,19(p2),22] and quality of life.[23,24]

1.3 Specialized Psychosocial Oncology Support for advanced cancer

1.3.1 Integration of Psychosocial Oncology, Palliative, and Oncology Care

Palliative care is generally conceptualized as "interdisciplinary care focusing on improving patients' quality of life by addressing their physical, emotional, and spiritual needs, and on supporting their families."[25] The term, "supportive care," is sometimes used in place of "palliative care" as a way to bypass stigma associated with the word, "palliative," and to increase the likelihood of referral.[25–27] However, an evolving framework has been proposed in which disease stage is used to distinguish among "best/supportive care," "palliative care," and "hospice care." In this model, hospice care is a subsection of palliative care, which, itself, falls under a wider umbrella of supportive care.[25] Increasingly, psychosocial oncology is also included under the umbrella of supportive care as an integral aspect (either integrated or as a complementary form of support) of person-centred palliative care.[28] For the current study, palliative care is

characterized according to the American Society of Clinical Oncology Clinical Practice Guideline Update, which describes a number of characteristic components, including but not limited to: "symptom, distress, and functional status management;" "assessment and support of coping needs;" "assistance with medical decision making;" "coordination with other care providers;" and "exploration of understanding and education about illness and prognosis."[29] Early, integrated palliative care is essential to the delivery of holistic, person-centered medicine and is rapidly becoming a global standard of care.[30–33] According to a recent American Society of Clinical Oncology (ASCO) Clinical Practice Guideline update, "patients with advanced cancer…should receive dedicated palliative services, early in the disease course, concurrent with active treatment".[31] Key features of early palliative care include: 1) early referral to palliative services, at the time of diagnosis of an advanced cancer, or with prognosis of 6-24 months;[32] 2) provision of comprehensive, integrated supportive care services, including psychosocial care.[32–35] Study findings indicate that early palliative care helps with patients' quality of life, mood, ability to cope with their prognosis, communication with the healthcare team, and satisfaction with care.[24,30,32,34,36–38] In some populations, early palliative care has been associated with increased length of survival time.[38] Beneficial impacts on patients' loved ones have also been reported.[31,36,39]

The value of incorporating specialized psychosocial support within oncology is well recognized. Psychosocial Oncology, or Psycho-Oncology, is an established, evidence-based interdisciplinary field that aims to address the complex needs and improve well-being of people who are diagnosed with cancer.[40] Psycho-Oncology interventions support individuals and loved ones in the management of emotional concerns (e.g., fear of mortality), physical symptoms of cancer (e.g., pain), treatment optimization (e.g., adherence), spiritual aspects (e.g., meaning and

purpose), practical concerns (e.g., return to work), family and relationship concerns, and general health/lifestyle (e.g., stress management).[40] In the context of advanced cancer, psychosocial care is associated with significant improvements in symptoms of depression, relationships with healthcare providers, preparation for end of life,[35,37,41,42] and rates of physician referral to palliative care.[43] In spite of an accumulating body of evidence in support of the integration of palliative, psychosocial and oncology care, real-world implementation is impeded by many individual- and institution-level factors (e.g., structural/institutional barriers, and stigma or limited understanding of the full spectrum of support offered through palliative services); as a consequence, gaps in care persist.[34,35,44–46] Patients are often referred to palliative care late, typically within 30-60 days of death.[35,46]

Based on results of previous studies and systematic reviews, there has been a call to merge the often separate silos of oncology, palliative, and psychosocial care, [31,34,35,43,46] and to develop a "standardized care pathway where oncology and palliative care is fully integrated".[34] Although numerous studies have been conducted to evaluate the effects of integrated care, there is a persistent lack of understanding about referral procedures and routes (e.g., automatic referrals through oncology clinics) that might best fit local cancer care contexts. A recent Lancet Oncology Commission[34] speaks to the urgent need for development and implementation of standardized care pathways, involving coordinated activities of multidisciplinary teams, to enhance integration and, ultimately, patient care.

In Alberta, Canada, although there is a rich array of resources available across the province through Psychosocial Oncology as well as community-based programming, there is no clearly defined pathway specific to individual interventions for people with advanced cancer. Alberta's Psychosocial Oncology program is world-renowned and comprehensive, offering tumour-site-

specific individual, couples, and family counselling, as well as psychiatry and social work support (please see the Methods section for further details). Although work is underway to differentiate support options for early versus advanced cancers (e.g., early-stage versus metastatic cancer support groups), there remains a need to offer psychosocial support that specifically addresses the unique needs of people with advanced cancer. In a recent study, Watson and colleagues (2020) reported significantly lower levels of satisfaction and less positive experiences of oncology care among those with more advanced disease, thus highlighting the need to better understand and meet the needs of patients with non-curative cancer.[47]

With its comprehensive, 4-domain model, the Managing Cancer and Living Meaningfully (CALM) intervention may represent a programmatic mechanism whereby the clinical silos of oncology, psychosocial, and palliative care can be bridged. Importantly, the CALM intervention was developed based on the self-reported needs of people living with advanced cancer. As of this writing, a direct referral procedure for advanced cancer patients (e.g., through the province-wide electronic medical record system) to CALM does not yet exist. Moreover, as described in de Groot et al (in preparation),[48] indirect referral to CALM, via an initial referral to general psychosocial service, has lower uptake and high loss to follow-up.

1.3.2 CALM Therapy

CALM therapy is an evidence-based, manualized psychotherapeutic approach designed to address the concerns of those with advanced, life-limiting disease and their close others.[5,49] A brief, semi-structured psychotherapeutic intervention, CALM involves three to six counselling sessions conducted over approximately three to six months, with additional booster sessions available as needed. Close others are invited to join at least one CALM counselling session. The CALM model was designed to reduce distress and to help patients navigate the complexities of

life with advanced cancer, in the midst of uncertainty, physical decline, and end of life.[5,49] As a therapeutic model, CALM incorporates theoretical elements of relational theory (e.g., co-creation of meaning), attachment theory (e.g., anxious or avoidant attachment styles), and existential theory (e.g., dilemmas pertaining to mortality).[5,49] A central aim of CALM therapy is to support patients' capacity for reflection and "double awareness," or the ability to live with a sense of hope and continued engagement while simultaneously anticipating decline and end of life.[5,49,50] The CALM model involves four broad domains that can be flexibly approached throughout the course of therapy: (1) symptom management and relationships with health care providers; (2) changes in self and relationships with close others; (3) sense of meaning, purpose and spirituality; (4) the future, hope, and mortality. The CALM approach is gaining momentum in clinical and research spheres across the globe; indeed, the CALM literature milieu is growing. Findings from numerous trials indicate that CALM therapy helps to reduce depressive symptoms, enhance preparation for end of life, reduce cancer-related fatigue, and improve cancer-related cognitive impairment.[49,51–54]

1.3.3 Other Psychotherapeutic Approaches for Advanced Illness

Several psychotherapeutic modalities have been developed or adapted to address the psychosocial needs of individuals with advanced cancer and their close others. These interventions are offered in a variety of formats, including individualized models, couples- or family-based approaches, and group-based programming. Evidence suggests that supportive-expressive group therapy,[55,56] mindfulness-based therapies,[57–60] meaning-centered psychotherapy (MCP),[20,61] Dignity therapy,[62,63] and psychedelic-assisted therapies[64,65] may have particular benefit within this population. These approaches can differ in terms of timing and the number of persons included (e.g., one-on-one therapy, inclusion of a close other, or group-based).

Timing of the intervention: CALM therapy and MCP tend to be provided earlier in the trajectory of advanced illness (prognosis of at least 1 year),[20,49] while Dignity Therapy is generally offered closer to end of life (prognosis <6 months).[62] However, an adapted, abbreviated version of MCP has been successfully implemented among individuals admitted to an inpatient palliative care hospital, with life expectancy of 4-6 weeks.[66] Psychedelic-assisted therapies can be implemented among people with diverse prognoses.[64,65] For example, in a study by Rosenblat et al. (2023), participants' life expectancies ranged from 1 to 12 months.[64] Similarly, mindfulness-based approaches are associated with improvements in cancer-related distress and depressive symptoms, mindful coping skills, sense of acceptance, and meaning in life among different cancer populations with varying life expectancies.[59,60]

Number of persons included in therapy: In an effort to best address the complex, changing needs of individuals with advanced cancer, interventions such as CALM therapy, MCP, Dignity Therapy, and Mindfulness-based approaches offer individualized, couples-based, and group-based approaches. The availability of one-on-one sessions, as offered through CALM therapy, MCP, and Dignity Therapy, is particularly relevant in the context of declining health status, mobility difficulties, and scheduling conflicts with ongoing medical appointments.[20] Also pertinent in this population, these approaches allow patients to freely discuss death and dying concerns with a professional who doesn't impose a sense of needing to remain positive. Uniquely, CALM therapy provides an opportunity to include a close other as part of therapy sessions (e.g., a partner, adult child, close friend), thereby facilitating exploration of "changes in self and relations with close others," a core domain of CALM.[49]

Group-based therapies: Benefits associated with group-based approaches have been observed in studies of supportive-expressive group therapy (SEGT)[56] and Meaning-Centered Group

Psychotherapy (MCGP)[61]. Group-based approaches offer opportunities for participants to share and learn from each other, to become "witnesses, or repositories of meaning, for each other".[61] In addition to the many benefits of group-based therapies, there are inherent challenges for participants and therapists (e.g., when a group member dies).[56] SEGT incorporates peer support with professionally facilitated discussion surrounding existential concerns, emotional expression, life priorities, and changes in one's sense of self.[67–70] Studies exploring SEGT among cancer patient populations have found associations between SEGT and the prevention or reduction of depressive symptoms, changes in affect-regulation strategies, reductions in hopelessness-helplessness, and self-reported improvements in social functioning,[67–69,56] Designed to address existential distress among those with advanced illness, Meaning-Centered Psychotherapy (MCP) is a manualized psychotherapy approach in which patients are supported to identify sources of meaning in their lives.[20,61] Application and evaluation of MCP in both group-based and individualized formats suggests that MCP can help to improve (1) quality of life, spiritual well-being, sense of meaning, anxiety; and (2) to reduce self-reported desire for hastened death.[20,61]

Individualized therapies: Dignity Therapy is a manualized psychosocial intervention that was developed to "engender a sense of meaning and purpose, thereby reducing suffering in patients nearing death".[62] In Dignity Therapy, therapists facilitate a "life review" process, which ultimately culminates in the creation of a legacy document for each patient. [62,63] Evidence from numerous studies suggests that Dignity Therapy is well received by patients and their loved ones, is associated with improvements in patients' sense of meaning and purpose, and may impact symptoms of depression and anxiety, though further studies with larger sample sizes are needed to assess potential impacts on psychological symptoms (e.g., major depression).[63]

Mindfulness-based therapies may be delivered individually,[57,58,71] in a group-based format,[57–59] with patient-caregiver dyads,[57] or using a combination of group-based delivery with individualized mindfulness practice.[59] The application of mindfulness-based approaches is less researched among populations of advanced cancer patients, specifically. However, findings from recent studies indicate that mindfulness-based interventions are feasible, acceptable, and help to improve anxiety, depression, quality of life, and mindfulness skills (e.g., non-judgement about inner experience, as per the Five Facet Mindfulness Questionnaire).[58,59,71] Successfully implemented mindfulness interventions tend to incorporate adaptations that are sensitive to the changing needs and physical capacity of people with advanced disease (e.g., home-based, shorter session duration).[59,71] Further research is needed to expand upon initial findings from pilot feasibility studies, particularly among people with advanced cancer. Although findings thus far are positive, there is considerable heterogeneity in mindfulness-based interventions, and in the assessment measures employed across studies; there are currently few high-quality, rigorous trials assessing the application of mindfulness-based interventions among advanced cancer patient populations.[57]

Psychedelic-assisted therapies are generally administered individually; however, recently studies have been conducted in which novel group-based therapies are implemented and assessed.[65,72] An accumulating body of evidence supports the efficacy of psychedelic-assisted therapies among people with advanced cancer in terms of improvements in anxiety, depression, existential distress, demoralization, suicidal ideation, spiritual well-being, and quality of life.[64,65,73–76] Importantly, for a high proportion of participants, these effects appear to be sustained for months to years post-intervention.[65,73,76,77] There is a call for larger, more

rigorously-conducted, government-funded trials to assess implementation and effectiveness of psychedelic-assisted psychotherapies in different populations of patients with advanced cancer.

Although findings associated with these approaches are promising, results must be interpreted in light of several methodological limitations. Studies assessing psychosocial and palliative care interventions among individuals with advanced cancer are frequently hindered by attrition related to participants' declining health and death. In the recent CALM implementation study (de Groot et al., in preparation; see below), 20% of consented participants (n=14/69) died during the course of the study. Challenges with recruitment, unpredictable disease trajectories, and death of participants continue to impede methodological rigour of these studies.[78] This has been associated with a persistent dearth of "high-quality, adequately powered, well-conducted clinical studies in palliative and end-of-life care"(p. 278).[79] Moreover, there is a particularly high need for good-quality studies among underrepresented and marginalized ethnic/racial groups.[80] Most intervention studies involve participants who are predominantly White, English-speaking, from higher SES/educational backgrounds, thus limiting generalizability to more diverse groups.

Psychosocial intervention studies often utilize different measures to assess patient-reported outcomes (e.g., mood, quality of life, physical symptoms). As a consequence, it is difficult to compare findings across studies. Similarly, study rigour is affected by inconsistencies in therapists' fidelity to a psychotherapeutic model, particularly when a number of therapists are involved in providing a therapy.

Uniquely, the four-domain CALM model comprehensively addresses psychological health (e.g., supporting "double awareness" and reflection),[50] relationships with close others, spiritual well-being, mortality concerns, hope, communication with medical teams, and self-advocacy within medical systems. This encompassment of multiple dimensions of personhood, with

particular awareness of concerns specifically related to advanced cancer, is distinct from other psychotherapeutic approaches developed for people with advanced, life-limiting diseases. Importantly, the CALM model was developed bottom-up, based on analyses of patients' self-reported descriptions of their support needs.[19,81]

1.4 Research Regarding Patient-Specific Factors in Psychosocial Interventions

Implementation of evidence-based psychosocial interventions within established health care settings requires knowledge of, and adaptation to, nuances of local contexts, practices, and perspectives.[82–84] It is increasingly acknowledged that uptake of interventions is influenced by a multitude of factors, by an interplay of "multiple causalities" (p. 353).[85] Such factors may include local socio-cultural norms (e.g., gender norms), previous exposure to psychological support, personal history of mental health conditions, and current level of informal social support.[85–89] Study findings suggest that patients' and caregivers' expectations about psychotherapeutic interventions impact their experiences of referral to, and engagement in, psychological treatments; ultimately, this can affect therapy outcomes.[88,89] Positive perceptions and outcome expectations of help-seeking and of psychosocial support, in particular, are associated with willingness to be referred and to engage counselling.[88,89]

A perplexingly high proportion of individuals diagnosed with cancer choose not to engage in psychosocial support, even when support is readily available, free of charge, and explicitly offered.[86,87] Results of a recent meta-analysis indicate that almost half of those who are offered psychosocial support ultimately do not engage in it.[86] Previous studies have explored a broad array of patient-related factors associated with utilization of psychosocial support (e.g., readiness or willingness to engage in counselling), among individuals diagnosed with diverse types and stages of cancer. According to a large, mixed-methods study involving over 300 oncology

patients, four factors are associated with an openness to utilize psychosocial oncology support: attitude about psychosocial support (e.g., psychosocial support as helpful); coping strategies (e.g., psychosocial support as an empowering strategy for dealing with a difficult situation); distress level (e.g., higher distress related to physical deterioration), and availability of formal or informal support (e.g., lower support from family/friends).[90] Across the literature, self-reported symptoms of depression or anxiety, as well as lower levels of social support, have been associated with greater willingness to be referred for psychosocial treatment.[87] There are nuances to consider, however, when exploring the role of distress in uptake of psychosocial support. Although elevations in self-reported distress are associated with increased uptake of psychosocial oncology interventions, some studies suggest that higher distress does not necessarily predict greater openness to, or uptake of, psychosocial support.[86,87]

Findings from some studies reveal disparities in uptake according to sociodemographic characteristics such as gender, age, and education level.[88,91] It has been reported that female patients, those who are younger, and those who are undergoing active or more intensive treatment may be more likely to engage in psychosocial services.[88,89] Illness-related mobility concerns, often more prevalent among those with advanced cancer, also influence patients' level of engagement in psychosocial services. Accordingly, findings suggest that patients are often more willing to participate if virtual or telephone-based options are offered.[86]

1.5 CALM Implementation Study

A pragmatic, single-arm implementation pilot study (2020 – 2024) was conducted to examine the feasibility and acceptability of offering CALM, and its effectiveness within the context of Southern Alberta, alongside other psychosocial oncology and palliative care services (de Groot et al., in preparation).[48] The current Master's thesis study was completed as a branch of this larger

CALM project. In particular, an essential component of the Master's study involved a secondary analysis of baseline data originally collected as part of the CALM implementation project.

1.6 Literature Review

1.6.1 Inclusion criteria

A literature review was conducted to explore the landscape of CALM-focused research. Consistent with the aims of the current Master's project, we chose to include only pragmatic or implementation-based studies, rather than more rigidly conducted randomized controlled trials (RCTs). The search term, "Managing Cancer and Living Meaningfully," was employed in searches using PubMed, CINAHL, Medline, and Embase databases. All English-language studies, from any date range, were included. All pragmatic studies, implementation trials, pilot trials, Phase I or Phase II studies, and qualitative studies (and protocols) were included. Studies were excluded if they used a RCT design, if they were not written in English, and if their primary clinical focus was not oncology.

1.6.2 Study Characteristics

The initial search returned a total of 42 results, of which 13 met criteria for inclusion. Eligible studies included review articles (*n*=4), Phase II or IIa feasibility or preliminary effectiveness studies (*n*=3),[92] qualitative studies (*n*=3), protocols for single-arm trials (*n*=2), a mixed methods study (*n*=1), and an implementation study (*n*=1). Studies were conducted by teams in Canada (*n*=6), the Netherlands (*n*=2), Japan (*n*=2), Australia (*n*=1), Chile (*n*=1), and the United States (*n*=1). The number of participants in each study ranged from 10 for a qualitative study[81] to 64 for a multi-site implementation study[93]. For two studies,[94,95] participants were healthcare providers who were training to become CALM therapists. Six of the studies administered questionnaires at baseline and follow-up to assess demographics, mood, quality of life, treatment satisfaction, and

treatment integrity at baseline and follow-up.[19,51,93,94,96,97] Interviews or focus groups were conducted for 5 of the studies.[51,81,94,95,98] Four articles were purely narrative and employed a CALM-specific lens to discuss psychotherapeutic and palliative care interventions for people with advanced disease.[5,50,99,100] All but two of the articles include the co-founders of CALM as a co-author.

1.6.3 Implementation of CALM: feasibility, acceptability, and preliminary effectiveness

Findings from recent implementation and feasibility studies conducted in the Netherlands, Canada, and United States suggest that CALM is a feasible, acceptable intervention that can be offered at a variety of clinical sites by HCPs from diverse professional backgrounds. Kool and colleagues (2023) trained HCPs at 3 clinical sites across the Netherlands as part of a study assessing feasibility, acceptability, sustainability, and effectiveness of CALM. Of the 24 HCPs who were trained to offer CALM therapy, 15 (54%) continued to provide CALM for the duration of the study. Although the training of HCPs was deemed feasible, the authors highlighted certain impediments to therapists' ability to complete CALM certification (e.g., other clinical duties, difficulties with patient recruitment for CALM, time to attend the mandatory peer supervision sessions).[93] Therapists' adherence to the CALM model was not evaluated, however. Importantly, this study involved a fairly large cohort of patients (n = 64) with diverse advanced cancer diagnoses, 55% of whom were women. The age of patients ranged from 26 to 77 years (median = 59). Results pertaining to the administration of questionnaires at baseline, 3 months post-, and 6 months post-intervention indicated significant improvements in patients' self-reported depression (p = 0.006), death anxiety (p = 0.008), and anxiety (p = 0.024) over time. As this study did not involve a control group, these findings, though promising, must be interpreted with caution. Insight into patients' perceptions of CALM therapy, beyond self-report through a

Clinical Evaluation Questionnaire (CEQ),[101] would enhance study findings. The authors note that qualitative findings will be reported in a future study.

Feasibility of CALM therapist training was also assessed by van Klinken and colleagues (2023) in a mixed-methods study based in the Netherlands. For this study, a nursing-specific training, called CALM-Nurses (CALM-N) was developed and evaluated. Of the initial 55 nurses who participated, 63% (n = 22) completed all sessions.[94] The authors note that lower than the targeted 75% adherence may have been related to the COVID-19 pandemic, which occurred during the launch of the study. Results of questionnaires and end-of-study focus groups suggested that CALM-N is a feasible program, with self-reported improvements in trainees' self-efficacy, knowledge, and ability to reflect and employ perspective-taking when working with patients.[94] This study did not involve an exploration of patients' perceptions of the program, or of nurse-patient interactions. It would be helpful to triangulate patient-reported and nurse-reported outcomes to assess the impacts of CALM-N.

A study conducted in the United States by Loughan and colleagues (2022) assessed feasibility, acceptability, and preliminary effectiveness of CALM therapy among patients with malignant glioma.[51] Notably, this study focused exclusively on patients with glioma, a population generally excluded from psychosocial oncology intervention trials due to disease-specific effects on cognition and mood.[51] In this Phase IIa, proof-of-concept trial, 14 patients with glioma and comorbid elevations in depression and/or death anxiety symptoms were offered CALM, of whom 12 completed baseline questionnaires and started CALM therapy. Nine of the 12 participants (75%) completed follow-up questionnaires and an exit interview. Patients' ages ranged from 27 years to 81 years (mean = 56 years), and 75% were female. Overall, results of follow-up questionnaires and exit interviews were very promising, suggesting that CALM

therapy is feasible, acceptable, and beneficial among patients with malignant glioma. Indeed, 100% of participants noted they would be willing to complete CALM again, and 100% confirmed a willingness to recommend CALM to others. According to results of follow-up questionnaires, CALM therapy was associated with significant improvements in death anxiety, depression, generalized anxiety, and spirituality. There was no change, however, in fear of cancer recurrence or quality of life, which the authors speculate may be related to specific psychological challenges and end-of-life changes associated with brain tumour diagnoses.[51] Although this study involved a relatively small cohort of patients, findings suggest benefits associated with application of the CALM therapy model to broader patient populations. This study primarily involved women, though glioma diagnoses tend to occur more frequently among men. As the authors note, the lack of observed change in patients' self-reported quality of life may have been related to the small sample size (i.e., low power to detect an effect), or to the clinical characteristics of advanced brain tumours. Further, interviews were not conducted with people who withdrew from the study.

In a study that preceded a large randomized controlled trial in Toronto, Ontario, Lo and colleagues (2014) conducted a Phase 2 intervention-only study to evaluate the feasibility and preliminary effectiveness of CALM in reducing distress and promoting psychological well-being.[19] Questionnaires were administered at baseline and follow-up (3 and 6 months after initiation of CALM) to assess depressive symptoms, death anxiety, attachment security, spiritual well-being, and psychological growth. Fifty patients with advanced or metastatic cancer consented to participate, of whom 78% (n=39) completed baseline, 48% (n=24) completed the 3-month follow-up, and 32% (n=16) completed 6-month follow-up. Fifty-eight percent of patients completed the minimum dose of 3 CALM sessions, an outcome that was attributed primarily to

physical decline and death. In this regard, attrition is a common feature of studies among palliative care populations.[79] Results of multilevel regression analyses indicated significant improvements over time in depressive symptoms, death anxiety, and spiritual well-being. Although this study had a smaller sample size and suffered from attrition, findings provide evidence of CALM therapy's effectiveness among patients in the final months of life, when depressive symptoms and death anxiety tend to be heightened.[9,10] Adherence to the CALM model by the (n = 6) professionals who administered CALM was strengthened by weekly group supervision and case discussion with CALM founders. It is noted that findings align with outcomes of a previously-conducted qualitative study (Nissim et al., 2012) in which patients endorsed CALM therapy as "a unique opportunity to process the experience of advanced cancer that gave permission to explore issues of death and dying" (p. 240).[19] The authors also acknowledge that most participants in the study were Caucasian, English-speaking, and relatively well-educated. Collaboration with patient partners and community organizations, particularly those from underrepresented or marginalized groups, may have led to improved diversity in recruitment and participation.

1.6.4 Qualitative Studies

A seminal qualitative study by Nissim and colleagues (2012) out of Toronto, Ontario, provided essential insights into patients' experiences and perceptions of CALM therapy. Findings from this study supported subsequent trials by the Toronto CALM team, including a later large-scale RCT. Seven women and 3 men, all of whom had attended at least 3 CALM sessions, were invited to share their stories of cancer and of CALM therapy. Participants were Caucasian (*n*=8), Black (*n*=1), and Asian (*n*=1), with an average age of 59 years (range = 49 – 70 years). Cancer diagnoses included lung (n=2), Hodgkin's lymphoma, breast, ovarian, prostate, cervical, brain,

sarcoma, and multiple myeloma. Semi-structured interviews were transcribed and analyzed using thematic analysis, the results of which culminated in the generation of five overarching benefits of CALM therapy. Patients described CALM as a "safe place to process the experience of advanced cancer," in which they had "permission to talk about death and dying" (p. 713).[81] CALM therapy also offered "assistance in managing the illness and navigating the healthcare system," as well as support with "resolution of relational strain," and "an opportunity to 'be seen as a whole person' within the healthcare system" (p. 713).[81] Of note, the timing of interviews ranged from two weeks to eight months after the last CALM therapy session. Therefore, there may have been variability in terms of patients' ability to recall details of CALM therapy. As recruitment was conducted through the cancer centre's psychosocial oncology service, participants included only those who sought and were motivated to participate in a psychosocial intervention. Interviews were coded by the first author, only, which may affect dependability (though other members of the research team reviewed coding). Furthermore, the paper does not include a reflexivity statement from authors or any discussion of audit trails or member checking. Overall, findings were foundational within the CALM literature milieu, informing future CALM research around the world.

In 2020, the Toronto CALM team published a second qualitative study, conducted as a branch of their Phase 3 RCT.[98] For this qualitative study, a subset of RCT participants (n = 17) were invited to participate in semi-structured interviews exploring their death-related distress and their perceptions of the ways in which CALM therapy might affect communication about distress. Participants were all Caucasian, 47% female, and had been diagnosed with gastro-intestinal (29%), genitourinary (29%), gynecological (18%), breast (12%), and lung (12%) cancers. Three themes pertaining to death-related distress were generated from thematic analysis of interview

transcripts: (1) “diffuse and overwhelming fear;” (2) “fear of uncertainty;” and (3) “fear of suffering” (p.1). In terms of patients’ perceptions of the ways in which CALM facilitated communication about death-related distress, the authors reported two key findings: (1) patients found CALM to be a “secure space in which to discuss death and dying;” and (2) patients felt that CALM therapists facilitated their communication with loved ones about death-related concerns (p. 5). Purposive recruitment was used to ensure the sample included individuals with a range of scores on the Patient Health Questionnaire-9 and the Death and Dying Distress Scale. Coding of transcripts was conducted by two researchers and was later reviewed by the research team. Although the authors describe their qualitative analysis methodology in some detail, including the generation of themes and subthemes, there is no discussion of reflexivity or audit trails to promote credibility, confirmability, and dependability of the study. Overall, findings from interviews offered a nuanced view of patients’ perceptions surrounding their ability to navigate obstacles to communicating about death.

Using a slightly different lens, a recent qualitative study out of Santiago, Chile, explored the perceptions of health professionals who were participating in a CALM training program.[95] For this study, Fernandez-Gonzalez and colleagues held a focus group with a subset of CALM trainees to better understand perceived barriers and facilitators to the local implementation of CALM. A group of 24 health professionals from oncology and/or palliative care completed the CALM training program, which consisted of 3 monthly 3-hour sessions. Six of the 24 trainees participated in a post-training focus group. Participants included 2 psychologists, 2 psychiatrists, and 2 nurses, all of whom identified as women. Transcripts were analyzed using thematic analysis, the results of which led to generation of several key themes. In terms of perceived facilitators of implementation, trainees endorsed (1) the feasibility of CALM within the context

of Chilean health care; (2) the acceptability of the CALM model and content in terms of their clinical practice; (3) the fidelity of the CALM intervention to their clinical realities.[95] Sustainability was cited as a key barrier to implementation. In particular, trainees highlighted difficulties in completing the full CALM training. Similarly, time constraints and heavy workloads were perceived as impediments to the training of other professionals and the dissemination of the CALM model. Last, institutional resistance to change and "to the adoption of new interventions" was found to be a significant barrier (p. 5).[95] Notably, the authors report that health professionals found CALM to be "a culturally sensitive and feasible intervention for application in Chile" (p.1). This finding seems reflective of the burgeoning presence of CALM in healthcare settings around the world. In terms of study rigour: only one focus group was held, and all participants who attended the focus group were women. Future research might therefore implement additional focus groups, with participants of more diverse gender identities. Furthermore, the authors do not describe reflexivity, audit trails, or member checking.

1.6.5 Summary of literature review

Across all of the implementation studies, Phase 2 trials, and qualitative studies included in this literature review, CALM therapy was deemed feasible, acceptable, and effective among cohorts of individuals with a range of cancer diagnoses. Patients and health professionals, alike, endorsed the value of CALM therapy; moreover, beneficial effects of CALM were reported by teams across different clinical sites and health care systems globally (i.e., the Netherlands, the United States, and Canada). Findings reported by Lo et al. (2014), Loughan et al. (2022), and Kool et al. (2023) affirm the effectiveness of CALM therapy in helping to improve depressive symptoms, death anxiety, and spiritual well-being among adults with advanced cancer. Importantly, these effects were observed in cohorts of individuals with diverse cancer diagnoses,

including those with unique disease-specific challenges related to the diagnosis of malignant glioma (e.g., cognitive impairments).[51]

The feasibility of training new CALM therapists was reported by van Klinken et al. (2023) and by Fernandez-Gonzolez et al. (2021). In both studies, health professionals from different professional backgrounds, including psychology, psychiatry, and nursing, endorsed the value of CALM therapy and training programs. Notably, feasibility and benefits were reported by teams from different clinical contexts, cultures, and health care systems (i.e., the Netherlands and Chile). Trainees noted several ways in which their clinical practice was enhanced through CALM training, including a strengthening of the capacity to be reflective and to employ perspective-taking with patients).[94] These studies also offered important insights into the factors that impede implementation and sustainability of CALM therapy, including clinicians' high workloads, limited time to complete all elements of training, and institutional resistance to new psychosocial interventions.[94,95]

Qualitative studies by Nissim et al. (2012) and An et al. (2020) incorporated patients' voices to offer more nuanced conceptualizations of the patient experience of advanced cancer and of CALM therapy. Across both studies, patients described a sense of valuing their CALM therapy experience. Patients reported that CALM offered a context in which they felt safe to speak about death and dying. Along these lines, patients were supported in their efforts to communicate about death-related distress, and to manage relational aspects of life with advanced cancer (e.g., communication with family and with health care providers about death-related concerns).[98]

As is common in research among palliative populations,[79] these studies were impacted by difficulties with recruitment and attrition due to disease progression and death. Moreover, study samples predominantly included Caucasian, English-speaking, more educated individuals. To

promote inclusion of people from more diverse racial, ethnic, and socioeconomic backgrounds, patient-oriented research approaches might have been employed (e.g., involvement of patient partners and community advisors).

Overall, the studies included in this literature review provide evidence of the benefits and challenges of implementing CALM therapy within oncology care, across varied cultural and institutional contexts. By assessing feasibility, acceptability, effectiveness, and by including the patient voice, these studies offer a pragmatic look at CALM therapy 'in the real world,' where the complexities of health care systems affect implementation, and where time and resources tend to be limited.

1.7 Study Rationale

Studies conducted across the globe continue to offer evidence of the efficacy of CALM therapy. However, there remains a lack of data pertaining to the patient-specific factors that influence decisions to pursue or decline CALM therapy. Currently, very few studies have employed mixed methods approaches to assess CALM therapy. Notably, at the time of writing, this is the first CALM study to involve a team of patient partners in the interpretation of findings and in Knowledge Translation planning. Moreover, further research is needed to elucidate potential ways in which CALM may facilitate the integration of palliative, psychosocial, and oncology care. For example, the availability of CALM, as a dedicated psychosocial service for those with advanced cancer, may offer referring oncology and palliative care clinicians with a clearly defined referral pathway by which to refer patients for specialized support. Indeed, Loughan et al. (2022) identified gaps in the CALM literature milieu, highlighting the need to better understand factors associated with a willingness or desire to address existential and end-

of-life concerns.[51] Accordingly, it is essential to explore patients' perceptions about the timing of referral to and initiation of CALM.[51]

A variety of factors affect uptake of psychosocial care in oncology and palliative care settings, contributing to persistent gaps in care.[34,35,44,45,102] Patient-specific factors associated with uptake of psychosocial oncology care[8690] may include socio-cultural norms (e.g., gender norms), previous exposure to psychological support, personal history of mental health conditions, and current level of informal social support.[85–89] Attitude and expectations about psychosocial support also affects willingness to pursue psychosocial oncology care.[90] The availability of virtual or telephone-based options is key among those with illness-related mobility difficulties and/or who live further from metropolitan-based cancer care centres.[86]

To assess the feasibility and acceptability of implementing CALM therapy alongside established referral routes for psychosocial oncology and palliative care across Southern Alberta, a CALM implementation trial was launched in 2020. As a part of this broader, ongoing project, the goal of the current Master's project was to explore patient-specific factors associated with referral to and engagement in CALM, according to findings from a secondary analysis of baseline questionnaires and semi-structured interviews with patients. A mixed methods approach, known to be particularly useful when applied within the realm of palliative and end-of-life care,[103] was used to bring more nuanced insights into patient experiences. Across medical, psychosocial, and research spheres, the value of seeking and responding to patients' perspectives is increasingly acknowledged. As stated in a recent Lancet Oncology Commission on the integration of oncology and palliative care, "the patient's voice must be heard" (p.e595).[34]

With an emphasis on patient engagement in research,[104] this study is thus based on the following overarching question: What are the patient-specific socio-demographic factors, timing-

related factors, advanced cancer characteristics and psychological factors that identify individuals with advanced cancer who are most likely to accept and benefit from CALM – a semi-structured and evidence-based psychological intervention to prevent depression and enhance preparation for end-of-life? Of note: for this project, "engagement" in CALM counselling denotes the number of CALM sessions a patient completes; it does not refer to a patient's psychological engagement in, or level of commitment to, the therapeutic process during CALM counselling sessions.

1.8 Aims and Objectives

A key aim of the study is to refine the current state of understanding about timing of referral and personal characteristics of those who initiate and engage in CALM counselling. Three primary research questions emerged from this line of inquiry: (1) Are there differences in demographic, illness-related, and psychological characteristics, or in referral route, according to the number of CALM therapy sessions patients participated in? (2) What were patients' experiences with referral to and participation in CALM? (3) Is there a more appropriate time to participate in CALM therapy in terms of the illness/treatment trajectory, or in terms of certain characteristics identified through patient interviews?

CHAPTER TWO: METHODS

2.1 Concurrent Triangulation Mixed Methods

To explore the complexities of patient engagement in CALM, a concurrent triangulation mixed-methods design was used.[103,105,106] Quantitative and qualitative data were collected and subsequently analyzed within the same time period, a strategy particularly pertinent given the unpredictability of participants' health status.[107] Convergence of quantitative and qualitative findings during interpretation allowed for contextualization of the data[105] and offered more

nuanced insight into the factors affecting CALM engagement. Reporting Guidelines for Mixed-Methods[108,109] were followed.

Mixed methods designs facilitate a more comprehensive exploration of the complexities of psychosocial phenomena, lending particular usefulness to their application within health research.[103,110] Accordingly, mixed methods approaches are increasingly employed in projects involving psychosocial and palliative care interventions, which are inherently complex and context-dependent.[106,110] The *concurrent triangulation* mixed methods design is time efficient, allowing for the incorporation of qualitative and quantitative data simultaneously or within a similar timeframe.[105] In line with this approach, the current study involved collecting and analyzing quantitative and qualitative data at approximately the same time, with subsequent convergence of findings during interpretation.[107] In the current study, quantitative data (i.e., baseline questionnaire and demographic data) were first collected, followed by qualitative data (i.e., interviews) prior to analysis. Quantitative and qualitative data collection might therefore be considered temporally sequential. This, however, is distinct from methodologically sequential mixed methods designs, in which the collection and analysis of one type of data occurs prior to, and may inform, the subsequent collection and analysis of the other type.[105,107] Triangulation of findings from quantitative and qualitative data allowed for deeper exploration of the many factors contributing to engagement in CALM.

2.2 Interpretive Description and Thematic Analysis

Within an Interpretive Description (ID) research framework,[111–113] interview transcripts were analyzed qualitatively using Thematic Analysis[114]. Thematic analysis is a flexible qualitative approach that can be applied across a range of research questions and epistemologies, facilitating the generation of diverse themes and 'thick description'.[114] It can be particularly useful when

applied to studies involving collaboration between research team members and patient partners, as is the case with the current study.[114]

Interpretive Description is frequently utilized within health research and has several key features that align with the goals of the current study. For example, ID provides a reliable methodology to holistically explore concepts pertaining to health and illness, using a relational perspective, a feature which corresponds with the CALM psychotherapeutic approach.[111] Furthermore, ID offers insights into the complexities of participants' experiences, including the co-construction of experiences and the ongoing interaction between physiological and psychosocial phenomena, something particularly apt for research in psychosocial oncology.[111,113,115] This is important in the context of advanced cancer, when increasing symptom burden frequently affects psychological experiences of self, mood, and relationships.[5,116] Relevance to clinical practice is another feature that has importance in terms of the aims of the current study. ID offers a methodological framework to enhance knowledge about participants' experiences and perspectives, to generate findings from this deepening of understanding, and to apply these findings toward advancement of clinical practice.[111,113,115]

2.3 Setting and Context

This study was conducted within the complex clinical context of Southern Alberta's oncology and palliative care services. Alberta is home to a comprehensive, internationally renowned Psychosocial Oncology Program, offered primarily through the Tom Baker Cancer Centre (Calgary, Southern Alberta) and the Cross Cancer Institute (Edmonton, Northern Alberta). Systematic screening for distress, the sixth vital sign,[117] is integrated within oncology care across Alberta. During all oncology care visits, patients are invited to complete the Putting Patients First (PPF) screening process, which identifies those with elevated distress and subsequently triggers

referral to psychosocial oncology services.[117] Support for patients and family members is also available through Southern Alberta Palliative Care programming, which includes an Advanced Care Planning and Goals of Care Program, Palliative Care Consultation Services, an Intensive Palliative Care Unit (Foothills Medical Centre), Palliative Home Care, Hospices, and the Southwest Palliative Care Service (Lethbridge). The innovative Palliative Care Early and Systematic (PaCES) project is also underway in Alberta to implement and assess evidence-based early palliative care practices across the province.[118]

In Southern Alberta, Psychosocial Oncology provides individual, couples-based and family-based counselling, triaged by tumour group, as well as psychiatry services. Evidence-based group programs for individuals with lung,[119] gastrointestinal,[69,70] and ovarian cancer[56] are available. The only services specifically focused on people affected by advanced cancer include a metastatic breast cancer Supportive Expressive group[55] and a caregivers group for those supporting someone with any advanced cancer. Tumour group-specific individual counselling is offered by psychosocial oncology clinicians from psychology, psychiatry, and social work, all of whom see patients across the disease trajectory. Currently, however, there is no integration of psychosocial oncology with palliative care for interdisciplinary collaboration. Moreover, in rural areas, single social workers are responsible for all counselling, across tumour sites and stages. Within this setting of specialized Psychosocial Oncology and Palliative care, the CALM intervention contributes an evidence-based approach that can be implemented by clinicians from various professional backgrounds (e.g., psychology, social work, psychiatry, nursing) among patients with diverse advanced cancer diagnoses. Notably, individuals who engage in CALM counselling may also choose to participate in group programming offered through the

Psychosocial Oncology Department, or through other community organizations (e.g., Wellspring Alberta).[120]

This study was conducted in the midst of the COVID-19 pandemic, during a time when patients had to wrangle with fears surrounding risks of contracting the virus. This context likely impacted participants' experience of life with advanced cancer, oncology care, and CALM therapy, including treatment decision-making (e.g., fears surrounding in-person appointments, and/or lowered immunity with treatments).

2.4 Participants and Recruitment

Participants were recruited for the CALM Implementation Study from 2020-2022, through the Tom Baker Cancer Centre, the Southwest Palliative Care program, and community cancer care organizations (e.g., Wellspring).[120] A subset of CALM participants who provided consent for follow-up were invited to complete interviews for this thesis project (Appendix D). Eligible patients for the CALM implementation study and thus for interviews included persons who: 1) had a diagnosis of metastatic cancer, recurrent stage III or IV (solid tumour only); 2) were experiencing distress, as assessed by the referring clinician; 3) had an anticipated life expectancy of 12 to 18 months, as assessed by referring clinician: 4) were age 18 or older; 5) were English speaking; 6) were not impeded from participating by cognitive impairment.

Recruited participants include those with the following cancer diagnoses: glioblastoma, breast, cholangiocarcinoma, renal cell, gastrointestinal, endometrial, fallopian tube, head and neck, liver, lung, ovarian, prostate, pancreatic, and urothelial. Participants' home locations ranged from urban centres to rural/regional sites across Southern and Central Alberta.

Approximately half-way through the implementation trial (2022), a reconsent process was conducted to seek participants' consent for contact about follow-up interviews (Appendix E).

Any participant who registered for the CALM study prior to May 2022 was provided with a revised consent form on which they could indicate consent to be contacted about a follow-up interview (Appendix E).

Recruitment included three referral routes: direct, indirect, and self-referral. In direct referral, oncology and palliative care healthcare providers (Calgary and Lethbridge) referred patients specifically to the CALM research trial. In indirect referral, patients with advanced cancer proceeded through the usual care pathway: Offered a counselling appointment with a tumour-specific psychosocial clinician working in the general Psychosocial Oncology program. During initial calls and following the establishment of a counselling appointment, psychosocial administration or triage provided information about CALM counselling as an alternative option. Wait-times for Psychosocial Oncology appointments (average 2-3 months) often exceeded the wait-time for CALM therapy (generally 1-3 weeks). In terms of self-referral: some patients contacted the CALM study team directly after finding program information on the website or during local community cancer care organization presentations. For the purposes of analyses, self-referrals were categorized as 'direct referral' in the current study.

In alignment with the goals of Alberta's Strategy for Patient Oriented Research (AbSPORU),[104] this study involves patient engagement in research via a team of patient partners (i.e., individuals with lived experience of advanced cancer as a patient and/or caregiver). Recruitment of patient partners was conducted with the support of the Cancer Care Alberta (Patient Experience and Evaluation, Applied Research and Patient Experience) team. The Cancer Care Alberta team shared information about the CALM study with individuals from the Provincial Patient and Family Advisory Council and connected us with those who were

interested in becoming involved as patient partners. All initial correspondence was conducted by email to set up subsequent Zoom meetings (individually and as a team).

2.5 Data Collection

2.5.1 Quantitative Data:

Subsequent to the informed consent process, and prior to the first CALM appointment, each participant completed an online baseline questionnaire package, which included a 17-item demographics questionnaire and a series of validated measures (detailed below). Baseline questionnaire responses from participants (n = 69) in the CALM Implementation Study were analyzed to explore associations between patient-specific sociodemographic, psychological, and illness-related factors and session attendance. REDCap survey software, managed through the University of Calgary's Clinical Research Unit (CRU), was used for administration and management of all questionnaires.

Measures

1. *17-item demographics questionnaire*. Developed for use in the CALM Implementation Study, the demographics questionnaire includes questions pertaining to age, gender identity, ethnicity, relationship status, living situation, cancer diagnosis, and patients' close others (i.e., informal caregivers).
2. *Patient Health Questionnaire (PHQ-9*). The PHQ-9, a self-report screening tool for depressive disorders, is applied widely within oncology.[121,122] This 9-item questionnaire has high validity and excellent internal reliability and test-retest reliability.[121] Although some symptoms of depression may overlap with physical symptoms associated with cancer and its treatment, research findings suggest that both the somatic and non-somatic

items of the PHQ-9 have utility in identifying depression among oncology patients.[122] Total scores range from 1 – 27, where higher scores indicate more severe depression.

3. *The Death and Dying Distress Scale (DADDS).* Designed specifically to assess the experience of death anxiety among individuals with advanced cancer, the DADDS self-report questionnaire includes 15 items (score range 0 – 75) that assess fears about dying, distress related to lost opportunities, and perceptions of the self as a burden to others.[123] The DADDS has been shown to be a valid measure of death anxiety among persons with advanced cancer.[123]
4. *The Quality of Life at the End of Life–Cancer Scale (QUAL-EC).* This 17-item self-report questionnaire was developed to assess quality of life specifically among persons with advanced cancer.[124] Its four subscales assess impacts of symptoms, relationships with healthcare providers, preparation for end of life, and sense of life completion. In a study involving 464 patients with advanced cancer, the QUAL-EC was found to have good factor structure, internal reliability, and construct validity.[124]
5. *Experiences in Close Relationships Scale – Modified (ECR-M-16).* The modified, 16-item ECR-M-16 instrument was designed to assess attachment orientations (e.g., insecure attachment and avoidant attachment) among individuals with cancer or other serious medical illnesses.[125] Found to be a valid and reliable measure of attachment orientations, the ECR-M-16 assesses patients' capacity to rely on others with whom they feel close as a source of support when distressed.[125]

2.5.2 Qualitative Patient Interviews:

Brief, semi-structured interviews were conducted and recorded using an Alberta Health Services licensed version of Zoom. An interview script was developed iteratively and

collaboratively by the author and the supervisory committee (Appendix C). A copy of the interview script was provided to participants in advance of the interview if requested. Interview duration ranged from approximately 20 to 100 minutes. Interview items include – but were not limited to – the following questions (Please see Appendix C for the full interview script.):

- *Could you please tell me a little bit about how you first heard about CALM? For example, were you referred directly by a member of your healthcare team, or did you hear about the study from the TBCC Psychosocial Department (front desk/triage)?*
- *How did you feel about the length of time from the initial call to completing the pre-appointment questionnaire to seeing the CALM therapist?*
- *May I also ask for your feelings about the timing of referral or introduction to CALM (e.g., would it have been helpful to learn about CALM earlier, when first diagnosed, or perhaps later in your treatment)?*
- *CALM counselling might mean different things to different people. We're interested in hearing what the experience of CALM counselling was like for you. Can you tell me a bit about what the experience of CALM counselling was like for you? We welcome any comments about your experience that you'd like to share with our research team.*

2.6 Data Analysis

2.6.1 Quantitative Analysis:

An exploratory analysis of baseline data, originally collected as part of the CALM implementation study, was conducted to assess the demographic, illness-related, and psychosocial characteristics of those who attended a range of CALM sessions. Initially, descriptive statistics and frequencies associated with the following variables were assessed:

referral route (i.e., direct referral, including self-referral, or indirect referral through TBCC Psychosocial Oncology); cancer diagnosis/tumour group; self-identified gender; age; date of diagnosis of advanced cancer; duration of time between advanced cancer diagnosis and referral to CALM/Psychosocial; duration of time between referral to CALM/Psychosocial and death; cancer treatment type and status (e.g., ongoing or discontinued); number of CALM sessions completed; baseline demographic and questionnaire data (e.g., PHQ-9, DADDS, QUAL-EC, ECR-M-16). Baseline depression (PHQ-9) and death anxiety (DADDS) scores are often utilized as eligibility criteria throughout CALM studies, with clinical cut-offs for depression set as ≥10 on the PHQ-9[51,126] and ≥15 on the DADDS.[51] Clinical cut-offs for the PHQ-9 and DADDS scales remain in flux; baseline PHQ-9 and DADDS scores were analyzed as continuous variables and were categorized according to the cutoffs defined by recent studies from the CALM research milieu.

Distributional properties of all variables were first assessed, the results of which informed decision-making about subsequent statistical tests. Graphical methods and descriptive statistical methods (e.g., variable ranges) were used to identify out-of-bounds values and possible data entry errors. These were reconciled prior to data analysis (e.g., if a patient completed the baseline questionnaire more than once, any duplicate records were deleted, and responses from the most recently completed questionnaire were included in analyses). In order to preserve data that might be relevant to triangulation of findings, any outliers were not deleted from the data set for analyses of baseline data (e.g., participants with >6 CALM sessions). We allowed for up to 20% of missing items when computing summary scale scores on baseline measures.

Initially, a variety of approaches for analysis were considered, including count-based models (i.e., Poisson Regression, Negative Binomial Regression Modelling). Based on

preliminary findings from patient interviews, in addition to feedback from the patient advisory group, it was determined that CALM session attendance was not entirely determined by baseline variables. Rather, it became clear that a multitude of factors likely contributed to CALM session attendance, including fluctuations in participants' health status over time. Modelling based exclusively on baseline variables was therefore deemed inappropriate. Rather than focusing on predictors of rates of attendance (i.e., as a count variable in a regression model), we decided to directly describe and characterize patterns of attendance, looking at the broader scope of factors contributing to attendance over time.

Furthermore, data pertaining to the independent variable of interest (i.e., engagement, as defined by total number of CALM sessions attended) were not normally distributed. Accordingly, the following non-parametric tests were used to compare groups according to baseline characteristics: Mann-Whitney for binary variables; Kruskal-Wallis for categorical variables with more than two categories; and Spearman's correlation for continuous variables. Potential differences in the following baseline variables were explored: (1) referral route (e.g., direct referral, including self-referral, vs indirect referral through TBCC Psychosocial Oncology); (2) baseline psychosocial characteristics, including distress (PHQ-9 and DADDS), quality of life (QUAL-EC), and attachment orientation (ECR-M-16); (3) duration of time between diagnosis of advanced cancer and first CALM session; (4) as applicable, duration of time between referral to CALM/Psychosocial and death; (5) age; (6) sex; (7) cancer diagnosis/tumour group; (8) cancer treatment type and status (ongoing versus discontinued); and (9) home location (metropolitan versus non-metropolitan). Based on geriatric oncology guidelines,[127] and on the distribution of participants' ages, data were stratified into two

categories: < 65 years and ≥ 65 years. Similarly, data were stratified according to those who lived ≤ 10 months and > 10 months after referral.

Of note: *Non-metropolitan* is inclusive of the following categories, as defined by Alberta Health Services: moderate metro influence, urban, rural, moderate urban influence.[128] Alberta Health Services categorizes metropolitan areas as greater than 500,000 people, and urban areas as greater than 25,000 but less than 500,000.[128] Metro centers (Calgary & Edmonton) have specialized psychosocial oncology services; Lethbridge, Medicine Hat and Red Deer, cities considered to be urban, tend to have a single social worker providing psychosocial service, who often carry very high caseloads of patients with complex needs.[129] Statistical analyses were conducted using SPSS software (version 25).[130]

In preliminary analyses, baseline demographic, illness-related, and psychosocial characteristics of those who consented to future contact about follow-up interviews (n = 24) were compared to those of participants who didn't provide consent (n = 46), to evaluate potential differences between groups. Key baseline characteristics (i.e., mood, death anxiety) and total CALM appointments of those who completed an interview (n = 10) versus those who did not complete an interview (n = 59) were also compared.

2.6.2 Qualitative Analysis:

Qualitative analysis was conducted using Thematic Analysis,[114] within an Interpretive Description (ID) framework.[112] As per the ID approach, data collection and analysis were completed concurrently.[105,111,112] Initially, two members of the research team (C.S., J.d.G) independently reviewed and coded each transcript. First, each coder familiarized herself with the data by reading through each transcript. Upon reviewing the transcript a second time, coders generated initial codes and subsequently collated codes into themes, as per thematic analysis.[114]

To inform subsequent interviews and analyses, coding was conducted iteratively. Coding was subsequently discussed together and with other members of the research team to ensure consensus in interpretation. Themes were further refined through discussion with the research team and patient partners over several team meetings. In accordance with the ID approach, themes were interpreted and organized into a set of cohesive findings relevant to clinical practice.[113] Reflexive journalling and field notes were used to strengthen confirmability, dependability, and trustworthiness of the study. Qualitative data were managed using NVivo (version 12) software.[131]

2.7 Reflexivity statement

The research team is composed of female-identifying and male-identifying persons from a variety of personal and professional backgrounds. All team members have completed higher education. In addition to their roles as researchers and academics, some team members also work as clinicians in psychosocial oncology, psychiatry, and palliative care. Two members of the research team were involved in the CALM implementation study as clinicians offering CALM counselling to participants.

2.8 Patient Engagement

As described above, three individuals with lived experience of advanced cancer joined the project as patient partners/advisors, as facilitated by Cancer Care Alberta. Three virtual meetings were held (approximately once per month) with patient partners and members of the research team. During these 1-hour meetings, team members and patient partners discussed analysis and interpretation of interview findings, triangulation of qualitative and quantitative findings, and planning for knowledge sharing. The author met one-on-one with patient partners who were unable to join group meetings due to scheduling conflicts. AbSPORU's definition of Patient

Engagement dictates that patients may be involved in any or all phases of research;[104] however, due to restrictions related to the timing of their involvement, we were unable to consult patient partners about earlier stages of the research cycle (e.g., planning, development of research questions, recruitment of participants, data collection). Advisement of patient partners during the stages of interpretation and knowledge-sharing was critical, particularly given the complexity and significance of interpreting qualitative results and navigating the triangulation quantitative and qualitative findings.

Of note: the terms "patient partner" and "patient advisor" are used interchangeably in this study. According to the Patient Advisors Network (PAN), the term "patient partner" became more commonly used around 2018, in place of "patient family advisor," within some health care settings and research.[132] Similarly, as discussed above, AbSPORU describes the variety of ways in which patient partners might be involved in health research, from the planning and research proposal stage, to data collection, through to knowledge translation and evaluation in quality assurance.[104] Given the nature of involvement of patient partners/advisors in the current study, and in accordance with the definitions provided through PAN and AbSPORU, it seems appropriate to use either "patient partner" or "patient advisor". The term, "patient partner," will be used herein.

2.9 Ethical Considerations

Participants completed an informed consent form prior to initiating CALM counselling, as approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA.CC-20-0269). All participants were assigned a unique study identification number that was used for study documents, audio files, records, and interview transcripts. Interview recordings are stored on a secure server. A record of patients' study ID numbers and their identifying information is

kept in a separate, password-protected spreadsheet, stored in a private folder on the secure server. Each interview was conducted using an Alberta Health Services-licensed Zoom account held by the interviewer. Participants were offered the option to review the interview questions in advance of their interview, and they were informed of their right to discontinue the interview at any point or to skip any questions they were not comfortable with. Participants had the option to withdraw their data up to one week post-interview, after which point the interviews were transcribed and analyzed. Study documents will be stored on the AHS server for a maximum of 10 years, after which they will be deleted.

2.9.1 Equity, Diversity, and Inclusion Considerations

This study involved exploration of referral and engagement differences in terms of sex (as per chart check) and ethnicity (as per demographics questionnaire). However, the majority of participants in the study self-identified as white (85.5%), and female (78.3%), with education beyond high school (72.5%) and higher socioeconomic status (i.e., above $50,000 per year; 47.8%). The research team is composed of individuals from different professional and personal backgrounds, including those who identify as female and those who identify as male. However, all team members are Caucasian, with higher levels of education. We will aim to invite peer review of findings and manuscripts from individuals with varying personal (e.g., gender, ethnicity) and professional backgrounds.

CHAPTER THREE: Exploring patient-related contextual factors and personal reflections about the Managing Cancer and Living Meaningfully (CALM) intervention for adults with advanced cancer in metropolitan and non-metropolitan Southern Alberta: A Mixed Methods Study

Carly Sears,[1,2] Dr. Fay Strohschein,[3] Dr. Scott Patten,[1]

Dr. Andrea Feldstain,[2,4] Dr. Jessica Simon,[2,5] Dr. Janet de Groot[1,2]

[1]University of Calgary, Community Health Sciences Department, Calgary, Canada

[2]University of Calgary, Department of Oncology, Calgary, Canada

[3]University of Calgary, Faculty of Nursing, Calgary, Canada

[4]Tom Baker Cancer Centre, Dept. of Psychosocial & Rehabilitation Oncology, Calgary, Canada

[5]Palliative and End of Life Care, Alberta Health Services, Calgary, Canada

Key words: advanced cancer, oncology, psychosocial oncology, referral routes, psychological intervention,

3.1 Abstract

Objective: We sought to understand patient-specific factors and referral routes that influence initiation and continuation in the evidence-based, brief *Managing Cancer and Living Meaningfully* (CALM) intervention for people with advanced cancer.

Methods: An Interpretive Description framework and concurrent triangulation mixed-methods design was used to analyze baseline patient-specific variables for prediction of engagement (number of sessions) in CALM following recruitment from cancer centres, palliative care services, and community cancer care organizations across Southern Alberta, Canada. Quantitative variables included demographics, baseline distress (PHQ-9, DADDS), cancer type, and referral route (direct, indirect and self-referral). Qualitative triangulation data (n = 10) was collected with semi-structured interviews exploring experiences with advanced cancer, CALM referral and engagement.

Results: Among consented individuals (n = 69), those directly referred by healthcare providers (HCPs) and self-referred (total n = 32), engaged in more CALM sessions (M = 4.97, SD = 3.51) than those referred indirectly (M = 3.19, SD = 2.26, $p < 0.05$), particularly younger participants (<65 years) and those with longer life expectancy (>10 months). Participants chose CALM based on experiences of distress, wanting to talk openly, and expecting benefit. Participants specified that referrals to CALM should include comprehensive intervention information with sensitivity to mortality fears following an advanced cancer diagnosis.

Conclusions: Greater patient engagement in the CALM intervention following HCPs' direct referrals may be based on trust in the HCP-patient relationship, and accurately prognosticating sufficient physical well-being for participation and benefit. Future health systems research may

evaluate systematic programing with offering CALM referrals following an advanced cancer diagnosis.

3.2 Introduction

Individuals diagnosed and living with advanced cancer navigate numerous physical and psychological challenges from diagnosis through months to years of treatment for progressive, life-limiting disease.[7,10,49] Distress, death anxiety, and depression are common,[7,10–14] the latter reported to affect one-third of patients with metastatic cancer[133,134] compared to 5.5% of the general adult population annually.[135] Individuals with advanced cancer may struggle with lost or evolving conceptualizations of life purpose, meaning, and hope,[11,49] which may not be targeted in standard psychosocial programming. Evidence-based, standardized psychosocial programming is needed to address these unique concerns, including facing one's mortality, managing treatment decision-making, end-of-life preparation, and promoting quality of life.[5]

One model of psychosocial support that helps to bridge psychosocial, palliative, and oncology care is *Managing Cancer and Living Meaningfully* (CALM) therapy, a brief (4-6 session) evidence-based, manualized intervention designed to address the specific needs of those with advanced cancer and their caregivers.[5,49] Consistent with early palliative care, CALM is offered when life expectancy is 12–18 months.[136,137] In clinical trials and qualitative studies world-wide, CALM therapy is associated with reduction or prevention of depressive symptoms, improved relationships with health care providers (HCPs), enhanced preparation for end of life, reductions in cancer-related fatigue, and improved cognitive function.[49,51–54] However, Loughan and colleagues (2022) identified gaps in the CALM literature and recommended assessing for

patient profiles associated with a willingness or desire to address existential and end-of-life concerns.[51]

Influential patient-specific factors associated with utilization of psychosocial oncology care may include distress level, coping strategies, socio-cultural norms (e.g., gender norms), previous exposure to psychological support affecting attitudes and expectations, personal history of mental health conditions, and current level of informal social support.[85–90] Virtual or telephone-based therapy may be a key consideration among individuals with illness-related mobility difficulties and among those living distant from metropolitan-based centres.[86]

Inclusion of the patient voice is central to this project, consistent with a Lancet Oncology Commission on the integration of oncology and palliative care. Across clinical and research spheres, seeking and responding to patients' perspectives is increasingly endorsed.[138] A National Institute of Health consensus conference advocated for patient perspectives as a valid outcome in clinical medicine.[138]

Through exploring data from a CALM implementation project, and individual interviews with patients following CALM completion, this study aims to increase understanding about optimal timing of referral and personal characteristics of individuals most likely to participate in CALM. This line of inquiry addressed 3 primary research questions: (1) Are there differences in demographic, illness-related, and psychological characteristics, or in referral route, according to the number of CALM therapy sessions patients participated in? (2) What were patients' experiences with referral to and participation in CALM? (3) Is there a more appropriate time to participate in CALM therapy by illness/treatment trajectory, or by patient-identified characteristics described in patient interviews?

3.3 Materials and Methods

3.3.1 Design

To comprehensively examine the complexities of patient engagement, defined by number of CALM sessions completed, a concurrent triangulation mixed-methods design was employed.[103,105,106] Quantitative and qualitative data were collected and analyzed concurrently, a strategy particularly pertinent given participants' changing health status.[107] Convergence of quantitative and qualitative findings during interpretation promoted data contextualization [105] and facilitated comprehensive insights into patient-specific factors affecting CALM engagement. Reporting Guidelines for Mixed-Methods[108,109] were followed.

3.3.2 Setting and Recruitment

Health Research Ethics Board of Alberta – Cancer Committee (HREBA.CC-20-0269) provided ethics approval. The implementation study for evidence-based CALM therapy (2020-2024) took place in Southern Alberta, Canada, across two clinical sites. The research-intensive Tom Baker Cancer Centre's (TBCC) (Calgary) psychosocial oncology and rehabilitation services includes tumor-site specific psychosocial clinicians who provide supportive-expressive groups and/or individual counseling for persons with cancer, including advanced cancer. The second site, Southwest Palliative Care Service (SPCS) (Lethbridge), has a dedicated outpatient social worker who provides counselling support. Evidence-based psychosocial programming specifically tailored to this population's needs is lacking.

Patients and caregivers participated in the CALM implementation study from 2020-2022, and were recruited through TBCC, SPCS, and a community cancer support organization, Wellspring Alberta (self-referrals).[120] The current mixed-methods study involved secondary analysis of baseline data already collected for the CALM implementation study, triangulated

with analysis of follow-up interviews conducted subsequently with a subset of consented participants. Eligibility criteria included: 1) diagnosis of metastatic cancer, stage III recurrent or IV (solid tumour only); 2) experiencing distress, assessed by the referring clinician; 3) 12 - 18 months anticipated life expectancy, assessed by referring clinicians; 4) ≥ 18 years; 5) English speaking; 6) not impeded from consenting or participating by cognitive impairment (de Groot et al., in preparation). Approximately half-way through the implementation study, a reconsent process was conducted to seek participants' consent for contact about follow-up interviews.

CALM trial recruitment included three referral routes (direct, indirect, and self-referral). Oncology HCPs referred patients to the CALM study (i.e., direct referrals). Additionally, patients with advanced cancer referred to the general Psychosocial Oncology service were provided with a counseling appointment and then introduced to the CALM study as an alternative opportunity by Psychosocial administrative staff (i.e., indirect referral). Wait-times for Psychosocial Oncology appointments often exceeded the wait-time for CALM therapy (2-3 months versus 1-3 weeks). Some patients directly contacted the CALM study team based on program information on study website or during local community cancer care organization presentations (i.e self-referral from Wellspring).

3.3.3 Procedures:

Questionnaire measures:

1. *17-item demographics questionnaire*. Socio-demographic and health characteristics items included gender, ethnicity, employment status, relationship status, and living situation.
2. *Patient Health Questionnaire (PHQ-9*). The PHQ-9, a valid and reliable[121] 9-item self-report screening tool for depressive symptoms, is applied widely within oncology populations (score range 1-27).[122]

3. *The Death and Dying Distress Scale (DADDS).* The DADDS, a valid measure of death anxiety among persons with advanced cancer[123] with 15 items (score range 0-75) that assess fears, distress, and self-perception as a burden to others.[123]
4. *Experiences in Close Relationships Scale – Modified (ECR-M-16).* The ECR-M-16, a valid and reliable 16-item measure of attachment orientations (e.g., insecure, avoidant), assesses capacity to rely on others for support when distressed.[125]
5. *Quality of Life at the End of Life – Cancer Scale (QUAL-EC).* The QUAL-EC, a 17-item scale with good internal reliability and construct validity, was designed to assess quality of life among persons with advanced cancer.[124]

Questionnaire administration:

Following the informed consent process, and prior to the first CALM appointment, participants completed an online baseline questionnaire package. REDCap survey software was used for administration and management of questionnaires.

Interviews:

A semi-structured interview script (see Appendix), iteratively developed by the authors, invited participants to reflect upon experiences with CALM, both beneficial aspects and what which might be done differently. Consented participants were contacted by email and/or telephone to introduce and discuss interview participation.

Brief, semi-structured interviews with CALM patients were conducted using virtual meeting software[139] 1 – 13 months after participants' final CALM sessions, except one participant who had a subsequent "booster" session.

3.3.4 Data Analysis

Quantitative Data:

Survey variables' distributional properties informed decision-making about subsequent statistical tests. Graphical methods and descriptive statistical methods (e.g., variable ranges) identified out-of-bounds values and possible data entry errors for reconciliation prior to data analysis.

Quantitative analyses aimed to directly describe and characterize patterns of CALM sessions attended, exploring factors associated with session attendance over time. As data pertaining to the independent variable of interest (i.e., number of CALM sessions attended) were not normally distributed, non-parametric tests were used: Mann-Whitney for binary variables; Kruskal-Wallis for categorical variables with more than two categories; and Spearman's correlation for continuous variables. Potential differences in the following baseline variables were explored: (1) referral route (e.g., direct referral, including self-referral, vs indirect referral); (2) baseline psychosocial characteristics, including distress (PHQ-9 and DADDS), quality of life (QUAL-EC), and attachment orientation (ECR-M-16); (3) time (months) between diagnosis of advanced cancer and first CALM session; (4) as applicable, time (months) from referral to CALM and death; (5) age; (6) sex (electronic medical record data); (7) cancer tumour group; (8) cancer treatment status (ongoing versus discontinued); and (9) home location (metropolitan versus non-metropolitan). *Non-metropolitan* defined by Alberta Health Services as moderate metro influence, urban, moderate urban influence, rural, remote.[128] Utilizing geriatric oncology guidelines[127] in relation to participants' age distribution, data were stratified into two categories: <65 years and ≥ 65 years. Similarly, data were stratified according to those who lived ≤ 10 months and > 10 months after referral.

Independent-samples Kruskal-Wallis tests were conducted to explore potential differences in baseline characteristics (e.g., mood, death anxiety) between follow-up interview

participants (n = 10) and non-participants (n = 59). Statistical analyses were conducted using SPSS software (version 25).[130]

Qualitative Data:

Transcribed, audio recorded interviews were analyzed using Thematic Analysis, within an Interpretive Description framework.[112–114] Interpretive description generates findings from a deepened understanding of participants' experiences and perspectives, and applied toward advancement of clinical practice.[111,113,115] Data collection and analysis were completed concurrently.[105,111,112] Findings about participants' experiences with referral to and participation in CALM are presented here; full qualitative findings are presented separately (in preparation).

Initially, two research team members (C.S., J.d.G.) independently familiarized themselves with the data by reviewing all transcripts, and subsequently generated initial codes, followed by collating codes into themes (as per thematic analysis).[114] Research team discussion refined the themes and, consistent with interpretive description, organized themes into a narrative relevant to clinical practice.[113] Patient partners/advisors with experience of advanced cancer joined the research team on three occasions to discuss data analysis and interpretation. Reflexive journaling and field notes strengthened study confirmability, dependability, and trustworthiness.

Qualitative data were managed using NVivo (version 12) software.[131]

3.4 Results

3.4.1 Participant Characteristics

Of 149 patients screened, 69 were eligible and consented to participate in the CALM implementation study [See Table 1 and Table 2 for complete demographic and health details]. Average time duration from diagnosis of advanced cancer to referral for psychosocial support

was 12 months (*SD* = 5.5 months). Total number of CALM appointments ranged from 0 to 14, with an average of 4.01 appointments (Median = 3.00; *SD* = 3.02). [See Figure 1, Appendix B]

3.4.2 Qualitative Sample

Of 24 participants who agreed to be contacted for a follow-up interview, 10 (41.7%) were interviewed, 4 died prior to follow-up and 10 didn't respond or were too ill to participate. The interview cohort (*n* = 10), vs. non-interviewed cohort (*n* = 59), had significantly lower baseline PHQ-9 total scores (M = 5.90, vs M = 9.88, respectively, *p* = 0.04) and DADDS total scores (M = 19.70 vs M = 29.26, respectively, *p* = 0.03), as well as significantly greater total number of CALM appointments (M = 5.80 vs M = 3.71), respectively, *p* = 0.03).

See Tables 1-3 for details about sociodemographic information, baseline mood, and treatment history.

3.4.3 Triangulated Qualitative and Quantitative Results

<u>WHO participates in CALM: patient characteristics</u>

The full and interview cohort's mean initial PHQ-9 scores are consistent with mild depression.[51,122,140] Among outpatients with cancer, the full sample's mean score, above 8, would prompt assessment for depression.[140] Additionally, the full cohort's mean death anxiety score, 27.84 (SD = 14.59), was in the moderate range (20-50).[141]

Psychosocial factors contributing to initiation of CALM: Participants stated various psychosocial factors triggered referral to and initiation of CALM therapy. However, a few participants had difficulty recalling the procedures or individuals involved in referral to CALM and experienced the time of referral as very "blurry" (#170, age 58, stage IV gastrointestinal cancer), while feeling overwhelmed by numerous investigations, referrals, treatment decisions, and appointments. Participants' reasons to initiate CALM counselling, including: (1) distress,

depression, and coping with an advanced cancer diagnosis; (2) a wish for someone to listen and talk with openly about any topic (e.g., mortality concerns), particularly someone outside of friends/family; (3) anticipation of benefit for oneself and potentially others (e.g., through contribution to the study); (4) alignment of CALM counselling with palliative care needs.

Evolving physical and mental health needs: Limits in one's physical and emotional capacity to engage in counselling sessions may have importantly influenced the number of CALM sessions attended, particularly among those with progressive metastatic disease. Participants noted their needs evolved across diagnosis, treatments, and disease trajectory. One participant with stage IV metastatic breast cancer described this evolution:

> *…all the pillars [of CALM] apply when you're first diagnosed. 'Cause you need to know how to communicate with your…medical team… You need to, eventually, get into…how to move forward with your life. How it's affecting your relationships…. As you go through and have lived with this longer…different areas become more of the focus… living with purpose* (#139, age 54, Stage IV breast cancer).

Participants endorsed the opportunity for CALM 'booster' sessions, as needed, particularly among those who lived longer.

<u>HOW CALM is introduced to patients impacts uptake</u>

Referral route: Participants directly referred to CALM attended significantly more CALM appointments (Mean = 4.97, Median = 4.50, SD = 3.51, Range = 0 – 14) compared to those referred indirectly (Mean = 3.19, Median = 3.00, SD = 2.26, Range = 0 – 9) ($U = 765.00$, $p = 0.04$). There was effect modification by age (<65 years vs ≥ 65 years) and by time from referral to TBCC Psychosocial/CALM and life duration (≤10 months vs >10 months). Stratified analyses suggest referral route may be more important in the < 65-year age group, and among those surviving over 10 months post referral.

Participants under 65 years completed significantly more sessions following direct referral (M = 5.17, SD = 3.17) compared to those referred indirectly (M = 2.90, SD = 1.90, p = 0.02). Those who lived longer attended more sessions following direct referrals to CALM (M = 6.58, SD = 3.34, Range = 2 – 14) versus those referred indirectly (M = 2.45, SD = 2.58, Range = 0 – 8, $p < 0.05$). Referral route did not predict engagement for participants who were older ($\geq$ 65 years) and those nearer death.

Referral information: Participants identified the context of overwhelm in living with advanced cancer and treatment, and numerous choices for psychosocial support (e.g., group programs, community programs, and one-on-one counselling). Participants suggested providing CALM information in "very simple terms" (#237, age 69, stage IV metastatic lung cancer) to convey "what to expect" (#330, age 55, stage IV metastatic sarcoma). Wording was considered important, particularly about mortality. A participant in a "fearful spot" following her diagnosis suggested framing information as "how it could help…with wherever you are on journey," and "not all just about end of life" (#237, age 69, stage IV lung cancer).

CALM appointments: Virtual appointments (e.g., Zoom-based sessions) were endorsed as a "game changer" (#332, age 56, recurrent metastatic gynecological cancer), eliminating travel time and reducing stress of driving/parking. Virtual appointments were highly relevant for non-metro participants and for those declining physically, who often had an abundance of oncology appointments.

Importance of WHEN CALM is introduced

Timing of initiation and continuation of CALM sessions depends on highly individualized factors that vary across the disease trajectory.

Time between diagnosis and Psychosocial support referral: Baseline data analysis found no significant association for duration of time between advanced cancer diagnosis and referral to Psychosocial support/CALM. Some participants' interview responses suggested any time is appropriate for referral, while others preferred sooner post-diagnosis, rather than later. One participant stated:

> *I probably should have done this earlier…. Because, I know, every time I had to go and have a CT scan… and see the oncologist… it's a little death every time, because you never know what's going to be said or what's going to happen. So…I really regret that I didn't contact the psych services earlier* (#249, age 72, stage IV lung cancer).

Time from referral to death: Spearman's Rank Correlation indicated a statistically significant positive correlation between number of CALM appointments attended and time between referral to TBCC Psychosocial Support/CALM and death ($r(41) = 0.32$, $p = 0.04$), where those who lived longer attended more sessions. However, visual assessment of the scatter plot suggests heteroscedasticity, with greater variability among participants who lived longer (Figure 2, Appendix B). Medians were tested using different cut-points, but findings were, overall, not robust.

Evolving factors across the disease trajectory: A participant poignantly highlighted the impact of her diminished health on participation, linking this to the perceived importance of starting CALM early. She noted:

> *I think the last session… I cancelled it multiple times because I was so sick…that's why I think – the referral… better is sooner because so many people may not complete treatment. And I think you probably need the mental health even to start and to go through treatment* (#170, age 58, stage IV gastrointestinal cancer).

Automatic referrals & patient decision-making: In recognition of the oncology context with busy clinics and time pressures limiting discussion of psychosocial support, participants suggested automatic CALM referrals following advanced cancer diagnoses. One participant

explained that early provision of information to the patient allows him/her/them to decide if or when to participate:

> *... I think that they should be made aware of it, so [it] is the patient's choice and not the health care providers…saying, 'Well, I think you need it now'. [laughs] So I think that should be given to the patient… I would say immediately at diagnosis, and that…then [they can participate] when they feel that the program would be beneficial* (#330, age 55, stage IV metastatic sarcoma).

3.5 Discussion

This mixed methods study offers preliminary insights into experiences with advanced cancer, as well as referral to and participation in CALM counselling. With attention to honouring patient voices, qualitative findings provide insight into the nuances of patients' perceptions of referral to and engagement in CALM. Numerous individualized, evolving factors (e.g., health status, psychosocial needs) influence patients' initial and ongoing participation in CALM. Additionally, referral route, referral timing, prognosis, and age may influence CALM attendance.

WHO participates in CALM: patient characteristics

Study participants had mild depression and moderate death anxiety when beginning CALM; interviewees cited psychological distress, depression, and anxiety as key to choosing to participate in and continue with CALM. Previous oncology research also found self-reported depression, anxiety, and distress was associated with a willingness for referral for psychosocial treatment.[87,90] Further, participants spoke of difficulty coping, of a desire to share their story and mortality concerns with someone outside of friends/family, and of anticipating benefits from CALM participation. Fluctuating depressive symptoms throughout therapy, rather than an absolute level of depression at baseline, may motivate patients to continue in therapy. Nevertheless, baseline mood and death anxiety were not associated with the total number of CALM sessions.

Similarly, the current study's findings point to the multiplicity of factors – often inextricable from ramifications of advanced cancer – that may trigger referral to and initiation of CALM. Positive outcome expectations, positive perceptions of psychosocial support, and accepting attitudes about help-seeking are associated with willingness to be referred and to engage in psychosocial support, and subsequently affect therapy outcomes.[88,89] Illness-related mobility concerns, often more prevalent among those with advanced cancer, influence patients' level of engagement in psychosocial services.[86] CALM patients affirmed the value of virtual/telephone sessions including the possibility of participation when at a distance from the cancer centre.

HOW CALM is introduced: referral route

Uniquely, this study shed new light on potential referral route influences on the number of CALM sessions patients attended. Generally, those referred directly to CALM by their HCP participated in more CALM sessions, compared to those who were referred indirectly via the Psychosocial Department. It is important to acknowledge the complexities of the context in which referral routes were established. Patients may be more likely to accept a CALM referral from a trusted HCP, thus creating expectancies about the trustworthiness and benefits of participating.[142,143] Alternatively, it may be the case that HCPs did not inform patients about the full range of psychosocial services available when referring them to CALM; it therefore could be argued that direct referral, in the context of very busy oncology clinics, may risk under-informing patients of all available services. Further, wait-times for CALM appointments were generally less than those of the psychosocial service, although some patients still chose the established service despite the wait.

HCP direct referrals may be more influential among those who live longer than 10 months after referral and among those younger than 65 years of age. Indeed, the CALM therapy co-founders recommend initiation of sessions for those with a 12- to 18-month prognosis.[49] Referring clinicians will ideally consider the estimated prognosis in determining whether to refer someone to CALM, as referral nearer to end-of-life may limit CALM sessions due to declining mental and physical well-being; it may not, however, limit the value of CALM sessions patients do participate in.

WHEN CALM is introduced – the importance of referral timing

Systematized programing that includes offering referral to CALM for patients recently diagnosed with advanced cancer may serve a similar purpose as a trusted HCP's referral. That is the standard referral may convey that their health care considers CALM an essential aspect of care, and supports integration of oncology and supportive care (e.g., integrated palliative and psychosocial care). Additionally, as endorsed by interviewees, patients have autonomy to accept or decline the referral. Further, systematized programming ensures referrals are not reliant on HCPs remembering CALM during busy clinics.

Patients whose death followed referral more quickly may have lacked time and sufficient energy (particularly if still undergoing treatment) to complete more sessions. With great variability (heteroskedasticity) in total sessions attended among those living longer, it may be valuable for CALM clinicians to explore the desire for additional "booster" sessions among those who have a longer prognosis. Interviewees noted the importance of the option to pursue additional "booster" sessions as needed.

To the authors' knowledge, other CALM studies have not addressed referral route or patient perceptions of factors contributing to CALM therapy initiation. The current study's

findings may offer unique insights into mental and emotional factors, as well as referral route considerations, which contribute to CALM engagement.

Limitations and Future Directions

We acknowledge the need for caution when describing patient engagement as the number of sessions attended. This study did not explore patients' levels of psychological engagement with the CALM therapeutic process. Attending fewer sessions may reflect declining physical health and an inability to attend more sessions or, alternatively, patients may experience sufficient benefit with fewer sessions.

Given the vulnerability to Type II Error, testing of baseline data should be repeated with a larger dataset. Tumour group categories ultimately had too few participants to enable reliable analysis. Instead, descriptive statistics about tumour groups are provided in Table 1.

The homogenous nature of interview participants' demographic characteristics may not reflect experiences of diversity, inclusive of but not limited to gender, culture, race, sexuality and nearing end-of-life. However, this sample provided rich data about women's experience with engagement in CALM when living with advanced cancer. Findings may therefore speak to the experiences of the dominant demographic most likely to access psychosocial services.[88,89,144]

Future Directions

Future research may benefit from a control arm of patients who decline CALM, to compare mood, death anxiety scores, and experiences with advanced cancer. Further research is needed to determine feasibility and acceptability of CALM among more diverse patient and tumour group populations. Additionally, we require research to evaluate the feasibility and acceptability of implementing systematized programming with referrals following an advanced cancer diagnosis. We don't yet understand why some of those who were referred indirectly

ultimately declined CALM or chose to pursue other options for psychosocial support (even when the wait-times may have been longer).

Implications for Practice

Three key patient-informed findings were derived from this study: (1) *To Whom* CALM is introduced may have significance. Study findings provide a signal toward the characteristics that may affect engagement, including psychosocial needs, expectations of counselling, and slower cancer progression (i.e., longer prognosis and better health status). (2) *How* CALM is introduced may be important. Future engagement as per number of sessions attended may be impacted by introduction and referral to CALM directly from a HCP or, as interviewees suggested, routine referral upon advanced cancer diagnosis. Additionally, descriptions of CALM, whether verbal or via pamphlet/website, should balance comprehensiveness, clarity, and sensitivity, highlighting benefits at a time when patients may be overwhelmed and fear death. (3) *When* CALM is introduced is pertinent. Participants expected to live more than 10 months at referral have greater opportunity to choose how many sessions may best meet their needs. A potential solution may be to provide patients with a clear, complete, sensitively worded introduction to CALM therapy (e.g., through pamphlet, website, and/or short video summary) following an advanced cancer diagnosis, ensuring information access and supporting personal choice of when to initiate CALM therapy. Timing a referral to CALM following an advanced cancer diagnosis is consistent with recommendations to further integrate tumour-focused and whole person care, through systematic programming between oncology, palliative care, and psychosocial oncology care.[138]

Conclusions

With its mixed-methods design, this study offers unique insights into the experiences and perspectives of individuals who are navigating the worlds of oncology, palliative, and psychosocial care following diagnosis of advanced cancer. Inclusion of patient voices through semi-structured interviews provides nuanced information about the psychosocial factors and referral route considerations that contribute to engagement in the CALM therapy.

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Author Contributions:

C. Sears: conceptualization, formal analysis, investigation, methodology, project administration, interviewing; writing – original draft, writing – review & editing.

F. Strohschein: conceptualization, methodology, writing – review & editing.

A. Feldstain: conceptualization, methodology, writing – review & editing.

J. Simon: conceptualization, funding acquisition, methodology, supervision, writing – review & editing.

S. Patten: conceptualization, formal analysis, methodology, supervision, writing – review & editing.

J. de Groot: conceptualization, formal analysis, funding acquisition, investigation, methodology, project administration, supervision, writing – review & editing

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Conflict of Interest: The authors have no conflicts to declare.

Data Availability: The data underlying this article will be shared on reasonable request to the corresponding author.

3.6 Tables and Figures

Table 1. Summary of CALM patient sociodemographic information (*n* = 69).

	All participants (n=69)		Interviewed participants (n=10)	
	M (SD)	**Range**	**M (SD)**	**Range**
Age (years) at time of referral to CALM/TBCC Psychosocial	62.36 (10.84)	33.58 - 83.74	60.12 (6.25)	52.86 - 71.83
	N	**%**	**N**	**%**
Gender				
Female	54	78.3%	10	100.0%
Male	15	21.7%	0	0.0%
Home location (Metro vs Non-Metro)				
Metro	45	65.2%	7	70.0%
Non-Metro	24	34.8%	3	30.0%
Referral Route				
Referral through psychosocial oncology (Indirect)	37	53.6%	5	50.0%
Referral from HCP (Direct)	28	40.6%	3	30.0%
Self-referral	4	5.8%	2	20.0%
Cancer Diagnosis				
Gynecological	20	29.0%	4	40.0%
Lung	13	18.8%	2	20.0%
Gastrointestinal	12	17.4%	1	10.0%
Breast	11	15.9%	2	20.0%
Genitourinary	6	8.7%	0	0.0%
Endocrine	2	2.9%	0	0.0%
Melanoma	2	2.9%	0	0.0%
CNS	1	1.4%	0	0.0%
Head and Neck	1	1.4%	0	0.0%
Sarcoma	1	1.4%	1	10.0%
Included close other in at least one CALM session				
No	42	60.9%	4	40.0%

Yes	27	39.1%	6	60.0%
Caregiver Details				
Spouse/Partner	22	31.9%	6	60.0%
Adult child or other family[1]	11	15.9%	2	20.0%
Friend	1	1.4%	0	0.0%
Income				
Prefer not to answer	18	26.1%	1	10.0%
$50,000 - $100,000	16	23.2%	2	20.0%
$100,000 - $250,000	15	21.7%	4	40.0%
$26,000 or less	8	11.6%	1	10.0%
$26,000 - $50,000	7	10.1%	2	20.0%
Missing	3	4.3%	0	0.0%
$250,000 or higher	2	2.9%	0	0.0%
Employment Status				
Not currently employed/working	56	81.2%	9	90.0%
Currently employed/working	9	13.0%	1	10.0%
Missing	3	4.3%	0	0.0%
Prefer not to answer	1	1.4%	0	0.0%
Education				
College/Trade	19	27.5%	3	30.0%
Undergraduate	14	20.3%	2	20.0%
Post-graduate/Professional School (e.g., law, pharmacy, medical)	11	15.9%	3	30.0%
High school/secondary school not completed	8	11.6%	0	0.0%
High school/secondary school	6	8.7%	1	10.0%
Some college/university/trade school (did not graduate)	6	8.7%	1	10.0%
Missing	3	4.3%	0	0.0%
Prefer not to answer	2	2.9%	0	0.0%

Ethnicity				
White (European)	59	85.5%	10	100.0%
Other	3	4.3%	0	0.0%
Missing	3	4.3%	0	0.0%
Filipino	2	2.9%	0	0.0%
Indigenous (First Nations, Metis, Inuk, American Indian, or Alaska Native)	1	1.4%	0	0.0%
South Asian (East Indian, Pakistani, Sri-Lankan, etc.)	1	1.4%	0	0.0%
Relationship Status[2]				
Married	39	56.5%	6	60.0%
Common Law	7	10.1%	1	10.0%
Divorced	7	10.1%	1	10.0%
Widowed	5	7.2%	0	0.0%
Separated	4	5.8%	1	10.0%
Other	3	4.3%	0	0.0%
In a Relationship	2	2.9%	2	20.0%
Employment				
Retired	25	36.2%	3	30.0%
Unemployed due to illness	18	26.1%	4	40.0%
Missing	18	26.1%	1	10.0%
Other	7	10.1%	2	20.0%
Homemaker	1	1.4%	0	0.0%

[1] For 6 participants, a spouse and/or adult child attended at least once. Two participants invited both a spouse and an adult child.

[2] Participants may have answered "yes" to more than one category.

Table 2. History of medical and psychosocial/mental health treatments.

	All participants (*n* = 69)		Interviewed participants (*n* =10)	
	N	**%**	**N**	**%**
History of psychosocial support prior to CALM				
No	36	52.2%	5	50.0%
Yes	33	47.8%	5	50.0%
Engaged in other psychosocial support concurrent with CALM				
No	64	92.8%	10	100.0%
Yes	5	7.2%	0	0.0%
History of previous medication management (psychiatry) prior to CALM				
No	48	69.6%	7	70.0%
Yes	21	30.4%	3	30.0%
Medication management from psychiatry concurrent with CALM				
No	49	71.0%	8	80.0%
Yes	20	29.0%	2	20.0%
History of previous group support prior to CALM				
No	63	91.3%	9	90.0%
Yes	6	8.7%	1	10.0%
Accessed group support concurrent with CALM				
No	58	84.1%	6	60.0%
Yes	11	15.9%	4	40.0%
Unsure about participating in CALM vs general psychosocial counselling, so attended at least one of each				
No	62	89.9%	10	10.0%
Yes	7	10.1%	0	0.0%
Prior or current psychosocial support through the community				
No	58	84.1%	9	90.0%
Yes	11	15.9%	1	10.0%
Surgery				

completed	48	69.6%	8	80.0%
n/a	20	29.0%	2	20.0%
ongoing	1	1.4%	0	0.0%
Chemotherapy				
ongoing	37	53.6%	5	50.0%
completed	21	30.4%	3	30.0%
n/a	11	15.9%	2	20.0%
Radiation Therapy				
n/a	38	55.1%	7	70.0%
completed	26	37.7%	3	30.0%
ongoing	5	7.2%	0	0.0%
Immunotherapy				
ongoing	30	43.5%	3	30.0%
n/a	29	42.0%	4	40.0%
completed	10	14.5%	3	30.0%

Table 3. Summary of CALM session attendance and baseline questionnaire scores (n = 69).

	N	Range	Mean	SD	N	Range	Mean	SD
	All participants (n=69)				**Interviewed participants (n=10)**			
Total Number of CALM Appointments	69	0-14	4.01	3.02	10	1-10	5.80	2.86
Number of CALM Appointments with Caregiver	69	0-8	.67	1.23	10	0-8	1.70	2.45
Time (months) between diagnosis of advanced cancer and referral to CALM/ Psychosocial	69	0.33-82.27	12.07	16.35	10	0.33-29.90	11.80	11.34
Time (months) between referral to CALM/ Psychosocial and death	43	1.08-18.76	9.78	5.46	3	10.91-16.89	13.53	3.06
PHQ-9 Total Score	67	0.00-27.00	9.28	5.89	10	0.00-17.00	5.90	4.77
DADDS Total Score	67	0.00-67.00	27.84	14.59	10	9.00-29.00	19.70	7.76
ECR Total Score	67	1.00-5.75	2.77	0.97	10	1.00-4.25	2.68	0.88
ECR - Anxiety	67	1.00-6.50	2.63	1.21	10	1.00-5.13	2.83	1.15
ECR – Avoidance	67	1.00-5.88	2.90	1.17	10	1.00-4.38	2.53	0.91
QUALEC – Symptom Control	65	3.00-15.00	7.89	2.57	10	6.00-12.00	8.60	2.22
QUALEC - Relationship with Healthcare Providers	66	8.00-25.00	16.94	4.17	10	8.00-24.00	16.30	4.37
QUALEC – Preparation for End of Life	66	4.00-19.00	12.53	3.34	10	9.00-18.00	13.60	3.17
QUALEC - Life Completion	66	7.00-25.00	17.91	4.71	10	12.00-25.00	18.80	4.87

Figure 1: Distribution of the total number of CALM appointments attended by all consented participants (n = 69).

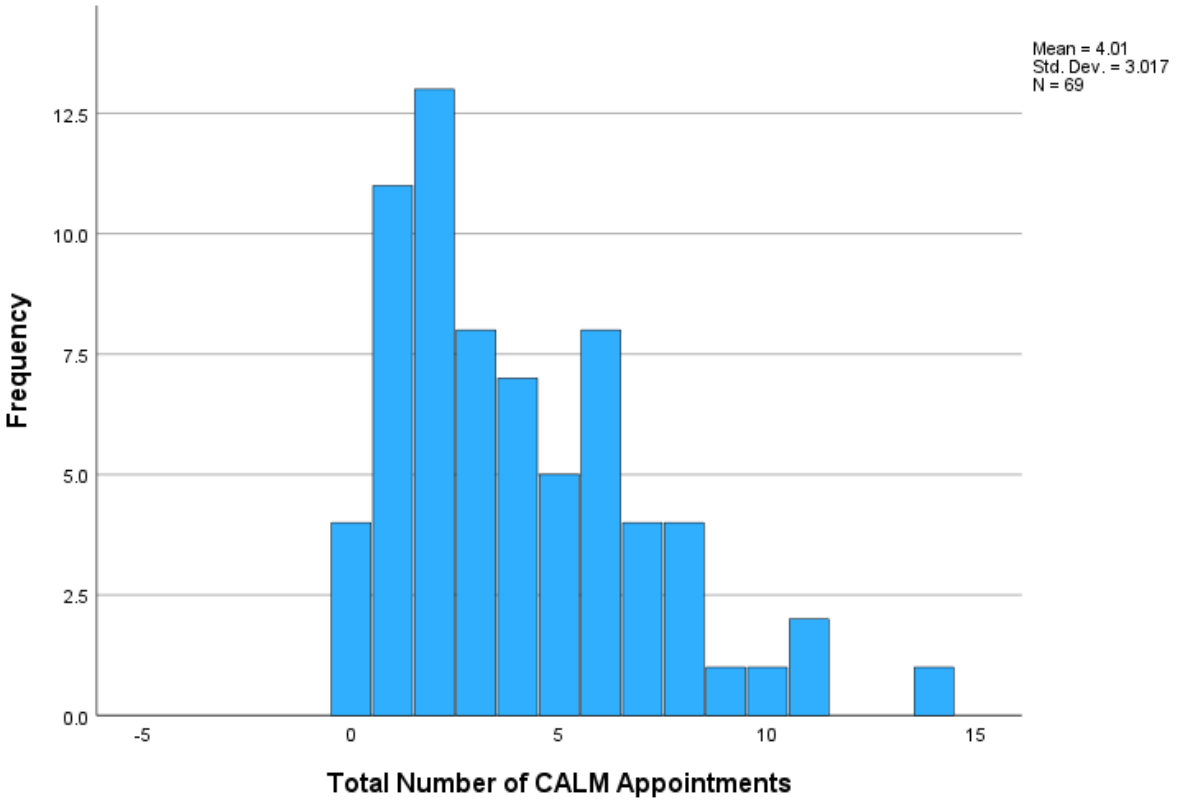
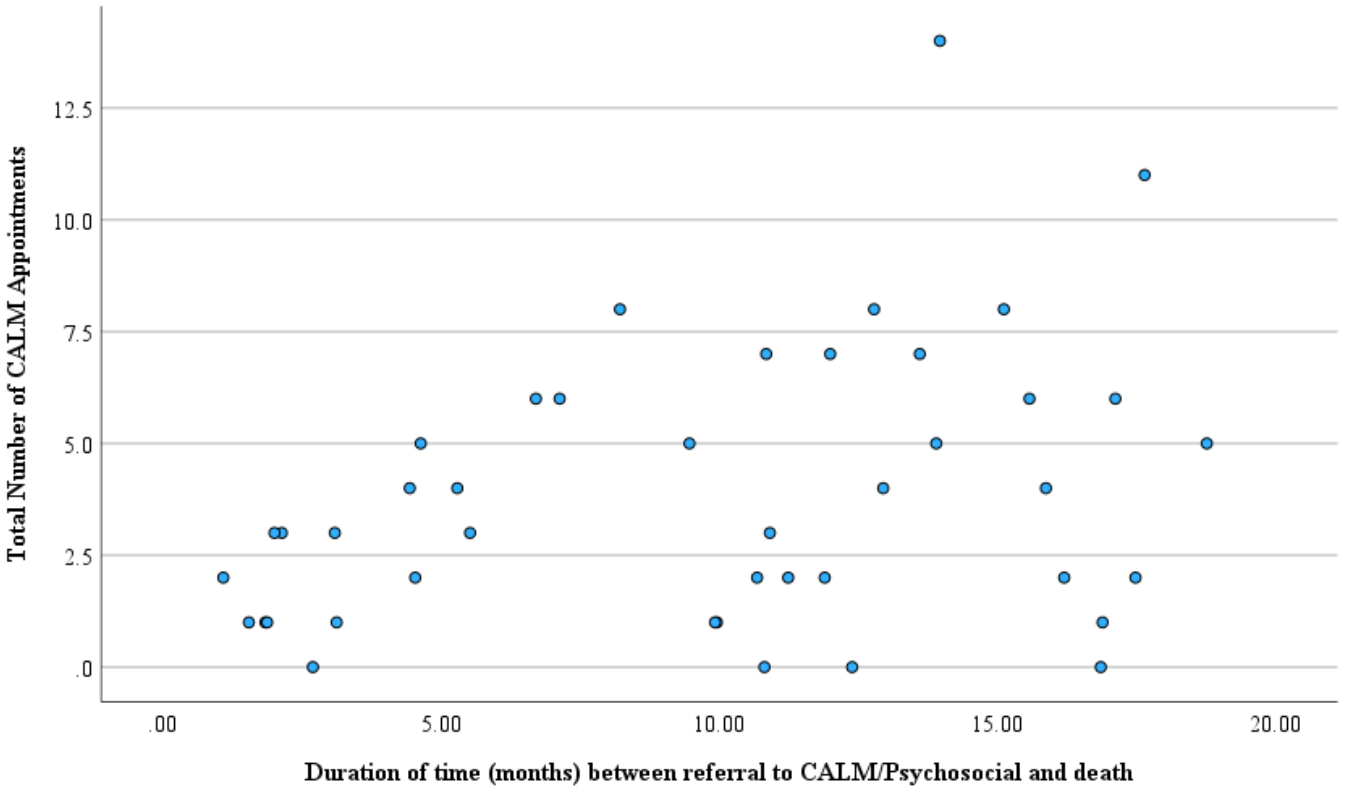


Figure 2: Association between total number of CALM appointments and the number of months between referral for Psychosocial Support (Psychosocial Oncology or CALM) and death.



CHAPTER FOUR: DISCUSSION

4.1 Overview

The central aim of this thesis project was to enhance our understanding of patient-specific factors, referral routes, and referral timing associated with patients' participation in CALM therapy. A concurrent triangulation mixed methods design was used, with convergence of quantitative and qualitative findings during interpretation to promote data contextualization. Quantitative analysis was conducted with baseline data initially collected as part of the Southern Alberta CALM implementation study (2020-2024). Inclusion of patient voices through semi-structured interviews provided nuanced information about the multitude of factors that affect engagement in, and subjective experiences of, CALM therapy. Results indicate that a multitude of factors trigger referral to, initiation of, and continued engagement in CALM therapy. These factors may include evolving physical symptoms, oncology treatments, disease progression, and changing psychosocial needs. Findings suggest that certain patient characteristics may be associated with a desire to start and/or continue with CALM, including distress, depressive symptoms, difficulty coping, positive expectations of counselling, and slower cancer progression (i.e., better health status and capacity to attend appointments). Introduction and referral to CALM directly from a HCP may differentially impact future engagement in CALM sessions. Descriptions of CALM, whether conveyed verbally or via pamphlet/website, should offer clearly- and sensitively-worded information about what to expect, including benefits, in consideration of the potential sense of overwhelm and fear that patients frequently experience after advanced cancer diagnosis. To the authors' knowledge, this is the only study of CALM therapy to address referral route and patient perceptions of factors contributing to CALM therapy initiation. The current study's findings thus offer unique insights into patients' experiences, as

well as psychosocial factors and referral route considerations, that influence participation in CALM.

Importantly, the 4-domain CALM model comprehensively supports patients with navigation of oncology care and, if applicable, palliative care through self-advocacy and communication with health care teams. Additionally, CALM provides an opportunity for discussion about the full range of services offered through palliative care, thus helping to address misconceptions and stigma surrounding palliative care. Integration of psychosocial, palliative, and oncology care may therefore be enhanced via CALM. Additionally, the flexibility with which CALM can be offered (i.e., short term, by clinicians from diverse professional backgrounds) seems key to its capacity to bridge oncology, palliative, and psychosocial care. At different sites around the world, CALM is provided by clinical social workers, nurses, psychologists, psychiatrists, and palliative care physicians.[93–95] When offered by non-psychosocial oncology clinicians, CALM might represent an effective means to more broadly provide psychosocial intervention to those with advanced cancer (as per Fitch's framework of supportive care).[145] In this way, psychosocial support is extended beyond the more intensive, one-on-one counselling provided by a smaller group of highly specialized psychosocial clinicians. Multidisciplinary collaboration may also be fostered if clinicians from diverse backgrounds are trained to offer CALM counselling, and/or if a designated psychosocial role is established within palliative care.[146]

Moreover, the flexibility of CALM clinician training is particularly significant for health systems in which other psychosocial resources are limited or not available. In many rural-regional sites across Canada, for example, a psychosocial oncology service does not exist. At these sites, oncology or palliative care clinicians might be trained to offer CALM counselling,

thus helping to fill a significant gap in care.[138] A key consideration for busy clinicians, however, is the need to find designated clinical time for CALM trainings, ongoing supervision, and patient sessions.[93–95]

4.2 Summary of results

4.2.2. Who participates in CALM: patient characteristics

One hundred forty-one patients were screened, following referral, of whom 69 were eligible and consented to participate in the CALM implementation study. For the current study, a secondary analysis of baseline data from these 69 participants was conducted. Following a re-consent process mid-way through the implementation study, 24 participants agreed to be contacted for a follow-up interview. Of these, 10 (41.7%) were interviewed, 4 died prior to follow-up, and 10 didn't respond or were too ill to participate. These participation rates are common to pilot studies among palliative care populations.[78,79]

Among the full cohort of 69 participants, the average duration of time from diagnosis of advanced cancer to referral for psychosocial support was 12 months (*SD* = 5.5 months). Total number of CALM appointments ranged from 0 to 14, with an average of 4.01 appointments (Median = 3.00; *SD* = 3.02). A majority of participants were white (86%, n = 59), female (78%, n = 54), and had completed post-secondary education (64%, n = 44). Sixty-five percent (n = 45) lived in a metropolitan centre. Participants ranged in age from 34 – 84 years (M = 62.36, SD = 10.84). Slightly more than half (54%, n = 37) were referred to CALM indirectly through the TBCC Psychosocial Oncology Department, while 41% (n = 28) were referred directly to CALM by a healthcare provider, and 6% (n = 4) self-referred. A large proportion of participants had been diagnosed with gynecological cancer (29%, n = 20), followed by thoracic (19%, n = 13), gastrointestinal (17%, n = 12), and breast (16%, n = 11). [See Appendix A]

As per analysis of baseline questionnaires, mean PHQ-9 scores prior to the initiation of CALM therapy (M = 9.28, SD = 5.89) were consistent with mild depression.[51,122,140] Among outpatients with cancer, scores in this range (i.e., above 8) would be sufficient cause for assessment of depression.[140] Additionally, participants' mean death anxiety scores at baseline (M = 27.84, SD = 14.59), fell within the moderate range (i.e., 20 – 50).[141] [See Appendix A]

According to analysis of patient interviews, various psychosocial factors triggered referral to and initiation of CALM therapy. For some, the time of referral was experienced as very "blurry" (#170, age 58, stage IV gastrointestinal cancer). Patients noted a profound sense of overwhelm associated with their diagnosis, and with the succeeding flood of investigations, referrals, treatment decisions, and appointments. During interviews, patients spoke of numerous reasons to initiate CALM counselling, including: (1) distress, depression, and difficulty coping with cancer diagnosis; (2) a wish for someone to listen and talk with openly about any topic (e.g., mortality concerns), particularly someone outside of friends/family; (3) anticipation of benefit for oneself and potentially others (e.g., through contribution to the study); (4) perceived alignment of CALM therapy with the needs of those with advanced cancer.

In terms of continued engagement in CALM therapy sessions, participants noted that disease progression and/or ongoing treatments frequently affected their physical and emotional capacity to attend CALM sessions. Of particular significance, interview responses indicated that patients' psychosocial needs evolved across diagnosis, treatments, and disease trajectory. Patients noted that certain CALM domains may have been more pertinent at different time-points (e.g., sooner versus later after diagnosis/treatments).

4.2.3 How CALM is introduced: referral route and communication of program information

In concordance with descriptions of heightened distress and overwhelm associated with an advanced cancer diagnosis, participants emphasized the importance of providing CALM information in 'very simple terms' (#237, age 69, stage IV metastatic lung cancer) to allow a sense of 'what to expect' (#330, age 55, stage IV metastatic sarcoma). The difficulty of navigating multiple options for psychosocial support (e.g., group programs, community programs, and one-on-one counselling), while already overwhelmed by the challenges of living with advanced cancer, was highlighted. Whether providing details via pamphlet, website, and/or conversation with a HCP, participants' responses indicated a need for careful attention to the language used, particularly in terms of mortality. One participant described being in a 'fearful spot' at the time of diagnosis, during which she needed information framed in terms of 'how it could help…with wherever you are on [the cancer] journey,' and 'not all just about end of life' (#237, age 69, stage IV metastatic lung cancer).

According to results of quantitative analyses, referral route may influence future engagement in CALM, as indicated by the total number of CALM sessions attended. Generally, patients who were referred directly to CALM by their HCP participated in more CALM sessions compared to those who were referred indirectly via the Psychosocial Department. It may be the case that referral from a trusted HCP engenders a sense of trustworthiness and anticipated benefit associated with the program/therapy to which the patient is referred. Patients may therefore be more likely to accept a referral and continue to engage in CALM therapy sessions if the program is endorsed by their HCPs.[142,143]

There was evidence of effect modification by age and by duration of time between referral to psychosocial support and death. As per stratified analyses, direct referral from a HCP

was only statistically significant among those who lived longer than 10 months after referral, and among those younger than 65 years of age. This aligns with recommendations from CALM therapy co-founders regarding initiation of CALM among those with a 12- to 18-month prognosis.[42] Among those who lived longer than 10 months, direct referral was associated with higher attendance at CALM sessions (M = 6.58, SD = 3.34, Range = 2 – 14) versus indirect referral (M = 2.45, SD = 2.58, Range = 0 – 8, $p = 0.004$). Among those younger than 65 years of age, direct referral was associated with higher session attendance (M = 5.17, SD = 3.17) versus indirect referral (M = 2.90, SD = 1.90, $p < 0.05$). The effect of referral route was not statistically significant among those over 65 years of age or among those who died within 10 months of referral. [See Appendix B]

In the context of Southern Alberta, where comprehensive psychosocial programming is offered, findings pertaining to referral route may have important implications. Patients who are referred directly to CALM by a HCP may not have an opportunity to learn about the full scope of general psychosocial programming available (e.g., tumour-site specific counselling, group programs). During time-limited oncology appointments, referring providers may simply not have time to discuss all available options. As suggested by some interviewees, it is valuable to have a centralized triage, through which patients can access one-on-one guidance in navigating psychosocial services. Notably, this psychosocial triage process has since been implemented in the Alberta South Zone.

4.2.4 When CALM is introduced: the importance of referral timing

Timing, in terms of initiation and continuation of CALM sessions, seems dependent on a number of highly individualized factors that vary across the disease trajectory. Ongoing oncology treatments and changes in health status appear to influence the number of CALM

sessions attended. One participant noted: 'And I think the last session… I think I cancelled it multiple times because I was so sick' (#170, age 58, stage IV metastatic gastrointestinal cancer). The participant went on to say, "…that's why I think – the referral… better is sooner because so many people may not complete treatment. And I think you probably need the mental health even to start and to go through treatment."

Quantitative analysis of baseline data failed to detect a significant association between the duration of time between advanced cancer diagnosis and referral to Psychosocial support/CALM. However, participants' interview responses highlighted the complexity of referral timing. Some stated that any time is good to be referred; others noted that sooner is better; still others noted a sense of overwhelm, of feeling 'mixed up and confused' (#292, age 60, stage IV metastatic breast cancer) at the time of initial diagnosis ("I was still figuring this out" [#292]). For some patients, the introduction of CALM materials during the initial diagnosis period may require particular awareness of, and attention to, this context of overwhelm.

In recognition of the reality of busy oncology clinics and paucity of time to discuss options for psychosocial support, it was suggested that automatic referral to CALM, at the time of advanced cancer diagnosis, may be a helpful strategy. As described above, provision of clearly- and sensitively worded referral materials is of importance at this time; patients may then make an informed decision about whether to pursue CALM counselling. As one participant explained, it is important to give information to the patient so he/she/they can decide if or when to participate:

> *"… I think that they should be made aware of it, so [it] is the patient's choice and not the health care providers…saying, 'Well, I think you need it now'. [laughs] So I think that should be given to the patient… I would say immediately at diagnosis, and that…then when they feel that the program would be beneficial to them." (#330, age 55, stage IV metastatic sarcoma)*

An automatic referral system for patients recently diagnosed with advanced cancer may serve a similar purpose as referral from a trusted HCP. Systematized referral may convey to patients that CALM is considered an essential aspect of care by their health care team; importantly, this system would support the integration of oncology, palliative, and psychosocial care. A recent qualitative study found perceived acceptability and benefit of an automatic referral process for early palliative and supportive care among people with newly-diagnosed stage IV lung cancer.[146] There are, however, important considerations associated with an automatic referral system. As described in interviews, patients frequently experience profound fear and overwhelm at the time of diagnosis. It is possible that automatic referral to CALM at the time of diagnosis may heighten the sense of overwhelm or may trigger existing negative beliefs about counselling.[88–90] The language used to describe CALM counselling, particularly when it comes to words like 'mortality' and 'advanced cancer,' may be especially key if an automatic referral process were implemented. Moreover, as described above, automatic referral to CALM may affect the likelihood that a patient is informed about the full range of psychosocial programming offered by Alberta's comprehensive psychosocial oncology service. One option may be to equip referring providers with referral materials/resources (e.g., a script to introduce psychosocial oncology and CALM, pamphlets, and/or a QR code or link to website with further details), in parallel with implementation and assessment of an automatic referral process, to ensure patients are informed about all available services.

4.3 Strengths

With its mixed methods design, this study provides unique insights into the experiences and perspectives of those who were eligible and chose to engage in CALM counselling in Southern Alberta. Inclusion of the patient voice through interviews provides greater depth of

understanding regarding the nuances of advanced cancer patients' experiences of navigating the intersecting worlds of oncology, psychosocial, and palliative care. In terms of cancer diagnoses, treatment histories, and disease course (e.g., aggressive, treatment-resistant cancers to more stable, treatment-controlled cancers) diverse experiences were represented amongst the full cohort and the 10 women who were interviewed. Triangulation of findings from baseline data and interview data lends confirmability and broadens the scope of understanding regarding the complexities of patients' experiences with advanced cancer, navigation of the cancer care system, and referral to and engagement in CALM.

Guided by the principles of Interpretive Description,[112] we sought to generate clinically-relevant findings that might be applied to clinical practice, with the intention to ultimately enhance patient care. Findings may therefore equip referring HCPs and CALM clinicians with actionable knowledge and an enhanced view of patient perspectives and preferences regarding referral to and engagement in CALM.

To our knowledge, this is the only study within the CALM research arena to have addressed referral routes, timing, and patient perceptions of factors contributing to initiation and continuation of CALM therapy. Findings may therefore inform future efforts to establish appropriate procedures to facilitate timely referral to CALM after diagnosis of advanced, incurable cancer.

This study was strengthened by the involvement of a patient advisory team comprised of individuals with lived experience of advanced cancer (as a patient and/or caregiver). With their invaluable contribution to the interpretation of study findings and the design of knowledge translation plans, the patient advisory team helped to ensure findings were grounded in the patient experience and relevant to patients and HCPs, thus increasing the study credibility.

Furthermore, this study is among a very small proportion of CALM papers (as per Literature Review, above) to be published independently of the CALM co-founders. Most of the co-authors and committee members of this thesis project were relatively new to CALM, thus lending a different perspective on CALM research.

4.4 Limitations

It is important to acknowledge the need for caution when describing patient engagement in terms of the number of CALM sessions attended. In the current study, we were not able to explore patients' levels of engagement with the CALM therapeutic process. A patient may not have been less engaged in therapy if he/she/they attended fewer sessions; rather, he/she/they may have been more ill and therefore unable to attend more sessions. Furthermore, patients may have perceived sufficient benefit with only 1-3 sessions. Future research may inquire as to the impacts of illness severity on the likelihood of referral to CALM therapy. It may be the case that people who were more ill or closer to end of life were more or less likely to be referred. The way a patient's cancer behaves seems integral in terms of who may benefit from a direct referral to CALM, and in terms of timing of referral (i.e., a more aggressive versus a more chronic cancer). In addition, although participants were asked to describe their experiences with referral to CALM, they were not queried specifically about what it meant for them to be referred by the particular person who first informed them about CALM therapy.

A further consideration pertains to the homogenous nature of participants' socio-demographic characteristics. Findings may therefore not reflect experiences of diversity, inclusive of but not limited to gender, culture, race, and sexuality. Patients with hematological cancers, those very near end-of-life, and those who declined a referral to CALM therapy are also not represented in the current study. Moreover, all 10 interviewees were women who lived more than 10 months

after referral. Our interview data thus only pertain to women who survived longer and were physically able to engage in a greater number of sessions. Along these lines, findings cannot be generalized to settings where similar oncology and psychosocial resources are not available. It is important to acknowledge that data were collected from patients who received oncology care from well-resourced centres (e.g., Tom Baker Cancer Centre, Jack Ady Cancer Centre) in Alberta. Comprehensive psychosocial programming is offered across the province through cancer centres and community organizations. Results may differ if data were obtained from less well-resourced centres and/or sites where comprehensive psychosocial services are not widely available.

For this study, we did not collect information about use of psychotropic medications, so it is not possible to assess the potential impact of medications on patients' engagement in, or experiences of, CALM counselling.

Given the vulnerability to Type II Error, testing of baseline data should be repeated with a larger dataset. Along these lines, tumour group categories ultimately had too few participants to enable reliable analysis. Although our data analysis plan originally included the tumour group variable, the number of participants in several tumour group categories was too small. Given the clinical heterogeneity of different cancer diagnoses, it was not feasible to combine groups. Instead, descriptive statistics about tumour group membership are provided.

When looking at the association between total number of CALM appointments attended and the duration of time between referral to psychosocial support and death, findings of statistical significance must be interpreted carefully. Visual assessment of the scatter plot suggests heteroskedasticity, with greater variability among participants who lived longer than 10 months.

Medians were tested using different cut-points, but findings were, overall, not robust (see Appendix B).

Further, patient interviews were conducted by the author, who previously had been involved in registering all participants for the CALM implementation study and helping to schedule CALM sessions. It is therefore possible that interview findings are affected by response bias. However, interviewees were informed that all responses would be anonymous; further, interview questions were carefully developed and discussed amongst the research team to ensure questions were worded as neutrally as possible.

4.5 Clinical Implications

As participants reinforced during interviews, all descriptions of CALM, whether verbally or via pamphlet/website, should balance comprehensiveness, clarity, and sensitivity. Information should highlight the details and benefits of CALM therapy at a time when patients may be overwhelmed and trying to cope with multiple oncology appointments and fears surrounding mortality.

Generally, patients who were referred directly to CALM by their HCP participated in more CALM sessions compared to those who were referred indirectly via general Psychosocial Oncology. It may be the case that a trusting relationship with a HCP contributes to the creation of expectancies about the trustworthiness and benefits CALM therapy.

Patients who died shortly after referral may have lacked time and sufficient energy to complete additional sessions, particularly if cancer treatments were ongoing. Given the higher variability in total sessions attended among those who survived more than 10 months after referral, it may be valuable for CALM clinicians to explore the desire for additional "booster" sessions among those who have a longer prognosis. Indeed, several of those interviewed noted

the importance of the option to pursue additional sessions, beyond the usual 6, as needed. Similarly, the option to attend CALM sessions virtually is an important factor, particularly among those with disease progression and/or those who live further from the cancer centre.

Some patients also expressed support for implementation of an automatic referral system, wherein patients are referred to CALM at the time of advanced cancer diagnosis and can opt out if desired. Automatic referral, like HCP-facilitated referral, may promote a sense of trust in the service to which patients are referred. Importantly, an automatic referral process would reduce the burden on HCPs to make decisions about eligibility (e.g., prognosis) and to conduct the necessary steps for referral to CALM. Overall, findings indicate that patients value the autonomy to make an informed decision when it comes to accepting or declining a referral. It will therefore be essential to provide patients with comprehensive information (e.g., on a user-friendly website) about the full range of psychosocial services available through their local cancer centre (e.g., individual counselling and group programs offered through TBCC Psychosocial Oncology).

Previous research suggests significant benefits associated with the availability of an integrated, dedicated psychosocial clinician within palliative care.[146] In Alberta, the palliative tumour group (i.e., people with advanced, non-curable cancers) doesn't have a dedicated psychosocial clinician; it is the only tumour group for which this is the case. Overall, findings from this study align with previous reports of the value of collaborative psychosocial and palliative care.[45,146]

4.6 Future Directions

4.6.1 Automatic referrals:

As suggested by interviewees, it will be valuable to investigate the feasibility and acceptability of an automatic referral process, with early, systematic referral to CALM within

one month of advanced cancer diagnosis. This work may align with current efforts by the PaCES group in Southern Alberta to assess early and systematic referral to palliative care.[118,147] Furthermore, the implementation of an automatic referral system, in which all patients diagnosed with advanced cancer are referred, may ensure that people from diverse backgrounds have an opportunity to learn about and participate in CALM. As mentioned above, findings from a recent qualitive study suggest acceptability and benefit of an automatic referral process for early palliative care among newly-diagnosed stage IV lung cancer patients.[147]

4.6.2 Diversity:

There remains a lack of understanding about the ways in which CALM may meet the needs of culturally, ethnically, sexually, and socioeconomically diverse individuals with advanced cancer. As an extension of the current project, more research is needed to elucidate strategies for identifying and referring people with diverse backgrounds, ethnicities, genders, and sexual orientations.

4.6.3 Impacts of age and life expectancy:

Our findings indicate that referral route may differentially affect CALM engagement depending on age and duration of life after referral. It would be useful to gain a better understanding of the potential differences in the referral routes or referral approaches (e.g., direct referral, automatic referral, pamphlets) that might best align with patients' needs when they are younger versus older, or when they have a longer or shorter prognosis.

4.6.4 Control arm:

This study did not include patients who declined CALM therapy. It would therefore be valuable for future research to include a control arm of patients who decline CALM, or who

choose other psychosocial support, in order to assess potential differences in patient characteristics such as mood, death anxiety scores, and experiences with advanced cancer.

4.7 Knowledge Translation/Dissemination

The Knowledge Translation (KT) plan for this study is informed by the Knowledge Translation Planning Template [Barwick, M. (2008). Knowledge Translation Planning Template. ON: The Hospital for Sick Children].[148] Connections with several KT partners have been established via previous work for the CALM implementation trial. Partners include: oncology and palliative care clinicians, psychosocial oncology clinicians, as well as community cancer care organization team members. These individuals will be invited to attend follow-up presentations and meetings pertaining to outcomes of the current Master's project. Additionally, members of the CALM study team and the current Master's project (including Dr. JdG) are part of the Global CALM program, a network of researchers and clinicians from around the world who are engaged in research pertaining to the CALM intervention. Involvement in the Global CALM program provides opportunities to join international meetings during which the progress and outcomes of CALM-related studies are discussed. There may therefore be opportunities to present progress and/or outcomes of the current study to other Global CALM members from various sites around the world.

A manuscript has been submitted for publication in a peer-reviewed journal. In addition, findings will be presented at national and international conferences. The research team has presented at the 39th Annual Canadian Association of Psychosocial Oncology conference in Calgary, Alberta (June, 2024). Findings will also be presented at the International Psycho-Oncology Society congress in the Netherlands (September, 2024).

Knowledge Users (those who could potentially benefit from study results): Results may have relevance to researchers from psychosocial oncology and palliative care, clinicians from oncology, psychosocial oncology, and palliative care, staff from community cancer care organizations, and patients who may wish to engage in CALM counselling in the future. Results may inform future trials with more diverse patient populations from sites around the world at which CALM is offered. Oncology, psychosocial oncology, and palliative care clinicians may also benefit from knowledge pertaining to referral practices (e.g., how and when to introduce CALM to a patient). Findings pertaining to patient-related factors (e.g., mood, prognosis) may help to inform efforts to identify and refer patients to CALM counselling. Administrators and volunteers from community cancer care organizations who may refer patients to CALM programming could benefit from learning more about patients' perspectives on CALM.

Knowledge Translation/Dissemination Plan: Planning for knowledge translation/ dissemination has been conducted in collaboration with the current study's patient advisory team. In terms of sharing study findings with KT partners (i.e., HCP teams and community cancer care organizations), patient partners recommended reaching out to specific health care providers who can support future referrals. In particular, it was suggested that clinic nurses, nurse navigators, and nurse practitioners may have opportunities during clinic time to discuss CALM with patients. Advisors and research team members also highlighted the value of integrating referral procedures within already-established processes in the electronic medical records system (i.e., Connect Care in Alberta). In doing so, any additional burden on busy HCPs is minimized.

In an effort to raise and maintain awareness of CALM amongst HCP teams, it will be important to offer ongoing presentations and small-group meetings to communicate updates and to answer questions. Accordingly, we plan to present findings at the cancer centre's tumour group

rounds, and to offer small group and one-on-one meetings with oncology and palliative care teams. Within these presentations and meetings, we will honour the patient voice by sharing patients' perspectives on CALM counselling (obtained from interviews conducted as part of the current study).

Comprehensive, sensitively worded program information will be key to KT/ dissemination efforts, as endorsed by interviewees and patient partners. Written information may be provided via newsletters, pamphlets, and on a program website. As suggested by interviewees, written materials about CALM should provide patients with a clear idea of what to expect from CALM counselling without adding to their sense of overwhelm.

4.8 Conclusion

The aim of this thesis project was to advance our understanding of patient-specific factors and referral considerations associated with initiation and continuation of the evidence-based CALM therapy in Southern Alberta. With its mixed methods design and incorporation of in-depth patient interviews, this study offers 3 principal findings. (1) *To Whom* CALM is introduced may have significance. Findings from triangulation of quantitative and qualitative data suggest that certain characteristics influence patients' decisions to initiate and continue with CALM sessions. These patient-specific factors include psychosocial needs (e.g., mood, difficulty coping, desire for someone to talk to outside of family/friends), expectations of counselling, and cancer progression (i.e., prognosis and health status). (2) *How* CALM is introduced is important. Direct referral from a trusted HCP may impact patients' decision to pursue and continue with CALM counselling. Alternatively, as interviewees suggested, automatic referral to CALM upon advanced cancer diagnosis may facilitate timely referral, ensuring all patients are informed early and are offered the option to pursue, decline, or delay CALM therapy according to their evolving

needs. Critically, descriptions of CALM, whether provided verbally or via pamphlet/website, should balance comprehensiveness, clarity, and sensitivity, in recognition of the profound fear and overwhelm frequently experienced following diagnosis of advanced cancer. (3) *When* CALM is introduced is pertinent. Participants with longer prognoses have more opportunity to choose the number of CALM sessions that may best meet their needs. Providing patients with a clear, complete, sensitively worded introduction to CALM therapy (e.g., verbally, through pamphlet, website, and/or short video summary) following an advanced cancer diagnosis ensures information access and supports patient autonomy in terms of whether and when to initiate CALM. Importantly, ensuring a timely referral to CALM following advanced cancer diagnosis is consistent with recommendations for further integration of oncology, palliative, and supportive care.[31,44,44,138]

REFERENCES

1. National Cancer Institute at the National Institutes of Health. Advanced Cancer. NIH - National Cancer Institute. Published 2024. Accessed April 29, 2024. https://www.cancer.gov/about-cancer/advanced-cancer

2. National Cancer Institute at the National Institutes of Health. Cancer Staging. NIH - National Cancer Institute. Published 2024. Accessed April 29, 2024. https://www.cancer.gov/about-cancer/diagnosis-staging/staging

3. Canadian Cancer Society. Cancer Statistics at a Glance. Canadian Cancer Society. Published 2024. Accessed April 29, 2024. https://cancer.ca/en/research/cancer-statistics/cancer-statistics-at-a-glance

4. Office of Cancer Survivorship. Statistics and Graphs. NIH - National Cancer Institute - Division of Cancer Control & Population Sciences. Published 2024. Accessed April 29, 2024. https://cancercontrol.cancer.gov/ocs/statistics

5. Sethi R, Rodin G, Hales S. Psychotherapeutic approach for advanced illness: Managing Cancer and Living Meaningfully (CALM) therapy. *Am J Psychother*. 2020;73(4):119-124. doi:10.1176/APPI.PSYCHOTHERAPY.20190050

6. Garcia ACM, Schneiders M, Da Mota KS, Da Conceição VM, Kissane DW. Demoralization and spirituality in oncology: an integrative systematic review. *Support Care Cancer*. 2023;31(5):259. doi:10.1007/s00520-023-07722-6

7. Bail JR, Traeger L, Pirl WF, Bakitas MA. Psychological Symptoms in Advanced Cancer. *Semin Oncol Nurs*. 2018;34(3):241-251. doi:10.1016/j.soncn.2018.06.005

8. Greer JA, Applebaum AJ, Jacobsen JC, Temel JS, Jackson VA. Understanding and Addressing the Role of Coping in Palliative Care for Patients With Advanced Cancer. *J Clin Oncol*. 2020;38(9):915-925. doi:10.1200/JCO.19.00013

9. Vehling S, Kissane DW, Lo C, et al. The association of demoralization with mental disorders and suicidal ideation in patients with cancer. *Cancer*. 2017;123(17):3394-3401. doi:10.1002/cncr.30749

10. An E, Lo C, Hales S, Zimmermann C, Rodin G. Demoralization and death anxiety in advanced cancer. *Psychooncology*. 2018;27(11):2566-2572. doi:10.1002/pon.4843

11. Fitzgerald P, Lo C, Li M, Gagliese L, Zimmermann C, Rodin G. The relationship between depression and physical symptom burden in advanced cancer. *BMJ Support Palliat Care*. 2015;5(4):381-388. doi:10.1136/bmjspcare-2012-000380

12. Caruso R, Nanni MG, Riba M, et al. Depressive spectrum disorders in cancer: prevalence, risk factors and screening for depression: a critical review. *Acta Oncol*. 2017;56(2):146-155. doi:10.1080/0284186X.2016.1266090

13. Soleimani MA, Bahrami N, Allen KA, Alimoradi Z. Death anxiety in patients with cancer: A systematic review and meta-analysis. *Eur J Oncol Nurs*. 2020;48:101803. doi:10.1016/j.ejon.2020.101803

14. Hong Y, Yuhan L, Youhui G, et al. Death anxiety among advanced cancer patients: a cross-sectional survey. *Support Care Cancer*. 2022;30(4):3531-3539. doi:10.1007/s00520-022-06795-z

15. Janberidze E, Hjermstad MJ, Haugen DF, et al. How Are Patient Populations Characterized in Studies Investigating Depression in Advanced Cancer? Results From a Systematic Literature Review. *J Pain Symptom Manage*. 2014;48(4):678-698. doi:10.1016/j.jpainsymman.2013.11.013

16. Marziliano, Allison, Tuman, Malwina, Moyer, Anne. The relationship between post-traumatic stress and posttraumatic growth in cancer patients and survivors: A systematic review and meta-analysis. *Psychooncology*. 2020;29:604-616. doi:10.1002/pon.5314

17. Kissane DW, Bobevski I, Appleton J, et al. Meaning and Purpose (MaP) therapy in advanced cancer patients: a randomised controlled trial. *Support Care Cancer*. 2023;31(12):734. doi:10.1007/s00520-023-08189-1

18. Damen A, Raijmakers NJH, Van Roij J, et al. Spiritual Well-Being and Associated Factors in Dutch Patients With Advanced Cancer. *J Pain Symptom Manage*. 2022;63(3):404-414. doi:10.1016/j.jpainsymman.2021.10.004

19. Lo C, Hales S, Jung J, et al. Managing Cancer and Living Meaningfully (CALM): Phase 2 trial of a brief individual psychotherapy for patients with advanced cancer. *Palliat Med*. 2014;28(3):234-242. doi:10.1177/0269216313507757

20. Breitbart W, Pessin H, Rosenfeld B, et al. Individual meaning-centered psychotherapy for the treatment of psychological and existential distress: A randomized controlled trial in patients with advanced cancer. *Cancer*. 2018;124(15):3231-3239. doi:10.1002/cncr.31539

21. Temple WJ. Inspiring hope—A physician's responsibility, translating the science into clinical practice. *J Surg Oncol*. 2018;117(4):545-550. doi:10.1002/jso.24887

22. Lau J, Khoo AM, Ho AH, Tan K. Psychological resilience among palliative patients with advanced cancer: A systematic review of definitions and associated factors. *Psychooncology*. 2021;30(7):1029-1040. doi:10.1002/pon.5666

23. Wang CW, Chow AY, Chan CL. The effects of life review interventions on spiritual well-being, psychological distress, and quality of life in patients with terminal or advanced cancer: A systematic review and meta-analysis of randomized controlled trials. *Palliat Med*. 2017;31(10):883-894. doi:10.1177/0269216317705101

24. Vanbutsele G, Van Belle S, Surmont V, et al. The effect of early and systematic integration of palliative care in oncology on quality of life and health care use near the end of life: A

randomised controlled trial. *Eur J Cancer*. 2020;124:186-193. doi:10.1016/j.ejca.2019.11.009

25. Hui D, De La Cruz M, Mori M, et al. Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Support Care Cancer*. 2013;21(3):659-685. doi:10.1007/s00520-012-1564-y

26. Hausner D, Tricou C, Mathews J, et al. Timing of Palliative Care Referral Before and After Evidence from Trials Supporting Early Palliative Care. *The Oncologist*. 2021;26(4):332-340. doi:10.1002/onco.13625

27. Fadul N, Elsayem A, Palmer JL, et al. Supportive versus palliative care: What's in a name?: A survey of medical oncologists and midlevel providers at a comprehensive cancer center. *Cancer*. 2009;115(9):2013-2021. doi:10.1002/cncr.24206

28. Loiselle CG, Brown TL. Increasing access to psychosocial oncology services means becoming more person-centered and situation-responsive. *Support Care Cancer*. 2020;28(12):5601-5603. doi:10.1007/s00520-020-05659-8

29. Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *J Clin Oncol*. 2017;35(1):96-112. doi:10.1200/JCO.2016.70.1474

30. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J Clin Oncol*. 2012;30(8):880-887. doi:10.1200/JCO.2011.38.5161

31. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. *J Clin Oncol*. 2017;35(1):96-112. doi:10.1200/JCO.2016.70.1474

32. Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial. *The Lancet*. 2014;383(9930):1721-1730. doi:10.1016/S0140-6736(13)62416-2

33. World Health Organization. *Planning and Implementing Palliative Care Services: A Guide for Programme Managers*.; 2016.

34. Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol*. 2018;19(11):e588-e653. doi:10.1016/S1470-2045(18)30415-7

35. Salins N, Ghoshal A, Hughes S, Preston N. How views of oncologists and haematologists impacts palliative care referral: a systematic review. *BMC Palliat Care*. 2020;19(1):1-19. doi:10.1186/s12904-020-00671-5

36. Hannon B, Swami N, Rodin G, Pope A, Zimmermann C. Experiences of patients and caregivers with early palliative care: A qualitative study. *Palliat Med*. 2017;31(1):72-81. doi:10.1177/0269216316649126

37. Vanbutsele G, Pardon K, Van Belle S, et al. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. *Lancet Oncol*. 2018;19(3):394-404. doi:10.1016/S1470-2045(18)30060-3

38. Temel JS, Greer JA, El-Jawahri A, et al. Effects of early integrated palliative care in patients with lung and gi cancer: A randomized clinical trial. *J Clin Oncol*. 2017;35(8):834-841. doi:10.1200/JCO.2016.70.5046

39. McDonald J, Swami N, Hannon B, et al. Impact of early palliative care on caregivers of patients with advanced cancer: Cluster randomised trial. *Ann Oncol*. 2017;28(1):163-168. doi:10.1093/annonc/mdw438

40. Lang-Rollin, Isabelle, Berberich, Gotz. Psycho-oncology. *Dialogues Clin Neurosci*. 20(1):13-22. doi:10.31887/DCNS.2018.20.1/ilangrollin.

41. Mah K, Swami N, O'connor B, Hannon B, Rodin G, Zimmermann C. Early palliative intervention: effects on patient care satisfaction in advanced cancer. *BMJ Support Palliat Care*. Published online 2021:1-8. doi:10.1136/bmjspcare-2020-002710

42. Rodin G, Lo C, Rydall A, et al. Managing Cancer and Living Meaningfully (CALM): A randomized controlled trial of a psychological intervention for patients with advanced cancer. *J Clin Oncol*. 2018;36(23):2422-2432. doi:10.1200/JCO.2017.77.1097

43. Sorensen A, Le LW, Swami N, et al. Readiness for delivering early palliative care: A survey of primary care and specialised physicians. *Palliat Med*. 2020;34(1):114-125. doi:10.1177/0269216319876915

44. Qureshi M, Robinson MC, Sinnarajah A, Chary S, de Groot JM, Feldstain A. Reflecting on palliative care integration in canada: A qualitative report. *Curr Oncol*. 2021;28(4):2753-2762. doi:10.3390/curroncol28040240

45. Robinson MC, Qureshi M, Sinnarajah A, Chary S, de Groot JM, Feldstain A. Missing in action: Reports of interdisciplinary integration in Canadian palliative care. *Curr Oncol*. 2021;28(4):2699-2707. doi:10.3390/curroncol28040235

46. Wentlandt K, Krzyzanowska MK, Swami N, Rodin GM, Le LW, Zimmermann C. Referral practices of oncologists to specialized palliative care. *J Clin Oncol*. 2012;30(35):4380-4386. doi:10.1200/JCO.2012.44.0248

47. Watson L, Qi S, Photitai E, DeIure A. A Cross-Sectional Analysis of Ambulatory Oncology Experience by Treatment Intent. *Curr Oncol*. 2020;28(1):98-106. doi:10.3390/curroncol28010013

48. de Groot, Janet, Hales, Sarah, Sitter, Kathleen, et al. Implementation of Managing Cancer and Living Meaningfully (CALM) for people with advanced solid tumour cancers in Southern Alberta: Is it feasible and acceptable? *Forthcoming*. Published online 2024.

49. Rodin G, Lo C, Rydall A, et al. JOURNAL OF CLINICAL ONCOLOGY Managing Cancer and Living Meaningfully (CALM): A Randomized Controlled Trial of a Psychological Intervention for Patients With Advanced Cancer. *J Clin Oncol*. 2018;36:2422-2432. doi:10.1200/JCO

50. Colosimo K, Nissim R, Pos AE, Hales S, Zimmermann C, Rodin G. "Double awareness" in psychotherapy for patients living with advanced cancer. *J Psychother Integr*. 2018;28(2):125-140. doi:10.1037/int0000078

51. Loughan AR, Willis KD, Braun SE, et al. Managing cancer and living meaningfully (CALM) in adults with malignant glioma: a proof-of-concept phase IIa trial. *J Neurooncol*. 2022;157(3):447-456. doi:10.1007/s11060-022-03988-8

52. Mehnert A, Koranyi S, Philipp R, et al. Efficacy of the Managing Cancer and Living Meaningfully (CALM) individual psychotherapy for patients with advanced cancer: A single-blind randomized controlled trial. *Psychooncology*. 2020;29(11):1895-1904. doi:10.1002/pon.5521

53. Ding K, Zhang X, Zhao J, Zuo H, Bi Z, Cheng H. Managing Cancer and Living Meaningfully (CALM) Intervention on Chemotherapy-Related Cognitive Impairment in Breast Cancer Survivors. *Integr Cancer Ther*. 2020;19:153473542093845. doi:10.1177/1534735420938450

54. Jing Y, Zhao J, Yang Z, et al. Managing cancer and living meaningfully (CALM) as an intervention for severe fatigue in gastrointestinal cancer survivors.

55. Goodwin PJ, Leszcz M, Ennis M, et al. The Effect of Group Psychosocial Support on Survival in Metastatic Breast Cancer. *N Engl J Med*. 2001;345(24):1719-1726. doi:10.1056/NEJMoa011871

56. Walker LM, Bischoff TF, Robinson JW. Supportive Expressive Group Therapy for Women with Advanced Ovarian Cancer. *Int J Group Psychother*. 2010;60(3):407-427. doi:10.1521/ijgp.2010.60.3.407

57. Krueger E, Secinti E, Stewart JC, Rand KL, Mosher CE. Cognitive-behavioral and mindfulness-based interventions for distress in patients with advanced cancer: A meta-analysis. *Psycho-Oncol Chichester Engl*. 2024;33(1):e6259-n/a. doi:10.1002/pon.6259

58. Kubo A, Kurtovich E, McGinnis M, et al. Pilot pragmatic randomized trial of mHealth mindfulness-based intervention for advanced cancer patients and their informal caregivers. *Psycho-Oncol Chichester Engl*. 2024;33(2):e5557-n/a. doi:10.1002/pon.5557

59. Zimmermann FF, Burrell B, Jordan J. The acceptability and potential benefits of mindfulness-based interventions in improving psychological well-being for adults with

advanced cancer: A systematic review. *Complement Ther Clin Pract*. 2018;30:68-78. doi:10.1016/j.ctcp.2017.12.014

60. Milbury K, Li Y, Durrani S, et al. A Mindfulness-Based Intervention as a Supportive Care Strategy for Patients with Metastatic Non-Small Cell Lung Cancer and Their Spouses: Results of a Three-Arm Pilot Randomized Controlled Trial. *The Oncologist*. 2020;25(11):e1794-e1802. doi:10.1634/theoncologist.2020-0125

61. Lichtenthal WG, Roberts KE, Pessin H, Applebaum A, Breitbart W. Meaning-Centered Psychotherapy and Cancer: Finding Meaning in the Face of Suffering. Published online 2021.

62. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *J Clin Oncol*. 2005;23(24):5520-5525. doi:10.1200/JCO.2005.08.391

63. Fitchett G, Emanuel L, Handzo G, Boyken L, Wilkie DJ. Care of the human spirit and the role of dignity therapy: a systematic review of dignity therapy research. *BMC Palliat Care*. 2015;14(1):8. doi:10.1186/s12904-015-0007-1

64. Rosenblat JD, deVries FE, Doyle Z, et al. A Phase II, Open-Label Clinical Trial of Intranasal Ketamine for Depression in Patients with Cancer Receiving Palliative Care (INKeD-PC Study). *Cancers*. 2023;15(2):400. doi:10.3390/cancers15020400

65. Ross S, Agrawal M, Griffiths RR, Grob C, Berger A, Henningfield JE. Psychedelic-assisted psychotherapy to treat psychiatric and existential distress in life-threatening medical illnesses and palliative care. *Neuropharmacology*. 2022;216:109174. doi:10.1016/j.neuropharm.2022.109174

66. Rosenfeld B, Saracino R, Tobias K, et al. Adapting Meaning-Centered Psychotherapy for the palliative care setting: Results of a pilot study. *Palliat Med*. 2017;31(2):140-146. doi:10.1177/0269216316651570

67. Giese-Davis J, Koopman C, Butler LD, et al. Change in emotion-regulation strategy for women with metastatic breast cancer following supportive-expressive group therapy. *J Consult Clin Psychol*. 2002;70(4):916-925. doi:10.1037/0022-006X.70.4.916

68. Kissane DW, Grabsch B, Clarke DM, et al. Supportive-expressive group therapy for women with metastatic breast cancer: survival and psychosocial outcome from a randomized controlled trial. *Psychooncology*. 2007;16(4):277-286. doi:10.1002/pon.1185

69. Martopullo C, Oberoi D, Levin G, et al. “In the same boat”—a mixed-methods exploration of reasons why male gastrointestinal cancer patients joined a professionally led men-only cancer support group. *J Cancer Surviv*. 2020;14(3):261-272. doi:10.1007/s11764-019-00838-x

70. Oberoi D, Martopullo C, Bultz BD, Carlson LE. The effectiveness of a men-only supportive expressive group therapy intervention for psychosocial health outcomes in gastrointestinal

cancer patients: a 6-month longitudinal study. *Health Qual Life Outcomes*. 2021;19(1):47. doi:10.1186/s12955-021-01687-y

71. Zimmermann FF, Jordan J, Burrell B. Coping with cancer mindfully: A feasibility study of a mindfulness intervention focused on acceptance and meaning in life for adults with advanced cancer. *Eur J Oncol Nurs*. 2020;44:101715. doi:10.1016/j.ejon.2019.101715

72. Agrawal, Manish, Richards, William, Beaussant, Yvan, et al. Psilocybin-assisted group therapy in patients with cancer diagnosed with a major depressive disorder. *Cancer*. 2024;130:1137-1146. doi:10.1002/cncr.35010

73. Agin-Liebes GI, Malone T, Yalch MM, et al. Long-term follow-up of psilocybin-assisted psychotherapy for psychiatric and existential distress in patients with life-threatening cancer. *J Psychopharmacol (Oxf)*.

74. Gasser P, Kirchner K, Passie T. LSD-assisted psychotherapy for anxiety associated with a life-threatening disease: A qualitative study of acute and sustained subjective effects. *J Psychopharmacol (Oxf)*. 2015;29(1):57-68. doi:10.1177/0269881114555249

75. Grob CS, Danforth AL, Chopra GS, et al. Pilot Study of Psilocybin Treatment for Anxiety in Patients With Advanced-Stage Cancer. *ARCH GEN PSYCHIATRY*. 2011;68(1).

76. Griffiths RR, Johnson MW, Carducci MA, et al. Psilocybin produces substantial and sustained decreases in depression and anxiety in patients with life-threatening cancer: A randomized double-blind trial. *J Psychopharmacol (Oxf)*.

77. Ross, Stephen, Bossis, Anthony, Guss, Jeffrey, et al. Rapid and sustained symptom reduction following psilocybin treatment for anxiety and depression in patients with life-threatening cancer: A randomized controlled trial. *J Psychopharmacol (Oxf)*. 2016;30(12):1165-1180.

78. Jones TA, Olds TS, Currow DC, Williams MT. Feasibility and Pilot Studies in Palliative Care Research: A Systematic Review. *J Pain Symptom Manage*. 2017;54(1):139-151.e4. doi:10.1016/j.jpainsymman.2017.02.015

79. Hagen NA, Biondo PD, Brasher PMA, Stiles CR. Formal Feasibility Studies in Palliative Care: Why They Are Important and How to Conduct Them. *J Pain Symptom Manage*. 2011;42(2):278-289. doi:10.1016/j.jpainsymman.2010.11.015

80. Jones T, Luth EA, Lin SY, Brody AA. Advance Care Planning, Palliative Care, and End-of-life Care Interventions for Racial and Ethnic Underrepresented Groups: A Systematic Review. *J Pain Symptom Manage*. 2021;62(3):e248-e260. doi:10.1016/j.jpainsymman.2021.04.025

81. Nissim R, Freeman E, Lo C, et al. Managing Cancer and Living Meaningfully (CALM): A qualitative study of a brief individual psychotherapy for individuals with advanced cancer. *Palliat Med*. 2012;26(5):713-721. doi:10.1177/0269216311425096

82. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implement Sci*. 2009;4(1). doi:10.1186/1748-5908-4-50

83. Geerligs L, Shepherd HL, Rankin NM, et al. The value of real-world testing: A qualitative feasibility study to explore staff and organisational barriers and strategies to support implementation of a clinical pathway for the management of anxiety and depression in adult cancer patients. *Pilot Feasibility Stud*. 2020;6(1). doi:10.1186/s40814-020-00648-4

84. Jull J, Giles A, Graham ID. Community-based participatory research and integrated knowledge translation: Advancing the co-creation of knowledge. *Implement Sci*. 2017;12(1). doi:10.1186/s13012-017-0696-3

85. Andersen RS, Risør MB. The importance of contextualization. Anthropological reflections on descriptive analysis, its limitations and implications. *Anthropol Med*. 2014;21(3):345-356. doi:10.1080/13648470.2013.876355

86. Brebach R, Sharpe L, Costa DSJ, Rhodes P, Butow P. Psychological intervention targeting distress for cancer patients: a meta-analytic study investigating uptake and adherence: Psychological intervention for cancer patients: uptake and adherence. *Psychooncology*. 2016;25(8):882-890. doi:10.1002/pon.4099

87. Admiraal JM, van Nuenen FM, Burgerhof JGM, Reyners AKL, Hoekstra-Weebers JEHM. Cancer patients' referral wish: effects of distress, problems, socio-demographic and illness-related variables and social support sufficiency: Predictors of cancer patients' referral wish. *Psychooncology*. 2016;25(11):1363-1370. doi:10.1002/pon.4067

88. Faller H, Weis J, Koch U, et al. Utilization of professional psychological care in a large German sample of cancer patients: Utilization of psychological care in cancer. *Psychooncology*. 2017;26(4):537-543. doi:10.1002/pon.4197

89. Steginga SK, Campbell A, Ferguson M, et al. Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer diagnosis. *Psychooncology*. 2008;17(10):997-1005. doi:10.1002/pon.1317

90. Tondorf T, Grossert A, Rothschild SI, et al. Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study. *Psychooncology*. 2018;27(6):1656-1663. doi:10.1002/pon.4735

91. Puts M, Waked JAA, Strohschein F, et al. Implementing geriatric assessment and management for older Canadians with cancer: Adherence to and satisfaction with the intervention, results of the 5C study. *J Geriatr Oncol*. 2023;14(7):101586. doi:10.1016/j.jgo.2023.101586

92. Czajkowski SM, Powell LH, Adler N, et al. From ideas to efficacy: The ORBIT model for developing behavioral treatments for chronic diseases. *Health Psychol*. 2015;34(10):971-982. doi:10.1037/hea0000161

93. Kool M, Hafkamp E, Gol J, et al. Managing cancer and living meaningfully (CALM): Implementation in Dutch cancer care. *Psychooncology*. 2024;33(1):e6281. doi:10.1002/pon.6281

94. Van Klinken M, Hafkamp E, Gualtherie Van Weezel A, et al. Teaching Oncology Nurses a Psychosocial Intervention for Advanced Cancer: A Mixed-Methods Feasibility Study. *Semin Oncol Nurs*. 2023;39(6):151507. doi:10.1016/j.soncn.2023.151507

95. Fernández-González L, Namías MR, Bravo P. Facilitators and barriers perceived by health professionals in the implementation of Managing Cancer and Living Meaningfully (CALM) psychotherapy in Santiago. *ecancermedicalscience*. 2021;15. doi:10.3332/ECANCER.2021.1256

96. Lynch FA, Rodin G, Jefford M, et al. Evaluation of Managing Cancer and Living Meaningfully (CALM) in people with advanced non-small cell lung cancer treated with immunotherapies or targeted therapies: protocol for a single-arm, mixed-methods pilot study. *BMJ Open*. 2023;13(7):e072322. doi:10.1136/bmjopen-2023-072322

97. Miyamoto S, Yamazaki T, Shimizu K, et al. Brief, manualised and semistructured individual psychotherapy programme for patients with advanced cancer in Japan: Study protocol for Managing Cancer and Living Meaningfully (CALM) phase 2 trial. *BMJ Open*. 2022;12(3). doi:10.1136/bmjopen-2021-056136

98. An E, Wennberg E, Nissim R, Lo C, Hales S, Rodin G. Death talk and relief of death-related distress in patients with advanced cancer. *BMJ Support Palliat Care*. 2020;10(2):e19-e19. doi:10.1136/bmjspcare-2016-001277

99. Terao T, Satoh M. The Present State of Existential Interventions Within Palliative Care. *Front Psychiatry*. 2022;12:811612. doi:10.3389/fpsyt.2021.811612

100. Rodin G. From evidence to implementation: The global challenge for psychosocial oncology. *Psychooncology*. 2018;27(10):2310-2316. doi:10.1002/pon.4837

101. de Vries FE, Mah K, Malfitano C, et al. Clinical evaluation questionnaire in advanced cancer: a psychometric study of a novel measure of healthcare provider interactions. *BMJ Support Palliat Care*. Published online February 16, 2022:bmjspcare-2021-003408. doi:10.1136/bmjspcare-2021-003408

102. Wentlandt K, Krzyzanowska MK, Swami N, Rodin GM, Le LW, Zimmermann C. Referral Practices of Oncologists to Specialized Palliative Care. *J Clin Oncol*. 2012;30(35):4380-4386. doi:10.1200/JCO.2012.44.0248

103. Farquhar M, Preston N, Evans CJ, et al. Mixed methods research in the development and evaluation of complex interventions in Palliative and end-of-life care: Report on the MORECare consensus exercise. *J Palliat Med*. 2013;16(12):1550-1560. doi:10.1089/jpm.2012.0572

104. AbSPORU. Patient Engagement (PE) Definitions. AbSPORU: Alberta SPOR Support Unit. Published 2024. Accessed May 5, 2024. https://absporu.ca/patient-engagement/definitions/

105. Castro FG, Kellison JG, Boyd SJ, Kopak A. A methodology for conducting integrative mixed methods research and data analyses. *J Mix Methods Res*. 2010;4(4):342-360. doi:10.1177/1558689810382916

106. Östlund U, Kidd L, Wengström Y, Rowa-Dewar N. Combining qualitative and quantitative research within mixed method research designs: A methodological review. *Int J Nurs Stud*. 2011;48(3):369-383. doi:10.1016/j.ijnurstu.2010.10.005

107. Cresswell, John W, Plano Clark, Vicki L. *Designing and Conducting Mixed Methods Research*. 2nd ed. Sage Publications; 2011.

108. Lee SYD, Iott B, Banaszak-Holl J, et al. Application of Mixed Methods in Health Services Management Research: A Systematic Review. *Med Care Res Rev*. 2022;79(3):331-344. doi:10.1177/10775587211030393

109. Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suárez-Orozco C. Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *Am Psychol*. 2018;73(1):26-46. doi:10.1037/amp0000151

110. Fàbregues S, Hong QN, Escalante-Barrios EL, Guetterman TC, Meneses J, Fetters MD. A methodological review of mixed methods research in palliative and end-of-life care (2014–2019). *Int J Environ Res Public Health*. 2020;17(11):1-16. doi:10.3390/ijerph17113853

111. Thompson Burdine J, Thorne S, Sandhu G. Interpretive description: A flexible qualitative methodology for medical education research. *Med Educ*. 2021;55(3):336-343. doi:10.1111/medu.14380

112. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive Description: A Noncategorical Qualitative Alternative for Developing Nursing Knowledge. *Res Nurs Health*. 1997;20(2):169-177. doi:10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I

113. Thorne S, Kirkham SR, Flynn-Magee KO. The Analytic Challenge in Interpretive Description. *Int J Qual Methods.* 2004;3(1):1-11.

114. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa

115. Hunt MR. Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qual Health Res*. 2009;19(9):1284-1292. doi:10.1177/1049732309344612

116. Saracino RM, Rosenfeld B, Breitbart W, Chochinov HM. Psychotherapy at the End of Life. *Am J Bioeth*. 2019;19(12):19-28. doi:10.1080/15265161.2019.1674552

117. Bultz BD, Groff SL, Fitch M, et al. Implementing screening for distress, the 6th vital sign: a Canadian strategy for changing practice. *Psychooncology*. 2011;20(5):463-469. doi:10.1002/pon.1932

118. Ahmed S, Naqvi SF, Sinnarajah A, McGhan G, Simon J, Santana MJ. Patient & Caregiver Experiences: Qualitative Study Comparison Before and After Implementation of Early Palliative Care for Advanced Colorectal Cancer. *Can J Nurs Res*. Published online March 7, 2022:084456212210795. doi:10.1177/08445621221079534

119. de Groot JM, Lamont L, Gour M, et al. The preferred psychosocial intervention needs of persons living with lung cancer and their carers: A quantitative study. *Psychooncology*. 2008;17:S178-S179.

120. Wellspring Alberta. Wellspring: Cancer Support Alberta. Accessed February 18, 2024. https://wellspringalberta.ca/

121. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: Validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-613. doi:10.1046/j.1525-1497.2001.016009606.x

122. Grapp M, Terhoeven V, Nikendei C, Friederich HC, Maatouk I. Screening for depression in cancer patients using the PHQ-9: The accuracy of somatic compared to non-somatic items. *J Affect Disord*. 2019;254:74-81. doi:10.1016/j.jad.2019.05.026

123. Krause S, Rydall A, Hales S, Rodin G, Lo C. Initial Validation of the Death and Dying Distress Scale for the Assessment of Death Anxiety in Patients With Advanced Cancer. *J Pain Symptom Manage*. 2015;49(1):126-134. doi:10.1016/j.jpainsymman.2014.04.012

124. Lo C, Burman D, Swami N, Gagliese L, Rodin G, Zimmermann C. Validation of the QUAL-EC for assessing quality of life in patients with advanced cancer. *Eur J Cancer*. 2011;47(4):554-560. doi:10.1016/j.ejca.2010.10.027

125. Lo C, Walsh A, Mikulincer M, Gagliese L, Zimmermann C, Rodin G. Measuring attachment security in patients with advanced cancer: psychometric properties of a modified and brief Experiences in Close Relationships scale. *Psychooncology*. 2009;18(5):490-499. doi:10.1002/pon.1417

126. Caruso R, Nanni MG, Rodin G, et al. Effectiveness of a brief manualized intervention, Managing Cancer and Living Meaningfully (CALM), adapted to the Italian cancer care setting: Study protocol for a single-blinded randomized controlled trial. *Contemp Clin Trials Commun*. 2020;20. doi:10.1016/j.conctc.2020.100661

127. Dale W, Klepin HD, Williams GR, et al. Practical Assessment and Management of Vulnerabilities in Older Patients Receiving Systemic Cancer Therapy: ASCO Guideline Update. *J Clin Oncol*. 2023;41(26):4293-4312. doi:10.1200/JCO.23.00933

128. Sub-Local Geographic Area (SLGA). AHS GIS - Applied Research & Evaluation Services - PHC. Published 2022. Accessed June 19, 2023. https://ahs-geographic-information-systems-ahs.hub.arcgis.com/

129. Wilde M, Walton SL, Knapik G, Brigden M. Oncology social work services in the community oncology setting. 2018;17(1).

130. IBM SPSS Statistics for Windows [Computer software]. Version 29.0. Armonk, NY: IBM Corp; 2022.

131. NVivo [Computer software]. Version 12. Lumivero; 2017.

132. Patient Advisors Network. Patient Engagement. Published 2021. Accessed June 26, 2024. https://www.patientadvisors.ca/members/patient-engagement/

133. Arch JJ, Bright EE, Finkelstein LB, et al. Anxiety and Depression in Metastatic Cancer: A Critical Review of Negative Impacts on Advance Care Planning and End-of-Life Decision Making With Practical Recommendations. *JCO Oncol Pract*. 2023;19(12):1097-1108. doi:10.1200/OP.23.00287

134. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol*. 2011;12(2):160-174. doi:10.1016/S1470-2045(11)70002-X

135. Patten SB, Williams JVA, Lavorato DH, Fiest KM, Bulloch AGM, Wang J. The Prevalence of Major Depression is Not Changing. *Can J Psychiatry*. 2015;60(1):31-34. doi:10.1177/070674371506000107

136. Mah K, Chow B, Swami N, et al. Early palliative care and quality of dying and death in patients with advanced cancer. *BMJ Support Palliat Care*. Published online 2021. doi:10.1136/bmjspcare-2021-002893

137. Mah K, Swami N, O'Connor B, Hannon B, Rodin G, Zimmermann C. Early palliative intervention: effects on patient care satisfaction in advanced cancer. *BMJ Support Palliat Care*. 2022;12(2):218-225. doi:10.1136/bmjspcare-2020-002710

138. Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol*. 2018;19(11):e588-e653. doi:10.1016/S1470-2045(18)30415-7

139. Zoom [Computer software]. University of Calgary Licensed (Education) version. Zoom Video Communications, Inc. 2024.

140. Thekkumpurath P, Walker J, Butcher I, et al. Screening for major depression in cancer outpatients: The diagnostic accuracy of the 9-item patient health questionnaire. *Cancer*. 2011;117(1):218-227. doi:10.1002/cncr.25514

141. Tong E, Deckert A, Gani N, et al. The meaning of self-reported death anxiety in advanced cancer. *Palliat Med*. 2016;30(8):772-779. doi:10.1177/0269216316628780

142. Birkhäuer J, Gaab J, Kossowsky J, et al. Trust in the health care professional and health outcome: A meta-analysis. Nater UM, ed. *PLOS ONE*. 2017;12(2):e0170988. doi:10.1371/journal.pone.0170988

143. Kelley JM, Kraft-Todd G, Schapira L, Kossowsky J, Riess H. The Influence of the Patient-Clinician Relationship on Healthcare Outcomes: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. Timmer A, ed. *PLoS ONE*. 2014;9(4):e94207. doi:10.1371/journal.pone.0094207

144. Lindfors O. What patient characteristics predict treatment success or failure in short- and long-term psychotherapies? *Nord J Psychiatry*. 2021;75(sup1):S2-S2. doi:10.1080/08039488.2021.2019902

145. Fitch MI. Supportive care framework. *Can Oncol Nurs J*. 2008;18(1):6-14. doi:10.5737/1181912x181614

146. Feldstain A, Bultz BD, De Groot J, et al. Outcomes From a Patient-Centered, Interprofessional, Palliative Consult Team in Oncology. *J Natl Compr Canc Netw*. 2018;16(6):719-726. doi:10.6004/jnccn.2018.7014

147. Ahmed S, Simon J, Biondo P, et al. Acceptability of automatic referrals to supportive and palliative care by patients living with advanced lung cancer: Qualitative interviews and a co-design process. *Res Involv Engagem.* 2024;10(1):36. doi: 10.1186/s40900-024-00568-0.

148. Barwick M. Knowledge Translation Planning Template. Toronto, Ontario: The Hospital for Sick Children; 2008.

APPENDIX A

Table 1. Summary of CALM patient sociodemographic information (*n* = 69).

	All participants (n=69)		**Interviewed participants (n=10)**	
	M (SD)	**Range**	**M (SD)**	**Range**
Age (years) at time of referral to CALM/TBCC Psychosocial	62.36 (10.84)	33.58 - 83.74	60.12 (6.25)	52.86 - 71.83
	N	**%**	**N**	**%**
Gender				
Female	54	78.3%	10	100.0%
Male	15	21.7%	0	0.0%
Home location (Metro vs Non-Metro)				
Metro	45	65.2%	7	70.0%
Non-Metro	24	34.8%	3	30.0%
Referral Route				
Referral through psychosocial oncology (Indirect)	37	53.6%	5	50.0%
Referral from HCP (Direct)	28	40.6%	3	30.0%
Self-referral	4	5.8%	2	20.0%
Cancer Diagnosis				
Gynecological	20	29.0%	4	40.0%
Lung	13	18.8%	2	20.0%
Gastrointestinal	12	17.4%	1	10.0%
Breast	11	15.9%	2	20.0%
Genitourinary	6	8.7%	0	0.0%
Endocrine	2	2.9%	0	0.0%
Melanoma	2	2.9%	0	0.0%
CNS	1	1.4%	0	0.0%
Head and Neck	1	1.4%	0	0.0%
Sarcoma	1	1.4%	1	10.0%

Included close other in at least one CALM session				
No	42	60.9%	4	40.0%
Yes	27	39.1%	6	60.0%
Caregiver Details				
Spouse/Partner	22	31.9%	6	60.0%
Adult child or other family[1]	11	15.9%	2	20.0%
Friend	1	1.4%	0	0.0%
Income				
Prefer not to answer	18	26.1%	1	10.0%
$50,000 - $100,000	16	23.2%	2	20.0%
$100,000 - $250,000	15	21.7%	4	40.0%
$26,000 or less	8	11.6%	1	10.0%
$26,000 - $50,000	7	10.1%	2	20.0%
Missing	3	4.3%	0	0.0%
$250,000 or higher	2	2.9%	0	0.0%
Employment Status				
Not currently employed/working	56	81.2%	9	90.0%
Currently employed/working	9	13.0%	1	10.0%
Missing	3	4.3%	0	0.0%
Prefer not to answer	1	1.4%	0	0.0%
Education				
College/Trade	19	27.5%	3	30.0%
Undergraduate	14	20.3%	2	20.0%
Post-graduate/Professional School (e.g., law, pharmacy, medical)	11	15.9%	3	30.0%
High school/secondary school not completed	8	11.6%	0	0.0%
High school/secondary school	6	8.7%	1	10.0%
Some college/university/trade school (did not graduate)	6	8.7%	1	10.0%
Missing	3	4.3%	0	0.0%

Prefer not to answer	2	2.9%	0	0.0%
Ethnicity				
White (European)	59	85.5%	10	100.0%
Other	3	4.3%	0	0.0%
Missing	3	4.3%	0	0.0%
Filipino	2	2.9%	0	0.0%
Indigenous (First Nations, Metis, Inuk, American Indian, or Alaska Native)	1	1.4%	0	0.0%
South Asian (East Indian, Pakistani, Sri-Lankan, etc.)	1	1.4%	0	0.0%
Relationship Status[2]				
Married	39	56.5%	6	60.0%
Common Law	7	10.1%	1	10.0%
Divorced	7	10.1%	1	10.0%
Widowed	5	7.2%	0	0.0%
Separated	4	5.8%	1	10.0%
Other	3	4.3%	0	0.0%
In a Relationship	2	2.9%	2	20.0%
Employment				
Retired	25	36.2%	3	30.0%
Unemployed due to illness	18	26.1%	4	40.0%
Missing	18	26.1%	1	10.0%
Other	7	10.1%	2	20.0%
Homemaker	1	1.4%	0	0.0%

[1] For 6 participants, a spouse and/or adult child attended at least once. Two participants invited both a spouse and an adult child.

[2] Participants may have answered "yes" to more than one category.

Table 2. History of medical and psychosocial/mental health treatments.

	All participants (*n* = 69)		Interviewed participants (*n* =10)	
	N	**%**	**N**	**%**
History of psychosocial support prior to CALM				
No	36	52.2%	5	50.0%
Yes	33	47.8%	5	50.0%
Engaged in other psychosocial support concurrent with CALM				
No	64	92.8%	10	100.0%
Yes	5	7.2%	0	0.0%
History of previous medication management (psychiatry) prior to CALM				
No	48	69.6%	7	70.0%
Yes	21	30.4%	3	30.0%
Medication management from psychiatry concurrent with CALM				
No	49	71.0%	8	80.0%
Yes	20	29.0%	2	20.0%
History of previous group support prior to CALM				
No	63	91.3%	9	90.0%
Yes	6	8.7%	1	10.0%
Accessed group support concurrent with CALM				
No	58	84.1%	6	60.0%
Yes	11	15.9%	4	40.0%
Unsure about participating in CALM vs general psychosocial counselling, so attended at least one of each				
No	62	89.9%	10	10.0%
Yes	7	10.1%	0	0.0%
Prior or current psychosocial support through the community				
No	58	84.1%	9	90.0%
Yes	11	15.9%	1	10.0%
Surgery				

completed	48	69.6%	8	80.0%
n/a	20	29.0%	2	20.0%
ongoing	1	1.4%	0	0.0%
Chemotherapy				
ongoing	37	53.6%	5	50.0%
completed	21	30.4%	3	30.0%
n/a	11	15.9%	2	20.0%
Radiation Therapy				
n/a	38	55.1%	7	70.0%
completed	26	37.7%	3	30.0%
ongoing	5	7.2%	0	0.0%
Immunotherapy				
ongoing	30	43.5%	3	30.0%
n/a	29	42.0%	4	40.0%
completed	10	14.5%	3	30.0%

Table 3. Summary of CALM session attendance and baseline questionnaire scores.

	N	Range	Mean	SD	N	Range	Mean	SD
	All participants (*n*=69)				**Interviewed participants (n=10)**			
Total Number of CALM Appointments	69	0-14	4.01	3.02	10	1-10	5.80	2.86
Number of CALM Appointments with Caregiver	69	0-8	.67	1.23	10	0-8	1.70	2.45
Time (months) between diagnosis of advanced cancer and referral to CALM/ Psychosocial	69	0.33-82.27	12.07	16.35	10	0.33-29.90	11.80	11.34
Time (months) between referral to CALM/ Psychosocial and death	43	1.08-18.76	9.78	5.46	3	10.91-16.89	13.53	3.06
PHQ-9 Total Score	67	0.00-27.00	9.28	5.89	10	0.00-17.00	5.90	4.77
DADDS Total Score	67	0.00-67.00	27.84	14.59	10	9.00-29.00	19.70	7.76
ECR Total Score	67	1.00-5.75	2.77	0.97	10	1.00-4.25	2.68	0.88
ECR - Anxiety	67	1.00-6.50	2.63	1.21	10	1.00-5.13	2.83	1.15
ECR – Avoidance	67	1.00-5.88	2.90	1.17	10	1.00-4.38	2.53	0.91
QUALEC – Symptom Control	65	3.00-15.00	7.89	2.57	10	6.00-12.00	8.60	2.22
QUALEC - Relationship with Healthcare Providers	66	8.00-25.00	16.94	4.17	10	8.00-24.00	16.30	4.37
QUALEC – Preparation for End of Life	66	4.00-19.00	12.53	3.34	10	9.00-18.00	13.60	3.17
QUALEC - Life Completion	66	7.00-25.00	17.91	4.71	10	12.00-25.00	18.80	4.87

APPENDIX B

Figure 1: Distribution of the total number of CALM appointments attended by all consented participants (n = 69).

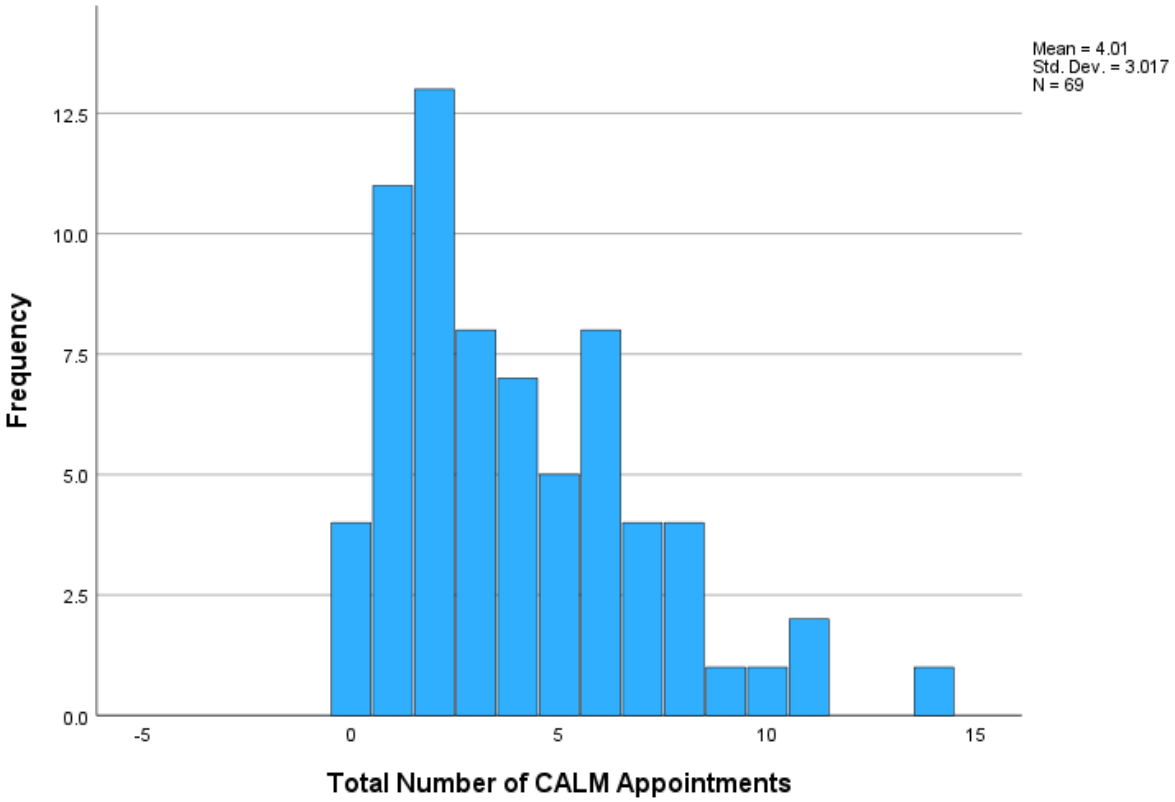
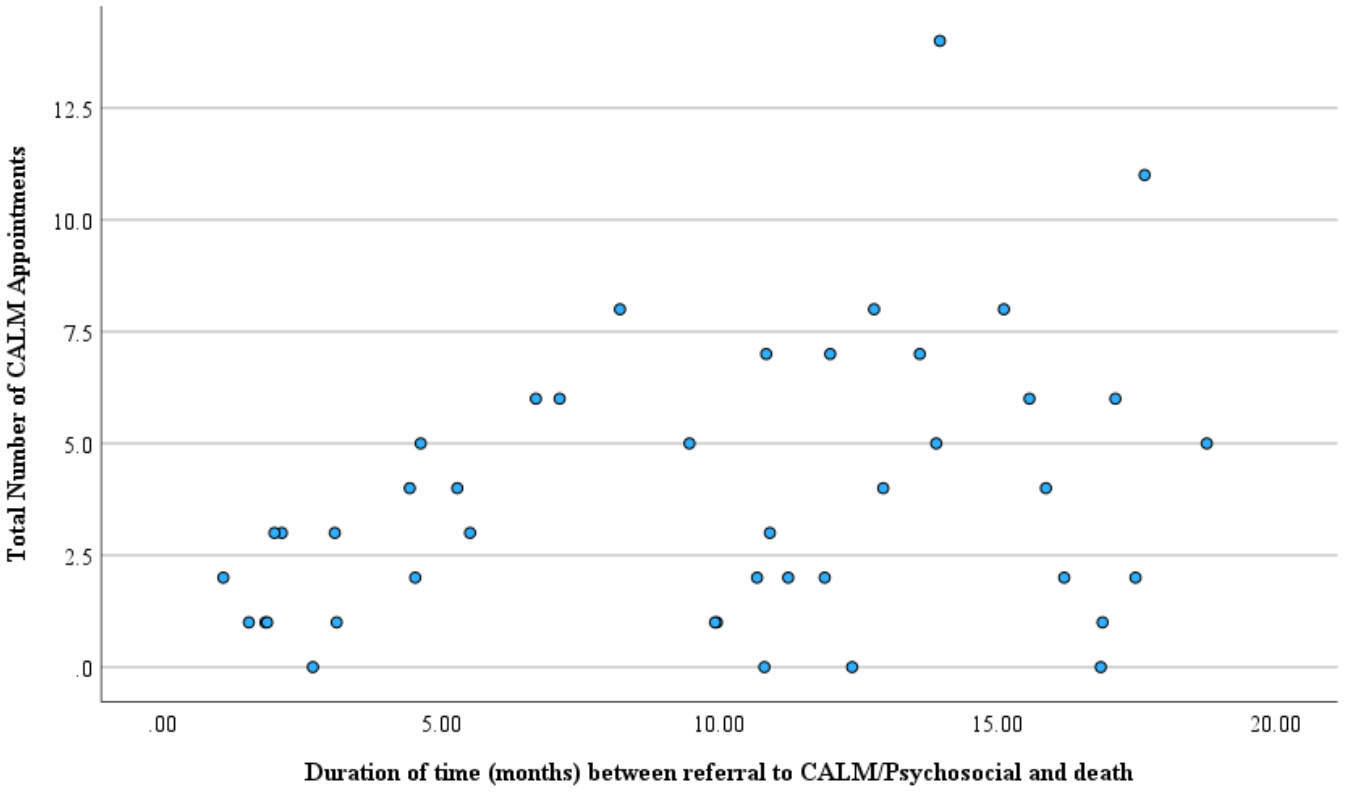


Figure 2: Association between total number of CALM appointments and the number of months between referral for Psychosocial Support (Psychosocial Oncology or CALM) and death (*n*=69).



APPENDIX C

Interview Guide

Thank you for taking the time to talk with me today. This interview will take about 30-45 minutes to complete and will be recorded. You're welcome to take breaks or stop at any time.

I'll first briefly review a little bit about the background and purpose of the interview. An important part of the CALM study involves conducting interviews to better understand people's experiences with CALM counselling. Ultimately, we would like to understand how CALM counselling can best meet the needs of people here in the context of Southern Alberta.

The interview today will be recorded. [If the interview is conducted via Zoom, only the audio file will be retained.] The audio file will be transcribed and de-identified, so your name and any potentially identifiable information will not be included. The de-identified transcript will be shared with members of our study team who will be helping with analyses. We may include de-identified quotes from the transcript in the final write-up of our results (i.e., research publications and presentations). This is therefore anonymous and not intended to offer feedback to your therapist, but rather is intended to garner greater understanding of providing CALM.

For the interview, I'll ask you a series of questions from a standard interview guide that was developed by the CALM study team. Please feel free to let me know if you're not comfortable with any of the questions or if you'd prefer not to answer. You're welcome to share as much or as little information as you're comfortable with.

Do you have any concerns or questions before we start the interview?

Would it be okay for me to now start the recording?

1. To start, could you please tell me a little bit about how you first heard about CALM. For example, were you referred directly by a member of your healthcare team, or did you hear about the study from the TBCC Psychosocial Department (front desk/triage)? [Refer to the date of referral, as a reminder.]
    a) How did you feel about the length of time from the initial call to completing the pre-appointment questionnaire to seeing the CALM therapist?
    b) When you first heard about CALM, what was your initial experience or response? Tell me more about that.
        - Probing questions: What was your gut reaction? What were your thoughts? [If applicable:] What changed your mind?
    c) May I also ask for your feelings about the timing of referral or introduction to CALM (e.g., would it have been helpful to learn about CALM earlier, when first diagnosed, or perhaps later in your treatment?).
    d) Once you were in CALM, how was the timing or length of sessions? Would you have liked more time between sessions, or less time between sessions? Did you miss or reschedule any CALM sessions? Can you tell me about that experience, such as the ease or challenge in rescheduling?

e) Were your sessions face-to-face, zoom, or by telephone? What was that like for you?
f) I wonder if you can tell me about the number of CALM sessions you attended? [If CALM sessions were discontinued:] Can you tell me a little bit about your reasons for discontinuing CALM sessions?

2. CALM counselling might mean different things to different people. We're interested in hearing what the experience of CALM counselling was like for you.
    a. Can you tell me a bit about what the experience of CALM counselling was like for you? We welcome any comments about your experience that you'd like to share with our research team.
    b. What were your goals/hopes for CALM counselling? Was this achieved?
    c. Did CALM counselling bring you something you weren't expecting?
    d. What seemed most helpful?
    e. What could have been changed, or what was missing?
        i. [Perhaps mention Wellspring programming/resources as another option for support, if applicable.]
    f. If you're comfortable sharing, may I ask if you've accessed other psychosocial support (e.g., counselling, group programs, Wellspring)? If so, how would you say CALM fits with these other supportive programs? How would you say your experiences compared with CALM counselling?
    g. Have you had peer support (others who have the same or different cancer)? How does peer support fit with CALM?
        i. [If the participant has experienced both a group support program and CALM:] Probing questions: If you're comfortable sharing, would this topic be something that you feel you could bring to the group? Is there something that keeps you from addressing this topic within a group setting?
    h. In addition to CALM, what other healthcare providers have you been connecting with for psychosocial support? For example: a palliative care physician, a palliative care nurse, or palliative home care, family doctors, oncologists, social workers? If so, how does CALM fit with these? How did CALM impact your use of these providers?
3. If we were to continue to provide CALM, what advice do you have for us?
4. Do you have any questions?

I'll now turn off the recording.

Thank you very much for your time today, and for your contribution to the study. You're welcome to reach out to us any time if you have concerns or questions.

Notes:

Version 3.0

New probes have been added following the completion of 2 interviews, during which the participants mentioned that ongoing one-on-one CALM counselling would be useful to address things like meaning/purpose following retirement. The following questions have been added (March 2023):

i. How did you feel about the length of time from the initial call to completing the pre-appointment questionnaire to seeing the CALM therapist?
ii. [If the participant has experienced both a group support program and CALM:] Probing questions: If you're comfortable sharing, would this topic be something that you feel you could bring to the group? Is there something that keeps you from addressing this topic within a group setting?

A brief mention/suggestion about Wellspring programming has also been added to provide information about additional support.

APPENDIX D

Email Template for Patient Stakeholder Interview Recruitment

Hello _____,

Thank you very much for your participation in the CALM program last year.

I'm reaching out about your interest and availability for a short interview (10 to 30 minutes) with me. We would like to learn from your words and hear about your experiences with and perspectives on CALM counselling.

For the next steps, I am happy to talk with you by phone or continue to communicate by email, if email is better for you.

You are welcome to let me know of any questions you have, or if you'd prefer not to be contacted by phone. I am also pleased to send a copy of the interview questions for your review.

All the best,

Carly

Carly Sears
MSc Candidate, Community Health Sciences
& Clinical Research Coordinator
Psychosocial Oncology Division,
Cumming School of Medicine, University of Calgary,
& Tom Baker Cancer Centre, Holy Cross Site
Phone: 403-465-2640
Email: carly.sears@albertahealthservices.ca

APPENDIX E

**An implementation study of
the Managing Cancer and Living Meaningfully (CALM)
intervention for individuals with advanced cancer
in Calgary and Region**

**Preventing depression among persons with
advanced cancer and their close other (Patient)**

INFORMED CONSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY

Protocol ID:	HREBA.CC-20-0269
Study Doctors (Calgary Site):	**Dr. Janet de Groot**, MD, FRCPC, MMedSc Tom Baker Cancer Centre, Psychosocial Resources Department of Psychiatry, Foothills Medical Centre Cumming School of Medicine, University of Calgary Phone: 403-355-3207 (Admin. Clerk, Holy Cross) Or 403-210-6900 (Alpana Malhotra, FMC) Or 403-944-4932 (Voicemail, FMC) Email: janet.degroot@albertahealthservices.ca **Dr. Kathleen Sitter**, PhD Faculty of Social work, University of Calgary Phone: 403-220-4573 Email: kcsitter@ucalgary.ca
Sponsor/Funder(s):	Alberta Cancer Foundation

Non-Emergency contact numbers are noted at the end of this document under the section heading “WHO DO I CONTACT FOR QUESTIONS?”.

You are being invited to participate in this research study because you are eligible to take part in the CALM intervention for individuals with advanced cancer. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision. You may find it helpful to discuss the study with family and friends so you can make the best possible decision within the given timelines.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take

part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

The principal investigators and research assistant will discuss this study with you and will answer any questions you may have. If you do consent to participate in this study, you will need to sign and date a printed or PDF copy of this consent form. If a digital consent form is used, you will be asked to indicate your consent by clicking on "I Agree". You will receive a PDF copy of the signed/completed form.

WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

We are conducting a research study to assess the feasibility and acceptability of an individualized supportive therapy in Calgary and South Zone locations; that is, we are evaluating whether or not this psychotherapy is appropriate for individuals living in Calgary and the South Zone. This study is taking place in different centres across the world. You are being invited to participate in this study because you have received a diagnosis of advanced cancer, you may be experiencing distress, you are fluent in English, and you are at least 18 years of age.

The therapy is called CALM, which is short for Managing Cancer And Living Meaningfully. CALM was developed to help people manage the challenges of living with cancer, reduce distress and promote psychological well-being. CALM therapy is a brief, semi-structured psychotherapeutic intervention for persons with advanced cancer, who are invited to include an informal caregiver (e.g., spouse, adult son/daughter, family member, close friend) to one or more sessions.

The results of this study will help inform the type of hospital support services that are best for patients with cancer in different parts of the world, including Calgary and the South Zone.

The Health Research Ethics Board of Alberta – Cancer Committee (HREBA-CC), which oversees the ethical acceptability of research involving humans, has reviewed and granted ethics approval for this study.

WHY IS THIS STUDY BEING DONE?

The developers of the CALM intervention have previously shown its effectiveness through psychotherapy evaluation studies at the Princess Margaret Hospital in Toronto, Ontario. The Calgary zone has the opportunity to join this global CALM initiative with this study.

The Calgary CALM implementation study will allow researchers and clinicians to better understand: 1) the factors involved in training Calgary and South Zone clinicians to be able to offer CALM therapy sessions; 2) the potential impacts of the CALM intervention on individuals with advanced cancer; 3) the experiences of individuals who are identified as the caregiver or close other of individuals with advanced cancer; and 4) the barriers and facilitators required to develop and sustain the CALM intervention in the Calgary and South Zone regional context.

WHAT ARE OTHER OPTIONS IF I DECIDE NOT TO PARTICIPATE IN THIS STUDY?

You do not have to take part in this study in order to receive continued medical or supportive

care. You may also choose to participate in more than one supportive care service or program, including the CALM intervention. Other alternatives, in addition to standard care, may include:

- Support groups for patients with some advanced cancers (e.g., ovarian, gastrointestinal, lung, and metastatic breast cancer);
- Individual, couples, and/or family counselling with a clinician from the Psychosocial Oncology Department of the Tom Baker Cancer Centre (Calgary & Area), Jack Ady Cancer Centre (Lethbridge & Area), or Southwest Palliative Care Team (Lethbridge & Area).

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Approximately 40 people with advanced cancer will take part in this study.

WHAT WILL HAPPEN DURING THIS STUDY?

If you agree to participate in this study, this is what will happen:

1) Prior to your first CALM appointment, you will be asked to complete an online questionnaire package containing questions regarding both your physical and mental health, some of which may not apply to you. The questionnaire package will take approximately 20-30 minutes to complete. You have the option to complete the package on your own, or with help from a research team member.
2) You will be asked to complete a similar questionnaire package in 3 and 6 months.
3) After you've completed all CALM counselling sessions and questionnaires, you will be invited to meet virtually or by telephone with a member of the study team to complete a 30- to 45-minute follow-up interview. During the interview, you will be asked a series of open-ended questions about your experience with CALM counselling. Interviews will be recorded, transcribed, de-identified, and analyzed to help the study team better understand the CALM counselling model and how it might be modified to best meet people's needs. You may choose to decline if you don't wish to participate in an interview.

CALM THERAPY:

- You will be offered three to six therapy sessions with a specially trained therapist for six months. Each session will last approximately 50 minutes to 1 hour, but the length and the number of the sessions may change based on your needs. You will have the chance to invite a caregiver or close other (e.g., spouse/partner, family member, or adult child, close friend) to one or more CALM sessions.
- CALM therapists are clinicians and trainees from a variety of backgrounds, including social work, psychiatry, psychology, and palliative care. You may be seen by a certified CALM therapist or by a clinician who is training and supervised weekly to become certified as a CALM therapist.
- The therapy addresses issues of: 1) symptom management and communication with health care providers; 2) changes in self and relations with close others; 3) spiritual well-being, or maintaining a sense of meaning and purpose; and 4) preparing for the future, sustaining hope and facing mortality.
- With your consent, therapy sessions may be recorded (video and/or audio) to make sure the therapy you receive meets treatment standards. Sessions may be recorded using Zoom or using a video camera (in-person sessions). Recordings may be transcribed or

written up; transcriptions or recordings may be used for research and/or educational purposes (e.g. training other clinicians). Identifying information in the recordings will be de-identified in the transcription of the session.

- As part of the study, the study team will look at your personal health information. They will collect only the information that is needed for this study. Personal health information is any information that could be used to identify you. It includes your name, address, contact information, and date of birth. It also includes new or existing medical records. The study team will also review your medical chart information, symptoms, and details about your disease and the treatments that you receive, including your CALM therapy. Some medical chart information for this study may be collected from your medical records and from the hospital database after your participation in the study has ended. Please see the section, 'HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL,' below, for further details.

Please note: Therapy sessions may be offered in person or, depending on the evolving state of COVID-19-related precautions, may be offered virtually or by telephone. Virtual sessions will be conducted using the AHS-licensed Zoom platform, a virtual meeting tool that has been approved by AHS for clinician use to facilitate virtual health care.

Certified CALM therapists and trainees will meet regularly with CALM colleagues to discuss cases. With your permission, video and/or audio recordings from therapy sessions will be shared and cases will be discussed as part of CALM training supervision.

Questionnaires

You will be provided with a questionnaire prior to your first CALM therapy session and again 3 months and 6 months later. The purpose of the questionnaire is to: 1) provide clinically relevant information that will be used to inform and guide therapy progress, and 2) allow the research team to better understand how the CALM intervention affects patients. Each questionnaire will take about 20-30 minutes to complete.

The information you provide is for research and clinical purposes only and will remain strictly confidential. Some of the questions are personal; you may choose not to answer them.

Due to the sensitive nature of some questions, it is possible you may experience emotional distress in response to the questionnaires. If you feel distressed, upset, or concerned by any questionnaire items, it is important that you inform your CALM therapist.

Even though you may have provided information on a questionnaire, these responses will not be reviewed by individuals not involved in this study (e.g., your health care practitioner/team). If you would like them to know this information, please bring it to their attention.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

The expected benefit from taking part in this study is to prevent or reduce distress and to provide support around 4 topics: 1) symptom management and communication with healthcare providers, 2) changes in self and relations with close others, 3) sense of meaning and purpose, and 4) the future and mortality. However, there is no guarantee that the intervention may be of direct benefit to you.

Based on the results of this study, it is hoped that in the long-term, patient care can be improved.

WHAT ARE MY RESPONSIBILITIES AS A STUDY PARTICIPANT?

If you choose to participate in this study, you will be expected to:

- Complete three online questionnaires (an initial questionnaire before your first CALM therapy session and a follow-up questionnaire three months and six months later);
- Attend three to six individual CALM appointments with a CALM-competent therapist. More sessions may be offered, if needed.
- Participate in a follow-up interview. You may choose to decline if you don't wish to participate in an interview.

HOW LONG WILL I BE PARTICIPATING IN THIS STUDY?

The study intervention will last for about six months.

CAN I CHOOSE TO LEAVE THIS STUDY EARLY?

You can choose to end your participation in this research (called early withdrawal) at any time without having to provide a reason. If you choose to withdraw early from the study without finishing the intervention, procedure or follow-up, you are encouraged to contact your CALM therapist, the principal investigator, or the research assistant.

Information that was recorded before you withdrew will be used by the researchers for the purposes of the study, but no additional information will be collected or sent to the sponsor after you withdraw your permission.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the study team know. However, this would also mean that you withdraw from the study.

HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the study team will only collect the information they need for this study.

Records identifying you, including information collected from your medical files/records, such as your Electronic Medical Records (EMR), ARIA, SCM, Meditech charts, etc., will be kept confidential to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Online questionnaires will be administered using REDCap Survey Software, which is housed on a secure, Canadian server through the University of Calgary. Electronic data will be de-identified and securely stored on the Canadian server associated with the online data collection software, REDCap. Only de-identified questionnaire response data (not personal or identifiable data) will

be stored on the REDCap servers. Although data collected using the REDCap resides on the REDCap servers, no assurance can be made about its confidentiality or that it will only be used for research purposes.

No personally identifying information (name, contact info, date of birth) will be stored along with the questionnaire data provided; instead, a unique study identification number is assigned to identify participants' data. De-identified questionnaire response data will be securely accessed with a login and password. Only the principal investigators, co-investigators and study coordinators will have access to the data. Upon study completion, the data will be removed from the REDCap server and exported to a data file for statistical analysis. This file will be stored in a private folder on a secure TBCC computer, only accessible to the principal investigators, co-investigators and study coordinators. An encrypted, password-protected copy of the de-identified questionnaire data will be shared with the Global CALM investigators (Princess Margaret Cancer Centre, Supportive Care Department). De-identified data from the Calgary site will be analyzed as part of the multi-site Global CALM study. Your name or other information that may identify you will not be provided (i.e., the information will be de-identified). The records received by the Global CALM study team will be coded with a number. The key that indicates what number you have been assigned will be kept secure by the Calgary study team and will not be released. After publication of study results, only completely de-identified datasets will be stored on the AHS and Princess Margaret servers. All data (i.e., electronic or paper files) relating to this study will be deleted 10 years after the publication of manuscripts resulting from this research.

Any identifying information (e.g., name, date of birth, contact information, date of diagnosis, dates and types of cancer treatments) will be stored in a separate password protected spreadsheet, in a folder stored on a secure TBCC server that will only be accessible to the Calgary-based principal investigators (Dr. de Groot, Dr. Sitter), co-Investigators, and study coordinator.

If applicable, signed paper copies of completed consent forms will be kept in a locked filing cabinet for 10 years after study completion and then will be destroyed. If you elect to complete paper versions of the questionnaire package, these will be stored in the same manner. Consent forms are stored separately from questionnaires and are linked with the unique ID number.

By consenting to participate in this study, you are also consenting to allow us access to your cancer care electronic medical record (ARIA, SCM, or Meditech, depending on clinician location) to confirm personal and cancer-related information (e.g., date of birth, type and date of initial cancer diagnosis, date of metastatic diagnosis, and treatment types and dates). Your CALM therapist will also document and track therapy progress by entering clinical progress notes in your medical chart (ARIA, SCM, or Meditech, depending on clinician location).

Use of Zoom for virtual therapy sessions: As per Alberta Health Service's recommendations for online meeting services, the Zoom platform will be employed for virtual CALM therapy sessions. Zoom is an easy-to-use virtual meeting tool that has been licensed by Alberta Health Services for clinician use to facilitate virtual health care.

With your permission, one or more CALM therapy sessions may be recorded (video and/or audio) to make sure the therapy you receive meets treatment standards. Sessions may be recorded using AHS Zoom or using a video camera (in-person sessions). If you choose to participate in a follow-up interview, audio from the interview will be recorded. Recordings from CALM therapy sessions and interviews may be transcribed or written up; transcriptions or

recordings may be used for research and/or educational purposes (e.g. training other clinicians). Identifying information in the recordings will be de-identified in the transcription of the session. Recordings will be password protected, stored on secure University of Calgary or TBCC servers, and will only be accessible to your CALM therapist and the Calgary study team.

Although absolute confidentiality can never be guaranteed, Alberta Health Services will make every effort to keep your identifiable health information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information in accordance with the Alberta Health Information Act and other regulatory requirements.

The information collected during this study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential. It is expected that the study results will be published as soon as possible after completion. Individual names of study participants will not be attached to any of the data that is published. Publications will only contain pooled data of all the study participants and in no way can be traced back to you.

The following organizations will receive de-identified study data:

- Global CALM study team, Princess Margaret Cancer Centre, Department of Supportive Care, Toronto, Ontario.
- Alberta Health Services, Virtual Health

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your identifiable information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information.

Studies involving humans sometimes collect information on race and ethnicity as well as other characteristics of individuals because these characteristics may influence how people respond to different interventions. Providing information on your race or ethnic origin is voluntary.

WILL MY HEALTHCARE PROVIDER(S) BE INFORMED OF MY PARTICIPATION IN THIS STUDY?

Your health care providers will not be informed by the study team that you are taking part in the study. You can choose to let your family doctor/health care provider know, if you like. If you are undecided, the principal investigator or your CALM therapist can discuss this with you.

WILL THERE BE ANY COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

Participation in this study will not involve any costs.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study.

WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please contact the principal investigator.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the hospital, investigators, sponsor, involved institutions for compensation or their agents, nor does this form relieve these parties from their legal and professional responsibilities.

Remember, you can refuse to take part or choose to leave the study at any time. This will in no way affect your care at the Tom Baker Cancer Centre.

IS THERE CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest declared between the principal investigators and sponsor of this study (Alberta Cancer Foundation).

WHO DO I CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you should talk to the principal investigators or study coordinator. These person(s) are:

Dr. Janet de Groot	403-944-4932
Name	Telephone
Dr. Kathleen Sitter	403-220-4573
Name	Telephone
Carly Sears (Research Assitant)	403-476-2458
Name	Telephone

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:

Telephone: 780-423-5727 Toll Free: 1-877-423-5727

SIGNATURES

Part 1 - to be completed by the potential participant.

	Yes	No
Do you understand that you have been asked to take part in a research study?	☐	☐
Do you understand why this study is being done?	☐	☐
Do you understand the potential benefits of taking part in this study?	☐	☐
Do you understand what you will be asked to do should you decide to take part in this study?	☐	☐
Do you understand the alternatives to participating in this study?	☐	☐
Do you understand that you are free to leave the study at any time, without out having to give reason and without affecting your future health care?	☐	☐
Do you understand who will see your records, including health information that identifies you?	☐	☐
Do you understand that by signing this consent form you are giving us permission to access your health information?	☐	☐
Do you understand that by signing this consent form that you do not give up any of your legal rights?	☐	☐
Have you had enough opportunity to ask questions and discuss this study?	☐	☐

Therapy Session & Interview Recordings:

Video & Audio Recordings:

Do you agree to allow one or more therapy sessions to be recorded (video & audio) for any of the following purposes:	Yes	No
- For educational purposes (to enhance learning and quality of care)? Videos will be reviewed by CALM therapists and trainees as part of therapist training and supervision.	☐	☐
- For presentation of de-identified clinical material at clinical workshops and/or conferences? Recordings will be modified so faces and names are excluded and anonymized.	☐	☐

Audio Recording:

Do you agree to allow one or more therapy sessions to be recorded (audio only) for any of the following purposes:	Yes	No
- For educational purposes (to enhance learning and quality of care)? Videos will be reviewed by CALM therapists and trainees as part of therapist training and supervision.	☐	☐
- For presentation of de-identified clinical material at clinical workshops and/or conferences? Recordings will be modified so names are excluded and anonymized.	☐	☐

- For audio recordings of therapy sessions to be transcribed, and for anonymized transcriptions or audio files to be used for future analyses? ☐ ☐

If you decide to participate in a follow-up interview, do you agree to allow a de-identified interview transcript to be analyzed as part of the current study? ☐ ☐

By signing this form I agree to participate in this study.

Signature of Participant	PRINTED NAME	Date

	Yes	**No**
(For Online Consent Form):		
By clicking this box (yes, I Agree) I give my consent and agree to participate in this study.	☐	☐

Part 2 - to be completed by the study doctor or designee who conducted the informed consent discussion. Only compete this section if the potential participant has **agreed** to participate.

I believe that the person signing this form understands what is involved in the study and has freely decided to participate.

Signature of Person Conducting the Consent Discussion	PRINTED NAME	Date

Part 3 - to be completed only if the participant is unable to read or requires assistance of an oral translator/interpreter.

- The informed consent form was accurately explained to, and apparently understood by the participant
- Informed consent was freely given by the participant.

Signature of Impartial Witness/Interpreter	PRINTED NAME	Date

******You will be given a paper or PDF copy of this signed and dated consent form prior to participating in this study.******