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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

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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.

Aims: To gain understanding of patient-specific factors and referral routes that influence initiation and continuation of CALM.

Methods: An Interpretive Description framework and concurrent triangulation mixed-methods design was used to analyse 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 organisations across Southern Alberta, Canada. Patient input ($n = 10$) occurred through 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.

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.

1 | Background

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 [1–3]. Distress, death anxiety, and depression are common [1, 3], the latter reported to affect one-third of patients with metastatic cancer [4] compared to 5.5% of the general adult population annually [5]. Individuals with advanced cancer may struggle with lost or evolving conceptualisations of life purpose, meaning, and hope [2, 6], which may not be targeted in standard psychosocial programing. Evidence-based, standardised psychosocial programing 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 [7].

One model of psychosocial support helping 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 for the specific needs of those with advanced cancer and their caregivers [2, 7]. Using supportive-expressive techniques within a relational framework, CALM addresses four areas of concern: symptom management and communication with healthcare providers; changes in one's self and close relationships; meaning and purpose; and the future, hope and mortality [7]. Consistent with early palliative care, CALM is offered when life expectancy is 12–18 months [8]. In 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 [2, 9–12]. However, Loughan and colleagues (2022) recommended assessing for patient profiles associated with a willingness or desire to address existential and end-of-life concerns [9].

Patient-specific factors associated with utilisation 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 [13–18]. Virtual or telephone-based therapy may be key among individuals with illness-related mobility difficulties and among those living distant from metropolitan-based centres [13].

Patient voices are central to this project, consistent with a Lancet Oncology Commission on the integration of oncology and palliative care [19]. Indeed, a National Institute of Health consensus conference advocated patient perspectives as valid outcomes in clinical medicine [19].

Using data from a CALM implementation project [20], and 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?

2 | Methods

2.1 | Design

To examine the complexities of patient engagement, defined by number of CALM sessions completed, a concurrent triangulation mixed-methods design was employed, in which different but complementary data are collected on the same topic to supplement one another and facilitate improved understanding [21–24]. This included collecting quantitative and qualitative data independently and in close succession, a strategy particularly pertinent given participants' changing health status [24]. The quantitative and qualitative data were then analysed concurrently and given equal value. Triangulation supported convergence of quantitative and qualitative findings during interpretation, promoting data contextualisation [21] and comprehensive insights into patient-specific factors affecting CALM engagement. Reporting Guidelines for Mixed-Methods [25, 26] were followed.

2.2 | Setting and Recruitment

Health Research Ethics Board of Alberta—Cancer Committee (HREBA.CC-20–0269) provided approval. The implementation study for evidence-based CALM therapy (2020–2024) took place in Southern Alberta, Canada, across two clinical sites [20]. The research-intensive Tom Baker Cancer Centre's (TBCC) (Calgary) psychosocial oncology department includes tumour-site specific psychosocial clinicians who provide supportive-expressive groups and/or individual counselling for persons with cancer, including advanced cancer. The second site, Southwest Palliative Care Service (SPCS) (Lethbridge), has a dedicated outpatient social worker.

Patients and caregivers were recruited from 2020 to 2022 through TBCC, SPCS, and a community cancer support organisation, Wellspring Alberta [27]. The current mixed-methods study involved secondary analysis of baseline data collected for the CALM implementation study, including demographic and medical variables obtained from the electronic medical record (age, sex, home location, tumour type and stage, diagnosis date). Interviews were completed 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 [20].

CALM recruitment included three referral routes (direct, indirect, and self-referral). Oncology HCPs referred patients to the CALM study (i.e., direct referrals). Patients with advanced cancer referred to the general Psychosocial Oncology service were provided with a counselling appointment and then introduced to the CALM study, which had shorter wait times (generally 1–3 weeks), as an alternative opportunity by Psychosocial administrative staff (i.e., indirect referral). Some patients directly contacted the CALM study team based on programme information on the study website or during local community cancer care organisation presentations (i.e., self-referral).

2.3 | Procedures

2.3.1 | 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 [28] 9-item self-report screening tool for depressive symptoms, is applied widely within oncology populations (score range 1–27) [29].
3. *The Death and Dying Distress Scale (DADDS)*. The DADDS, a valid measure of death anxiety among persons with advanced cancer [30], has 15 items (score range 0–75) that assess fears, distress, and self-perception as a burden to others [30].
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 [31].
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, includes four subscales assessing symptom control, relationship with HCP, preparation for end of life, and life completion to assess quality of life among persons with advanced cancer [32].

2.3.2 | 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.

2.3.3 | Interviews

A semi-structured interview script (see Supporting Information S1: Appendix), iteratively developed by the authors, invited participants to reflect upon experiences with CALM referral and session participation, beneficial aspects and what might be done differently. Consented participants were contacted by email and/or telephone to introduce and discuss interview participation.

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

2.3.4 | Data Analysis

2.3.4.1 | 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 characterise patterns of CALM sessions attended, exploring factors associated with session attendance. As data pertaining to the first research question's 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 selected baseline variables were explored: (1) referral route (e.g., direct referral, including self-referral, vs. indirect referral); (2) baseline psychological 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 referral to CALM; (4) as applicable, time (months) from referral to CALM and death; (5) illness-related: tumour group and treatment status (ongoing vs. discontinued); and (6) demographic: age, sex and living metropolitan versus non-metropolitan. *Non-metropolitan* is defined by Alberta Health Services as moderate metro influence, urban, moderate urban influence, rural, remote [33]. Utilising geriatric oncology guidelines [34], data were stratified into two age 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).

2.3.4.2 | Qualitative Data. Audio recorded, transcribed interviews were analysed using Thematic Analysis, within an Interpretive Description framework [35, 36]. Interpretive description generates findings from a deepened understanding of participants' experiences and perspectives, and applied towards advancement of clinical practice [37]. Data collection and analysis were completed concurrently [21, 35, 37]. 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 familiarised themselves with the data by transcript review, and subsequently generated initial codes, followed by collating codes into themes (as per thematic analysis) [36].

Research team discussion refined themes and, consistent with interpretive description, organised themes into clinically relevant narratives [35]. 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.

2.3.4.3 | Triangulation. Quantitative and qualitative data were merged to respond to each research question. Quantitative findings were compared to qualitative findings.

3 | Results

3.1 | Participant Characteristics

Of one hundred forty-one patients screened, 69 were eligible and consented to participate in the CALM implementation study. [See Tables 1 and 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.].

3.1.1 | 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 ($n = 10$), versus 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.

3.2 | Triangulated Qualitative and Quantitative Results

3.2.1 | Variables Affecting Participant Number of CALM Sessions

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 (≥ 65 years) and those nearer death.

Other demographic, illness-related and psychological variables were not associated with number of CALM sessions.

3.2.1.1 | Evolving Physical and Mental Health Needs. Participant physical and emotional capacity limits to counselling session participation may have importantly influenced the number of CALM sessions attended, particularly among those with progressive 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.

3.2.2 | Patient Experiences With Referral to and Participation in CALM

3.2.2.1 | Psychological Characteristics at CALM Initiation. The full and interview cohorts' mean initial PHQ-9 scores are consistent with mild depression [9, 29]. Among outpatients with cancer, the full sample's mean score, above 8, prompts assessment for depression [38]. Additionally, the full cohort's mean death anxiety score, 27.84 (SD = 14.59), was in the moderate range (20–50) [39].

Participants stated various subjective 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, experiencing 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 included: (1) distress, depression, and coping with 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

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				
Gynaecological	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[a]	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%

(Continues)

TABLE 1 | (Continued)

	N	%	*N*	%
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[b]				
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%

[a] For six participants, a spouse and/or adult child attended at least once. Two participants invited both a spouse and an adult child.
[b] Participants may have answered 'yes' to more than one category.

potentially others (e.g., through study contribution); (4) CALM counselling alignment with palliative care needs.

3.2.2.2 | Referral Information. Participants identified the context of overwhelm 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 diagnosis suggested framing information as 'how it could help… with wherever you are on that journey', and not 'all about end of life' (#237, age 69, stage IV lung cancer).

3.2.2.3 | CALM Appointments. Virtual appointments (e.g., Zoom-based sessions) were endorsed as a 'game changer' (#332, age 56, recurrent metastatic gynaecological cancer), eliminating travel time and stress of driving/parking. Virtual appointments were highly relevant for non-metro participants

TABLE 2 | History of medical and psychosocial/mental health treatments for all participants and interviewed participants.

	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 versus 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%

and for those declining physically, who often had numerous oncology appointments.

3.2.3 | Importance of WHEN CALM Is Introduced

Timing of initiation and continuation of CALM sessions depends on highly individualised factors varying across the disease trajectory.

3.2.3.1 | Time Between Diagnosis and Psychosocial Support Referral. Baseline data analysis found no significant association for time duration 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).

3.2.3.2 | 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 ($r(41) = 0.32$, $p = 0.04$). Those living longer attended more sessions. However, visual assessment of the scatter plot suggests heteroscedasticity, with greater session number variability among longer living participants (Figure 2). Medians were tested using different cut-points, but findings were, overall, not robust.

3.2.3.3 | Evolving Factors Across the Disease Trajectory. A participant poignantly highlighted how diminished health affected 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

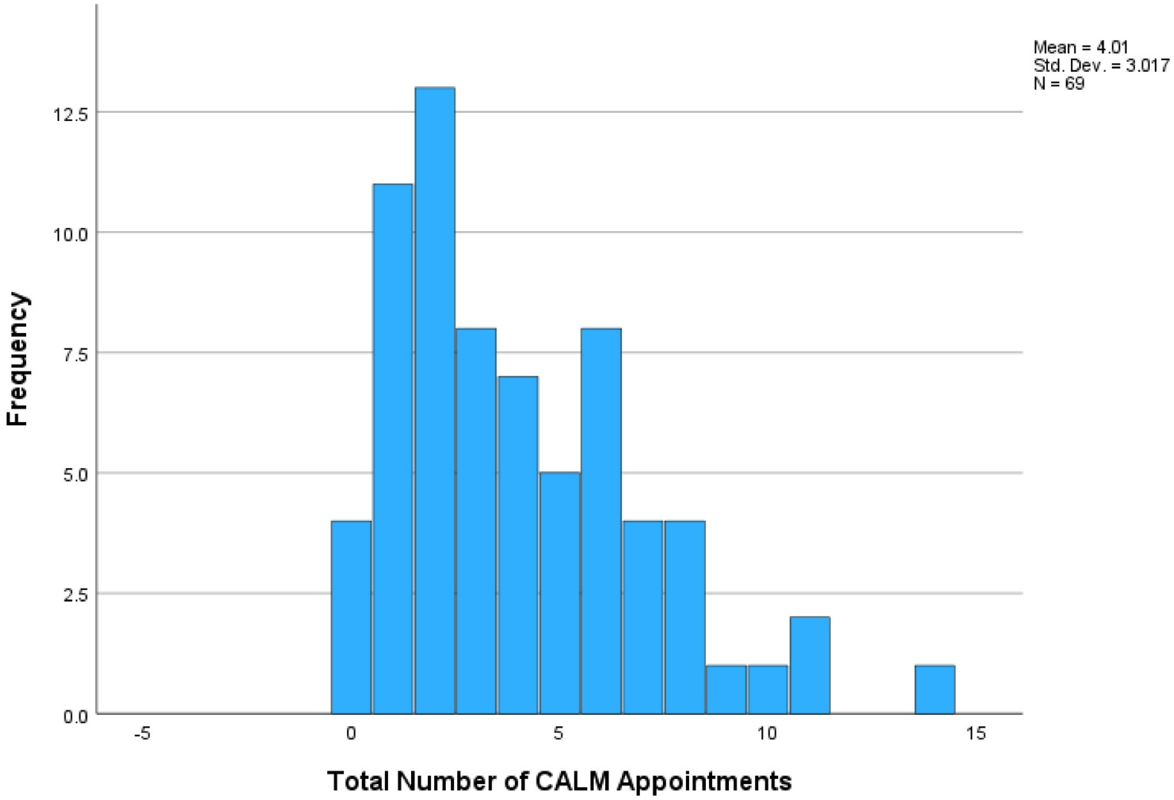

FIGURE 1 | Distribution of the total number of CALM appointments attended by all consented participants ($n = 69$).

> 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).

3.2.3.4 | Automatic Referrals & Patient Decision-Making. Recognising the oncology context of busy clinics and time pressures limiting discussion of psychosocial support, participants suggested automatic CALM referrals following advanced cancer diagnoses. One participant explained that early information provision allows patients 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).

4 | Discussion

This mixed-methods study offers preliminary insights into experiences with advanced cancer, as well as referral to and participation in CALM counselling. Qualitative findings honour patient voices, providing insight into nuanced perceptions of referral to and engagement in CALM. Numerous individualised, 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.

4.1 | WHO Participates in CALM: Patient and Referral Characteristics Influence CALM Session Numbers

Uniquely, this study sheds new light on potential referral route-related 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 [40, 41]. Furthermore, wait-times for CALM appointments were generally less than those of the psychosocial service.

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 [2]. 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-

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	0.67	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

being; it may not, however, limit the value of CALM sessions patients do participate in.

Nevertheless, baseline mood and death anxiety were not associated with the total number of CALM sessions.

4.2 | HOW CALM Is Introduced: Referral Experience and Participation

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 willingness for psychosocial treatment [14, 16]. Further, participants spoke of difficulty coping, a desire to share their story and mortality concerns with someone outside of friends/family, and 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.

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 acceptance of help-seeking are associated with willingness to be referred and engage in psychosocial support, and affect therapy outcomes [17, 18]. CALM patients valued virtual/telephone sessions when geographically distanced from the cancer centre. Illness-related mobility concerns, often prevalent among those with advanced cancer, can influence patients' level of engagement in psychosocial services [13].

4.3 | WHEN CALM Is Introduced—The Importance of Referral Timing

Systematised 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. Standardised referral may convey that CALM is considered an essential aspect of care and support integration of oncology and supportive care. Additionally, as endorsed by interviewees, patients have autonomy to accept or decline the referral. Systematised programing 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 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 with greater life expectancy. Interviewees noted the importance of access to additional 'booster' sessions as needed.

To the authors' knowledge, other studies within the CALM research arena 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, contributing to CALM engagement.

4.4 | Study Limitations

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

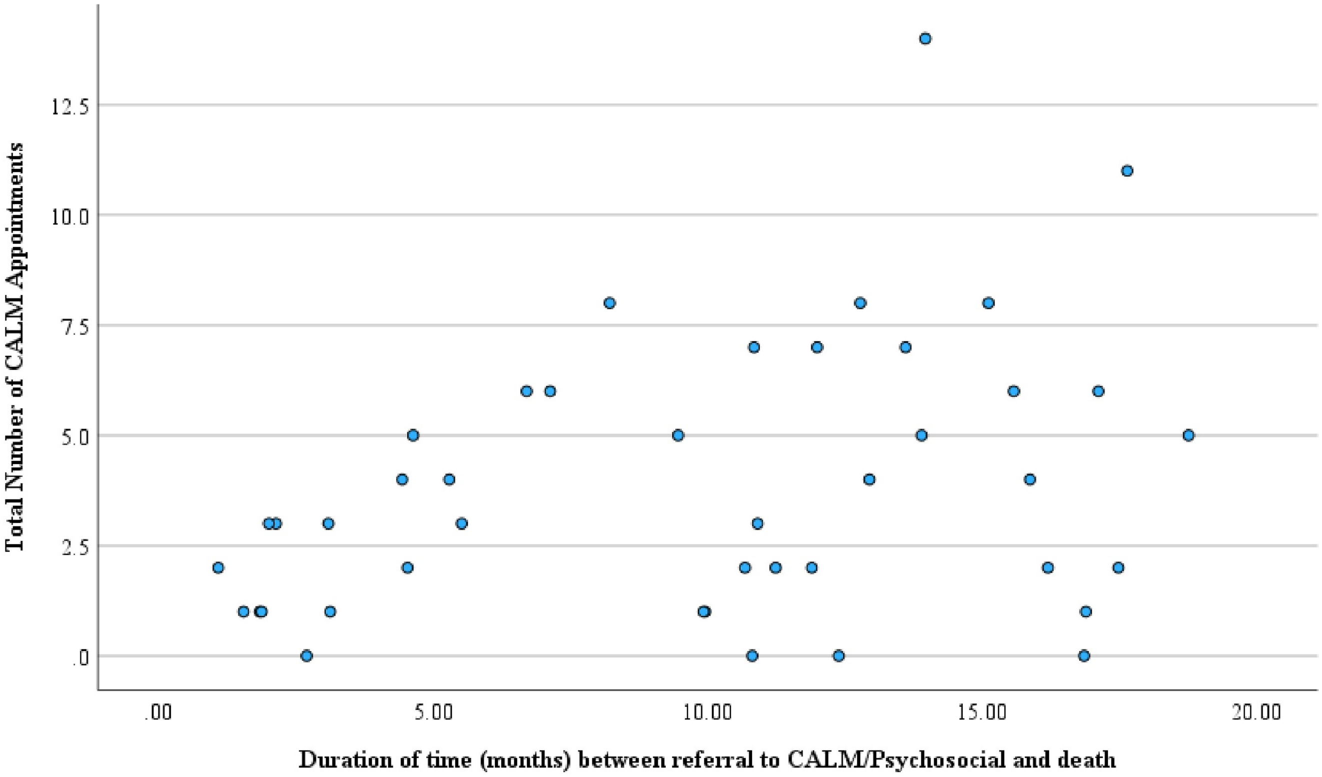

FIGURE 2 | Association between total number of CALM appointments and the number of months between referral for psychosocial support (psychosocial oncology or CALM) and death.

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, and sexuality. However, this sample provided rich data about women's experience with engagement in CALM when living with advanced cancer.

4.5 | 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 systematised programing with referrals following an advanced cancer diagnosis.

4.6 | Clinical Implications

Three key patient-informed findings were derived from this study: (1) Introduction and direct referral to CALM by a HCP or, as interviewees suggested, routine referral upon advanced cancer diagnosis may influence CALM engagement, defined by number of sessions. Qualitative findings signal the characteristics that may affect engagement, including psychosocial needs, expectations of counselling, and greater life expectancy. (2) *How* CALM is introduced may be important. 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 strategy may be to provide patients with information about CALM following an advanced cancer diagnosis, ensuring information access and supporting personal choice of when to initiate CALM therapy. Timing referral to CALM following an advanced cancer diagnosis is consistent with recommendations to further integrate tumour-focused and whole person care, through systematic programing between oncology, palliative care and supportive care [19].

4.7 | Conclusion

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

Author Contributions

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

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

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

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