

Hales S, Lo C, Rodin G. (2015). Managing Cancer And Living Meaningfully (CALM) Therapy (Chapter 62). In: Holland JC, Breitbart WS, Butow PN, Jacobsen PB, Loscalzo MJ, McCorkle R (Editors). Psycho-Oncology, Third Edition. Oxford University Press: New York, NY; pp. 487-491.

Book Title:

Psycho-Oncology, Third Edition

Chapter 62:

Managing Cancer And Living Meaningfully (CALM) Therapy

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Managing Cancer And Living Meaningfully (CALM) Therapy

Abstract

Managing Cancer And Living Meaningfully (CALM) is a brief, semi-structured individual intervention designed to alleviate distress and to promote psychological growth in individuals with advanced disease. This intervention emerged from a longitudinal program of research and from the theoretical traditions of relational, attachment and existential theory. Through a process that supports affect regulation, attachment security and reflective functioning, CALM focuses on four content domains: 1) symptom management and communication with health care providers; 2) changes in self and relations with close others; 3) sense of meaning and purpose; and 4) the future and mortality. Caregivers are invited to one or more CALM sessions, during which communication, strengths and disruptions in the relationship with the patients, and hopes and fears are addressed. Qualitative research has shown that the structure of CALM provides what cancer patients experience as a safe place for them to explore their fears, to be seen in human terms, and to face the challenges and threats of advancing disease. Quantitative studies have shown that CALM leads to a reduction in depressive symptoms and death anxiety and an increase in spiritual well-being. Therapist skill in the delivery of CALM is developed and maintained through didactic and experiential workshops and by ongoing supervision.

Keywords: Psychotherapy, advanced cancer, end of life, palliative care, distress, dying and death, death anxiety

Rationale for CALM

Advanced and life-threatening cancer brings multiple challenges, including the progressive physical burden of disease, complex treatment decisions, and significant treatment toxicity. These changes potentially undermine self-esteem and the sense of meaning and purpose in life and may evoke fears related to dependency, isolation, physical suffering and mortality. Symptoms of anxiety and posttraumatic stress are common in individuals with metastatic cancer; however, advancing disease may also provide an opportunity for psychological growth and development, an outcome referred to as posttraumatic growth.¹ This is consistent with the developmental crisis triggered by the threat of impending mortality that Erikson² suggested may lead to either despair or to psychological growth.

Managing Cancer And Living Meaningfully (CALM) therapy is a brief, manualized, supportive-expressive therapy³ that is intended to address the practical and profound issues that face individuals with metastatic cancer. This intervention emerged from a longitudinal program of research^{4,5} and from relational,⁶ attachment,⁷ and existential theory.⁸ It aims to alleviate distress and to promote psychological growth, by facilitating affect regulation, problem-solving and reflection in domains that typically present challenges to patients and caregivers facing metastatic cancer. The short-term nature of the intervention allows CALM to be delivered to patients with limited life expectancy and to be practically feasible in oncology and health care settings. The sense of limited time and of a foreshortened future in individuals with advanced disease may heighten their motivation to seek help and to engage in such an intervention.

CALM shares features with other psychotherapeutic interventions that have been developed for patients with advanced disease. These include supportive-expressive (Chapter 75), cognitive-existential,^{8,9} and meaning-centered (Chapter 63) group psychotherapy interventions.

As an individual therapy, CALM can be tailored to the unique needs of patients and allows privacy regarding the personal and sensitive issues that may arise, and flexibility regarding the content and timing of sessions. The last is important in order to accommodate the needs of patients struggling with fluctuating health status, complicated treatment schedules, and unpredictable hospitalizations. CALM shares with Dignity Therapy (see Chapter 64) a focus on identity and self-concept and death preparation for patients near the end of life. However, CALM, is intended for patients earlier in the course of illness (usually greater than 6 months prognosis), when they are as engaged with living as they are with facing the end of life.

Structure of CALM

CALM optimally consists of six individual sessions of 45 to 60 minutes delivered over a three to six month period, although the number of sessions may vary, depending on the clinical circumstances. The CALM sessions address four broad and interrelated domains found to be important and relevant in this population.^{4,5} These are: 1) symptom management and communication with health care providers; 2) changes in self and relations with close others; 3) sense of meaning and purpose; and 4) the future and mortality (see Figure 62.1). These domains are addressed with all patients at some point during the intervention, although the sequence and relative emphasis on each domain varies, depending on their urgency and relative importance in each case. Each participant's primary caregiver (e.g. spouse, adult son or daughter or friend) is offered the opportunity to participate in one or more sessions to allow exploration of the relationship between the patient and their primary caregiver and to support the dyad in anticipating and preparing for the future.

<Figure 65.1 here>

The CALM Patient

CALM is intended for patients with advanced and life-threatening cancer who have some interest and capacity for reflection and who are physically and cognitively well enough to engage in psychotherapeutic sessions over a three to six month period. Many such individuals have concerns about being flooded by unpleasant emotions, although CALM can help such individuals process and better tolerate unavoidable distressing thoughts. Those who are interested in thinking only positive thoughts may be unsuitable for the intervention, although an avoidant strategy of this kind almost inevitably becomes untenable with progressive disease. Appropriate candidates may vary in their capacity for affect regulation, trust in a helping relationship, and fear of exposure and reflective capacity, which must be taken into account in the conduct of the therapy.

The CALM Process

The following elements are the active ingredients of CALM therapy that contribute to its therapeutic effect.

The Supportive Relationship: The most important element of CALM therapy is the patient-therapist relationship. The openness of the therapist and the patient to each other at this time of tragedy and crisis allows depth in the relationship to develop in a relatively short period of time. The CALM therapist consistently works to understand empathically the patients' felt experience, and to understand its meaning. Therapists become witnesses to the experience of

patients, helping them to address fears of isolation and dependency, to manage feelings of grief and loss and to identify their strengths and potential adaptive coping strategies.

Authenticity: The therapeutic stance is one of authentic engagement with the patient. Authenticity in this context refers, not to verbal self-disclosure, but to mutual emotional presence. Therapists accept and resonate with the fears and hopes of the patient, including assumptions that their life is not worth living or that they are an unwanted burden on others. Paradoxically, the recognition that these are personal beliefs, rather than absolute or immutable truths, allows alternate possibilities and other perspectives to be considered.

Shifting Frame and Flexibility: Fluctuations in patients' clinical state, symptom control and the receipt of prognostic news may drastically alter their capacity or motivation for self-reflection. Such changes may necessitate shifts between exploratory and supportive approaches. The changing clinical status of patients and the conflict with other appointments, tests and treatments may also require adjustment of the content or timing of sessions. Although the brief nature of the intervention and the threat of mortality bring termination of the sessions to the foreground early in the treatment, clinical deterioration or death can occur unexpectedly or suddenly, without the opportunity to negotiate termination with the patient.

Modulation of Affect: Emotional hyperarousal and constriction may occur transiently, persistently or alternately, causing distress and interfering with the processing of emotional experience. CALM therapists aim to help patients modulate the intensity of emotions to keep them within a tolerable range, to facilitate safe access to their inner life and to help them make sense of what they are feeling and thinking. The communication of emotions within an atmosphere of support and understanding allows patients to develop a greater capacity and

confidence in their ability to manage disturbing and intense emotions that arise in the context of their illness.

Renegotiation of Attachment Security: The threat of illness heightens attachment needs and makes them more salient. Individuals with less confidence in the availability of attachment relationships or who are inflexibly self-reliant tend to have greater difficulty adjusting as the disease progresses. Disequilibrium in marital and other intimate relationships is common in these circumstances. Those who have tended to be self-sufficient and more comfortable in the caregiving role may feel threatened by the growing dependency imposed by their disease. Those who tend to worry about the availability of others may experience increasing fears about this. CALM therapy addresses the emotional disruption caused by these potential attachment crises and helps individuals and their caregivers re-establish equilibrium in their attachment relationships.

Mentalization and Double Awareness: Individuals vary widely in their capacity for self-reflection, and what has been termed mentalization (i.e. the capacity to reflect on feeling states, to distinguish them from literal facts and to accept the possibility of multiple perspectives). This is a particular challenge with advanced disease because the literal fact of the illness and of impending mortality may obscure that states of hopelessness or demoralization are mental constructions, even in such circumstances. Being able to mentalize diverse feeling states allows individuals to sustain a “double awareness”¹⁰ of the possibilities for living as well as the eventuality of dying. The CALM therapist promotes this by understanding and validating the experience of the patient and by entertaining the possibility of multiple and complex psychological responses to an incontrovertible dire prognosis. This is to be distinguished from false reassurance or from the correction of cognitive distortions.

The Joint Creation of Meaning: Relational theory emphasizes mutuality in the therapeutic situation, wherein patients and therapists co-create meaning and understanding of the patients' experience.⁶ The meanings which patients attach to their life history, to their accomplishments and failures, and to their disease are explored in CALM. New meanings, jointly created by the patient and therapist, may also emerge in the dialogue regarding the patients' life trajectory, goals, and the suffering associated with the disease and the end of life. Interpretations follow from dialogue and exchange and are offered tentatively and in the spirit of collaboration.

The Content of CALM

The content of CALM is organized into four interrelated domains. These are:

Domain One: Symptom Management and Communication with Health Care Providers

The disease, the symptoms and the cancer treatment process are central concerns of patients and their families. How to manage these concerns and the decision-making process are complex tasks that overwhelm and confuse many patients. Support for this process and for the relationship with the medical team is an important dimension of CALM. Important dimensions of Domain One may include:

Understanding the Disease and Managing Symptoms: CALM therapy provides a venue where patients can discuss information that they have received from their health care providers, their friends, and other sources. In some cases, this may involve clarifying or directing them to appropriate sources of information or to other health care providers, including specialized palliative care. Therapists may also facilitate more direct communication by patients to their health care providers about their symptoms and concerns. The intent is to support

patients so they can communicate and negotiate effectively with their health care providers in order to receive more optimal care for their symptoms.

Supporting Medical Decision Making: For many patients, decisions regarding the initiation, continuation or cessation of medical treatments are distressing and difficult, particularly when first-line treatments have failed. While the more recent empowerment of patients in their medical care has many benefits, some may feel overwhelmed by participation in complex treatment decisions. They may not understand the information that they have received and therefore may have difficulty making an informed and autonomous decision. Treatment decisions may also be complicated by their own desperation or by perceived pressure from their family or from the treatment team. CALM therapists can help patients to explore the range of feelings that emerge in relation to treatment decisions and to weigh their own feelings, distinct from those they perceive in their health care providers, family or friends. The role of CALM therapists as “insiders” in the cancer system but separate from the cancer treatment team makes them uniquely valuable in the decision-making process. However, therapists must take into account their own feelings and vicarious preferences, as they engage in questions about treatment that have high emotional and medical stakes.

Supporting Collaborative Relationships with Health Care Providers: The relationship with the treating team is often profoundly important to the patient and may be a source of support and/or one that may trigger anxieties about dependency, burden, rejection and abandonment. Some patients tend to disavow their own needs or to refrain from seeking assistance, while others may be demanding in ways that antagonize the treatment team or adversely affects their care.¹¹ Even in well-organized treatment settings, the fallibility of health care providers, lapses in continuity of care and inevitable limitations in health care resources

may be frustrating and distressing to patients and their families. The CALM therapist listens empathically to such experiences of disappointment and finds ways to support or repair the alliance with the treatment team, without taking sides in the problem.

Domain Two: Changes in Self and Relations with Close Others

Self-Concept: The presence of an advanced and progressive disease that will end life, the changes in physical appearance and the loss of the capacity to engage in physical, social and occupational activities all may undermine self-worth and personal identity. Indeed, for some, the loss of personhood that occurs in the course of cancer treatment is one of the most devastating consequences of the disease. Being “known” in CALM therapy helps patients to recover and sustain their sense of personhood that has been lost as a result of the ravages of the illness and the inevitable objectification that occurs in cancer treatment settings.

Care-giving and Care-receiving: The experience of advanced disease often leads to dramatic changes in primary relationships, including in the household division of labour, financial responsibilities, parenting roles, and/or emotional and physical intimacy. Many patients with advanced disease are able to flexibly seek and obtain emotional and practical support from loved ones. In others, however, fears of abandonment or of dependency may contribute to anxious clinging or to dismissive avoidance of needs. These relational tendencies may interfere with the ability to seek or obtain support from caregivers or to take their needs into account, resulting in tension and disequilibrium in these relationships. Identifying and acknowledging the relational tendencies of patients and their caregivers can facilitate mutual understanding and adjustments in behaviour that may lead to more satisfying and supportive relationship experiences.

Supporting Children and Other Family: While CALM therapy sessions do not usually include young children or extended family, their intent is to support the patient and caregiver dyad. This may, in turn, help the adaptation and adjustment of the larger family network. A common question that arises in CALM therapy is what and when to tell children and other family members about the illness and how to support them throughout the process. CALM therapy provides a place where patients can discuss and consider this issue, taking into account the developmental capacity and needs of the children in the family, the visible signs of the disease and the expected survival.

Domain Three: Sense of Meaning and Purpose

The Life Narrative: Empathic understanding and co-constructing an individual's personal narrative helps individuals to feel known in continuity, to clarify what has been important to them in their lives and to plan for the time that remains. To what extent they have felt supported, neglected or traumatized in their life and to what extent they tend to be optimistic or pessimistic in the face of uncertainty all contribute to their experience of illness. By weaving together with the patient the life narrative, a sense of coherence and intelligibility about their life can emerge. It may also help patients to perceive a sense of accomplishment and legacy about their lives.

The Personal Meaning of the Disease: The meaning of the disease is determined by the intersection of factors related to the disease, the individual, and the social and family environments. It may variably represent the frailty and transience of human life, an unfair or unjust blow, a burden to others or the will of God. Some blame the illness on stress caused by themselves or others or by the environment. Articulation of these explicit or implicit meanings

provides patients with a way of understanding their experience in illness and to reconsider meanings that are burdensome or punitive toward themselves or others.

Priorities and Goals in the Face of Advanced Disease: The experience of advanced disease and end of life often leads to a reconsideration of priorities and life goals. There may be mourning of the loss of physical functioning or productivity and a new emphasis on other domains of accomplishment, meaning or generativity toward others.⁷ As well, the recognition of finitude raises questions about how to spend remaining time. By encouraging consideration of priorities and goals, therapists can help patient to live more fully in the present, even when facing the end of life. In this process, therapists must take into account and disentangle their own desires for patients and their own fantasies about how they would live near the end of life

Domain Four: The Future and Mortality

Acknowledgement of Anticipatory Fears: Fears about dying and death are a common experience for those with advanced disease^{12,13} although they are often not addressed, even in palliative settings. The emphasis on hope and positive thinking that is common in the cancer community and in the media can be experienced as silencing and dismissing of the fears and concerns triggered by a diagnosis of life threatening disease. Such fears are likely to be heightened by specific symptoms such as dyspnea, pain or dysphagia. The CALM therapist provides opportunities for patients to speak openly about dying and death, to consider advance care planning and to have anxiety about dying and death understood and validated.

Balance of Living and Dying: The goal of the CALM therapist is to create opportunities for patients to explore the range of their feelings, so that they can hold onto what is satisfying and meaningful in their lives while also facing their fears and realities. Such “double

awareness”¹⁰ allows them to make appropriate plans for their care and for that of their family while also remaining engaged in life. When this does not occur, decision-making and personal planning, such as arranging a will or settling personal financial matters may be neglected. On the other hand, the continuous immersion in thoughts of illnesses, dying and death may interfere with the capacity to sustain meaningful engagement in life. CALM therapy helps patients to sustain the balance of living and dying so that patients can plan for the future, mourn their losses and continue to live life in the present.

Advance Care Planning: Research has consistently identified advance care planning, life closure and death preparation activities as important components of a positive dying experience.¹⁴ Unfortunately, health care providers and families may avoid addressing them until too late in the course of illness for adequate attention. Gentle enquiry by CALM therapists about hopes and fears of patients about the future and the end-of-life may give patients license to discuss issues. Such discussions may relieve anticipatory anxieties and may benefit the family and friends who will survive them.

CALM Therapist Selection, Training and Supervision

CALM therapists have come from a variety of health care backgrounds including social work, psychology, psychiatry, nursing and medicine, usually with some experience as therapists and in psychosocial oncology. Training includes an initial didactic training workshop followed by supervision of cases by a trained CALM clinician. CALM therapists do not simultaneously deliver primary oncology or palliative care to patients in CALM therapy in order to allow attention to the experience of patients in a contemplative rather than action-oriented mode. At the

same time, their knowledge of cancer and its treatment facilitates understanding when exploring such issues as symptom management, treatment options and aspects of advance care planning.

A regular time for supervision is an integral part of the CALM therapy model in view of the challenges this therapy presents. It requires courage to explore death anxiety and death preparation, to tolerate existential uncertainties and to be comfortable with the flexibility that is required. Supervision provides an opportunity to support, validate and monitor therapists and to ensure the quality and integrity of the intervention. Supervision also provides an opportunity for therapists to present and clarify their formulation of the dynamics to ensure that goals of CALM are sensitively applied and suitably individualized for each patient.

The therapeutic encounter with patients with advanced and terminal disease may be one of the most intimate and profound of all therapeutic relationships. The universality and the inescapability of the dilemma facing those with advanced disease creates an intimate bond and brings poignancy and power to the therapeutic relationship. Indeed, accepting the shared experience of human mortality and their own vulnerability may be one of the single most important challenges for therapists who allow themselves to become immersed in the emotional world of the terminally ill.

Evidence for CALM Therapy

A phase two intervention-only pilot study of CALM¹⁵ enrolled a total of 50 advanced cancer patients. Despite attrition due to disease advancement and death, the study found significant reductions in depressive symptoms and death anxiety in therapy participants over time. There was also a significant improvement in spiritual wellbeing over time. A companion pilot qualitative study found that participants valued the CALM intervention and indicated that it

made a positive and unique contribution to their cancer experience. Five interrelated themes were identified based on participant accounts of their CALM experience. CALM was found to provide: 1) a safe place to process the experience of advanced cancer; 2) the permission to talk about death and dying; 3) assistance in managing the illness and navigating the health-care system; 4) the resolution of relational strain; and 5) the opportunity to ‘be seen as a whole person’ within the health-care system. This contribution was unique in that it provided an experience that was not encountered anywhere else along the participants’ cancer journey.¹⁶

A large randomized controlled trial comparing CALM to usual care in patients with metastatic solid tumour cancers is now in progress in Canada (ClinicalTrials.gov Identifier: NCT01506492). The primary outcome for this study is the severity of depressive symptoms and secondary outcomes are distress related to death and dying, attachment security, spiritual wellbeing, quality of life, posttraumatic growth and satisfaction with care. Ongoing companion research is studying caregivers and the potential impact of CALM on relationship with caregivers, on reflective awareness within CALM participants and on the practice and professional identity of CALM therapists. A randomized controlled trial is also now being conducted in Germany (ClinicalTrials.gov identifier: NCT02051660) and teams from Italy and the United Kingdom are conducting pilot studies and adapting CALM to their settings.

Conclusion

CALM is a promising, new individual psychotherapy that has shown evidence of alleviating depression and death anxiety and increasing the sense of meaning and purpose in life in patients with advanced cancer. The threat of impending mortality in this circumstance may heighten the motivation to participate in this intervention and the power of the therapeutic

encounter. International training in CALM and dissemination of this intervention are underway and accumulating evidence may support its implementation as a standard of psychosocial care for patients with metastatic cancer and their caregivers.

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Figure 62.1. The Domains of CALM Therapy

