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# Adapting psychosocial interventions for older adults with cancer: A case example of Managing Anxiety from Cancer

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Medical oncology has come to recognize the needs of older adults and made efforts to address those needs. <sup>1–3</sup> For example, extensive research has been conducted on the Comprehensive Geriatric Assessment, a multi-dimensional assessment developed to identify older adults at risk for chemotherapy toxicities. <sup>4–6</sup> While more work is needed, geriatric oncology is an established subspecialty and increasing numbers of older adults with cancer (OACs) now have access to care that is sensitive to their needs.

Psychosocial oncology lags behind medical oncology in the consideration of the specific needs of older adults. This gap is notable given that over 40% of OACs report elevated distress (e.g., anxiety, depression)<sup>7–12</sup> that is associated with worse physical symptoms;<sup>13–17</sup> poor quality of life<sup>18,19</sup> and treatment adherence and response;<sup>20–22</sup> difficulty communicating with the healthcare team;<sup>23</sup> longer hospitalizations;<sup>24,25</sup> increased risk of an emergency department visit, overnight hospitalization, and 30-day readmission;<sup>26–28</sup> and shorter survival.<sup>29,30</sup>

Tailoring psychosocial interventions for OACs should be rigorous and informed by theory, prior research, and multi-level stakeholder perspectives (e.g., OACs, their caregivers, and oncology providers). This paper describes the initial development and evaluation of a telephone-delivered cognitive-behavioral therapy (CBT) intervention for anxiety in OACs and their caregivers. CBT is an empirically-supported treatment that targets thoughts and behaviors that negatively impact mood. 31,32 CBT has been used in older adults and cancer patients separately but has not been empirically tailored for OACs and their caregivers. We offer our experience as a call for theoretically informed intervention tailoring that includes the voices of older adults and their caregivers. All data collection described was approved by

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### **Developing initial intervention materials**

The intervention described in this paper, Managing Anxiety from Cancer (MAC) includes patient and caregiver workbooks and corresponding therapist manuals (Table 1). Development of the MAC materials was informed by the Contextual, Cohort-based, Maturity, Specific challenge model (CCMSC; Table 2)<sup>33,34</sup> and the Stage Model for Psychotherapy Manual Development (Stage Model; Table 3).<sup>35</sup> The CCMSC integrates principles from gerontology and psychotherapy to inform approaches with older adults. Stressors caused by cancer were integrated throughout CCMSC components. For example, people with cancer may have rational worries about the likelihood of death for which strategies from Acceptance and Commitment Therapy<sup>36,37</sup> are more appropriate than the traditional CBT technique of cognitive restructuring.<sup>31</sup>

The Stage Model informed the development of therapist manuals. In the MAC manual, therapist instructions are embedded directly into the patient and caregiver workbooks, allowing therapists to view both simultaneously. An introductory chapter includes information on the rationale for the intervention, unique and essential elements of MAC, and comparison of MAC to other approaches. This chapter also provides information on the specific needs of OACs and their caregivers and strategies for meeting these needs (e.g., slower pace of therapy to account for normal cognitive changes).

## Obtaining stakeholder feedback on intervention materials

Following completion of the intervention materials, OACs (n=15), caregivers of OACs (n=8), and professionals conducting research and/or clinical practice with OACs (n=11) provided feedback on the materials in-person or over the telephone (patients and caregivers) or electronically (providers). Based on this feedback, significant changes were made including adding information on the simultaneous experience of cancer and aging (e.g., symptoms of cancer added to the burden of other age-related illnesses), challenges specific to caring for an OAC (e.g., OAC needs assistance with daily activities and travel to oncology appointments), and caregiver strategies for effective communication with an older adult (e.g., short sentences for older adults with memory impairment).

We also increased the focus on OACs' strengths and the importance of caregiver self-care. We added a section in which the OAC identifies areas of personal expertise and discusses strategies for applying this expertise to anxiety management. A "values and expertise checkin" was added to each session to facilitate the integration of these identified characteristics into MAC. For the caregiver intervention, we added information on the importance of self-care and strategies for improving self-care. A "self-care check-in" and between session self-care exercises were integrated into each session to support continuous caregiver self-care.

Stakeholders also recommended that MAC content be simplified and reduced. Modifications included replacing technical language with simpler terms (e.g., replacing "behavioral strategies" with "new actions"), removing the model of CBTfor anxiety, eliminating

acronyms used to summarize multi-step techniques, and eliminating confusing content on different cognitions (e.g., thoughts about controllable versus uncontrollable stressors). The length of the intervention was reduced from seven to six sessions by removing problemsolving from the OAC intervention and willingness from the caregiver intervention. These sessions were removed because they do not include traditional CBT content (i.e., behavioral strategies and cognitive restructuring). Further, patients with cancer face many uncontrollable stressors (e.g., prognostic uncertainty) appropriate for willingness strategies (Acceptance and Commitment Therapy)<sup>39,40</sup> while caregivers often need to solve problems regarding OAC care (Problem-Solving Therapy).<sup>41,42</sup>

## Pre-post intervention evaluation

Patient-caregiver dyads (n=9) were then enrolled in a pre-post evaluation of the feasibility and acceptability of the modified intervention and study procedures. Eligible patients were 65 years of age or older with a diagnosis of cancer and a primary unpaid caregiver willing to participate. The patient and/or caregiver had a score of 8 on the Anxiety Subscale of the Hospital Anxiety and Depression Scale. Dyads were excluded if one or both members received CBT since the patient's diagnosis, the patient's anxiety was due solely to a medical procedure, or one member met diagnostic criteria for schizophrenia, substance or dependence, and/or bipolar disorder or endorsed active suicidal ideation.

Acceptability was assessed with questions assessing perceived helpfulness of MAC (1="not at all," 5="very"). The a priori benchmark for acceptability was defined as 70% of participants scoring rating the intervention as "moderately" to "very" helpful. The a priori benchmark for feasibility was defined as 70% of participants completing at least four of the six intervention sessions and post-intervention measures. The benchmark for acceptability was met with 100% of patients and caregivers reporting the intervention was moderately to very helpful. The benchmarkfor feasibility was also met with 89% of patients and 75% or caregivers completing all intervention sessions and post-intervention measures. Over three-quarters of the sample reported that intervention content was "not at all difficult" to understand (patients: 87.5%, caregivers: 80.0%), the intervention included the "right amount of information" (patients: 85.7%, caregivers: 100.0%), telephone delivery was acceptable (patients: 87.5%, caregivers: 100.0%), and session frequency (weekly) was acceptable (patients: 100%, caregivers: 100%).

Post-intervention, patients and caregivers were given a description of the session that was included in the workbook of the other dyad member but not in theirs and asked whether the content would have been helpful. Patients and caregivers indicated a preference for including the new material and all participants recommended the intervention be extended to seven sessions (patients: 100%, caregivers: 100%). Based on this feedback, the intervention was expanded to seven sessions with willingness and problem-solving techniques included in both workbooks.

#### Lessons learned and conclusions

Extensive resources are required to conduct even a small randomized controlled trial. Utilizing theoretically-informed and rigorous methods to develop an intervention creates a strong foundation for future efficacy testing. We conclude with a description of the lessons learned from this process as they apply to OACs and their caregivers, the MAC intervention, and study methods.

#### Population specific.

A component of MAC not included in standard CBT interventions is a focus on the dual stressors of cancer and aging. The degree to which OACs and their caregivers would resonate with this novel content was unclear. In fact, OACs and caregivers requested additional support for these dual stressors. Caregivers reported that the intervention did not adequately recognize the burden of caring for an OAC and requested additional strategies for managing this burden and improving self-care.

Stakeholders' resonance with the dual stressors of cancer and aging highlighted the importance of training interventionists in working with older adults. An intervention like MAC cannot provide comprehensive training in geriatric mental health. However, the interventionist manual and training procedures provide general information on characteristics and needs of older adults and their caregivers and strategies for addressing these needs. Given the shortage of mental health providers trained in geriatrics, this strategy may be a cost-effective and efficient method for increasing geriatric-specific mental health care.

Telephone-delivery was deliberately chosen to maximize OAC and caregiver access to MAC. OACs are often dealing with symptom burden from cancer and its treatment in addition to pre-existing co-morbidities associated with aging. OAC caregivers are often either older adults themselves or adult children caring for aging parents and dependent children. Further, cancer treatment requires numerous appointments; additional appointments for mental health services can be an obstacle to care. CBT delivered by telephone is efficacious for patients with cancer<sup>43–46</sup> and their caregivers<sup>47</sup> and improves psychotherapy access by reducing the time and travel burden associated with in-person appointments.

#### Intervention specific.

A strength of MAC is the concurrent treatment of the OAC and caregiver by separate therapists. A preference for this structure emerged during stakeholder interviews and is one example of the benefit of including OACs and their caregivers in the intervention development process. However, this method creates challenges for data analysis, privacy, and feasibility. Specifically, a dyad was eligible for this study if the OAC or caregiver reported elevated anxiety. This method increased dyads' access to the study and the pool of eligible dyads but reduced the average baseline anxiety for each group and the amount of possible change pre-to-post intervention.

The purpose of providing separate therapists for the OAC and caregiver was to allow each dyad member to express concerns independent of their partner. However, this structure created questions about confidentiality across dyad members. To protect OACs' and caregivers' ability to express freely during sessions, we maintained confidentiality within each participant-therapist relationship. However, this strategy limited each therapist's understanding of the dyadic relationship and precluded direct intervention on relationship dynamics.

Finally, an intervention requiring two therapists requires more resources than interventions delivered by a single therapist. This characteristic may reduce feasibility and interfere with dissemination and implementation. In a larger efficacy trial, we will examine whether a dyadic approach improves outcomes or whether the OAC and caregiver versions of MAC can potentially be viewed as independent interventions.

Additional lessons learned included the importance of a comprehensive therapist manual that provides detailed session-specific instructions. This manual facilitated therapist training, increased therapist confidence, and allowed for clear criteria for intervention fidelity. Further, the manual provided a resource with which to train therapists in basic strategies for working with older adults. As with a patient workbook, developing the manual based on an established framework (e.g., Stage Model) enhanced the rigor and comprehensiveness of the manual.

#### Study methods.

Pressure to complete a research project within a specified timeline can dissuade researchers from making iterative changes to an intervention. Modifying the intervention at multiple time points allowed us to capitalize on many stakeholder perspectives and resulted in a more focused and externally valid intervention. We modified MAC materials based on feedback from the study team, after receiving stakeholder feedback, and after the prepost examination of feasibility and acceptability. Maximizing opportunities to improve the intervention during early phases of development is important; changes are more difficult to make after initiating a large efficacy trial.

One limitation of our study methods was that stakeholders providing feedback on intervention content only reviewed three MAC sessions. This method limited their view of the flow and overall message of MAC but allowed us to obtain detailed feedback on each session while managing study burden. We considered providing participants with a summary of the entire intervention rather than the actual intervention materials. In hindsight, this would have been problematic. OACs and their caregivers are generally unfamiliar with psychotherapy. Providing the actual MAC materials eliminated the need for prior knowledge and provided a direct view of intervention content, format, and structure.

#### Conclusion.

We present an intervention development process designed to promote evidence-based and theory-driven intervention development. Medical oncology tailored assessments for OACs with the Comprehensive Geriatric Assessment. Psychosocial oncology should consider the

particular needs of OACs and their caregivers in the development of psychosocial interventions informed by fields such as gerontology and geriatric clinical psychology.

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## Table 1.

## MAC content by session

Session Content		
Session 1: Introduction	Overview of MAC structure and content Psychoeducation on anxiety Anxiety symptoms and triggers Cancer in older adulthood (patients only) Caring for an OAC (caregivers only) Personal strengths and values (patients only) Self-care information and planning (caregivers only)	
Session 2: New Actions	Deep breathing     Guided imagery     Muscle relaxation     Mindfulness     Activity planning (patients only)	
Session 3: New Thoughts	Identify irrational thoughts     Develop new ways of thinking     Apply new thoughts to daily life	
Session 4: Communicating Well	Assertive communication techniques (I-Statements)     Communicating with your loved one     Communicating with family and friends     Asking for what you need     Communicating with the medical team     Communicating about treatment decisions	
Session 5: Problem-Solving	Select a problem     Choose a solution to try     Create a plan     Follow the plan     Decide if the plan worked	
Session 6: Willingness (Acceptance)	Problem with trying to control emotions     Define willingness     Three steps to willingness (notice, imagine, allow)	
Session 7: Planning for the Future	Review effective MAC skills     Make a plan for managing future anxiety	

 Table 2.

 Application of the CCMSC model to intervention materials

Domain	Components	Intervention Characteristics
Contextual	Interdisciplinary medical context     Caregivers may play a large role in patient care     Patient and caregiver distress interdependent     Shrinking social networks	Teaches strategies for effective communication     Teaches strategies for communicating with the medical team     Treatment of caregiver distress     Includes strategies for increasing social interactions
Cohort-based	Lower levels of education     Less familiar with psychotherapy     Greater stigma toward psychotherapy     Paternalistic view of medical providers	Manual uses simple language and case examples     Provides basic information on psychotherapy     Normalizes anxiety in the context of cancer     Uses a collaborative model between patient and therapist
Maturity	Cognitive slowing     Slower processing speed     Memory impairment     Expertise and values developed over a lifetime	Information is presented in small pieces Therapy proceeds at a slower pace Material presented visually and orally Teaching aids used (e.g., binders, worksheets) Between session exercises to promote repetition Review prior session content to "bridge" sessions Integrates personal values and expertise Utilizes individual strengths to manage anxiety
Specific challenge	Reduced mobility     Sensory impairment     Lower energy levels     Cancer diagnosis	Telephone-delivered sessions     Manual is easy to read     Sessions focus on the most important elements     Content addresses unique stressors caused by cancer (e.g., prognostic uncertainty, rational thoughts about death)

 Table 3.

 Application of the Stage Model for Psychotherapy Manual Development to the MAC interventionist manual

Section	MAC Interventionist Manual	
Overview, description, rationale	Overview of the goal, theoretical rationale, and structure of MAC     Treatment rationale: Large number of older adults with cancer; High prevalence and under-treatment of anxiety	
Conception of the problem	Description of behaviors and cognitions that drive anxiety     Overview of cognitive behavior therapy     Description of additional techniques: Communication strategies, Problem solving, Acceptance     Application of the CCMSC to MAC     Description of patient/caregiver as primary agent of change	
Treatment goals	Primary goal: Improve patient/caregiver ability to manage anxiety     Secondary goals: Improve patient/caregiver communication and problem-solving skills, ability to accept uncontrollable situations, and relationship quality	
Contrast to other approaches	Similarities/differences from traditional CBT     Description of modifications for older adults and their caregivers     Difference from supportive psychotherapy and psychoanalytic treatment	
Specification of defining interventions	Unique/essential: Coping with cancer and aging, cancer and aging caregiving issues, interventionist education in working with older adults     Essential/not unique: Strong rapport, plan for between session exercises     Acceptable/not necessary: Informal conversation ("chatting"), appropriate clinician self-disclosure     Elements to avoid: Extensive reminiscing, exploration of unconscious processes or defense mechanisms	
Session content	Therapist instructions specific to session content	
General format	Delivered individually over the telephone     Seven weekly sessions, 45–50 minutes each     Limited flexibility across session     Consistent session format: Session plan, review of prior session, new information, take home messages, practice plan, worksheets	