

## Original Article

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**Corresponding author:** Sylvie D. Lambert;  
Email: [sylvie.lambert@mcgill.ca](mailto:sylvie.lambert@mcgill.ca)

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# Evaluating the acceptability of a self-directed, self-management intervention for patients and caregivers facing advanced cancer

Sydney Wasserman, R.N., M.Sc(A)<sup>1</sup> , Lydia Ould Brahim, R.N., M.Sc(A)<sup>1</sup> ,  
Andrea Maria Laizner, R.N., Ph.D.<sup>1,2,3</sup> , Anita Mehta, R.N., Ph.D.<sup>1,4,5</sup> ,  
José Côté, R.N., Ph.D.<sup>6,7</sup> , Melissa Henry, Ph.D.<sup>8</sup> ,  
Kimberly Thibodeau, M.S.W., P.S.W.<sup>2,9</sup>, Vasiliki Bessy Bitzas, R.N., Ph.D.<sup>1,10</sup>  and  
Sylvie D. Lambert, R.N., Ph.D.<sup>1,3,11</sup> 

<sup>1</sup>Ingram School of Nursing, McGill University, Montreal, QC, Canada; <sup>2</sup>McGill University Health Centre, Montreal, QC, Canada; <sup>3</sup>Research Institute, McGill University Health Centre (RI-MUHC), Montreal, QC, Canada; <sup>4</sup>Department of Psychiatry, CIUSSS West Central Montreal, Jewish General Hospital, Montreal, QC, Canada; <sup>5</sup>Montreal Institute of Palliative Care, Teresa Dellar Palliative Care Residence, Montreal, QC, Canada; <sup>6</sup>Faculty of Nursing, Université de Montréal, Montreal, QC, Canada; <sup>7</sup>Research Centre of the Centre Hospitalier de l'Université de Montréal (CR-CHUM), Montreal, QC, Canada; <sup>8</sup>Gerald Bronfman Department of Oncology, Faculty of Medicine, McGill University, Montreal, QC, Canada; <sup>9</sup>School of Social Work, McGill University, Montreal, QC, Canada; <sup>10</sup>Palliative Care, Jewish General Hospital, Montreal, QC, Canada and <sup>11</sup>St. Mary's Research Centre, Montreal, QC, Canada

**Abstract**

**Objectives.** Coping-Together is a self-directed, self-management intervention initially developed for patients in early-stages of cancer and their caregivers. This study evaluated its acceptability among patients with advanced cancer and their caregivers.

**Methods.** Twenty-six participants (patients with advanced cancer  $n = 15$  and their caregivers  $n = 11$ ) were given the Coping-Together materials (6 booklets and a workbook) for 7 weeks. Participants were interviewed twice during this time to solicit feedback on the intervention's content, design, and recommended changes. Audio-recorded interviews were transcribed verbatim, and thematic analysis was conducted.

**Results.** Participants found Coping-Together was mostly relevant. All ( $n = 26$ , 100%) participants expressed interest and a desire to improve their self-management skills. Perceived benefits included learning to develop SMARTTER (specific, measurable, attainable, relevant, timely, and done together) self-management plans, normalizing challenges, and enhancing communication within the dyad and with their healthcare team. Most ( $n = 25$ , 96%) identified strategies from the booklets that benefited them. Top strategies learned were skills to manage physical health ( $n = 20$ , 77%) (e.g., monitoring symptoms), emotional well-being ( $n = 21$ , 81%) (e.g., reducing stress by reframing thoughts), as well as social well-being ( $n = 24$ , 92%) (e.g., communicating with their healthcare team). Barriers included illness severity and time constraints. The unique advanced cancer needs that are to be integrated include support related to fear of death, uncertainty, palliative care and advanced care planning. Suggested modifications involved enhancing accessibility and including more advanced cancer information (e.g., end-of-life planning, comfort care, resources).

**Significance of results.** Participants reported several benefits from using Coping-Together, with minimal adaptations needed. Creating SMARTTER self-management plans helped them implement self-management strategies. Specific areas for improvement addressed the need for improved accessibility and more content related to advanced cancer. Findings demonstrate how Coping-Together is acceptable for those living with advanced cancer and their caregivers, offering much of the support needed to enhance day-to-day quality of life.

**Introduction**

Approximately 19.3 million people receive a cancer diagnosis annually worldwide (Sung et al. 2021), with cancer remaining the second leading cause of death globally (Mattiuzzi and Lippi 2019). In the past decade, there has been a shift away from in-hospital cancer treatment, toward at-home care delivered by unpaid family caregivers (Kent et al. 2019). Caregivers are defined as unpaid individuals (often family members) who are most involved with supporting patients as they manage the physical and psychosocial challenges of cancer. Caregivers often take on this role without formal training, and while being unacknowledged and undervalued (Warth et al. 2020). Taking on a caregiving role has been

shown to increase levels of distress (Bining *et al.* 2022). Caregiving is particularly challenging for those caring for individuals with advanced cancer (van der Velden *et al.* 2023; van Roij *et al.* 2021).

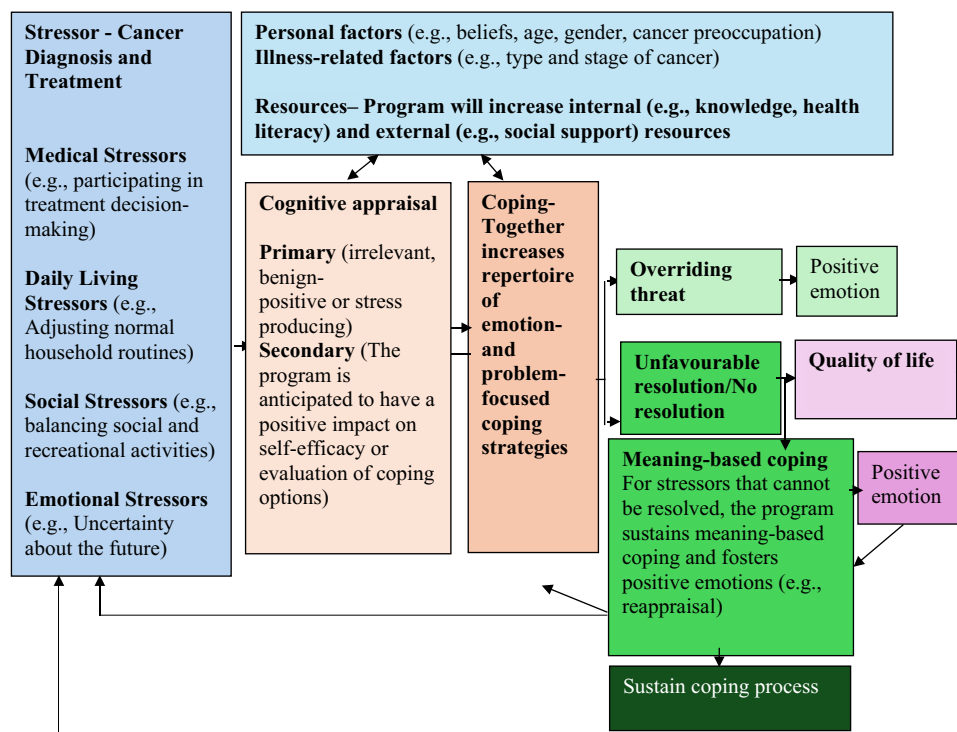
Caregivers of those living with advanced cancer face unique challenges. These include considerations for end-of-life, palliative care planning, and care for more debilitating symptoms (van Roij *et al.* 2019). Due to these challenges, they report higher levels of anxiety, depression, and unmet needs than caregivers of those with early stages of cancer (Girgis *et al.* 2013; Lambert *et al.* 2012b). Top unmet needs are managing feelings of anxiety, fear, and hopelessness; coping strategies to enhance quality of life (QoL); and learning to navigate the health care system (Wang *et al.* 2018). Given these unmet needs, patients and caregivers often seek information related to managing physical and psychological symptoms and improving their QoL (Warth *et al.* 2019). Support for coping with these types of challenges can be provided by self-management interventions (Girgis *et al.* 2013).

Self-management interventions offer users the skills and confidence to manage the physical, emotional, and social aspects of their own health (Bartlett *et al.* 2020). They are efficacious in addressing a number of unmet needs reported by patients with advanced cancer and their caregivers (Porter *et al.* 2021) as well as to relieve their anxiety and improve QoL (Warth *et al.* 2019). This especially rings true when the intervention is offered to both patients and caregivers, dyadically, due to the shared learning that occurs and synergistic benefits (Lambert *et al.* 2016b; Shaffer *et al.* 2020). However, most caregiver interventions are led by nurses or a combination of clinicians and are time- and personnel-intensive, rendering them too costly for integration in routine cancer care (Lambert *et al.* 2013b). Also, caregivers who might benefit from such interventions often do not access them, due to geographical or mobility barriers or they do not want to leave the patient (Lambert *et al.* 2016a). The urgency to find more sustainable and

accessible modes to deliver caregiver interventions has contributed to an increased interest in the self-directed format (Lambert *et al.* 2016a).

Self-directed interventions offer more flexibility to patients and caregivers since they can be used at their own pace and with privacy (Wong and Kan 2022). Self-directed interventions address barriers related to high costs and mobility constraints from having to seek guidance from healthcare professionals (Girgis *et al.* 2013). Reported benefits of self-directed, self-management interventions include improved QoL and psychological health outcomes (Warth *et al.* 2020). Despite these benefits, adherence can be low often due to a lack of time and energy (Kubo *et al.* 2019). Those coping with advanced cancer face additional barriers to accessing interventions due to the scarcity of research, support, and attention allocated toward this population (Lambert *et al.* 2016a). Few self-directed, self-management interventions have been developed for use by those coping with advanced cancer (Wang *et al.* 2018; Warth *et al.* 2020). This emphasizes the urgent need for more sustainable and accessible resources for advanced cancer patients and their caregivers (Lambert *et al.* 2016a).

Coping-Together is a self-directed, self-management intervention for patients with early-stage cancer and their caregivers. Mainly, Coping-Together expands patients' and caregivers' repertoire of coping strategies (and confidence to use these), by providing strategies to optimize the management of cancer challenges (Lambert *et al.* 2013b) (see Figure 1). This resource includes 6 booklets and 1 workbook. The booklets focus on coping strategies for: (1). Communication with your Healthcare Team, (2). Dealing with Stress and Worry, (3). Making your Treatment Decisions, (4). Getting on Top of Symptoms, (5). Getting the Support you Need, and (6). Supporting Each Other. The workbook focuses on developing a SMARTTER (specific, measurable, attainable, relevant, timely, and done together) self-management



**Figure 1.** Expected impact of Coping-Together on patients' and caregivers' quality of life.

**Table 1.** Coping-Together intervention



	Description	Example challenges	Example strategies
Getting on top of symptoms	Coping with common treatment side effects	<ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Pain</li> <li>• Nausea</li> </ul>	<ul style="list-style-type: none"> <li>• Use a symptom diary, talk to your health care team, and use self-care strategies</li> </ul>
Dealing with stress and worry	Addressing the emotional reactions to diagnosis and treatment	<ul style="list-style-type: none"> <li>• I feel tense, angry, and/or stressed</li> <li>• I feel worried or uncertain</li> </ul>	<ul style="list-style-type: none"> <li>• Use relaxation techniques</li> <li>• Use problem-solving techniques</li> </ul>
Getting what you need from your health care team	Working with your medical team, knowing how to ask the right questions, getting and understanding the information you need	<ul style="list-style-type: none"> <li>• We don't know what questions to ask</li> <li>• We leave our appointments feeling like we didn't get what we wanted</li> </ul>	<ul style="list-style-type: none"> <li>• Use question checklists</li> <li>• Prepare for and play an active role in your medical care</li> </ul>
Making your treatment decision	Considering your options, treatment planning, and adjusting to treatment-related delays	<ul style="list-style-type: none"> <li>• We feel overwhelmed by options</li> <li>• We want more of a say in the decision</li> </ul>	<ul style="list-style-type: none"> <li>• Understand your options and use decision aids</li> <li>• Use assertive communication and consider a second opinion</li> </ul>
Supporting each other	Enhancing your communication and connection to your partner while adjusting to changes that might arise in your relationship	<ul style="list-style-type: none"> <li>• I just don't know how to make my partner feel better</li> <li>• I am finding it harder to deal with conflict</li> </ul>	<ul style="list-style-type: none"> <li>• Use listening skills, body language and empathy, avoid roadblocks to listening well</li> <li>• Resolve disagreements in a way that you can be proud of later</li> </ul>
Getting the support you need	Finding appropriate support to address practical, emotional, financial, legal, and informational needs	<ul style="list-style-type: none"> <li>• We need to know what support we have around us</li> <li>• We need financial help</li> </ul>	<ul style="list-style-type: none"> <li>• Your plan to build a support network in your community</li> <li>• Understand what is available, where to find it, and how</li> </ul>
Workbook	<ul style="list-style-type: none"> <li>• Describes what the Coping-Together program is and how to use the booklets. Outlines the process for how to choose a booklet to read and make a SMARTTER coping plan.</li> </ul>		

plan (see Table 1). Previous studies found that patients and caregivers facing early-stage cancer learned needed coping strategies from Coping-Together (Lambert et al. 2013a, 2016b). However, there is currently a lack of such interventions for use by those coping with advanced cancer (Warth et al. 2020).

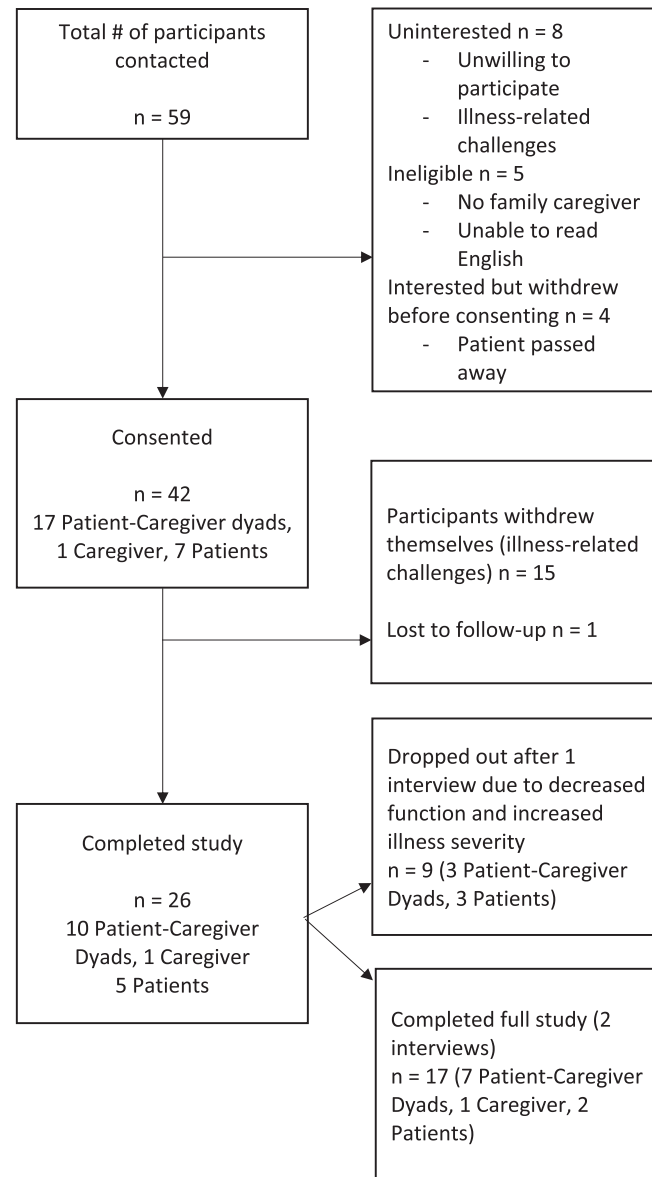
This study aimed to evaluate the acceptability of Coping-Together for patients with advanced cancer and their caregivers, for the future adaptation of a comparable intervention for this population. *Acceptability* was defined as the users' perception of the intervention's suitability as it pertains to the uptake or initiation, application or use, and perceived benefits (Feeley et al. 2009; Sidani and Braden 2011). As this is a qualitative study, acceptability benchmarks were not set. However, to enhance rigor we have

added the specification that acceptability would be determined by overall positive feedback for most participants and that they felt the content was relevant to them and they could learn a new self-management skill.

**Methods**

**Design**

Coping-Together was evaluated using a qualitative descriptive design (Sandelowski 2000). Reporting was informed by the consolidated criteria for reporting qualitative research checklist (EQUATOR Network n.d.).



**Figure 2.** CONSORT diagram (EQUATOR Network., n.d.).

### Sample

A purposive sample of 26 participants including 15 patients and 11 of their caregivers took part in this study (Figure 2). Patient inclusion criteria were: (a) being diagnosed with advanced cancer (stages III or IV, regardless of time since diagnosis and cancer type (Kleine et al. 2019)), (b) identifying a caregiver (e.g., family member or significant other most involved in providing support), (c) self-reporting feeling well enough to participate in a study that will last 7 weeks, and (d) being relatively independent in daily activities as per the Karnofsky Performance Status Scale (Yates et al. 1980).

### Setting and recruitment procedures

Recruitment primarily occurred across 2 cancer centers in Montreal, whereby clinicians introduced the study to patients and their caregivers and obtained their verbal permission for their contact information to be forwarded to the research assistant (RA).

Patients participating in other studies who had agreed to be recontacted for relevant future studies were recruited by having an RA send them an email invitation. Recruitment was also done through online forums with collaborating community organizations who forwarded the study invite through their social media and listservs. Potentially interested individuals contacted the team directly by email. In all cases, an RA followed up to screen for eligibility by phone or email, based on potential participant preference.

When eligibility of a dyad was confirmed, they were given the option of receiving their consent forms by mail with a stamped, addressed return envelope, or by accessing a password protected consent form and baseline sociodemographic questionnaire online using Qualtrics, a secure web-based electronic data capture system. Ethics approval was obtained across centers.

The Coping-Together intervention was then mailed to participants who returned their consent forms to be used for 7 weeks. Each participant received the 6 booklets and workbook, as previously described.

**Table 2.** Maintaining methodological rigor

Criteria & definition	Strategies that will be used
<b>Credibility:</b> Confidence in how well the findings are “believable”	<ul style="list-style-type: none"> <li>• Interviews will be audio-recorded and transcribed verbatim</li> <li>• Prolonged data collection</li> <li>• Discussion of findings among team members</li> <li>• Letting participants guide the inquiry process</li> <li>• Use of participants’ own words in reporting of findings</li> <li>• Discussing the emerging themes with participants</li> </ul>
<b>Transferability:</b> Degree to which the findings can be generalized to other contexts or settings	<ul style="list-style-type: none"> <li>• Delineating the scope of the study</li> <li>• Presenting direct quotations</li> <li>• Simultaneous literature review and highlighting similarities between the findings and the caregiver intervention literature</li> <li>• Specific coding procedures</li> </ul>
<b>Confirmability:</b> Degree to which the findings could be corroborated by others	<ul style="list-style-type: none"> <li>• Maintain an audit trail that includes the raw data (interview and focus group transcripts), use a coding book, and have many drafts of the findings</li> </ul>

### Data collection

Strategies to enhance qualitative rigor are summarized in Table 2. Sociodemographic questionnaires were either completed online at baseline or over the phone after the first interview. As they used Coping-Together, patients and caregivers were invited to an initial 45–60-minute-long in-depth semi-structured interviews halfway through their study participation (i.e., 3 weeks) and then again at the end of the 7 weeks. Interviews focused on identifying facilitators and barriers to use, perceived usefulness, the intervention’s content/design, and highlighting any recommended changes. At the 7-week interview, there were questions about how their experienced with Coping-Together might have changed over time. All interviews were audio-recorded and conducted by a trained RA then transcribed verbatim by an independent professional transcribing company. Preferably, patients and caregivers were invited to participate in interviews as a dyad, though they were offered the choice to be interviewed separately.

### Data analysis

Interview transcripts were uploaded to NVIVO, a qualitative analysis software. The transcripts were analyzed using thematic analysis (Braun and Clarke 2022). Codes, which identified excerpts relevant to the objectives, were derived from the transcripts. As much as possible codes were labelled using words in the transcripts. Similar codes were combined into subcategories and then into larger categories. Categories were (1) approach to using Coping-Together and perceived ease of use; (2) reported usefulness and perceived benefits of Coping-Together; and (3) suggested improvements. Codes from all categories were then compared across interviews to identify similarities and differences, which led to the identification of themes.

## Results

### Sample

Ten patients and their caregivers participated as a dyad, and 5 patients and 1 caregiver participated as singletons, for a total of 26 individuals. Two dyads interviewed separately, whereas the other 8 interviewed together. All participants were either individuals living with advanced cancer ( $n = 15$ ) or the caregiver of someone who identified as such ( $n = 11$ ), with most participants identifying as women ( $n = 15$ ). Participants’ ages ranged between 50 and 88 years old, with most participants having achieved higher

education above postsecondary diplomas. Nine participants were interviewed before the COVID-19 pandemic and 17 from January 2021 to November 2023. Eighteen interviews were conducted at week 3 and 11 interviews at week 7, yielding a total of 29 transcripts. Those who did not complete the second interview at week 7 ( $n = 9$ ) stopped participating mainly due to decreased function and increased illness severity. Full sociodemographic information can be seen in Table 3.

### Reported usefulness and perceived benefits of Coping-Together

The main finding overall is that even if Coping-Together was not adapted for use among those facing advanced cancer, it had high-relevance for all participants ( $n = 26$ , 100%). An overview of findings is summarized in Table 4. The most used booklet was “Supporting Each Other,” which details strategies for communicating within the dyad and understanding each other’s perspectives. The other most used booklets were “Dealing with Stress and Worry” and “Getting the Support You Need.” While the top booklets used by patients were “Getting on Top of Symptoms” and “Getting the Support You Need,” caregivers used “Supporting Each Other” and “Dealing with Stress and Worry” the most.

The most common benefit of using the booklets, as they are, was learning coping and self-management strategies, as reported by most participants ( $n = 25$ , 96%). The top self-management strategies learned were related to skills to manage physical health ( $n = 20$ , 77%), emotional well-being ( $n = 21$ , 81%), as well as social well-being ( $n = 24$ , 92%). Examples of managing physical health included monitoring symptoms using the symptom diary. For example, in terms of managing physical symptoms, 1 patient used the skills to promote sleep hygiene (e.g., eating before bed and turning off electronics). The strategies for managing emotional well-being included reducing stress by reframing thoughts for a more positive outlook on life and illness, a more thoughtful approach to challenges, coping with difficult emotions such as fear and uncertainty and managing lifestyle changes. The skills for managing social well-being included methods for finding social support within the community, communicating with the healthcare team, and strategies to find financial support. Others emphasized what they had learned in terms of communicating with their healthcare team. One caregiver acknowledged that “There’s a lot of things, like, that are suggested in the booklets I could use with my [own doctor].” In terms of the dyadic benefits, the overall benefits included

**Table 3.** Participant sociodemographic information

Sociodemographic data	N (%)
<b>Age (n = 26)</b>	
Between 50 and 59	5 (19%)
Between 60 and 69	7 (27%)
Between 70 and 79	10 (39%)
Between 80 and 89	4 (15%)
<b>Sex (n = 26)</b>	
Men	11 (42%)
Women	15 (58%)
<b>Patients vs. caregivers (n = 26)</b>	
Patients	15 (58%)
Caregivers	11 (42%)
<b>Dyadic relationship (n = 16)</b>	
Marital status:	
Married	11 (69%)
Common law	3 (19%)
Single	1 (6%)
Divorced	1 (6%)
Partnership patient-caregiver:	
Mother/Son	2 (13%)
Wife/Husband/Partner	14 (87%)
Living situation:	
Living together	14 (87%)
Living apart	2 (13%)
<b>Socioeconomic status (n = 16)</b>	
Level of education:	
Postsecondary diploma	4 (25%)
Undergraduate university degree	3 (19%)
Graduate diploma	4 (25%)
Master's degree	3 (19%)
Postdoc degree	2 (12%)
Employment status:	
Full time:	6 (38%)
Retired:	7 (44%)
Unemployed	2 (12%)
Prefer not to answer	1 (6%)
Income range:	
20–40k	1 (6%)
60–80k	1 (6%)
80–100k	3 (19%)
100k	4 (25%)
Prefer not to answer	7 (44%)

(Continued)

**Table 3.** (Continued.)

Sociodemographic data	N (%)
<b>Cancer types (n = 15)</b>	
Cancer types:	
Breast cancer	3 (20%)
Prostate cancer	3 (20%)
Leukemia	1 (7%)
Melanoma	1 (7%)
Colorectal cancer	3 (20%)
Lung cancer	2 (13%)
Femoral vein cancer	1 (7%)
Bone cancer	1 (7%)
Cancer stages:	
Metastasized, Stage 4	15 (100%)
<b>Other illness details (n = 9)</b>	
Date of cancer diagnosis:	
2014	1 (11%)
2015	1 (11%)
2016	1 (11%)
2020	3 (34%)
2021	2 (22%)
2022	1 (11%)
Comorbid illnesses:	
At least one comorbid illness present	7 (78%)
None present	2 (22%)

feeling connected through improved communication and normalizing cancer-related challenges. The booklets offered new skills to address participants' existing challenges, while also acting as a reminder to the many who were already using similar strategies to manage their challenges.

All participants recognized that using a self-directed intervention offered them more autonomy over their health and contributed to their self-management of their illness in their own way, meaning at their own pace and readiness to learn. Participants reported that the self-directed format made them feel capable of implementing these coping skills in the long-term rather than only for the duration of this study.

### **Dyadic approach to using Coping-Together**

More than half of participants read the booklets separately ( $n = 16$ , 62%), sometimes covering the same sections and other times covering different sections, then came together as a dyad to discuss the salient content they believed to reflect their shared needs. The dyads who used the booklets together ( $n = 10$ , 38%) felt it helped them understand the content. One patient mentioned: “[We] go through it together, so at least if one or the other doesn't understand something at least we can help each other with it” – Patient

**Table 4.** Summary of findings

Categories	Findings
1. Approach to using <i>Coping-Together</i>	<ul style="list-style-type: none"> <li>• Started with the most salient booklets.</li> <li>• Dyadic use enhanced understanding and motivation.</li> <li>• Booklets used (most to least used): “Supporting Each other,” “Dealing with Stress and Worry,” “Getting the Support You Need,” “Getting on Top of Symptoms,” “Communicating with your Healthcare Team,” and “Making Your Treatment Decision.”</li> <li>• Barriers to use: Overwhelming material, emotionally distressing, occupied with cancer, perception of disagreement by healthcare team, English as a second language, already coping well, time restraints, and symptom severity, late timing of introduction.</li> <li>• Facilitators to use: Desire to improve coping skills and having an interest in the material.</li> <li>• Content and design: User friendly, flowcharts, graphics, font size, color, tables/charts, subtitles, bolding/italicizing of key words and professional look, quotes from professionals.</li> <li>• Implementing strategies: SMARTTER goal setting, variety of options, easiest strategies to implement being skills for improving sleep (e.g., symptom diary) and communication with healthcare team (e.g., preparing questions).</li> </ul>
2. Reported usefulness and perceived benefits of <i>Coping-Together</i>	<ul style="list-style-type: none"> <li>• Overall perceived benefits: Increased use of strategies, more meaningful impact on life, and increased knowledge of evidence-based skills.</li> <li>• Most useful strategies: Finding social support in the community, communicating effectively with the healthcare team, dealing with difficult emotions.</li> </ul>

(PID: A0304). Most used the booklets as a reference guide, rereading some of the parts deemed most pertinent by participants for retention of key strategies. It was noted that a few participants found the material to be more directed at patients, but still applicable to caregivers: “I mean this is more towards a person who has a condition, but at the same time, [managing psychosocial distress] does apply to caregivers” – Caregiver (PID: B0304). According to caregivers, the main strategy to address this was learning to take control over their own well-being from adopting better communication skills and stress management skills.

### Barriers to use

The barriers to using the booklets were most commonly psychological across patients and caregivers. Several participants avoided the booklets because the quantity of material was overwhelming ( $n = 5$ , 19%). The emotional distress of reading the booklets and being reminded of acute challenges experienced in early stages also deterred a few participants ( $n = 3$ , 12%) from using the material, with 2 caregivers expressing that they were tempted not to use them at all because of this, though all participants ended up using them.

Participants also spoke of practical barriers. Some participants ( $n = 12$ , 46%) felt as though they were already prepared at this stage in their advanced cancer journey, having already established successful coping mechanisms: “A lot of it I’ve kind of already done – been there done that” – Caregiver (PID: B2012). Half of participants ( $n = 13$ , 50%) spoke to the timing of introduction of this intervention being more appropriate for early stages. However, most participants acknowledged that despite already knowing about some of the suggested coping skills, they appreciated the way the booklets were a reminder to practice them. In terms of physical barriers, all the patients recognized that cancer-related symptoms, such as fatigue, memory difficulties, and vision problems, made it difficult for them to use the booklets. More than half of caregivers ( $n = 7$ , 64%) mentioned that their caregiving tasks required time commitments that interfered with their ability to use the intervention. A few indicated that when the patient was medically unstable, it would be more difficult to find the time to read. Although less frequent, a few participants mentioned social barriers such as having stress from supporting their sick friends also living with cancer (outside of the dyad).

### Facilitators to use

The most common facilitator was patients’ and caregivers’ desire to improve their coping skills to address specific challenges. Other facilitators included having a general interest in the material, being medically stable enough to find the time to read and wanting to support one another, as expressed by most participants ( $n = 17$ , 65%). These facilitators were more impactful than the barriers, resulting in all participants having used the booklets to some extent by the time of the first interview.

Despite their length, booklets were also deemed to be “user friendly” due to their consistency in formatting and structure: “The books followed a certain pattern, so you get into it almost as a flow. That worked for me” – Caregiver (PID: B1406). The flowcharts provided in each booklet were helpful for guiding users to the most salient topics to address their needs. The excerpts and quotes from real people motivated participants to continue to use the booklets, by offering an “authentic, human touch,” normalizing emotions, and making them feel less alone.

The exercises provided in the booklets offered participants a chance to put their skills into practice. A few participants specifically identified that the SMARTTER goal setting strategy made it easier to apply the self-management strategies.

### Improvement suggestions for Coping-Together

Table 5 provides a list of the modifications requested by participating patients and caregivers.

### Missing information

Participants reported a lack of information about palliative care (e.g., planning for end-of-life, options for comfort care, and stopping treatment) and about resources available for advanced cancer. For example, some participants requested resources related to support for return to work, financial aid in late-stages, and government recognition and support. Furthermore, most participants addressed the need for more coping strategies for challenges related to their advanced cancer stage, such as fear of uncertainty, fear of death, and change of lifestyle and capacity. While many found ways to implement strategies from the booklets, this was made more difficult due to challenges related to advanced cancer. For example, participants all defined their physical and emotional symptoms

**Table 5.** Suggested adaptations for Coping-Together advanced

Suggestion	Description
Practical accessibility	Increase size of font, translated to different languages, shortened booklets with workbook integrated within, digital option.
Familiar language	Use local terms and resources from Quebec (e.g., Liaison nurse).
Added guidance or prompts to help navigate use of booklets	Navigate with the help of a lay coach or involve healthcare team to help use the booklets or having automatic prompts to use the booklet with reminders to come back to sections that have been flagged as important by users.
Adding sections relevant for advanced cancer	Advanced cancer challenges (palliative care, stopping treatment, return to work, long-term financial support, government recognition in advanced stages), connecting with others in similar situations, adaptations for skills with COVID-19 precautions, adapted content to other countries, moving on with life posttreatment while living with advanced cancer.
Added personalization	For participants to feel that the booklets are made for them in particular and that they could follow their own progress, having more interactive features with the intervention.

and challenges as being more debilitating than they were in early stages, with previous coping mechanisms no longer offering the same support.

Overall, most participants expressed facing challenges related to accessing sufficient social support. These challenges related to feeling like a burden by others, social isolation, limitations due to COVID-19, as well as the capacity, inaccessibility (e.g., distance, language), or cost of resources for social support. Other barriers to receiving support included that friends and family would not understand their current situation, or participants not wanting to burden others who are busy or living too far away to help. More information and strategies on social support was identified as a gap by all participants. The response from dyads was consistent with the premise that patients and caregivers rely on each other for physical and emotional support.

Many participants addressed the need for more information about connecting with others in similar situations. Participants wanted information to be adapted to the context of the COVID-19 pandemic: “Because some of the things most of us would do or could use coping strategies has also been impacted during this pandemic period” – Caregiver (PID: B1406). Infection control concerns related to COVID-19 were also expressed as being relevant beyond this pandemic. Another element that was determined to be missing from the Coping-Together booklets was content adapted to those coming from other countries. For instance, reliance on technology might be less common in other countries so some resources and suggestions were thought to be less universally relevant as they may not speak as accurately to the needs of immigrants. Participants also expressed the need for more positive coping strategies for everyday life, outside of the cancer-related symptoms: “Okay, you’ve got cancer. Now let’s move on. Yes, you’re dealing with it and everything, but give me tips on what I can do to feel better, to have a better outlook on life” – Patient (PID: A0304).

Another aspect participants reported could be improved was consideration for the “whole picture” – Patient (PID: A1406). While the booklets were reported by many as having addressed a wide variety of concerns, some noted that this “divided attention” approach to addressing challenges did not offer enough of a personalized touch and neglected to capture the whole picture holistically. To do so, participants suggested that more patient and caregiver testimonies could help in capturing this perspective.

### *Enhanced accessibility*

Specific to this population, suggested changes to enhance learning in time of stress and illness include design changes to attend to the

specific need for shorter sections in larger font given the increased severity of symptoms, such as fatigue, energy, attention, and memory problems. The main topics specific to advanced cancer that need to be added are palliative care treatment options, end-of-life planning, long-term financial aid, government recognition, and support for return to work, coping strategies for challenges such as fear of uncertainty, fear of death, and change of lifestyle and capacity. The dyads who had been patient-caregiver for longer periods of time tended to report having preestablished coping strategies. This led them to report not learning as much new information as compared to the newer dyads. This finding about learned coping skills rang true for those who had received their diagnosis longer ago as compared to more recently (Shaffer *et al.* 2020). Many participants also reported the desire for a digitized version of this resource to enhance accessibility.

### **Discussion**

The results support Coping-Together’s acceptability among both patients with advanced cancer and their caregivers. The results showed that participants found the booklets to be beneficial overall, with most expressing that the flowchart and the dyadic approach facilitated the self-directed process of achieving SMARTTER goals. The 4 key findings of this study are as follows: (a) changes are needed to further support learning new coping skills in terms of increased stress as well as including content specific to advanced cancer, (b) dyadic self-management does not mean that patients and caregivers use the same sections of Coping-Together, (c) learning, timing and readiness are key considerations that are acknowledged by the self-directed format for this self-management interventions, and (d) the main identified facilitators to using Coping-Together overcame the reported barriers. Each of these is discussed in turn.

While the overall impressions of Coping-Together were positive, the main barriers highlighted needed adaptations that were both general to increase accessibility and to enhance learning as well as those specific to the needs of patients with advanced cancer. Overall, most participants learned new coping skills and health behaviors despite the timing of diagnosis, which can be attributed to Coping-Together supporting behavior change techniques validated by experts, not yet typically integrated into usual care (Glidewell *et al.* 2018). Key components of behavior change theory are: clear health goals, perceived barriers and facilitators to change, self-efficacy, self-regulatory skills, knowledge of benefits of health behaviors, and outcome expectations, all of which



are established with the format of the SMARTTER approach to Coping-Together (Cuthbert et al. 2019).

The benefits of dyadic self-management interventions have been well established. When both the patient and caregiver are involved together, both of their individual needs as well as their collective needs in the relationship are addressed (Badr et al. 2019). Interestingly, while patients and caregivers benefited from using the intervention together, they did not necessarily use the same booklets. Caregivers tended more toward the content related to social support and care planning, whereas patients focused on symptom management, with most improvement suggestions relating to the accessibility and ease of use of the booklets. Dyads referenced the importance of having a partner available to support them in using the booklets. While needs between patients and caregivers differed, their approach to using this self-management intervention showed that they complemented one another (Shaffer et al. 2020).

The fact that all participants acknowledged the benefits of the self-directed format of this intervention is consistent with the literature that shows how people tend to prefer to follow self-management interventions at their own pace (Bamgboje-Ayodele et al. 2021). This finding was further validated by the fact that participants who used the booklets during the COVID-19 pandemic recognized the importance of self-directed interventions that were not limited by physical accessibility restraints (Gonzalo-Encabo et al. 2022). Literature indicates that self-directed learning allows for a mastery and ownership of material that supports participants in regulating and becoming more accountable for their learning (Wong and Kan 2022). To adopt behavior changes and achieve self-management goals, evidence shows that the consideration of timing and readiness are key factors that are prerequisites for effective learning (Gottlieb 2014). This aligns with the finding that participants would acknowledge the timing of introduction as being an important influence in whether they felt prepared to engage with the booklets.

While participants reported several barriers to using Coping-Together including feeling overwhelmed, being reminded of more acute challenges, having severe physical symptoms, there were more prominent facilitators that motivated their use of the intervention, which outweighed these barriers. The findings about facilitators from this study echo what has been found among other self-management interventions, with the most pertinent benefits from the literature being improved sense of control and empowerment, forming dynamic relationships and communication with healthcare providers, and facilitating treatment decision-making (McKenna et al. 2020).

### Clinical and research implications

This study has many clinical and research implications. Clinically, our results support that patients and caregivers may establish positive coping mechanisms for advanced cancer-related challenges to be undertaken together. Healthcare providers and researchers may also better understand the unique needs patients with advanced cancer and their caregivers' experience (Porter et al. 2021; Teo et al. 2019). This study adds value to the existing Coping-Together intervention by offering more insight into its implications for practice with advanced cancer. These findings will directly contribute to the adaptation of the Coping-Together booklets for an advanced cancer population.

### Study limitations

One limitation is that ethnicity was not measured in this study, given that it was less common to measure this variable when the sociodemographic sheet was first created and approved. However, previous studies have found that age and sex were the most important predictors for influence on adherence to self-management interventions (Xie et al. 2020). Nonetheless, future studies will consider ethnicity among sociodemographic data. Second, the narrow participant inclusion criteria made the feasibility for recruitment more difficult, which is consistent with other studies' findings related to recruitment of dyads with advanced cancer (Edwards et al. 2019; Pii et al. 2019). To enhance recruitment, singletons were accepted into the study to participate without the other member of their dyad. Five dyads stopped participating for reasons revolving around a lack of functionality related to illness progression. All participants were anglophone, and materials were only offered in English since the original Coping-Together intervention was developed in Australia (Lambert et al. 2012a). The primary focus of this study was to evaluate acceptability, and as this was the first time Coping-Together was used in this subgroup of patients, we relied on qualitative interviews.

### Conclusion

Patients with advanced cancer and caregivers in this study overall agreed that the Coping-Together intervention has great potential for supporting their physical, emotional, and psychosocial needs. They overall found the Coping-Together intervention was acceptable and had many perceived benefits. Despite the benefits, this population highlighted some key specifications that would make this intervention even more applicable to their unique needs. These suggested adaptations include having shorter booklets that also address additional information related to palliative care, end-of-life, long-term financial aid, government recognition, support for returning to work, and coping strategies for challenges such as fear of uncertainty, fear of death, and change of lifestyle and capacity. The future directions of this study will be to integrate patients' and caregivers' feedback in an adapted version of *Coping-Together* ready for pilot testing.

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