



Development of an evidence-based educational resource in oncology: ‘Living safely with bone metastases’

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ABSTRACT

Objective: To create an evidence-based patient education resource to better support cancer patients with bone metastases in carrying out safe movements during activities of daily living, to maintain their bone health and reduce the risk of fractures.

Methods: A quality improvement project was conducted in three phases: Development of the Resource, Preliminary Feedback and Revision, and French Canadian Translation.

Results: The educational resource *Living Safely with Bone Metastases* focuses on safe movement, activities of daily living, and exercise, organized within the sections *Move with care*, *Stay safe in different environments* and *Follow an exercise program prescribed by a physiotherapist*. Translation yielded a Canadian French version *Vivre en toute sécurité avec des métastases osseuses*.

Conclusion: *Living Safely with Bone Metastases* is an accessible online and paper resource for patients and healthcare professionals, in order to promote ongoing disease management of individuals with bone metastases.

Innovation: Cancer patients with bone metastases are at high risk of pathological fractures however resources on fracture prevention are lacking. *Living Safely with Bone Metastases* is an innovative health education resource that fills an important gap in oncology practice and has the potential to reduce the occurrence of fractures.

1. Introduction

Bone metastasis is the process whereby cancer cells spread from the primary tumour site to the bone [1]. Bone is the third most frequent site of spread, after the lung and liver [2]. The development of bone metastasis is common in patients with multiple myeloma and advanced cancer of the breast, prostate, lung, thyroid, and kidney [3-4]. Post-mortem examinations have shown that approximately 70% of patients dying from these cancers have evidence of metastatic bone disease [3]. Bone metastasis impacts the process of normal bone physiology by altering the balance between osteoclasts (cells that break down bone) and osteoblasts (cells that form the bone) [5].

Due to advancements in cancer treatment, the life expectancy of patients living with cancer and bone metastases has generally improved [6]. While survival in advanced lung cancer is only measured in months, the median survival time from diagnosis of bone metastases in prostate and breast cancer is 4 and 6 years, respectively [3]. During this time, bone metastasis often leads to skeletal complications such as bone pain, impaired mobility, bone marrow aplasia, spinal cord compression or instability,

spinal paralysis, hypercalcemia, and pathological fractures [7-8]. These physical sequelae, coupled with psychological disorders [9-10], negatively impact patients' quality of life and engagement in activities of daily living [2,6,8,11,12]. Despite the detrimental effects of bone metastasis on physical and psychosocial functioning, the majority of patients receive sub-optimal care for fracture prevention [8].

While physical activity is often perceived as contraindicated in the presence of bone metastases, the literature suggests that safe adoption of physical activity, as well as targeted exercise interventions, have the potential to improve overall bone health by increasing muscle strength, aerobic fitness, and muscle mass. Physical activity was also shown to reduce rates of adverse health events and improve patients' quality of life [13]. Despite a growing body of evidence on the benefits of physical activity in patients with bone metastases, there are limited information resources or guidelines on safe movement and activity practices. This lack of information is compounded by time constraints encountered by health care providers in clinical practice, which limit their ability to deliver comprehensive patient education.

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For optimal care delivery, it is essential to facilitate patients' understanding of their condition and the availability of safe and effective interventions, such as fracture prevention strategies, proper biomechanics in carrying out activities of daily living, and safe exercise. Patient education tools are therefore needed for individuals with bone metastases to enhance their knowledge about their condition and promote safe movement and activity [14]. As such, our objective was to create an evidence-based patient education tool addressing safe movements during activities of daily living, to support individuals with bone metastases in maintaining their bone health and reducing the risk of fracture.

2. Methods

We carried out a quality improvement project with a team consisting of a clinical specialist in oncology rehabilitation, two patient partners, four final-year students in a professional Master's program (three in physical therapy, one in occupational therapy), a university faculty member in physical therapy, and two patient education specialists with expertise in medical writing and illustration. The final deliverable was an evidence-based educational resource on safe activity for individuals with bone metastases, designed for on-line use with an electronic device or to be printed in a paper booklet format. The terms resource and booklet are therefore used interchangeably. This article will focus on the creation of the educational resource, carried out in three phases: Development of the Resource (2.1), Preliminary Feedback and Revision (2.2), and French Canadian Translation (2.3).

2.1. Phase 1 - Development of the Resource Content, Illustrations and Text

To inform the content of the educational resource, a narrative literature review was conducted to identify resource materials and research studies on safe activity and fracture prevention strategies for patients with bone metastases. Databases searched were MEDLINE, Embase, and Google Scholar. Search terms included bone metastases, fractures, and fracture prevention, which were exploded where appropriate. The search yielded 422 abstracts. Two reviewers (IN, KC) screened 422 titles and abstracts, of which 42 were retained for full text review by two other reviewers (VS, KY). Abstracts were included for full article review if they were published in English and pertained to individuals aged 18 years or older and who had cancer that had metastasized to the bone. Articles were excluded if study participants had primary bone cancer, or if the research study included a pharmacological or surgical intervention. These inclusion/exclusion criteria were applied again to the 42 articles, with 2 articles meeting all criteria. Due to the scarcity of literature on fracture prevention in patients with bone metastases, a literature search on osteoporosis and fracture prevention was conducted as the pathophysiology of fracture is similar between osteoporosis and bone metastasis. Additionally, expertise from the clinical specialist in oncology rehabilitation (MI) complemented the literature findings and further informed the booklet content.

Movements and activities of daily living, which often are performed poorly or with difficulty by individuals with bone metastases, were selected for illustration in the booklet. Two photography sessions took place, in which the medical illustrator took photographs of project team members performing movements or activities. These photographs provided clear visual representations to the medical illustrator of both safe and unsafe body positioning, as well as the environment in which an activity is carried out. Based on the photographs, the medical illustrator created digital images. The project team provided feedback on the images to ensure that they accurately depicted the desired movement, activity, or environment.

Once the images were completed, the research team developed the written text to accompany the images with concise and easy-to-understand instructions. The writing process was iterative, involving ongoing revisions by members of the project team and guidance from the writing specialist to ensure the text was written in plain language and at a Grade 6 literacy level. Sequential drafts were created to promote clarity and readability of the written text, accuracy of the images, and alignment between the written text and images.

2.2. Phase 2 - Preliminary Feedback and Revision

In the next phase of booklet development, we obtained preliminary feedback from our two patient partners with stage IV breast cancer with bone metastases, who had received treatment in oncology rehabilitation. They were invited by the first author to be part of the quality improvement team, in order to provide feedback on the educational resource from the perspective of individuals living with bone metastases. Informed consent was not required as the patient partners were members of the quality improvement team with a clearly defined role in the review and refinement of the booklet. This phase of the project was guided by recommendations for patient partnerships in quality improvement [15], as well as the Strategy for Patient-Oriented Research – Patient Engagement Framework [16].

The patient partners individually viewed the booklet in its entirety, including text and images. Both individuals then simultaneously provided feedback to other members of the project team. A semi-structured format stimulated reflection and discussion between patients, and allowed further questioning by other team members when necessary. Questions focused on the clarity, readability, understanding, and application of the booklet, as well as overall opinions. Feedback questions are listed in Table 1. The feedback session was audio recorded using a laptop computer. Recorded information was transcribed, after which the recording was deleted. From the transcribed feedback, the booklet's strengths and weaknesses were identified. To address the identified weaknesses, revisions were made to the booklet's text, images, and sequence of topics.

2.3. Phase 3 - French Canadian Translation

A forward translation from English to French was carried out by a professional translator experienced in translating patient education materials and whose first language is Canadian French. The French version was then reviewed in detail against the English version by three physical therapists, two of whose first language is French and one who is fluent in French. Two of the reviewers were members of the research team (IN, JS). A consolidated French version with the reviewers' questions and suggestions was returned to the translator. Following back and forth communication and

Table 1
Feedback questions.

Clarity of the booklet	Application of the content
<ul style="list-style-type: none"> Did you find that the images in the booklet corresponded well with the text? If not, which ones and why? Can you describe the office environment section in your own words? 	<ul style="list-style-type: none"> Did you find that some of the information pertains to your everyday life? Describe a situation in your everyday life where you believe you can use the information. Can you think of a situation in your life, which is NOT described in the booklet, where you can apply these recommendations?
<p>Readability of the booklet</p> <ul style="list-style-type: none"> Did you find the language used in this booklet to be appropriate? If it is not appropriate, in what way? Can you give us an example from the booklet? How easy was it to read the booklet? Elaborate. Was the text of sufficient size and colour? 	<p>Overall opinions</p> <ul style="list-style-type: none"> How do you see yourself using this booklet? Would you recommend this booklet to other patients? Tell us why. What did you like most about this booklet? And why? What did you like least? And why? When would you like to have a booklet of this type offered to you?
<p>Understanding of the content</p> <ul style="list-style-type: none"> How do the images in the booklet help you understand the written information? Are there any text or images that you feel are missing or could be further developed for your understanding? Do the titles and subtitles help you understand the information? Tell us why? What is one thing you learned from the booklet? 	

agreement on the required revisions, a finalized French booklet was produced.

3. Results

3.1. Phase 1 - Development of the Resource

Based on the literature reviews carried out separately in bone metastasis and osteoporosis, supplemented with expert opinion, the following main topics were identified for inclusion in the educational resource: cancer and bone metastases, fracture prevention, posture, biomechanics of movement, safe living, and exercise. An introductory section *What are cancer and bone metastases?* provides a basic description of the pathophysiology of bone metastases as well as common signs and symptoms. Also included were anterior and posterior illustrations of the human skeleton on which patients or clinicians can indicate the specific lesion sites where bone metastases were detected.

Following the introductory section, topics were organized within three sections: 1) *Move with care*, 2) *Stay safe in different environments*, and 3) *Follow an exercise program prescribed by a physical therapist*. To make the booklet interactive and stimulate discussion between the patient and healthcare professional, a box for Questions and Comments was added to the Introduction and Sections 1, 2 and 3. Sections 1 and 2 were further divided into subsections, each of which illustrates a common movement, activity or environment encountered in everyday life. Section 3 gives general information on the importance of safe exercise adapted according to each individual's circumstances. Sections, subsections, and example text and images are shown in [Table 2](#).

The final two sections of the booklet cover emergency situations and information on healthcare professionals who can provide additional resources or services. The section *When should I call or go to the hospital?* lists signs and symptoms of fracture and spinal cord compression associated with bone metastases, and includes a space to write emergency contact information of the medical team. The section *Looking for more information?* describes the role of occupational therapists, physical therapists, doctors, and nurses in the management of bone metastases. Both the English and French booklets are 28 pages in length.

3.2. Phase 2 - Preliminary Feedback and Revision

Five main topics emerged from the patient partner feedback. [Table 3](#) summarizes the topics, the initial text or image, and the corresponding final text or image after incorporating the feedback. In terms of overall opinions, both patients expected that the booklet *Living Safely with Bone Metastases* would clinically benefit individuals with bone metastases. They stated that the booklet would be most beneficial upon initial diagnosis of bone metastases by an oncologist. Question and comment boxes were viewed as a positive component of the booklet as they promote conversation between healthcare providers and patients and may lessen patients' anxiety when asking questions during appointments. They said that they would use the booklet in their everyday life and would recommend this educational tool to other patients with bone metastases.

3.3. Phase 3 - French Canadian Translation

Review of the French version of the booklet yielded several editorial suggestions for the French text, consisting of grammatical and spelling corrections as well as minor changes in wording. The wording changes ensured equivalent meaning between the French and English texts. In reviewing the French translation, there were instances where the French was superior to the English wording in clarity or style. In these instances, the English text was modified to match the French version. Both [English](#) and [French](#) documents are available on the patient education website of the McGill University Health Centre (navigate to Cancer/Radiotherapy), and the website of the Canadian Physiotherapy Association, Oncology Division (members section).

4. Discussion and conclusion

4.1. Discussion

We developed the booklet *Living Safely with Bone Metastases*, an evidence-based educational resource on safe activity for cancer patients with bone metastases. The booklet covers the pathophysiology and clinical presentation of bone metastases, safe movements using biomechanical principles, safe environments, and adoption of customized exercise. The final version incorporated feedback from patient partners on the booklet's clarity, readability, content, and overall usefulness. In collaboration with a professional translator, we also produced a Canadian French version *Vivre en toute sécurité avec des métastases osseuses*.

This project was a quality improvement initiative to help prevent and address musculoskeletal and functional difficulties often encountered by patients with cancer that has metastasized to the bone. *Living Safely with Bone Metastases* was developed using a pre-planned and stepwise methodology and involved a multi-disciplinary team of patients, clinicians, and researchers with expertise in rehabilitation, oncology, patient education, and graphic design. A booklet format was chosen, as it is a simple and cost-effective tool for improving cancer-specific knowledge [17-18]. This approach was consistent with a systematic review [19], which concluded that broad-reach (i.e. non-face-to-face) interventions, including print and web-based materials, are well suited to improving health behaviors, quality of life, and health outcomes in cancer survivors.

Living Safely with Bone Metastases is based on evidence from the literature on cancer-related bone metastases and osteoporosis, as well as expert opinion in rehabilitation oncology. Additionally, the booklet content and format align with best practices for health education materials, as outlined by the Centers for Disease Control and Prevention [20]. These practices include the use of key messages based on users' priority needs and knowledge level, headings and bulleted statements, active voice and short sentences, text at a sixth-grade reading level, instructive images, sufficient white space, and interactive boxes to promote user engagement. As well, the booklet's images reflect the populations affected by bone metastases by depicting men and women with diversity in age, race, and cultural or religious background.

Patient partners expressed that the booklet would be very beneficial to individuals with cancer and best introduced by the oncologist at the time of detection of bone metastases. The feedback also identified text and images requiring improvement in conciseness, clarity, and practicality in the messages conveyed. These opinions underscore the need for simple and user-friendly educational resources to promote independent activities of daily living while reducing the risk of fractures.

Although the clinical implementation and usage of the booklet will be the subject of future work, potential applications are already apparent. This educational resource could be administered alone or in combination with other medical and rehabilitative interventions. For example, *Living Safely with Bone Metastases* could be part of an individualized self-management program. In advanced cancer, self-management should be tailored to each individual's specific needs and phase of treatment, while being implemented in partnership with family members and health care professionals [21]. The booklet promotes a multidisciplinary approach, an essential aspect of self-management, by providing information on the role of different health professionals and their ability to provide individualized advice on topics not covered in the booklet. From a rehabilitation perspective, patients with bone metastases are often reluctant to move, which leads to sedentary behaviour and functional decline, further increasing the risk of fracture. To counter this downward spiral, the booklet can help decrease patients' anxiety and fear of movement by conveying that movement and exercise are crucial to maintaining musculoskeletal health, as long as these activities are performed in a safe manner.

The booklet was designed for use primarily during clinical visits with medical or rehabilitation professionals, however individuals may access it online and use it independently. To promote safe use of the booklet in collaboration with qualified professionals, the booklet includes statements

Table 2
Booklet sections and subsections (Booklet).

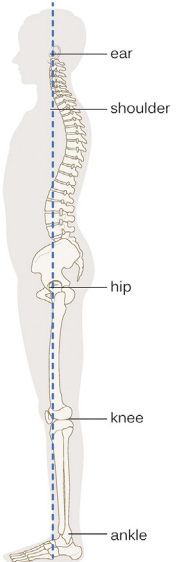

Section	Subsection	Example Text and Image
<p>1. Move with Care</p>	<p>1.1 Always maintain good posture (p.8) 1.2 Avoid bending forward (p.10) 1.3 Avoid twisting (p.12)</p>	<p style="text-align: center;">How can I prevent a fracture?</p> <p>1. Move with care</p> <p>Posture refers to how you position your body whether you are standing, sitting, lying down or moving.</p> <p>1.1 Always maintain good posture</p> <p>When standing, picture an imaginary line that starts at the top of your head and continues down to the bottom of your feet. Keep your back straight by making sure that your ear, shoulder, hip, knee and ankle are lined up with each other.</p> <p>To maintain good posture, avoid:</p> <ul style="list-style-type: none"> • slumping or hunching over • twisting • bending from the waist, or • any movement that requires a far reach 
<p>2. Stay safe in different environments</p>	<p>2.1 Using stairs (p.15) 2.2 At the office (p.16) 2.3 In the bathroom (p.18) 2.4 In the kitchen (p.20) 2.5 In the bedroom (p.23)</p>	<p>2. Stay safe in different environments</p> <p>Organize and adapt your home and workplace to make your surroundings safe and to prevent the risk of falls. In this section, we outline strategies for safety in everyday environments that you will encounter (e.g. stairs, office, bathroom, kitchen, and bedroom).</p> <p>2.1 Using stairs When going up the stairs, step up first using your stronger leg.</p>  <p style="text-align: right;">When going down the stairs, step down slowly with your weaker leg.</p>

Table 2 (continued)

Section	Subsection	Example Text and Image
3. Follow an exercise program prescribed by a physical therapist (p.25)	No sub-sections	

3. Follow an exercise program prescribed by a physical therapist

Always consult with a physical therapist specialized in cancer rehabilitation before starting any exercise or sport. They will work with you to make sure that your exercise plan:



- Is safe, considering you have bone metastases
- Has maximum health benefits (to improve and maintain your muscle and bone strength)
- Is customized to your cardiovascular and overall fitness levels
- Is adapted to your individual needs

If you have any questions about your exercise plan, write them below and speak to a physical therapist specialized in cancer rehabilitation.



at its start and end, which emphasize the need to consult a qualified healthcare practitioner to provide expert advice adapted to each person's situation. In the section on exercise, it is recommended to consult with a physical therapist specialized in cancer rehabilitation before starting any exercise or sport.

A major strength of the booklet is that it is available online in both official languages of Canada, thereby reaching a large audience of patients and healthcare professionals. Translation to other languages will eventually promote even greater accessibility of this education tool. Prior to additional linguistic translation, however, further review is planned of the English and French versions. Limitations of this project were that it was not feasible to carry out formal focus groups for feedback or back-translation from French to English, as the project team wished to prioritize the clinical availability of the booklet by disseminating the English and French versions in a timely manner.

Future work will include language-specific focus groups, involving native speakers of English and French to review each version. Focus group feedback, combined with a back-translation process, will enhance the linguistic accuracy of the Canadian French version. In addition, focus groups of healthcare professionals will be held to generate strategies on implementation of the booklet in the care of cancer patients with bone metastases, as well as any necessary adaptations due to the unique clinical characteristics of this patient group. Slight adaptations may be needed as we relied heavily on the osteoporosis literature, coupled with expert opinion in oncology rehabilitation, to guide the booklet content on fracture prevention in bone metastases. Healthcare professionals working with cancer patients with bone metastases may identify subtle differences between the two conditions, which could lead to slight modifications in the overall presentation of the booklet, wording of instructions, or illustration of fracture prevention strategies.

4.2. Innovation

This quality improvement project adds to the scarce literature on fracture prevention in patients with bone metastases. The development of

'Living Safely with Bone Metastases' contributes to innovation in healthcare by providing an accessible online resource for patients and healthcare professionals, to educate and support individuals living with bone metastases. Online educational materials are available on the topics of radiotherapy treatment and overall management of bone metastasis [22-25]. None of these resources, however, adequately cover strategies to minimize fracture risk through proper body positioning and movement, environmental adaptations, and exercise. To our knowledge, *Living Safely with Bone Metastases* is the first educational resource that focuses on these topics. As bone metastasis is a frequent site of cancer spread, this booklet fills an important gap in care for the many cancer patients living with advanced disease. By providing clear guidelines on safe movement and exercise, this booklet provides a basis for discussion between healthcare professionals and patients in the education and counselling process. Additionally, it serves as a practical reference to promote ongoing disease management, maximize functional mobility, and optimize quality of life.

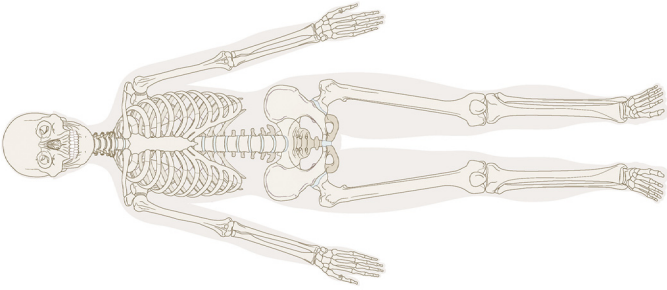
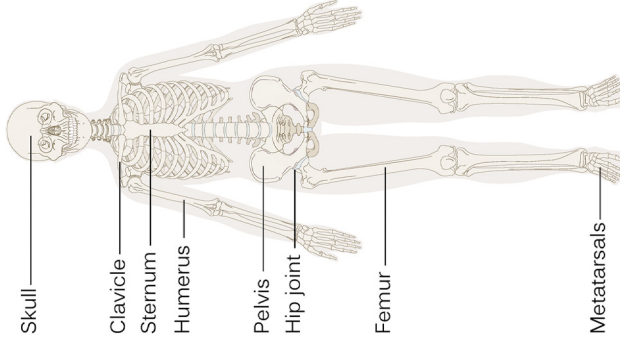
4.3. Conclusion

Cancer patients with bone metastases currently receive inadequate education on safe movement and fracture prevention strategies. To address this need, the booklet *Living Safely with Bone Metastases* was created through a three-phase process of development, revision, and French-language translation. The booklet includes information about bone metastasis, guidelines for seeking medical care, and three sections on fracture prevention: *Move with care*, *Stay safe in different environments*, and *Follow an exercise program prescribed by a physical therapist*. Future work will involve patient and healthcare professional focus groups to further refine the booklet and to guide its implementation in clinical practice.

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Table 3
Feedback and subsequent revisions.

Feedback Topics	Initial Text or Image	Final Text or Image
<p>1) Missing descriptors</p> <ul style="list-style-type: none"> • Names of bones are missing 		
<p>2) Language clarity</p> <ul style="list-style-type: none"> • Text is wordy and difficult to understand 	<p>To get into bed: Sit down on the edge of the bed. Lower the trunk to one side and lift the legs on the other at the same time. Use your arms to assist the movement but do not twist or rotate the trunk.</p>	<p>To get into bed:</p> <ol style="list-style-type: none"> 1. Use your arms to lower yourself on the bed. 2. Pivot your whole body (not at the waist) to lift your feet onto the bed. 3. Lie down on your side then roll onto your back.

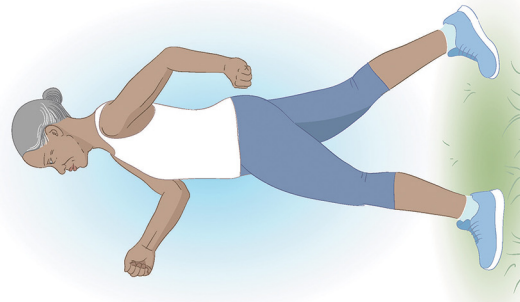
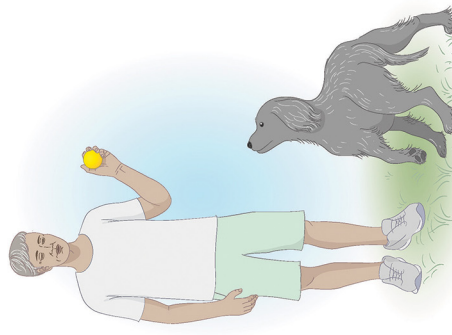
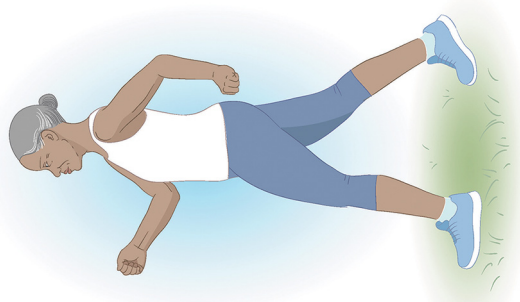
3) Image clarity

- Dynamic movement is not conveyed in image



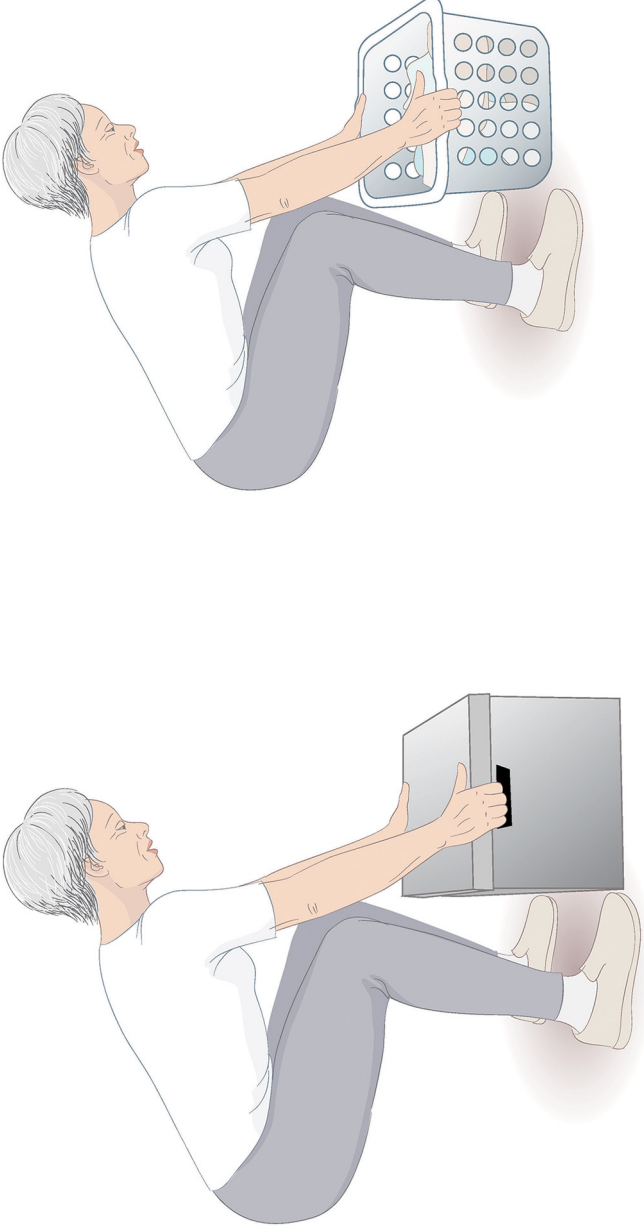
4) Gender equality

- Men are under-represented in images



(continued on next page)

Table 3 (continued)

Feedback Topics	Initial Text or Image	Final Text or Image
5) Practicality	<ul style="list-style-type: none">Image is not a realistic representation of everyday task	

design or conduct, article preparation, or the decision to submit the manuscript for publication.

Author contributions

All authors contributed to the design of the project and development of the resource 'Living Safely with Bone Metastases'. The literature search was carried out by Katrina Cardiff (KC), Isabelle Nhan (IN), Vanissa Savarimuthu (VS) and Kathryn Yao (KY). Marize Ibrahim (MI), KC, IN, VS, and KY obtained feedback from patient partners. Shie Kasai created all illustrations included in the educational resource, and contributed substantially to the final layout. Judith Soicher (JS) and IN contributed to French-language translation. Nancy Posel oversaw the involvement of the MUHC Patient Education Office, which provided assistance in medical writing, illustration, and professional translation. MI, KC, and JS wrote the manuscript, which was reviewed by all authors.

Permission

Permission to reproduce images was granted by Dr. Nancy Posel (co-author) from the Patient Education Office of the McGill University Health Centre.

Declaration of Competing Interest

The authors have no conflicts of interest or competing interests with respect to the research, authorship or publication of this article.

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