



Consensus recommendations for cancer rehabilitation: research and education priorities

S. McEwen PT PhD,† M. Egan OT PhD,‡§||
M. Chasen MBChB MPhil (Pall Med),‡§|| M. Fitch RN PhD,*†#
and the Partners in Cancer Rehabilitation Research Group***

ABSTRACT

As cancer survivorship increases, there is a need for additional and more complex rehabilitation services. The Partners in Cancer Rehabilitation Research group held a 3-day invitational working meeting aimed at defining the state of the science in cancer rehabilitation research and identifying key areas for development of research and education. In May 2012, 29 participants gathered to present their current work, review a synthesis of the current literature, generate ideas about research and education gaps, and develop consensus on priority areas. The conclusion of the meeting was that a main research priority is to develop and test personalized rehabilitation interventions and brief measures to identify the presence and severity of disabling sequelae. The education consensus statement concluded that a clear description of cancer rehabilitation and its mandate should be developed as a precursor to education activities, including both a conceptualization of complex interdisciplinary rehabilitation and the roles of individual professions, and further, that there is a great need to increase awareness among health professionals, patients, and families of the need for and general effectiveness of cancer rehabilitation. Numerous specific recommendations were also put forward, and it is hoped that those recommendations will provide the foundation for a new and productive era of research and will play a role in the improvement of functional health and participation outcomes for cancer survivors.

KEY WORDS

Rehabilitation, research, education

1. INTRODUCTION

More people than ever are surviving cancer, but the disease and its life-saving treatments often leave survivors with physical, cognitive, and emotional

sequelae that require rehabilitation services. Cancer rehabilitation is evolving to meet the complex needs of an increasing number of survivors: rehabilitation professionals are working to design interventions that restore the integrity of organ structure and function, remediate functional loss, and enable full participation in personally meaningful roles and activities¹. To move this work forward in the Canadian context, the Partners in Cancer Rehabilitation Research (PCRR) group held a 3-day invitational working meeting with rehabilitation researchers, influential clinicians, and cancer survivors. The main aims were to pool knowledge and resources, to increase multi-institutional partnerships and collaborations, and to contribute to the construction of a strong evidence base to support excellent patient^a care. The specific meeting objectives were to

- define the state of the science in cancer rehabilitation research.
- identify key areas for research and develop a consensus statement on priorities.
- identify key areas for future education and develop a consensus statement on priorities.

To meet the first objective, the meeting organizers compiled a comprehensive best-evidence synthesis^b. The second and third objectives are the focus of the present manuscript. It contains a summary of the meeting process and presents the research and education consensus statements developed by the PCRR group.

^a For the purposes of this manuscript, the term “patient” is used to describe people on active cancer treatment, and the term “survivor” is used to describe people who have had a diagnosis of cancer but are not currently on active treatment.

^b Egan M, McEwen S, Sikora L, Chasen M, Fitch M, Eldred S. Rehabilitation following cancer treatment: a best evidence synthesis. *Disabil Rehabil* (submitted).

2. MEETING SUMMARY

The PCRR meeting was held May 30 to June 1, 2012, at St. John's Rehab Hospital^c in Toronto, Canada. The organizing committee (SM, MC, ME, MF)—comprising researchers with nursing, occupational therapy, oncology physician, and physiotherapy backgrounds—began convening regularly in December 2011. The first priority of the organizing committee was to develop a broadly representative list of invitees. We strove to include a mix of researchers, clinicians, and cancer survivors from a broad range of disciplines and from all regions of Canada. The meeting attendees included 29 people from across Canada and from nursing, occupational therapy, oncology, physiotherapy, psychology, sociology, speech–language pathology, and vocational rehabilitation. The group included junior and senior researchers, frontline clinicians, students and post-doctoral fellows, and cancer survivors.

Day 1 consisted of presentations by participants (Table 1). Day 2 began with a presentation about theoretical models of cancer rehabilitation and presentation of the cancer rehabilitation literature synthesis conducted in the months before the meeting. That presentation was followed by idea generation with regard to gap areas and then by small group discussions to categorize the ideas generated as research needs or education needs. Day 3 included presentations on clinician education needs, small group discussions to develop consensus on research and education priorities, and a plenary session to discuss potential dissemination strategies.

3. PROCESS FOR DEVELOPING CONSENSUS STATEMENTS

Before this process began, participants had heard and discussed 22 presentations on areas of current work and a 45-minute presentation of the cancer rehabilitation literature synthesis. The process for idea generation and consensus development comprised these steps:

- Individual reflection
Participants were asked to think about what they had heard in the individual research and literature synthesis presentations in the context of their own knowledge and experiences. They were asked to write down their ideas about gap areas for research and education, writing separate thoughts on individual pieces of paper.
- Categorizing gap areas
Still working as individuals, participants were asked to categorize each idea under one of the

10 review areas from the literature synthesis: Cognition, Depression, Fatigue, General Rehabilitation, Nutrition, Pain, Participation, Physical Function, Return to Work, or Sexual Function.

- Small-group brainstorming
Participants were asked to self-select to one of the review areas listed in the preceding step. Because of the small number of participants overall, and because most participants were interested in more than one area, the self-selection was done in two rounds, with half the review areas covered in the first round and half in the second. In each small group, participants were asked to review the ideas that had been submitted. Ideas were to be clustered into categories when possible, and group members were to consider and add any new ideas that emerged. The organizing committee circulated, visiting the all groups and ensuring that discussion was occurring and that new ideas were being generated.
- Large-group walk-around
A representative of each small group provided a brief summary of the discussion that had taken place within the group, outlining the predominant themes and categories, to all members of the larger group.
- “Traffic light” grading system²
Participants used laptops or computer tablets to access electronic summaries of the literature synthesis in each review area and also the full text of review articles or randomized controlled trials published after the systematic review by Richardson *et al.*³. The electronic summaries and articles had been prepared ahead of time by the organizing committee.
Still working in small groups, participants were given approximately 45 minutes per review area to apply Novak's Traffic Light² appraisal system to the ideas generated, referring to available systematic reviews when appropriate. Green indicated “Go” (sufficient evidence to utilize the information in practice). Yellow indicated “Measure” (insufficient, low-quality, or conflicting evidence, and therefore a need for more research before firm recommendations can be made). Red indicated “Stop” (high-quality evidence of ineffectiveness; recommend against use).
- Consensus development
 - Research priorities
From among the ideas graded Yellow, small groups were asked to discuss and debate research priorities. The discussions were facilitated as necessary by members of the organizing committee, although the groups functioned mostly independently.

^c Now St. John's Rehab at Sunnybrook Health Sciences Centre.

TABLE 1 Partners in Cancer Rehabilitation Research day 1 sessions and presentations

<i>Session</i>	<i>Details</i>
<i>Setting the Stage and Identifying Real-World Gaps</i>	
<i>Panel Chair:</i> Martin Chasen	
<i>Presentations:</i>	
1.	Rehabilitation services: a cancer survivor’s perspective of the gaps (Margaret Tompson)
2.	Transition from acute care to rehabilitation to community—a process and a journey (Mila Bishev and Smitha Casper–Desouza)
3.	“Once upon a time” ... a 25-year tale: evolving clinical challenges in head-and-neck cancer rehabilitation (Marlene Jacobson)
4.	Improving the patients’ experience through cancer rehabilitation (Esther Green)
<i>Physical Functioning, Return to Work, and Participation</i>	
<i>Panel Chair:</i> Katherine Berg	
<i>Presentations:</i>	
1.	Barriers and facilitators of transition from pediatric to adult long-term follow-up: a qualitative study of survivors of cancer in childhood and adolescence (Leila Amin)
2.	Occupational therapy evaluated within an oncology rehabilitation program (Margaret Liu)
3.	Cancer and work: a Canadian perspective (Maureen Parkinson)
4.	Prehabilitation to enhance recovery following colon surgery: reflections from a randomized controlled trial (Nancy Mayo)
5.	CanWell: an exercise and education program for well cancer survivors (Oren Cheifetz)
<i>Psychosocial Issues and Cognition</i>	
<i>Panel Chair:</i> Mary Egan	
<i>Presentations:</i>	
1.	Challenges of brain fog in cancer rehabilitation (Bruno Gagnon)
2.	Chemo fog. Let’s clear the air (Barbara Collins)
3.	The role of awareness of the benefits and guidelines of physical activity in behavioural change in cancer survivors (Dan Pringle and Geoffrey Liu)
4.	Couple-focused sexual rehabilitation in prostate cancer (Deborah McLeod)
5.	ELLICSR: Building a collaborative research program in cancer survivorship (Jennifer Jones)
<i>Symptom Management and Nutrition</i>	
<i>Panel Chair:</i> Neil McDonald	
<i>Presentations:</i>	
1.	Patients with advanced cancer benefit from a palliative rehabilitation program (Andrea Feldstain and Martin Chasen)
2.	“I used to push the boat from the shore”: the implications of loss after breast cancer for rehabilitation (Roanne Thomas and Tricia Morrison)
3.	Head-and-neck cancer and dysphagia: incidence and common comorbidities (Rosemary Martino)
4.	Self-management and self-care approach to cancer rehabilitation at Princess Margaret Survivorship Program (Aleksandra Chafranskaia and Stephanie Phan)

The small groups were also asked to develop a justification for their particular list of priorities, and they were advised that they would be required to defend their priorities to the large group. A large-group walk-around was again used to permit all participants to hear the research priorities of each small group.

- Education priorities
This process was similar to that for research priorities, except that ideas graded as Green were used as a starting point for discussion and debate.
- Coding of priorities
Within 2 weeks of the meeting, all research and

education priorities were reviewed, and common ideas were coded by the first author (SM). The codes were reviewed and revised after a second reading and then synthesized into broader categories from which the initial consensus statements were formed.

- **Member checking**
The initial consensus statements were sent to PCRR group members, who were asked to verify that the statements accurately represented the discussion and decisions made at the meeting. Discrepancies were managed by discussion between the first author (SM) and the individual PCRR member who raised the issue.

4. CONSENSUS STATEMENTS

4.1 Consensus Statement on Research Priorities in Cancer Rehabilitation

In terms of how to rehabilitate people living with disability, there is sufficient evidence to make practice recommendations in certain niches of cancer rehabilitation, but there are also vast gaps in understanding related to specific cancers or specific treatments across the cancer trajectory and across most symptom areas. A main research priority is to develop and test personalized rehabilitation interventions and short-form instruments to detect the presence and severity of disabling symptoms specific to different types of cancer and different times in the trajectory, and to mesh with the personal characteristics of individual patients, such as age, comorbidities, and personal preferences. Patient-specific data, basic and clinical science, and health systems research will contribute to the development of cancer rehabilitation interventions.

Figure 1 provides a framework for cancer rehabilitation research. It shows the development and testing of personalized rehabilitation interventions as the central point. Patient-specific information includes cancer type and subtype, age, sex, comorbidities, personal goals and concerns, social context, physical context, and economic context. Basic and clinical science includes probable physical and psychosocial issues, actual individual cancer and treatment history, and predicted individualized responses to interventions, based on biomarkers and genetics. Health systems include indications for single rehabilitation services, indications for team interventions, indications for service location (inpatient, outpatient, home, community, long-term care, palliative care), issues of coordination with other cancer care services, and issues of health care transitions. Functional and participation outcomes and knowledge translation efforts will be monitored to judge the effectiveness of interventions and tools, and, as indicated by the bi-directional arrows, findings should be used to influence ongoing intervention development and testing.

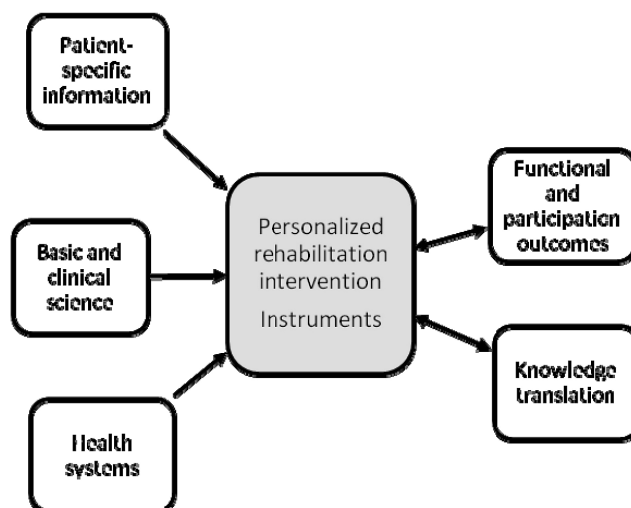


FIGURE 1 Cancer rehabilitation research framework.

Several specific research recommendations were made by small groups working in specific review areas.

4.1.1 General Rehabilitation and Health Services

- Investigate the optimal timing of general rehabilitation services.
- Investigate cancer rehabilitation in challenging contexts such as rural and remote communities.
- Investigate the impact of primary cancer treatment or reconstruction procedures (or both) on functional outcomes for situations in which choice exists.
- Develop and evaluate a triage or referral process to ensure that individuals receive the right rehabilitation services at the right time.
- Evaluate the cost-effectiveness of rehabilitation interventions.
- Investigate the impact of services on participation outcomes.

4.1.2 Cognition

- Extend the study of cognition beyond the brain cancer and breast cancer populations into other disease groups.
- Investigate the causes of cognitive deficits.
- Conduct longitudinal studies to further an understanding of the natural course of cognitive profiles, cancer-related cognitive dysfunction, and its association with functional health outcomes.
- Develop and test interventions to enhance cognitive function.
- Increase the understanding of the multifactorial nature of cognitive dysfunction, depression, and fatigue in cancer survivors and the interrelationships of those conditions, including genetic, biologic, character, oncologic treatment, and environmental factors.

4.1.3 *Fatigue*

- Identify which components of supervised community-based exercise programs are essential to their effectiveness in reducing fatigue.
- Improve the understanding of the causes of cancer fatigue.

4.1.4 *Nutrition*

- Investigate patient perspectives on nutrition needs, to contribute to the development of interventions to prevent malnutrition and cachexia.
- Develop individualized nutrition recommendations, taking into consideration cancer type, stage, and comorbidities.
- Evaluate the effectiveness of general guidelines for healthful eating for people living with cancer or its effects.

4.1.5 *Physical Function*

- Extend the study of the impact of exercise beyond the breast cancer population.
- Develop the capacity to individualize exercise prescription based on patient-specific information.
- Evaluate the impact of interventions for communication (speech, voice, language) and swallowing disorders beyond the head-and-neck cancer population.

4.1.6 *Sexual Function*

- Explore the role of rehabilitation in improving sexual function in cancer survivors.
- Evaluate the effectiveness of pelvic floor muscle retraining in cancer survivors.

4.1.7 *Return to Work*

- Develop, evaluate, and deploy a brief inventory of indicators to identify cancer survivors in need of specialized support for return to work.
- Investigate factors specifically associated with workforce re-entry and job maintenance, such as aging and job meaningfulness.

4.2 **Consensus Statement on Education Priorities in Cancer Rehabilitation**

The PCRR established two main education priorities:

- Develop and disseminate a clear, interdisciplinary description of the nature of cancer rehabilitation and its mandate.
- Increase awareness among health care providers and patients of the need for and general effectiveness of cancer rehabilitation.

Given the complex, interdisciplinary needs of cancer patients, a description of the nature of cancer rehabilitation and its mandate is a necessary precursor to any educational endeavours. Such a description will enable clear communication about how

cancer rehabilitation can help patients to meet their functional health goals. Although a desire to form a strong interdisciplinary approach to cancer rehabilitation was evident, there was concern that the roles of various professional groups are not well defined in the broader context of cancer rehabilitation and that each discipline needs to consolidate its scope of practice, educational needs, and research priorities to strengthen the interdisciplinary approach. Once developed, the resulting conceptualizations should be disseminated to key stakeholders, including organizations of health professionals, cancer-specific organizations, foundations, and cancer survivor-driven advocacy groups.

There was broad consensus within the PCRR group that patients, families, and health care professionals working in both rehabilitation and oncology are largely unaware of the need for and the general effectiveness of cancer rehabilitation. Thus, increasing awareness was repeatedly mentioned as an education priority. The best-evidence synthesis compiled initially as a working document for the PCRR meeting demonstrates that an emerging body of literature is suggesting that rehabilitation interventions can improve functional outcomes in cancer survivors. The information from the best-evidence synthesis should be used as a starting point to increase awareness among health care professionals, patients, and families about the general effectiveness of rehabilitation interventions, and to create awareness of the need for additional disease-specific research.

5. CONCLUSIONS

The 3-day PCRR working meeting brought together 29 cancer rehabilitation specialists from across Canada, representing a variety of disciplines and career stages, and including researchers, clinicians, and cancer survivors. The group reached these conclusions:

- A fundamental research priority is to develop and test personalized rehabilitation interventions.
- There is a need to develop, test, and deploy brief measures and inventories to identify the presence and severity of disabling sequelae, tailored for different types of cancers and different times in the disease trajectory.
- A clear description of cancer rehabilitation and its mandate should be developed as a precursor to education activities, including both a conceptualization of complex interdisciplinary rehabilitation and roles of individual professions.
- There is a great need to increase awareness among health professionals, patients, and families of the need for and general effectiveness of cancer rehabilitation.

The PCRR group is hopeful that the foregoing statements will initiate discussion among Canadian

cancer rehabilitation researchers, provide the foundation for a new and productive era of research, and play a role in the improvement of functional health and participation outcomes for cancer survivors.

6. ACKNOWLEDGMENTS

The PCRR meeting was funded by the Canadian Institutes of Health Research (KPE-117820), the Clinical Research Department of St. John's Rehab Hospital (now St. John's Rehab Program, Sunnybrook Research Institute), and the St. John's Rehab Hospital Foundation. The authors thank Supreet Grewal bsc for help with meeting preparation and organization, Jorge Rios bsc and Tanya Ramsey msc(OT) for their help with note-taking during the meeting, and Jorge Rios bsc for assistance synthesizing the meeting notes and preparing the present manuscript.

7. CONFLICT OF INTEREST DISCLOSURES

No financial conflicts of interest exist.

8. REFERENCES

1. Gilchrist LS, Galantino ML, Wampler M, Marchese VG, Morris GS, Ness KK. A framework for assessment in oncology rehabilitation. *Phys Ther* 2009;89:286–306.
2. Novak I, McIntyre S. The effect of education with workplace supports on practitioners' evidence-based practice knowledge and implementation behaviours. *Aust Occup Ther J* 2010;57:386–93.
3. Richardson A, Addington–Hall J, Amir Z, *et al.* Knowledge, ignorance and priorities for research in key areas of cancer survivorship: findings from a scoping review. *Br J Cancer* 2011;105(suppl 1):S82–94.

Correspondence to: Sara Elizabeth McEwen, St. John's Rehab Research Program, Sunnybrook Research Institute, and Department of Physical Therapy, University of Toronto, 285 Cummer Avenue, Toronto,

Ontario M2M 2G1.

E-mail: sara.mcewen@utoronto.ca

- * Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, ON.
- † University of Toronto, Toronto, ON.
- ‡ Élisabeth Bruyère Hospital, Ottawa, ON.
- § Bruyère Research Institute, Ottawa, ON.
- || University of Ottawa, Ottawa, ON.
- # Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, ON.
- ** Members: Leila Amin, Princess Margaret Hospital and VHA Rehab Solutions, Toronto, ON; Katherine Berg, University of Toronto, Toronto, ON; Aleksandra Chafranskaia, Princess Margaret Hospital, Toronto, ON; Oren Cheifetz, Oncology Division, Canadian Physiotherapy Association; Barbara Collins, Ottawa Hospital, Ottawa, ON; Janet Craik, Canadian Association of Occupational Therapists; Andrea Feldstain, University of Ottawa and Élisabeth Bruyère Hospital, Ottawa, ON; Bruno Gagnon, McGill University, Montreal, QC; Esther Green, Cancer Care Ontario; Marlene Jacobson, Sunnybrook Health Sciences Centre, Toronto, ON; Jennifer Jones, Princess Margaret Hospital, Toronto, ON; Geoffrey Liu, Princess Margaret Hospital, Toronto, ON; Margaret Liu, Toronto Rehabilitation Institute, Toronto, ON; Rosemary Martino, University of Toronto, Toronto, ON; Nancy Mayo, McGill University, Montreal, QC; Neil MacDonald, McGill University, Montreal, QC; Deborah McLeod, Dalhousie University, Halifax, NS; Tricia Morrison, University of Ottawa, Ottawa, ON; Maureen Parkinson, BC Cancer Agency; Stephanie Phan, Princess Margaret Hospital, Toronto, ON; Susan Rappolt, University of Toronto, Toronto, ON; Ana Maria Rodriguez, McGill University, Montreal, QC; Roanne Thomas, University of Ottawa, Ottawa, ON; Margaret Tompson, cancer survivor, Saskatoon, SK.