

INVESTMENT IN RESEARCH ON SURVIVORSHIP AND PALLIATIVE AND END-OF-LIFE CARE, 2005–2008

A SPECIAL REPORT FROM **THE
CANADIAN CANCER RESEARCH
ALLIANCE'S** SURVEY OF
GOVERNMENT AND VOLUNTARY
SECTOR INVESTMENT IN
CANCER RESEARCH



Canadian Cancer Research Alliance • Alliance
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SEPTEMBER 2011

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1. INTRODUCTION

1.1 REPORT PURPOSE AND PLAN

In 2005 the Canadian Cancer Research Alliance (CCRA) initiated the Canadian Cancer Research Survey (CCRS), a survey and supporting database of cancer research projects funded by many of the key organizations in Canada that invest in cancer research. The CCRA's first report, in 2007, looked at research investment in 2005. Three updates have been released since then. In addition to these annual scans of cancer research investment, the CCRA has also published investment reports on research topics of strategic importance to CCRA members such as childhood cancers, cancer risk and prevention, and early translation.

This report focuses on yet another special topic, cancer survivorship and palliative and end-of-life care. It is the first to quantify investment in these two related areas of research. The framework used to classify the research was developed specifically for this report and is detailed in the next chapter. It allows the investment to be stratified by subcategories of research and tracked over time.

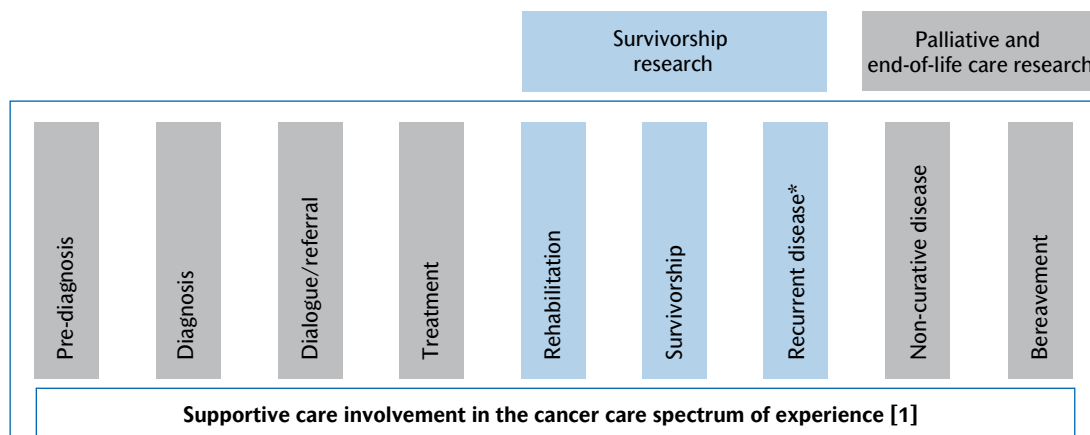
Fitch and colleagues¹ presented a conceptual framework of supportive care involvement across the cancer care spectrum (see Figure 1.1.1). It is a useful way to illustrate cancer survivorship research and palliative and end-of-life care research, and how they relate to other another in terms of the cancer care trajectory. In the next two sections, we fully describe each research area and then define how they are used in this report.

Cancer survivorship research and palliative and end-of-life care research are relatively new and emerging fields. We hope that the findings on the relative research investment in survivorship and palliative and end-of-life care in Canada will give funders key information to help them identify critical research gaps, enabling future investments to be strategically directed.

1. M.I. Fitch et al., eds., *Supportive Care Framework: A Foundation for Person-Centred Care* (Pembroke: Pappin Communications, 2008).

FIGURE 1.1.1

RESEARCH INCLUDED IN THIS REPORT



* Treatment of recurrent disease is not included.

[1] Conceptual image from M.I. Fitch et al., eds., *Supportive Care Framework: A Foundation for Person-Centred Care* (Pembroke: Pappin Communications, 2008): 143.

1.2 SURVIVORSHIP RESEARCH

“Issues facing the cancer survivor are not extensions of the issues facing the cancer patient in treatment. There is a diversity of sequelae encompassing physical and physiological sequelae that require medical management on the one hand and societal and interpersonal issues, including changed lifestyle, disruption of home and family roles and their fear of recurrence on the other.”

From Noreen M. Aziz, “Cancer survivorship research: challenge and opportunity,” *Journal of Nutrition* 132 (Suppl) (2002): 3496S.

Extrapolating from United States estimates,^{2,3} Canada will have nearly 2,000,000 cancer survivors by the end of the decade.⁴

2. S.F. Altekruse et al., “SEER cancer statistics review, 1975–2007” (Bethesda, MD: National Cancer Institute: 2010) (based on November 2009 data submission), as reported in *Morbidity and Mortality Weekly (MMWR) Report* 60(9) (March 11, 2011): 269–272. These data showed a 290% increase from 1971 to 2007 in the number of living persons ever diagnosed with cancer.
3. A.B. Mariotto, K.R. Yabroff, Y. Shao, E.J. Feuer, and M.L. Brown, “Projections of the cost of cancer care in the U.S.: 2010–2020,” *Journal of the National Cancer Institute* 103(2) (2011): 117–128. According to the projections by Mariotto et al., more than 5% of the U.S. population in 2020 will be cancer survivors.
4. At present, there is no agreed-upon international standard for calculating or projecting cancer prevalence, and data on point are not available in Canada. As reported in the Canadian Cancer Society’s Steering Committee on Cancer Statistics, *Canadian Cancer Statistics 2011* (May 2011), 748,897 people who had been diagnosed with one or more primary invasive cancers since 1997 were alive on January 1, 2007.

The growing number of cancer survivors is likely due to two major factors:

- improvements in survival rates over the last 30 years, from an overall five-year relative survival of about 40% for 1974–1978⁵ to 62% for 2004–2006.⁶ These improvements are largely due to earlier diagnosis through screening, public health initiatives like smoking cessation, and new and different cancer treatments, particularly combination treatments.⁷ Survival rates, however, vary among cancer types and improved rates have not been found for all cancer types.
- Canada’s aging population, which has created a steady rise in the number of new cancer cases: in 2011, the estimated number of new cases is 177,800.⁸

Views differ on when a person with cancer may be declared a cancer survivor and whether the term “survivor” is appropriate (see sidebar). The Cancer Journey Portfolio of the Canadian Partnership Against Cancer has defined “survivor” as follows: “a survivor is a person who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. So, in cancer, survivorship should be considered the state from the time of diagnosis until the end-of-life...”⁹ The impacts on family members are also included under the survivorship umbrella.

WHO IS A CANCER SURVIVOR?

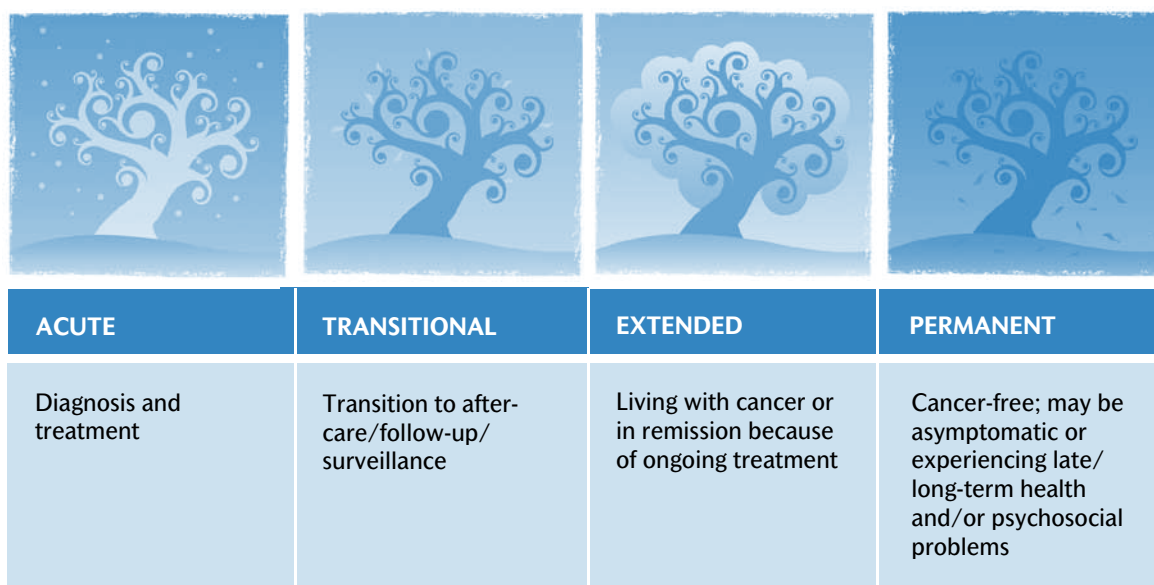
“Among health professionals, people with a cancer history, and the public, views differ as to when a person with cancer becomes a survivor. Many consider a person to be a survivor from the moment of diagnosis; in recent years, this view has become increasingly prevalent. Some, however, think that a person with a cancer diagnosis cannot be considered a survivor until he or she completes initial treatment. Others believe a person with cancer can be considered a survivor if he or she lives five years beyond diagnosis. Still others feel that survivorship begins at some other point after diagnosis or treatment, and some reject the term ‘survivor’ entirely, preferring to think of people with a cancer history as fighters, ‘thrivers,’ champions, patients, or simply as individuals who have had a life-threatening disease. A considerable number of people with a cancer history maintain that they will have survived cancer if they die from another cause.”

From *Living Beyond Cancer: Finding a New Balance*. President’s Cancer Panel 2003–2004 Annual Report. Prepared by S.H. Reuben for The President’s Cancer Panel (Bethesda, MD: National Cancer Institute, 2004): 5.

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5. National Cancer Institute of Canada, *Canadian Cancer Statistics 1989* (Toronto: National Cancer Institute of Canada, 1989).
 6. Canadian Cancer Society’s Steering Committee on Cancer Statistics, *Canadian Cancer Statistics 2011* (Toronto: Canadian Cancer Society, 2011).
 7. J. Corner, “Addressing the needs of cancer survivors: Issues and challenges,” *Expert Review of Pharmacoeconomics & Outcomes Research* 8(5) (2008): 443–451.
 8. Canadian Cancer Society’s Steering Committee on Cancer Statistics, *Canadian Cancer Statistics 2011* (Toronto: Canadian Cancer Society, 2011).
 9. See <http://www.partnershipagainstcancer.ca/priorities/cancer-journey/strategic-initiatives/survivorship/>. This definition is based on the U.S. National Cancer Institute’s definition of survivor.

Miller¹⁰ in an extension of Mullan's "seasons of survival,"¹¹ described cancer survivorship in four phases, from acute (the diagnosis and primary treatment phase) to permanent (the cancer-free phase, characterized by varying degrees of health or psychosocial problems). See Figure 1.2.1. The seasons of survival illustrates how the issues and needs of survivors vary depending on where they are in the cancer journey. The extended and permanent phases make the model relevant to different types of cancer and post-treatment outcomes. In addition, this model does not incorporate advanced disease or end of life, so it is consistent with our decision to separate the two areas in our report.

FIGURE 1.2.1
SEASONS OF CANCER SURVIVORSHIP [1]



[1] Adopted from K.D. Miller's, "Revisiting the seasons of survival," *Cure* (Summer 2009) (available at http://www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article_id/1142), which is based on F. Mullan's, "Seasons of survival: reflections of a physician with cancer," *New England Journal of Medicine* 313(4) (1985): 270–273.

The primary goal of survivorship research "is to understand, and thereby reduce, the adverse effects of cancer diagnosis and treatment and to optimize outcomes for cancer survivors and their families."¹² Survivorship research is focused on sustaining the success of treatment and addressing the immediate, mid-term, and long-term physiological, psychological, social, practical, functional and spiritual effects of cancer and its treatment.

10. Kenneth D. Miller, "Revisiting the seasons of survival," *Cure* (Summer 2009) (available at http://www.curetoday.com/index.cfm/fuseaction/article.show/id/2/article_id/1142).

11. Fitzhugh Mullan, "Seasons of survival: Reflections of a physician with cancer," *New England Journal of Medicine*, 1985, 313(4) (1985): 270-273.

12. Maria Hewitt, Sheldon Greenfield and Ellen Stovall, eds., *From Cancer Patient to Cancer Survivor: Lost in Transition* (Washington, D.C.: The National Academies Press, 2006): 434.

Conducting survivorship research has challenges. The cancer survivor population is diverse. The cancer site, stage, and histology, the treatment received (treatment protocols are ever evolving), and other pre-existing health conditions influence the nature of late effects and recurrence. Because cancer is predominantly a disease of older adults, it can be difficult to isolate the effects of cancer and its treatment from the processes of normal aging and concurrent comorbidities.¹³ Survivorship studies require extended follow-up periods especially if they focus on the identification of recurrent cancers, new primary cancers, and late effects with long latency periods.¹⁴ Child, adolescent, and young adult cancer survivors likewise require prolonged follow-up, because any studies must consider such additional issues as biological maturation, transitions of care, and educational attainment. Furthermore, the care that survivors receive varies widely. Although this variation has been attributed to a lack of research evidence, which would otherwise provide an adequate evidence base for practice,^{15,16} high quality evidence is generally only obtained when the outcomes of uniform practices can be observed and compared across a large number of subjects.¹⁷ Privacy legislation is another key consideration. Survivorship research projects, when they involve long-term follow-up and patient-level health-care data, may require accessing data from different jurisdictions.

For pragmatic reasons, projects includes only those projects conducted post-primary cancer treatment. They focused on:

- post-cancer treatment rehabilitation
- long-term or late complications of cancer and its treatments
- other physical and psychological impacts experienced by cancer survivors and their family/caregivers
- social support needs of cancer survivors and their family/caregivers
- economic sequelae of cancer for survivors and their family/caregivers
- interventions to improve quality of life
- the delivery of care, access to care, and quality of care received by survivors after their primary cancer treatment

Model systems research relevant to cancer survivors, like the effects of chemotherapy on the cognitive function in an animal model, is also included.

13. Smita Bhatia and Leslie L. Robinson, "Cancer survivorship research: Opportunities and future needs for expanding the research base," *Cancer Epidemiology, Biomarkers & Prevention* 17(7) (2008): 1551–1557.

14. Hewitt, Greenfield, and Stovall, 452.

15. Bhatia and Robinson, 1553.

16. The Partnership's Cancer Journey Survivorship Expert Panel will soon release the Pan-Canadian clinical practice guidelines on the organization and structure of survivorship services and psychosocial-supportive care best practices for adult cancer survivors.

17. Craig C. Earle, "Cancer survivorship research and guidelines: Maybe the cart should be beside the horse," *Journal of Clinical Oncology* 25(25) (2007): 3800–3801.

1.3 PALLIATIVE AND END-OF-LIFE CARE RESEARCH

“Palliative care is an interdisciplinary team approach to care, with a focus on comfort and quality of life rather than prolongation of life or ‘cure’ for a patient and their loved ones. Depending on the palliative care issue, many various treatment approaches may be available to manage symptoms and complications of advanced cancer. Common palliative care problems include pain, cachexia, asthenia, and wound issues.”

From Robert S. Krouse, “Palliative care for cancer patients: An interdisciplinary approach,” *Cancer Chemotherapy Review* 3(4) (2008): 152.

In 2007 the number of deaths caused by cancer surpassed those caused by major cardiovascular diseases.¹⁸ An estimated 75,000 people in Canada are expected to die from cancer in 2011.¹⁹ Although survival rates have increased for a number of cancers, unfortunately, for some people, cancer is terminal.

As defined by the World Health Organization, “palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”²⁰ There is no universally agreed-upon time when palliative care begins for the cancer patient. Recent literature, however, supports integrating palliative care throughout the cancer disease trajectory to recognize that the needs of individuals with advanced disease should be driving the care received.²¹ End-of-life care is part of palliative care and usually refers to the care provided during the last part of life when a progressive and rapid state of decline is evident: see Figure 1.3.1.

Research in the palliative and end-of-life care has been challenging in Canada, given considerable provincial differences in the organization and delivery of care and the lack of a national palliative and end-of-life care strategy.²² A recent study found that Canada was outranked by eight other countries in terms of the quality and availability of end-of-life care.²³

18. Statistics Canada, *Mortality, Summary List of Causes 2007* (November 2010), Catalogue No: 84F0209XWE. Available at <http://www.statcan.gc.ca/pub/84f0209x/84f0209x2007000-eng.pdf>.

19. Ibid.

20. <http://www.who.int/cancer/palliative/definition/en/>

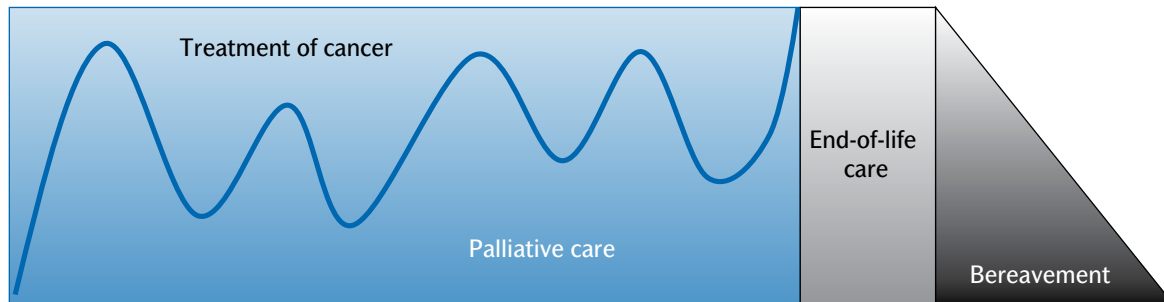
21. P. Mazanec et al., “A new model of palliative care for oncology patients with advanced disease,” *Journal of Hospice and Palliative Nursing* 11(6) (2009):324–331.

22. Active funding of Health Canada’s Canadian Strategy on Palliative and End-of-Life Care ended in 2007.

23. Economist Intelligence Unit, *The Quality of Death: Ranking End-of-Life Care Across the World*, 2010. Available at http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf.

FIGURE 1.3.1

MODEL OF PALLIATIVE AND END-OF-LIFE CARE [1]



[1] Adopted from P. Mazanec et al., "A new model of palliative care for oncology patients with advanced disease," *Journal of Hospice and Palliative Nursing* 11(6) (2009): 324–331.

The authors attributed Canada's ranking to the economic burden of home care largely shouldered by Canadian families at the end of life. Palliative and end-of-life care may be delivered in acute care settings, long-term care settings, hospices, and personal residences. Disseminating evidence-based interventions across this wide variety of settings is crucial. The literature identifies lack of research capacity and funding, lack of consensus on definitions and outcomes (for example, quality of death), and ethical issues as challenges in this research area.²⁴ The small size of the care community in Canada further complicates pediatric palliative and end-of-care research, making collaboration and partnerships critical to knowledge dissemination.²⁵

Within the context of this report, palliative and end-of-life care research included studies on:

- pain, cachexia, delirium, respiratory issues, and other physical symptoms associated with advanced and metastatic cancer
- the spiritual, emotional, and social support needs of patients with advanced disease and their families, and issues of bereavement and grieving
- end-of-life care and how best to deliver quality care for patients with advanced disease
- the quality of death
- ethical issues associated with death and dying

Model systems research relevant to palliative and end-of-life care, such as testing of palliative therapies for pain management using mouse models, is also included.

24. K.R. Sigurdardottir, "Clinical priorities, barriers and solutions in end-of-life cancer care research across Europe. Report from a workshop," *European Journal of Cancer* 46(10) (2010): 1815–1822.

25. L. Straatman et al., "Paediatric palliative care research in Canada: Development and progress of a new emerging team," *Paediatric Child Health* 13(7) (2008): 591–594.

2. METHODOLOGY

A list of key abbreviations used in this report is available in Appendix A.

2.1 PROJECT IDENTIFICATION

The data source for this study was the CCRS database. This database consists of peer-reviewed cancer research projects funded by 39 organizations or programs within the federal and provincial governments and the voluntary sectors from January 1, 2005 to December 31, 2008. It includes organizations that fund only cancer research (for example, The Cancer Research Society) and organizations that fund all types of health research (for example, the Nova Scotia Health Research Foundation), and general research and technology (for example, Canada Foundation for Innovation).

The database includes all research projects funded by cancer research organizations. Research projects funded by other health and general science research funders, however, are assessed for their cancer relevance. A project is included only if cancer is specifically mentioned in the available project descriptions (face validity), with the exception of research projects on tobacco control.²⁶

All projects in the CCRS database are coded in terms of the Common Scientific Outline (CSO), cancer site (using the International Statistical Classification of Diseases and Related Health Problems, ICD-10), and type of funding mechanism (definitions can be found in the sidebar on the following page). The CSO is an international standard for classifying cancer research. It has seven categories (1 – Biology, 2 – Etiology, 3 – Prevention, 4 – Early Detection, Diagnosis, and Prognosis, 5 – Treatment, 6 – Cancer Control, Survivorship, and Outcomes Research, and 7 – Scientific Model Systems), which are rolled up from 38 codes. (Details about the CSO can be obtained at <http://www.cancerportfolio.org/cso.jsp>.) The number of CSO codes assigned to projects in the CCRS ranges from one to nine.

The database currently holds 9,233 projects. For the purposes of this study, projects coded to the CSO category, 6 – Cancer Control, Survivorship, and Outcomes Research (n=1,355), were reviewed for their relevance to the topic of survivorship and palliative and end-of-life care.

Excluded projects focused on:

- surveillance of intervention strategies, risk factors
- tobacco control research
- behavioural research focused on cancer prevention and screening
- large-scale infrastructure projects with broad, multi-focused objectives

26. All tobacco projects funded by the organizations contributing to the CCRS are included in the database unless the research is focused solely on diseases other than cancer.

DEFINITIONS OF FUNDING MECHANISMS

Operating grants: competitive grants that support all the direct costs involved in conducting specific research projects performed by identified researchers. Operating grants typically cover salaries for laboratory staff and research assistants/associates/trainees, costs of research equipment and supplies, and other specific research-related expenses. Multi-component projects (program projects), feasibility grants, proof-of-principle grants, regional development grants, innovation grants, and knowledge translation grants are all included in this category.

Equipment/infrastructure grants: competitive grants that cover, in part or in full, the costs of construction or major remodelling of new research facilities, and/or the purchase, housing, and installation of equipment, scientific collections, computer software, information databases, and communication linkages used primarily for conducting research.

Career awards: competitive awards that provide protected time for research on either a long- or short-term basis to outstanding researchers who have demonstrated high levels of productivity and research accomplishments. These awards are given to only a small percentage of all researchers. (They may also be called salary awards.) Research chairs and establishment grants (grants designed to facilitate the recruitment of outstanding researchers) are also included under this funding mechanism.

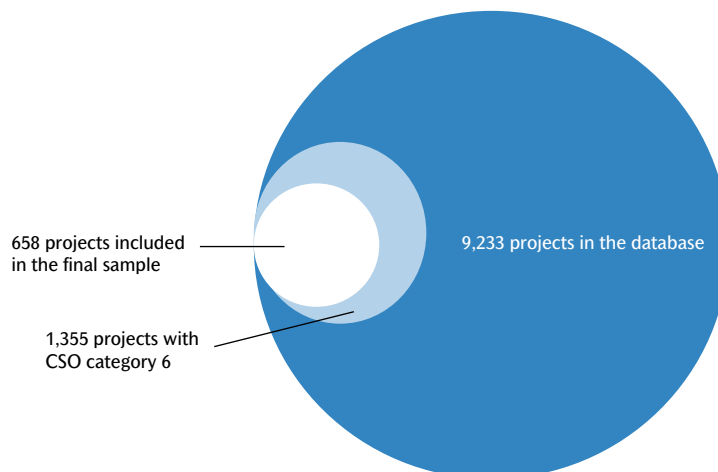
Trainee awards: competitive awards that recognize outstanding trainees and support them during their undergraduate, graduate, or post-graduate training. Trainees from Canada who are studying at institutions outside Canada may also be eligible for some types of trainee awards. Block training grants given to institutions, which, in turn, distribute the monies to trainees through a competitive process, are also included under this funding mechanism. These awards are in addition to trainee salaries covered in operating grants.

Related support grants: competitive grants that support travel, workshops/symposia, and researcher time for proposal development/letters of intent. These grants involve small sums of money.

The final sample of projects was 658 (see Figure 2.1.1).

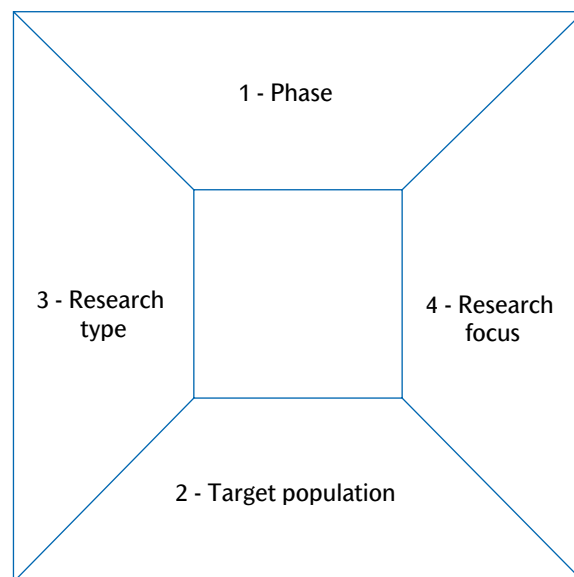
FIGURE 2.1.1

PROJECTS SELECTED FOR INCLUSION IN THE CALCULATION OF RESEARCH INVESTMENT IN SURVIVORSHIP AND PALLIATIVE AND END-OF-LIFE CARE



To assess the reproducibility of the exclusion criteria, a secondary coder reviewed a random sample of 200 projects from the pool of 1,355 projects. Observed agreement between the primary and secondary coders was 99.5% overall. The Cohen's kappa coefficient (unweighted) was 0.98 (95% confidence intervals 0.94–1.00), indicating “almost perfect agreement,” according to the interpretation guidelines developed by Landis and Koch.²⁷ For the sample of projects involved in the inter-rater reliability assessment, the two coders discussed discordant coding and they made a final determination to include or exclude.

FIGURE 2.2.1
FOUR DIMENSIONS OF PROJECT CLASSIFICATION



2.2 PROJECT CLASSIFICATION

The classification covered four different dimensions as summarized below (see overview in Figure 2.2.1).

DIMENSION 1 – PHASE

- **Palliative and end of life** – This phase focuses on both the care given to advanced and metastatic cancer patients and issues relevant to advanced and metastatic cancer patients at the end of life: for example, *Understanding and enhancing the quality of life of palliative care patients and their family/caregivers*
- **Survivor** – This phase focuses on all other post-primary cancer treatment care: for example, *Identifying and examining a model of stress management in breast cancer survivors: the role of physical activity*

27. J.R. Landis and G.G. Koch, “The measurement of observer agreement for categorical data,” *Biometrics* 33 (1977): 159–174.

DIMENSION 2 – TARGET POPULATION

- **Family/caregivers** – for example, *Psychological distress of informal caregivers who support patients suffering from advanced cancer*
- **Patients** – for example, *Examination of the impact of a physical activity intervention on adolescent cancer survivors: determinants of health related quality of life*

DIMENSION 3 – RESEARCH TYPE

TYPE	DESCRIPTION	EXAMPLE
Model systems	Research conducted in animals, human or animal cells, or other test systems or theoretical models.	Role of neurotensin receptors in a mouse model of chronic cancer pain
Descriptive	Studies that observe/describe human behaviour, interaction, or systems prospectively or retrospectively. Covers the range of studies from small, single-centre, non-randomized studies to cohort or population-based studies. Administrative data sources or registries may be involved.	Prevalence of neuropathic pain symptoms in patients with cancer bone pain referred for palliative radiotherapy
Intervention	Research on treatments/programs designed to prevent/control adverse treatment-related and late effects of cancer and/or optimize health/quality of life. The intervention may be directed at survivors, family/caregivers, or formal care providers. It may be pharmaceutical, surgical, psychotherapeutic, behavioural, supportive, informational, etc. Includes retrospective observational studies.	A Phase III international randomized trial of single versus multiple fractions for re-irradiation of painful bone metastases
Prediction/assessment	Studies focused on systematically assessing/ measuring and predicting symptoms, outcomes, and late effects. Includes research on instrument development, validation, and refinement as well as statistical approaches to improve measurement.	Identifying factors associated with functional decline in older women living with breast cancer: Development and validation of a self-reported risk profile
Knowledge synthesis	Projects that aggregate/summarize the existing body of knowledge by applying specific methods of research identification and appraisal (for example, systematic reviews, meta-analyses).	Systematic review: Measures of sexual quality of life for female cancer survivors
Other support	Funding for projects that support the conduct of research (for example, capacity building grants, support for research networks and workshops, equipment and infrastructure grants).	The Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research: Bridging the gap for chronic cancer care

DIMENSION 4 – RESEARCH FOCUS

Improved quality of life is the optimal goal of survivorship and palliative and end-of-life care. For this report, projects that addressed a broad range of symptoms and outcomes, rather than specific effects as identified under the other foci, were coded to quality of life. Descriptive studies of the impacts of survivorship on quality of life, studies on refinements in tools designed to measure quality of life, and intervention studies designed to improve overall well being are examples of the projects coded to quality of life.

FOCUS	DESCRIPTION	EXAMPLE
Physiological effects	Studies identifying and managing specific late/long-term physical effects of cancer/cancer treatment (e.g., cardiovascular, respiratory, digestive, neurological, reproductive) on patients and symptoms such as pain, cachexia/anorexia, dyspnea, etc., associated with end of life. Includes physiological effects experienced by family/caregivers.	Charting the course of arm morbidity in breast cancer: A prospective, longitudinal follow-up
Psychological effects	Research identifying and managing specific psychological effects (for example, depression, anxiety, distress, fear of recurrence, intimacy issues) of survivorship/end of life for patients and family/caregivers.	Screening for depression in breast cancer patients: Acute distress versus persistent distress
Quality of life	Research focused on a broad range of symptoms/outcomes rather than specific effects as identified under other foci. Includes projects focused on survivors and/or family/caregivers from post-treatment to end of life.	Exploring the impact of thyroid cancer on young women's quality of life
Social needs/social support	Studies on the social support needs of survivors and family/caregivers.	The role of prostate cancer support groups in health promotion
Economic sequelae	Studies of the economic effects of cancer for survivors and their families/caregivers. Research dealing with work/employment and vocational/educational issues are also included.	The impact of out-of-pocket costs, provincial/territorial medical travel and drug policies on breast and prostate cancer patients
Care delivery, access, and quality	Research on the ways that post-treatment and end-of-life care are delivered/organized and effects on individuals and systems. Includes evaluative studies, research on optimal care models, studies on gaps/inequities in access, costs/cost-effectiveness of care, and quality of care.	Different profiles of care received by patients dying of cancer during the last six months of life: A study based on administrative datasets
Thanatological issues	Research on death/dying and the psychological mechanisms of dealing with death/dying. Includes attitudes toward death, meaning and behaviours of bereavement and grief, and moral/ethical issues.	Engaging existential suffering in end-of-life: a grounded theory inquiry

To assess the robustness of the framework as applied to the CCRS dataset, a primary and a secondary coder classified 171 projects on the four dimensions. Results are summarized in Table 2.2.1. The two coders discussed discordant coding to arrive at a determination of the final project classification.

TABLE 2.2.1

INTER-RATER AGREEMENT ON THE FOUR DIMENSIONS OF THE CLASSIFICATION FRAMEWORK

Dimension	Observed Agreement	Unweighted Kappa (.95 confidence limits)	Interpretation [1]
1 – Phase	0.96	0.91 (0.84-0.97)	“Almost perfect” agreement
2 - Target population	0.96	0.87 (0.76-0.97)	“Almost perfect” agreement
3 - Research type	0.92	0.88 (0.87-0.97)	“Almost perfect” agreement
4 - Research focus	0.95	0.88 (0.83-0.94)	“Almost perfect” agreement

[1] J.R. Landis and G.G. Koch, “The measurement of observer agreement for categorical data,” *Biometrics* 33 (1977): 159–174.

2.3 REPORTING CONVENTIONS

The CCRS uses a calendar year time frame to standardize the disparate funding cycles of participating organizations to consistent 12-month periods. In this report the investment for each project was based on a prorated calculation that assumed that project dollars were paid in equal monthly instalments in accordance with project start and end dates. Project funding was calculated for the period January 1, 2005 to December 31, 2008 and the four-year totals were averaged to generate annual investments. Figures shown in the tables and charts are rounded and may not always equal the totals shown.

Project budgets are weighted or allocated in a variety of ways as summarized in Table 2.3.1. Project budgets were weighted from 10% to 100%. Most project budgets (79.2%) were included in full: see Table 2.3.2. Projects focused on end-of-life care that did not specifically mention a cancer patient population were weighted at 80%, based on Canadian experts' estimates of the proportion of the palliative and hospice care patients with a cancer diagnosis.²⁸

TABLE 2.3.1

EXAMPLES OF WAYS IN WHICH PROJECT BUDGETS WERE WEIGHTED

Issue	Example	Approach
Project is not entirely focused on cancer	Quality of end-of-life care: The perspectives of bereaved family members of lung cancer and chronic obstructive pulmonary disease	Budget was weighted at 50% as the research was looking at cancer and chronic obstructive pulmonary disease.
Project is focused on end-of-life without specifying a focus on cancer	Human dignity, narrative integrity and ethical decision-making at the end-of-life	Budget was weighted at 80% because a cancer target population was not mentioned.
Project does not entirely qualify as survivorship or palliative and end-of-life care research	Image guided radiotherapy for primary and metastatic liver cancer	Budget was weighted at 50% because the project had two parts: one focused on primary treatment and a second focused on palliative treatment.
Project involves more than one research focus	Emotion regulation among caregivers: Implications for psychological and physical health	Budget was split between physiological and psychological effects.
Project spans more than one research type	Protecting patients from fatigue and exhaustion due to advanced cancer in active treatment and palliative care settings	Budget was assigned 50-50 to both descriptive and intervention research types.
Project involves more than one cancer site	Post-traumatic stress disorder in young males diagnosed with testicular or lymphatic cancer	Budget was allocated to two cancers (testicular cancer and lymphoma) as the study looked at survivors who had one of these cancers.

28. This estimate was based on advice received from Ms Sharon Baxter (Canadian Hospice Palliative Care Association), Dr. Harvey Chochinov (CancerCare Manitoba), and Dr. G. Michael Downing (Victoria Hospice).

TABLE 2.3.2
DISTRIBUTION OF WEIGHTINGS APPLIED TO INCLUDED PROJECTS

Weighting	Number of Projects	% Projects	Investment
10	4	0.6	0.1
20	8	1.2	1.1
25	3	0.5	0.3
33	25	3.8	5.9
40	1	0.1	0.3
50	35	5.3	2.3
80	4	0.6	0.4
100	57	8.7	11.4
TOTAL	521	79.2	78.1

The institution with which the nominated principal investigator (PI) is affiliated was used in analyses based on geography (province). Each project has only one nominated PI. Components of multi-component projects are considered individual projects if the funders provided details on the component parts (description, researchers, budget, etc.). The Canadian Breast Cancer Research Alliance (CBCRA), the Canadian Cancer Society, National Research Council Canada, Ontario Institute for Cancer Research, and The Terry Fox Foundation gave this level of detail. Each site for each clinical trial supported by the Canadian Cancer Society through the NCIC Clinical Trials Group is treated as a separate project with its own PI and budget (based on per case and site administration funding).

All projects are coded to cancer sites using the ICD-10 in accordance with the level of detail provided in the project description. ICD-10 codes are consolidated into 24 cancer sites. Collectively, these cancer sites represent ~90% of all new cancer cases and deaths per year.

In contrast to the separate reporting of the multi-funded initiatives used in the annual cancer research investment reports from CCRA, investments are included in the figures of the relevant funders. Where the organization is not part of the CCRS (which is the case for some of the funders of the CBCRA), the investment is shown under the Canadian Breast Cancer Research Alliance, which is grouped under the voluntary sector and listed last in the relevant tables and figures.

2.4 LIMITATIONS

This study shares the same limitations as the CCRS. The CCRS captures data on projects funded on the basis of peer review and often in response to publicly announced research-granting competitions. The survey does not include all intramural cancer research supported by federal and provincial governments/agencies or by universities, hospitals, or cancer centres. The nature and scope of the investment from these excluded, sponsored research projects are not known. They may, however, be significant given the nature of research activities in the survivorship and palliative and end-of-life care areas and the level of activity conducted through the Cancer Journey Portfolio of the Canadian Partnership Against Cancer, the divisions of the Canadian Cancer Society, and others. Other non-cancer agencies that may also be investing in research on palliative and end-of-life care are not captured herein.

Health services and health economics research projects that are part of the CCRS are included in this study only if the available project descriptions specifically mentioned cancer survivorship and/or palliative and end-of-life care as a focus. It is possible that relevant projects were excluded.

Although there has been an attempt to include research funding by hospital foundations, to date, no data has been obtained. In addition, the BC Cancer Agency did not contribute data to the CCRS during the reporting period, so the figures shown for British Columbia may under-represent the investment in survivorship and palliative and end-of-life care research in that province. Research undertaken by industry is also not part of the CCRS database. Funding for survivorship and palliative and end-of-life care research by industry is expected to be far less than its investment in research on curative treatment.

This study is a snapshot of the 2005–2008 period and, as such, does not include the full amounts of specific investments in survivorship and palliative and end-of-life care areas by CCRS participating organizations. We have identified, however, the full scope of these investments in the following chapter.

3. RESULTS

Some key definitions are provided in the sidebar to help the reader in interpretation of the findings.

3.1 OVERALL INVESTMENT

From 2005 to 2008, a research investment of \$74.1M was made in the survivorship and palliative and end-of-life care research areas—an average annual investment of \$18.5M. This investment represented 4.6% of the overall cancer research investment.

The investment in survivorship and palliative and end-of-life care research rose from \$15.9M in 2005 to \$20.7M in 2008 (Figure 3.1.1). Although an upcoming report will focus on trends in investment, a net annual increase of 39.9% from 2005 to 2008 investment in survivorship is notable. This increase surpassed the increase of 21.1% for all cancer research. The net annual increase in investment in palliative and end-of-life care research, however, was much lower, at 11.7%. Investment data for all four years is shown in Figure 3.1.2.

KEY DEFINITIONS USED IN THIS REPORT

Cancer survivor: A person may be considered a survivor from the time the cancer is diagnosis until death. This report, however, includes only research projects conducted during the post-primary cancer treatment period.

Quality of life: effects of cancer on all aspects of a person's life. Unlike projects coded to specific physical or psychological effects, research projects coded to quality of life were broadly focused.

Palliative care: an approach that improves the quality of life for patients and their families who are facing a life-threatening illness.

End-of-life care: part of a palliative care approach and usually refers to the care given when the patient is progressively and rapidly declining.

Thanatological research: research on death and dying and the psychological mechanisms of dealing with death and dying. It includes research on attitudes toward death, the meaning and behaviours of bereavement and grief, and moral and ethical issues.

FIGURE 3.1.1
CUMULATIVE RESEARCH INVESTMENT BY PHASE, 2005 TO 2008

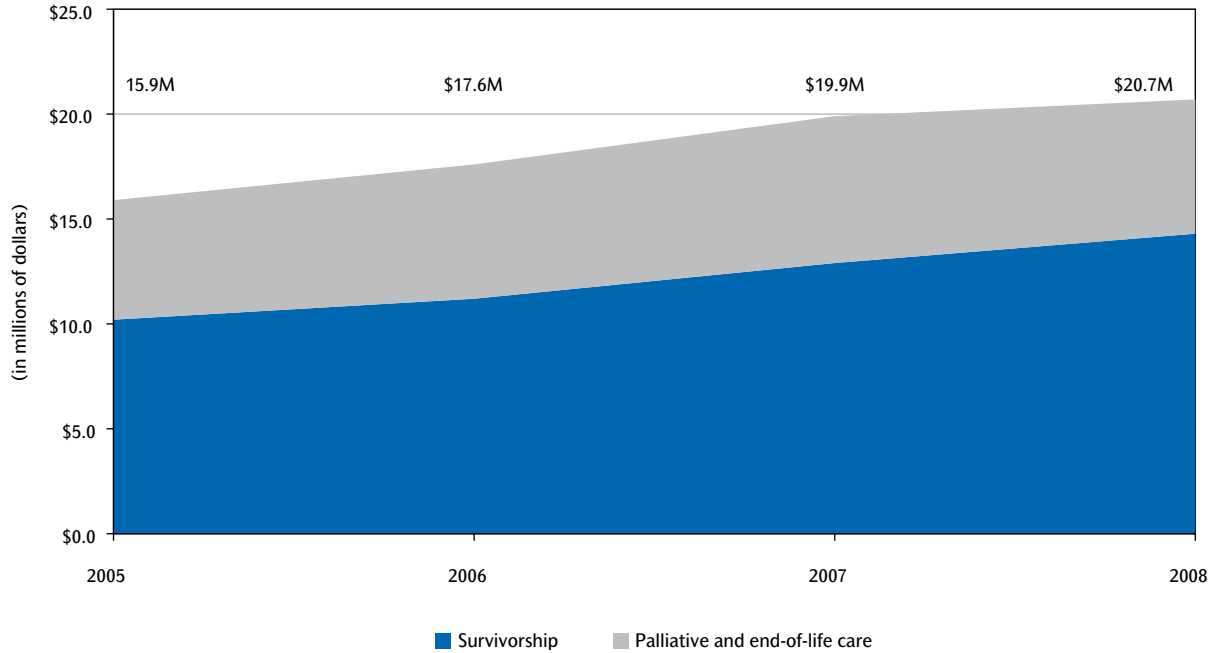
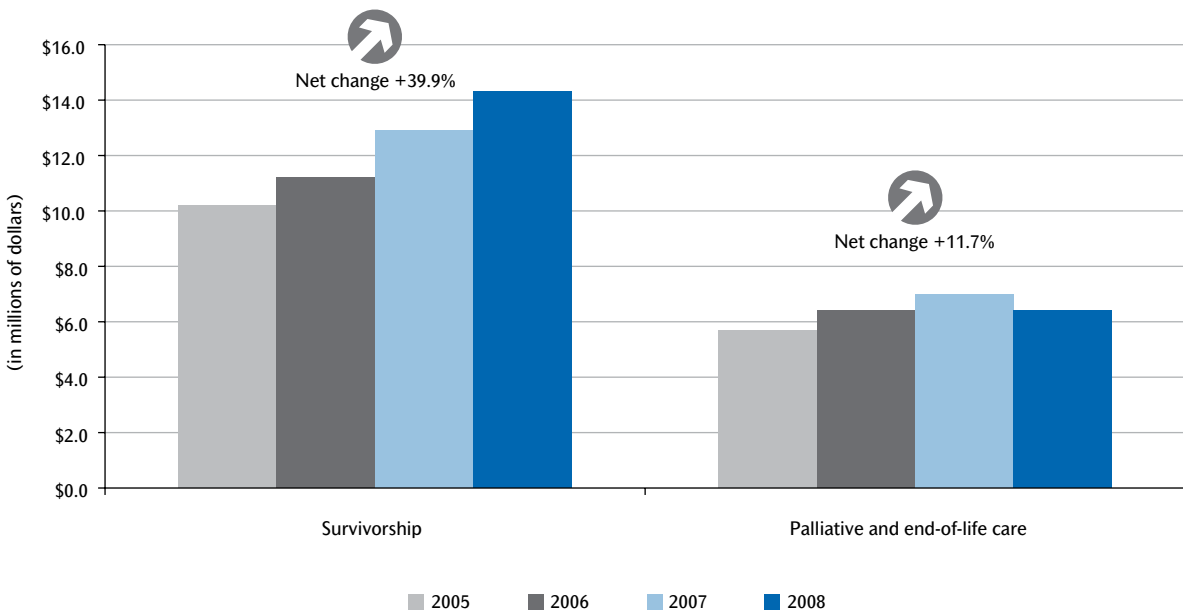


FIGURE 3.1.2
ANNUAL RESEARCH INVESTMENT IN SURVIVORSHIP AND PALLIATIVE AND END-OF-LIFE CARE, 2005 TO 2008



Nearly \$9 of every \$10 dollars was for research targeting patients with the balance targeting family/caregivers: see Figure 3.1.3. An average annual investment of \$1.6M (8.6% of the overall investment) was dedicated to research with child and adolescent study populations. A higher proportion of the research investment targeting children and adolescents focused on family/caregivers: see Figure 3.1.4, although only six projects in the palliative and end-of-life care phase focused on children and adolescents.

FIGURE 3.1.3

AVERAGE ANNUAL RESEARCH INVESTMENT BY PHASE AND TARGET POPULATION (\$18.5M)

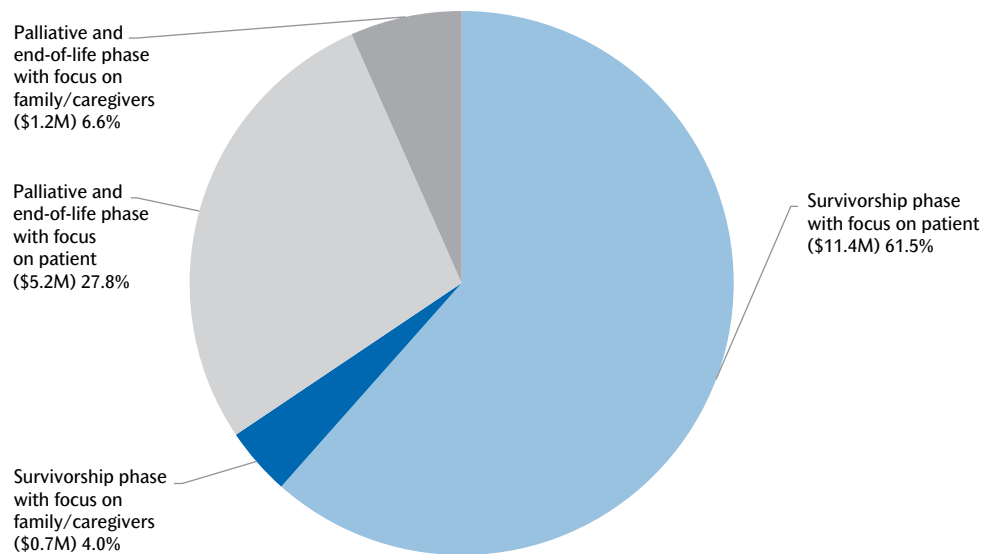
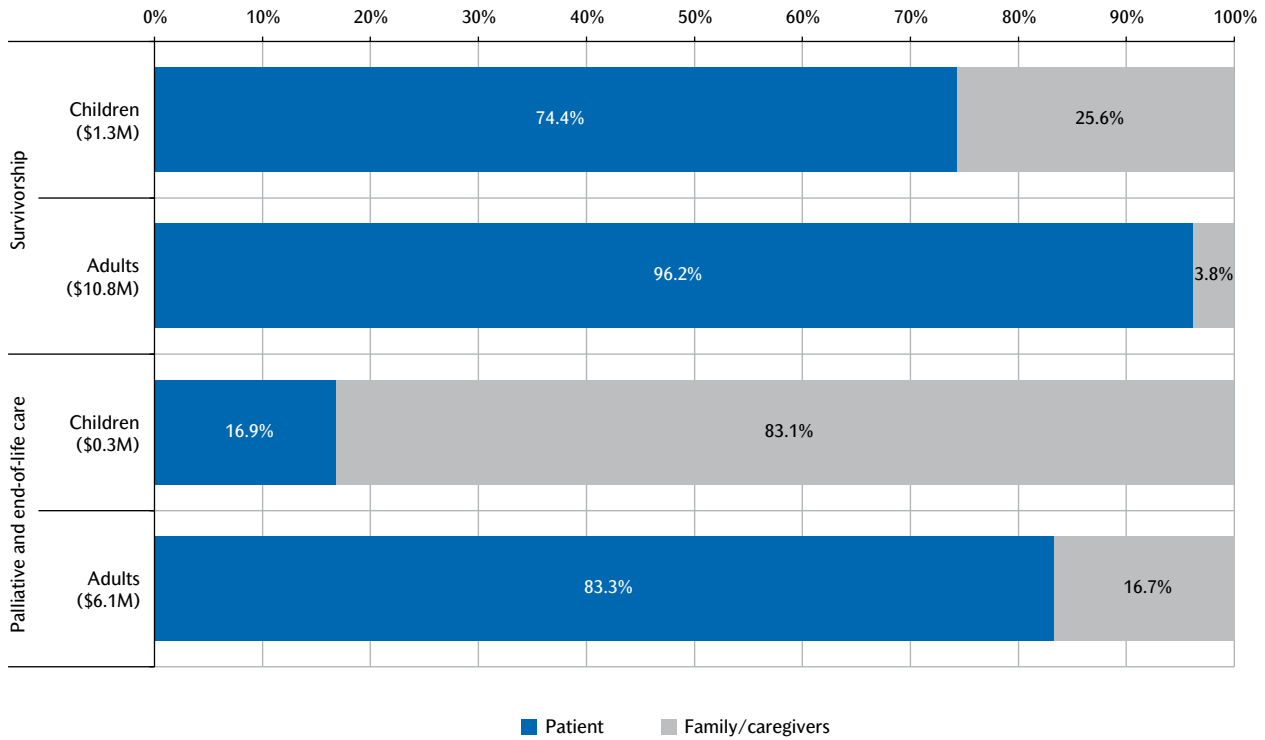


FIGURE 3.1.4

DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN RESEARCH FOCUSED ON CHILDREN AND ADULTS



Four targeted funding programs were offered during the 2005–2008 period: see details in Table 3.1.1. Together these amounted to an average annual amount of \$3.0M, or 16.4% of the total survivorship and palliative and end-of-life care research investment. Of note, the programs of the Canadian Institutes of Health Research themselves represented 28.3% of the entire investment in palliative and end-of-life care research for 2005–2008.

TABLE 3.1.1

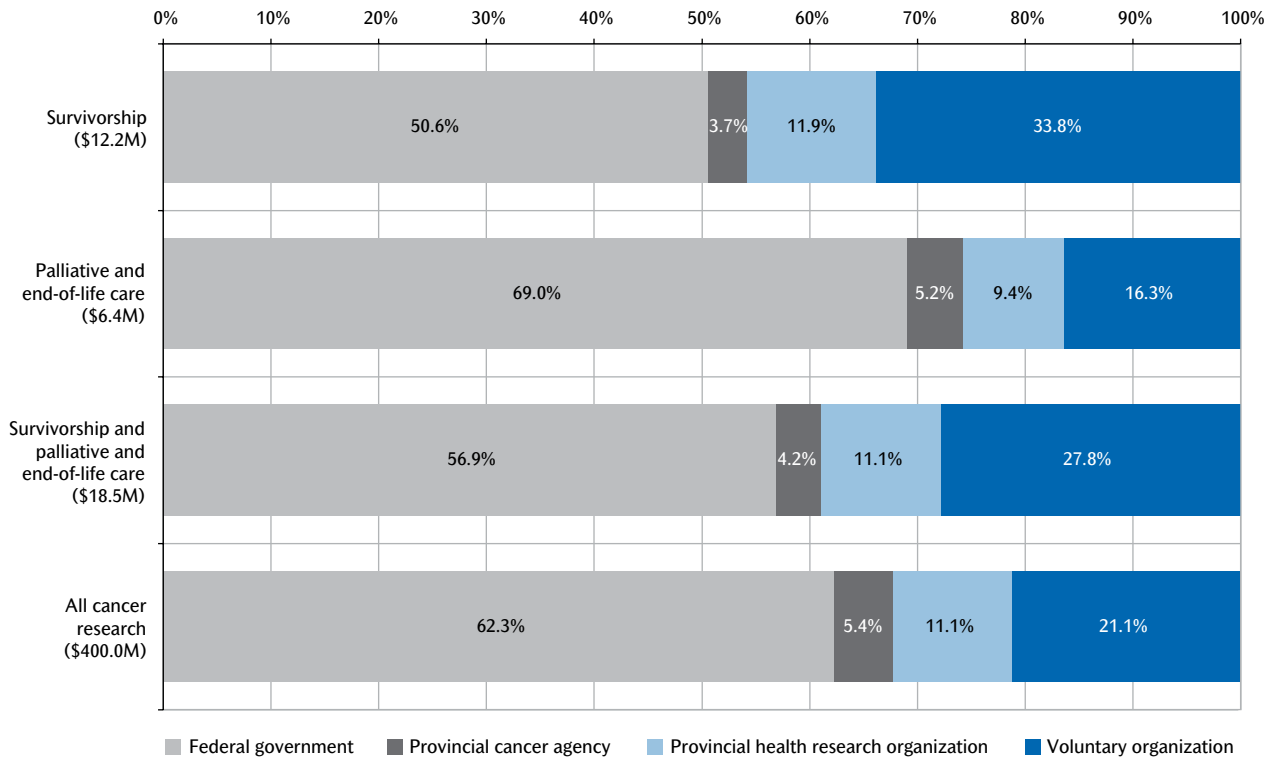
TARGETED PROGRAMS OFFERED BY ORGANIZATIONS PARTICIPATING IN THE CCRS BY INVESTMENT

Organization	Program Name	Total Program Investment	Investment Included in this Report (2005–2008)	% Total Investment in Survivorship and Palliative and End-of-life Care (\$74.1M for 2005–2008)
Canadian Breast Cancer Research Alliance	Quality-of-Life/Survivorship Research Grant	\$2,087,820	\$1,526,593	2.1
Canadian Cancer Society	Centre for Behavioural Research and Program Evaluation (CBRPE) [1]	\$6,455,864 [2]	\$3,439,455	4.6
Canadian Institutes of Health Research [3,4]	Palliative and End-of-life Care: Career Transition Awards	\$92,850	\$43,961	0.1
	Palliative and End-of-life Care: New Emerging Team Grants	\$11,123,011	\$7,175,698	9.7
TOTAL		\$19,759,545	\$12,185,707.00	16.4

- [1] This program includes one-third of the core funding for CBRPE and CBRPE's support of its three sociobehavioural cancer research network teams (Cancer Complementary and Alternative Medicine (67%), Palliative Care (100%), Physical Activity and Cancer (67%)). CBRPE was integrated with the Waterloo's Population Health Research Group in 2009 and renamed the Propel Centre for Population Health Impact.
- [2] The Canadian Cancer Society's full investment in CBRPE was \$17.6M. The figure reported in the table is weighted in terms of its relevance to survivorship and palliative and end-of-life care.
- [3] The entire strategic funding initiative from the Canadian Institutes of Health Research, under the leadership of its Institute of Cancer Research and in partnership with other organizations, was \$16.5M. The program, which ran from 2003 to 2009, focused on building research capacity and fostering research collaboration. Further support was committed in 2010 for a palliative and end-of-life care network.
- [4] The Strategic Training Program in Palliative Care Research was not included as a targeted program as it was not formally part of the Palliative and End-of-life Care Initiative.

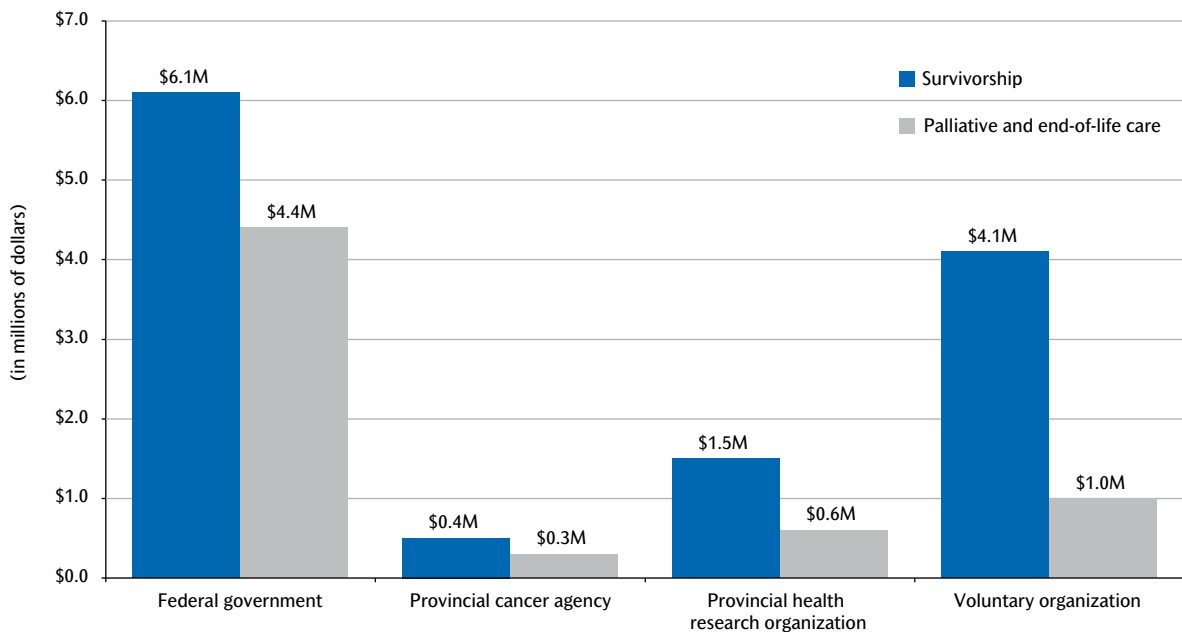
The federal government accounted for more than half the investment and its dominance was most pronounced for palliative and end-of-life care research at nearly 70% of the investment. The voluntary sector investment accounted for nearly one-third of the total survivorship research investment, significantly higher than the proportion it represented in terms of the overall cancer research investment. In contrast, the voluntary sector played a much smaller role in research funding on palliative and end-of-life care. For provincial cancer agencies and the federal government programs and agencies, there was a 3:2 ratio of investment in survivorship to palliative and end-of-life care research. For the voluntary sector, this ratio was 4:1. These data are summarized in Figures 3.1.5A and B.

FIGURE 3.1.5A
DISTRIBUTION OF AVERAGE ANNUAL RESEARCH INVESTMENT BY FUNDING SECTOR [1]



[1] The sector refers to the kind of organization that administered the funding program.

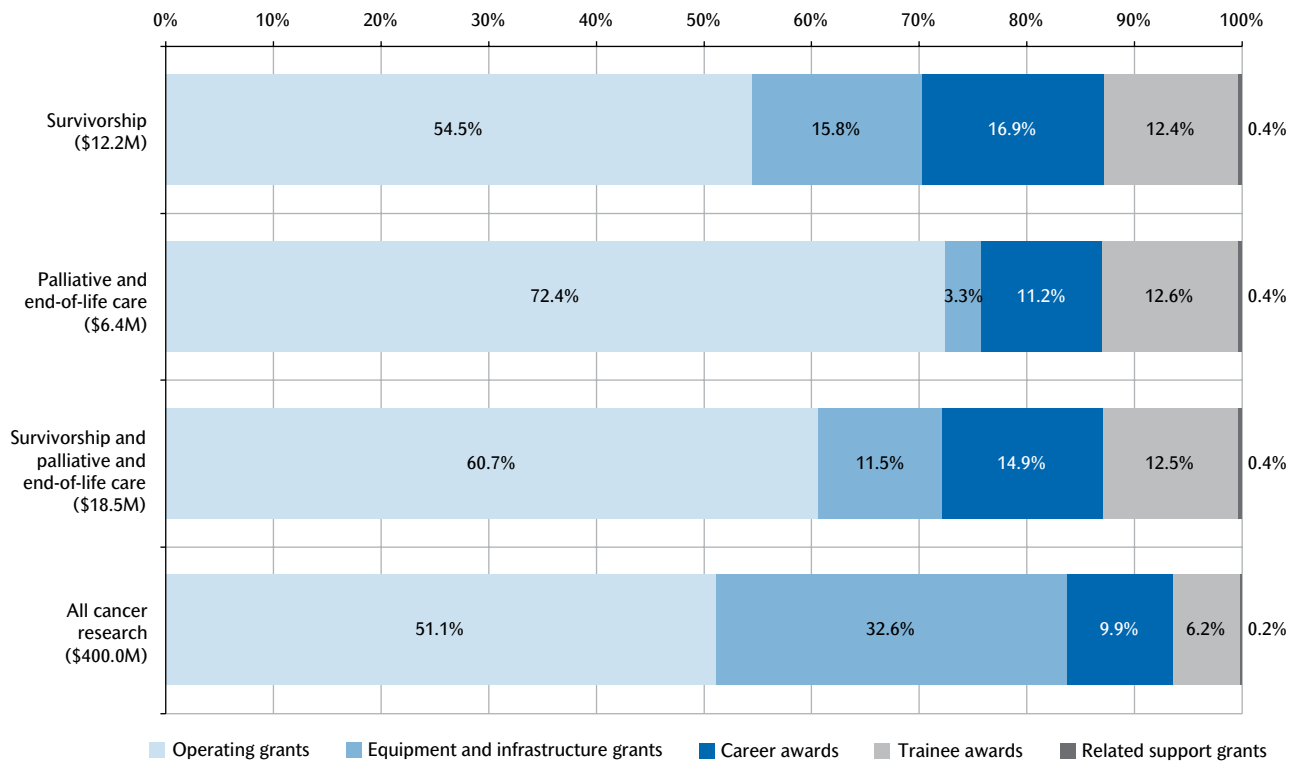
FIGURE 3.1.5B
AVERAGE ANNUAL RESEARCH INVESTMENT BY FUNDING SECTOR [1]



[1] The sector refers to the kind of organization that administered the funding program.

The investment data are stratified by funding mechanism in Figure 3.1.6. (Detailed analyses are provided in Appendix B.) The investment in operating grants for palliative and end-of-life care research was proportionately higher than in cancer research overall. Proportionately less investment in equipment and infrastructure grants and more in trainee awards was also typical of both research areas when compared with the overall cancer research investment. The investment in career awards was proportionately highest for survivorship research.

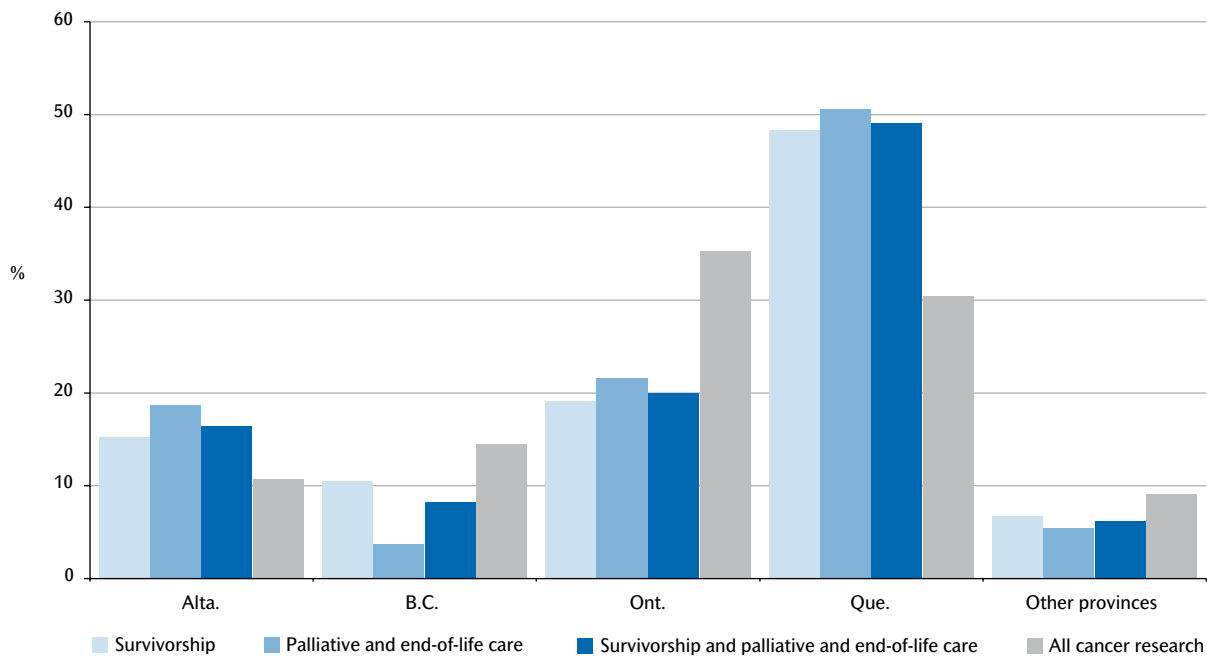
FIGURE 3.1.6
DISTRIBUTION OF AVERAGE ANNUAL RESEARCH INVESTMENT BY FUNDING MECHANISM



A detailed look at the investment data on trainee awards is presented in Figure 3.1.7. Unlike other provinces, the investments for Quebec and Alberta were proportionately higher in the survivorship and palliative and end-of-life care research areas than in cancer research overall. At almost 20% the proportional difference for Quebec was very striking. This difference resulted from the funding of two major CIHR training program grants relevant to survivorship (CIHR/ICR-funded Psychosocial Oncology Research Training (PORT) program) and palliative and end-of-life care (Palliative Care Cancer Research) awarded to principal investigators at McGill University.

FIGURE 3.1.7

**DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN TRAINEE AWARDS [1]
BY PROVINCE OF TRAINING INSTITUTION**



[1] The average annual investment includes awards given to individual trainees and to institutional training programs.

From 2005 to 2008, 245 principal investigators received operating grants, equipment and infrastructure grants, and/or career awards for research projects in the areas of survivorship and/or palliative and end-of-life care. The provincial distribution of these investigators is shown by numbers (Figure 3.1.8A) and by proportion of all cancer researchers (Figure 3.1.8B).

FIGURE 3.1.8A

NUMBER OF PRINCIPAL INVESTIGATORS CONDUCTING SURVIVORSHIP AND PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY PROVINCE (N=245)

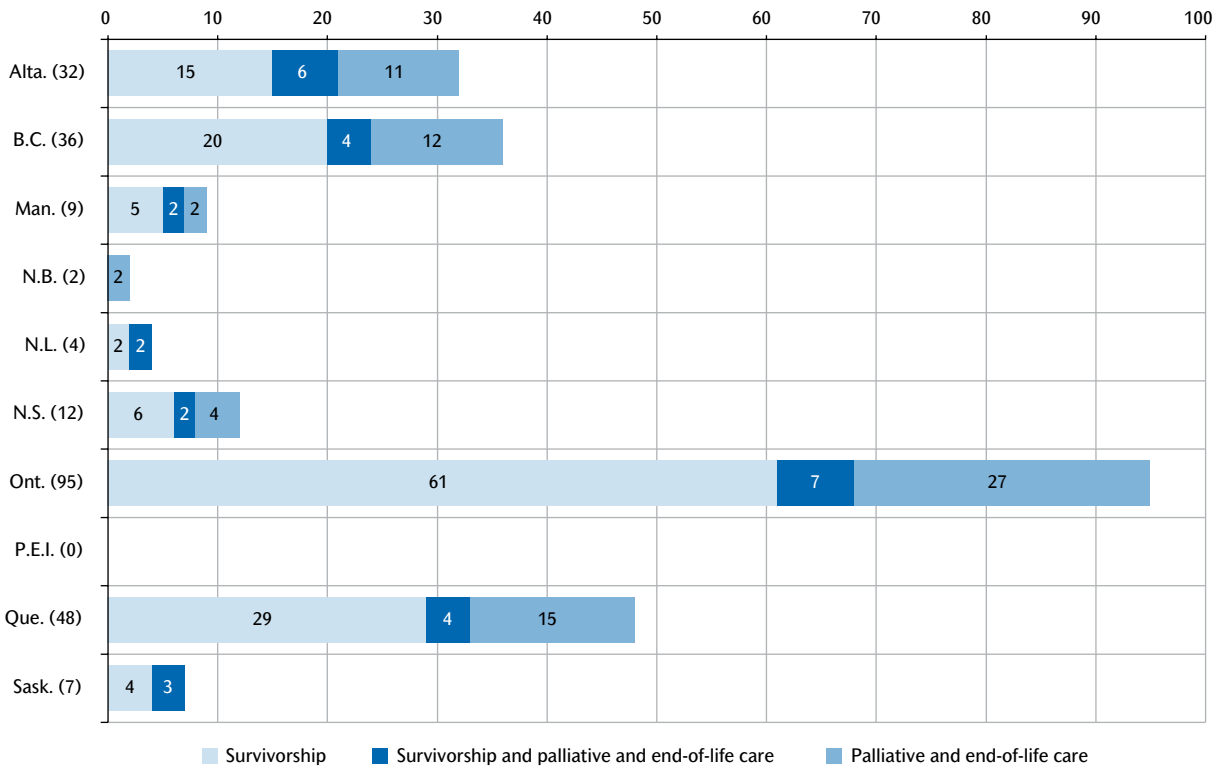
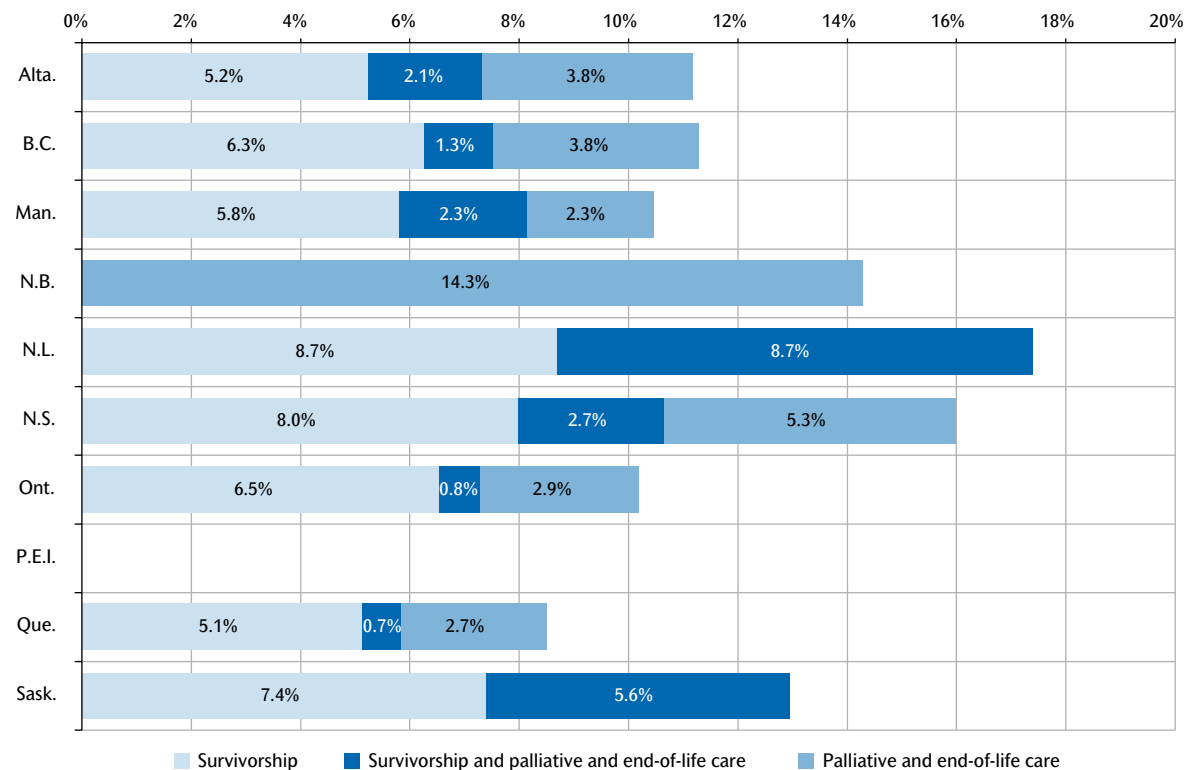


FIGURE 3.1.8B

PRINCIPAL INVESTIGATORS CONDUCTING SURVIVORSHIP AND PALLIATIVE AND END-OF-LIFE CARE RESEARCH PER ALL PRINCIPAL INVESTIGATORS CONDUCTING CANCER RESEARCH [1]



[1] The denominator is the number of cancer researchers who received at least one operating grant, career award, or equipment and infrastructure grant from 2005 to 2008.

3.2 INVESTMENT IN SURVIVORSHIP RESEARCH

The average annual investment in survivorship research (\$12.1M) is summarized in the treemap²⁹ shown in Figure 3.2.1. Investment was concentrated in three foci: physiological effects (44.6%), quality of life (24.8%), and psychological effects (16.8%). Research targeting family/caregivers (represented by the hatching) accounted for 6.4% (\$0.7M) of the average annual investment in survivorship, with the largest investment in research on psychological effects (45.1%), physiological effects (22.8%), and economic sequelae (18.4%).

FIGURE 3.2.1

DISTRIBUTION OF AVERAGE ANNUAL RESEARCH INVESTMENT IN SURVIVORSHIP BY FOCUS AND TARGET POPULATION [1]

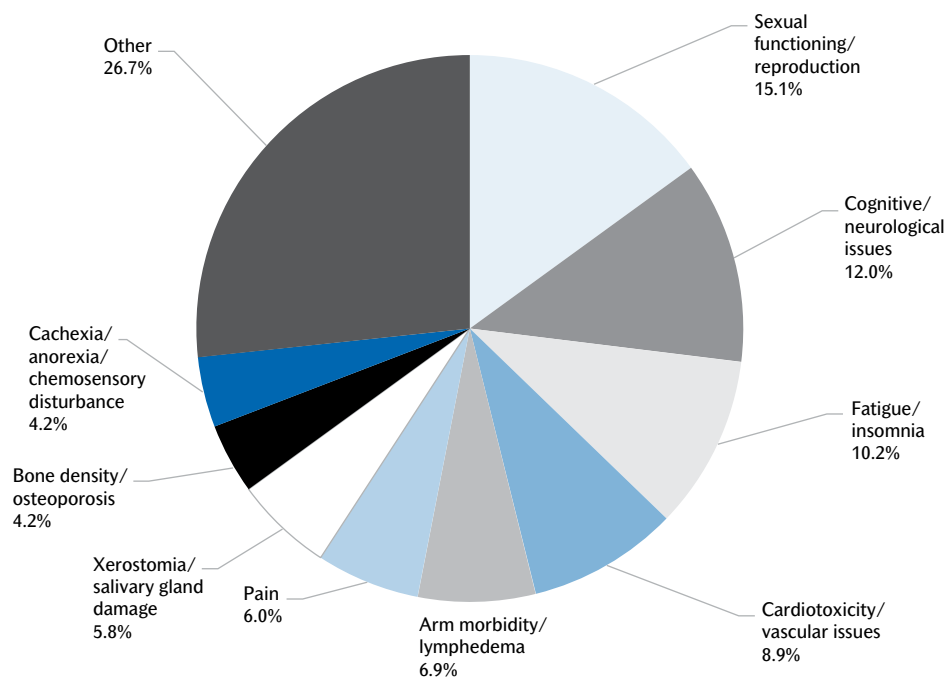


[1] This treemap was generated with the squarified tiling algorithm using Treemap 4.1 software (see <http://www.cs.umd.edu/hcil/treemap>).

29. Treemapping is a method of area-based visualization that uses nested quadrangles to summarize large amounts of hierarchically organized data. Each research focus (tree branch) is illustrated by a quadrangle, which is then tiled with smaller quadrangles (sub-branches) representing the target population.

The \$6.9M investment in physiological effects is further delineated in Figure 3.2.2. This pie chart includes those effects that individually represented at least 4% of the overall investment in physiological effects.

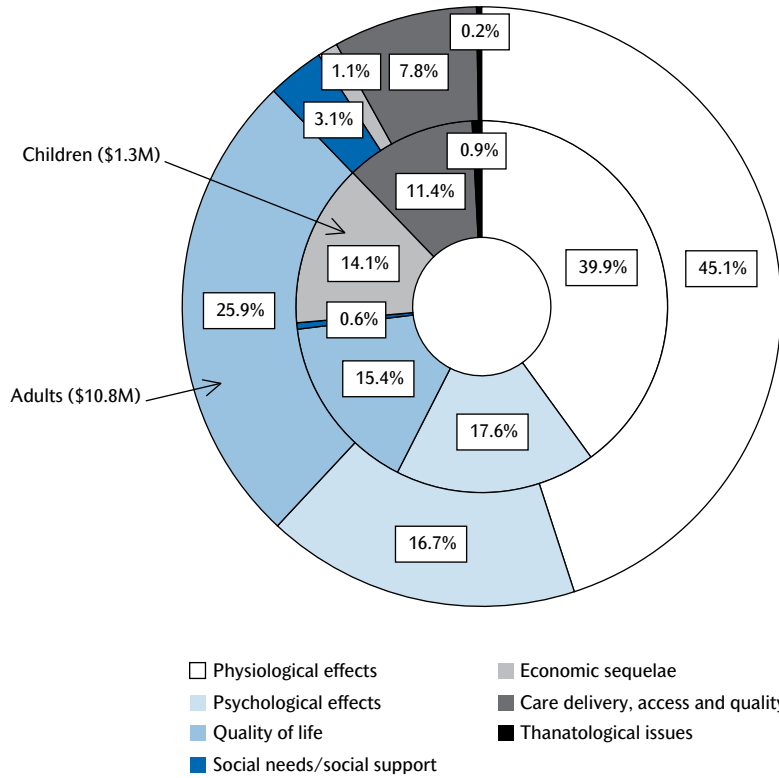
FIGURE 3.2.2
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH ON PHYSIOLOGICAL EFFECTS (\$6.9M)



Research targeting the child and adolescent population represented 10.7% (\$1.3M of \$12.1M) of the overall average annual investment in survivorship research. This investment was distributed across the foci in different proportions when compared with the investment in research focused on adults (see Figure 3.2.3).

FIGURE 3.2.3

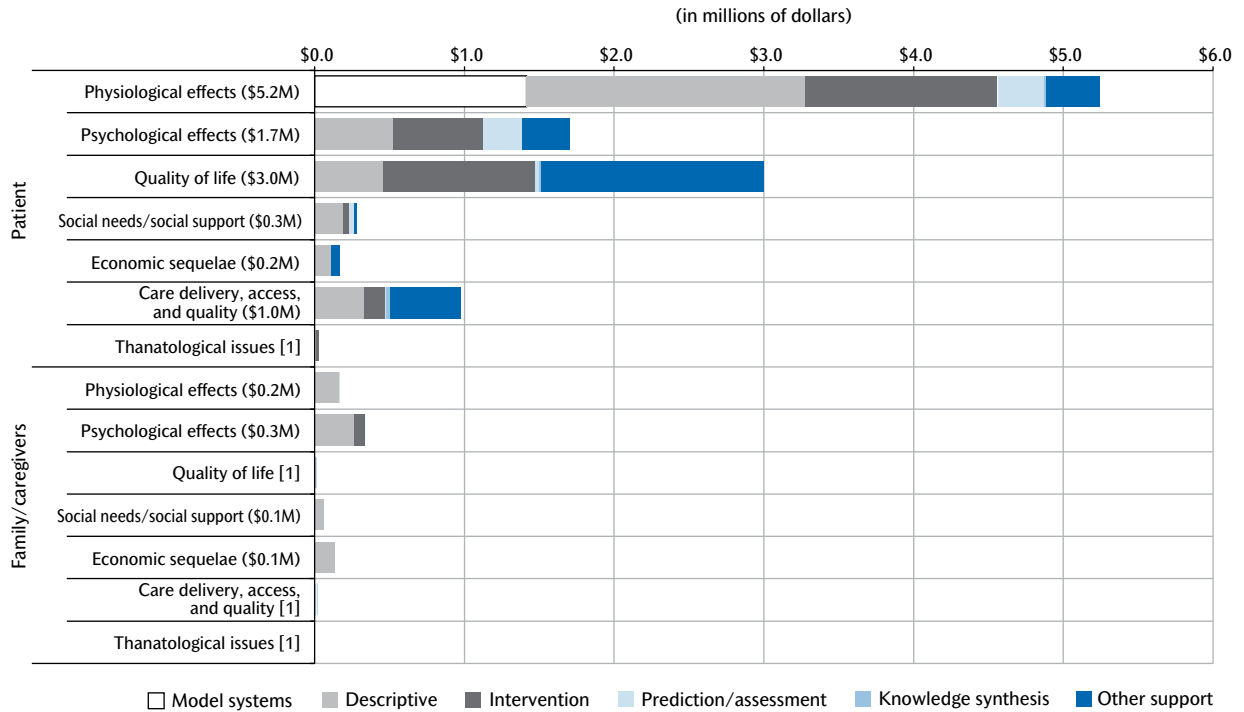
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH ON CHILDREN AND ADULTS BY RESEARCH FOCUS



The investment in terms of research target, focus, and type is shown in dollars and proportional breakdown in Figures 3.2.4A and 3.2.4B, respectively. (For full details on the 2005–2008 investment, please refer to Appendix C.) The main research types were Descriptive (34.1%), Intervention (26.1%), and Other support (22.5%). Investment in Model systems research was found only for research focused on physiological effects.

FIGURE 3.2.4A

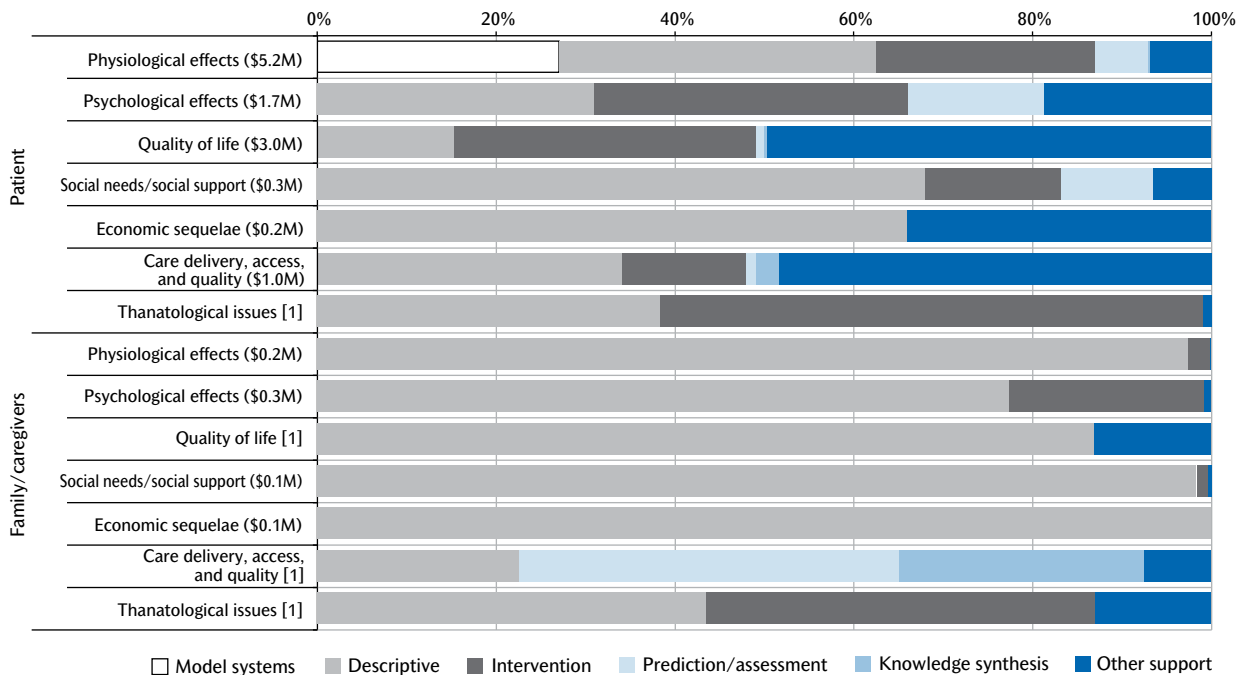
AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH BY TARGET POPULATION, RESEARCH FOCUS, AND RESEARCH TYPE



[1] The average annual investment was less than \$30,000.

FIGURE 3.2.4B

DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH BY TARGET POPULATION, RESEARCH FOCUS, AND RESEARCH TYPE



[1] The average annual investment was less than \$30,000.

Table 3.2.1 shows the investment in survivorship research by the funding organizations included in the CCRS. Thirty organizations had investments in this area. Together, the Canadian Institutes of Cancer Research (CIHR) and the Canadian Cancer Society (CCS) accounted for 58.5% of the overall average annual investment in survivorship research. Although the investments in survivorship represented small proportions of the overall cancer research investment by the two organizations, their relative investments were proportionately larger than what their investments represented in terms of the overall average annual cancer research investment of \$400M. (CIHR represented 27.8% of the overall cancer research investment and 36.5% of the survivorship research investment. For CCS these figures were 11.3% and 22.0%, respectively.) Investments by the Canadian Breast Cancer Foundation (CBCF) and Alberta Innovates – Health Solutions (AIHS) were also proportionately higher for survivorship research relative to the overall cancer research investment. (CBCF represented 2.2% of the overall cancer research investment, yet 8.6% of the survivorship research investment. For AIHS, these figures were 1.4% and 3.8%, respectively.) For the C¹⁷ Research Network and the Social Sciences and Humanities Research Council (SSHRC), investments in survivorship research represented large proportions of their overall cancer research investments. Of note, new guidelines for federal granting agencies regarding subject matter eligibility for health-related research came into effect in 2009. Social science or humanities research that is primarily intended to improve and/or increase knowledge of health, health care, and health-care systems is no longer eligible for support from SSHRC. In future reports based on the CCRS, the SSHRC investment in cancer research, including research on survivorship and palliative and end-of-life care, will decline and eventually end.

TABLE 3.2.1

AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH BY ORGANIZATION

Sector [1]	Organization Type	Organization	Average Annual Investment in Survivorship Research, 2005–2008		% of Overall Average Annual Cancer Research Investment Represented by Survivorship Research for Each Organization	Distribution of Overall Average Annual Cancer Research Investment (%)
			\$	%		
GOVERNMENT \$8,044,290 66.8%	Federal \$6,144,764 51.5%	Canada Foundation for Innovation	\$751,508	6.2	0.9	21.3
		Canada Research Chairs Program	\$486,458	4.0	2.5	4.9
		Canadian Institutes of Health Research	\$4,439,175	36.5	4.0	27.8
		Health Canada/Public Health Agency of Canada [2]	\$235,835	1.9	7.0	0.8
		Natural Sciences and Engineering Research Council	\$6,375	0.1	0.1	1.6
		Social Sciences and Humanities Research Council [3]	\$225,412	1.9	35.8	0.2
	Provincial cancer agency [4] \$447,426 3.6%	Alberta Health Services – Cancer Care [5]	\$346,778	2.9	2.7	3.2
		CancerCare Manitoba	\$37,273	0.3	3.6	0.3
		Cancer Care Nova Scotia	\$6,875	0.1	4.5	less than 0.1
		Cancer Care Ontario	\$55,250	0.5	0.8	1.8
		Saskatchewan Cancer Agency	\$1,250	less than 0.1	0.4	0.1
	Provincial health research organization \$1,452,100 11.7%	Alberta Innovates – Health Solutions	\$461,688	3.8	8.0	1.4
		Fonds de la recherche en santé du Québec	\$295,495	2.4	3.1	2.4
		Manitoba Health Research Council	\$8,766	0.1	1.6	0.1
		Medical Research Fund of New Brunswick	\$3,794	less than 0.1	13.5	less than 0.1
		Michael Smith Foundation for Health Research	\$360,914	3.0	5.3	1.7
		Nova Scotia Health Research Foundation	\$51,391	0.4	13.6	0.1
		Ontario Institute for Cancer Research	\$206,231	1.7	1.1	4.8
		Ontario Ministry of Research and Innovation	\$49,875	0.4	2.7	0.5
		Saskatchewan Health Research Foundation	\$13,948	0.1	4.2	0.1
	VOLUNTARY \$4,109,819 33.2%	Brain Tumour Foundation of Canada	\$26,839	0.2	14.2	less than 0.1
		C ¹⁷ Research Network	\$71,409	0.6	48.0	less than 0.1
		Canadian Association of Radiation Oncology	\$8,331	0.1	4.1	0.1
		Canadian Breast Cancer Foundation	\$1,049,405	8.6	12.2	2.2
		Canadian Cancer Society	\$2,678,285	22.0	5.9	11.3
		Prostate Cancer Canada	\$19,899	0.2	2.0	0.3
		The Cancer Research Society	\$70,000	0.6	1.2	1.5
The Leukemia & Lymphoma Society of Canada		\$10,875	0.1	1.1	0.3	
The Terry Fox Foundation		\$71,572	0.6	0.4	4.8	
Canadian Breast Cancer Research Alliance [6]		\$103,205	0.8	8.1	0.3	
TOTAL			\$12,154,110	100	3.0	94 [7]

[1] The sector refers to the kind of the organization that administered the funding program.

[2] This organization includes investment that flowed through the multi-funded initiatives but not funding programs that it administers directly.

[3] New guidelines regarding subject matter eligibility for health-related research came into effect in 2009. Social science or humanities research primarily intended to improve and/or increase knowledge of health, health care, and health-care systems is no longer eligible for support from SSHRC. This exclusion will affect investment figures for SSHRC in this area from 2009 onward.

[4] Data from BC Cancer Agency was not available for this report.

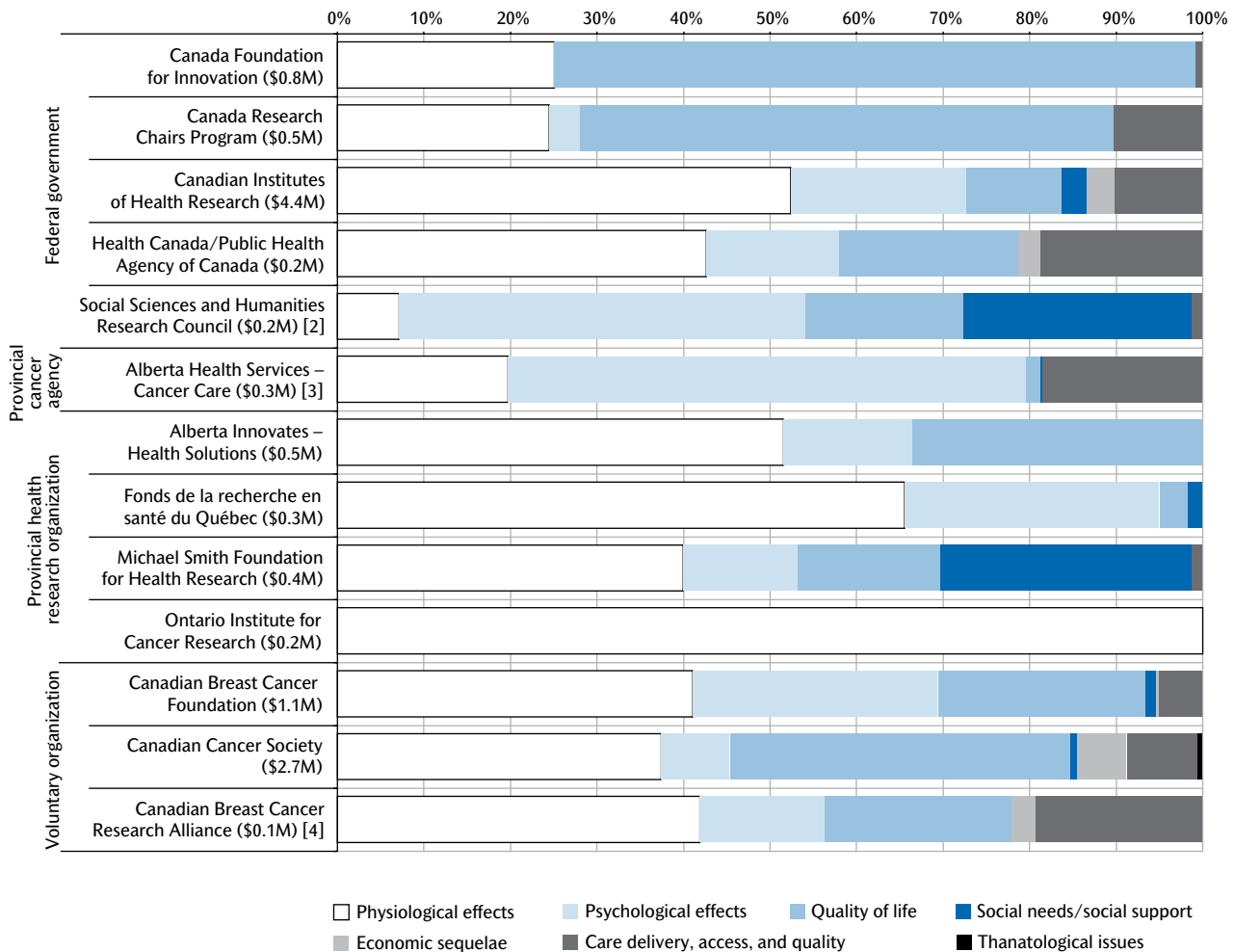
[5] As of April 1, 2009, the Alberta Cancer Board and 11 other provincial health authorities joined to form Alberta Health Services. The grants and awards program funded by both the Alberta Cancer Foundation and the Cancer Prevention Legacy endowment are included under this organization.

[6] This organization includes funders not already listed in the table.

[7] Organizations that did not invest in survivorship research represented 6% of the overall cancer research investment.

Figure 3.2.5 shows the distribution of the research foci for the 13 organizations that had an average annual investment of at least \$100,000 (combined, these organizations represented 95.8% of the overall survivorship research investment). Only the Canadian Cancer Society and the Canadian Institutes of Health Research had some investment in all seven foci. For eight organizations the highest proportion of the investment was for physiological effects. For Alberta Health Services – Cancer Care and the Social Sciences and Humanities Research Council, the highest proportion of the investment was found for psychological effects.

FIGURE 3.2.5
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH
BY RESEARCH FOCUS FOR SELECTED ORGANIZATIONS [1]



[1] These organizations have an annual average investment in survivorship research of at least \$100,000.

[2] New guidelines regarding subject matter eligibility for health-related research came into effect in 2009. Social science or humanities research primarily intended to improve and/or increase knowledge of health, health care, and health-care systems is no longer eligible for support from SSHRC. This exclusion will affect investment figures for SSHRC in this area from 2009 onward.

[3] As of April 1, 2009, the Alberta Cancer Board and 11 other provincial health authorities joined to form Alberta Health Services. The grants and awards program funded by both the Alberta Cancer Foundation and the Cancer Prevention Legacy endowment are included under this organization.

[4] This organization includes funders not already listed in the table.

In Table 3.2.2, the average annual investment in survivorship research has been broken down by the province of the principal investigator. The survivorship investment is compared to the overall cancer research investment. Per capita investment is also calculated. The proportion of the cancer research investment represented by survivorship research was highest in Saskatchewan and Manitoba, at 6.3%. While Ontario and Quebec accounted for the largest proportions of the survivorship research investment, the relative distributions for survivorship research were lower for those provinces than for the cancer research investment as a whole. For most of the other provinces, the relative distributions for survivorship research were higher than for the total cancer research investment. The differences were most striking for Alberta, Manitoba, and Saskatchewan. The highest per capita investment was found in Alberta.

TABLE 3.2.2

AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH BY PROVINCE OF PRINCIPAL INVESTIGATOR (\$12.1M) [1,2]

	Alta.	B.C. [3]	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.
Average annual investment in survivorship research	\$1.8M	\$1.5M	\$0.5M	less than \$10,000	less than \$60,000	\$0.3M	\$4.9M	\$2.7M	\$0.3M
Average annual investment in cancer research overall	\$39.3M	\$47.5M	\$8.5M	\$0.2M	\$1.1M	\$5.9M	\$191.1M	\$98.2M	\$4.7M
% of cancer research investment represented by survivorship research	4.6	3.2	6.3	1.5	5.1	4.7	2.6	2.8	6.3
Provincial distribution of the average annual survivorship research investment (%)	14.9	12.4	4.4	0.0	0.5	2.3	40.6	22.5	2.4
Provincial distribution of the average annual cancer research investment (%)	9.9	12.0	2.1	0.1	0.3	1.5	48.2	24.8	1.2
Per capita investment for survivorship research [4]	\$0.50	\$0.34	\$0.44	less than 1 cent	\$0.12	\$0.30	\$0.38	\$0.35	\$0.29

[1] The total average annual investment of \$12.1M excludes \$55,313, which was dispersed to trainees who conducted their studies outside Canada.

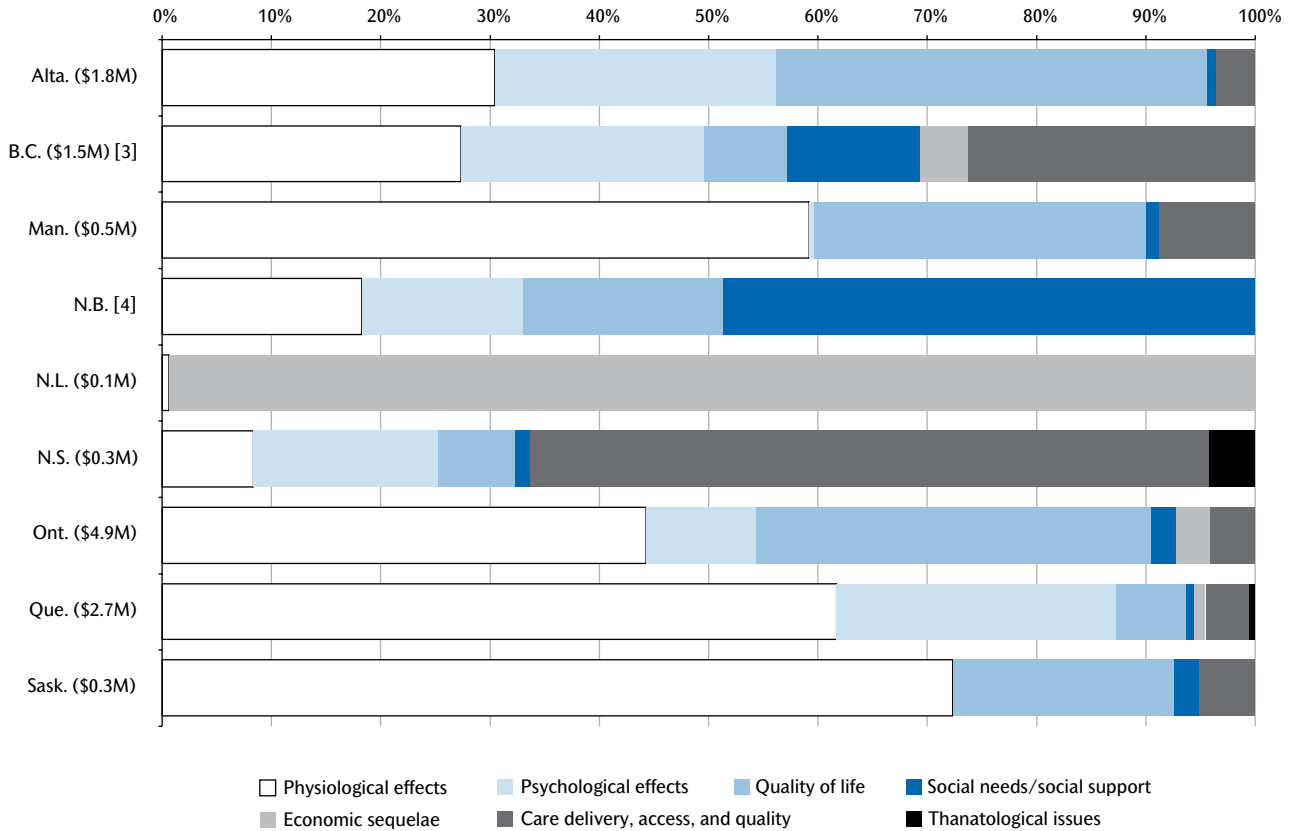
[2] There was no survivorship research investment in P.E.I.

[3] BC Cancer Agency data are not included so the figures may underestimate the investment in B.C.

[4] Provincial population figures based on July 1, 2008 estimates from Statistics Canada, CANSIM, table 051-0001, were used in the per capita investment calculation.

Figure 3.2.6 shows the distribution of survivorship research investment by research focus for each province. Principal investigators from Ontario and Quebec had research projects representing all seven foci. For five provinces, the largest proportionate investment was for physiological effects. The province-specific investment in quality of life was proportionately highest in Alberta (39.4%) and Ontario (36.1%). The investment distribution in British Columbia was proportionately more balanced across the research foci.

FIGURE 3.2.6
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN SURVIVORSHIP RESEARCH
BY PROVINCE OF PRINCIPAL INVESTIGATOR [1,2]



[1] The total average annual investment of \$12.1M excludes \$55,313, which was dispersed to trainees who conducted their studies outside Canada.

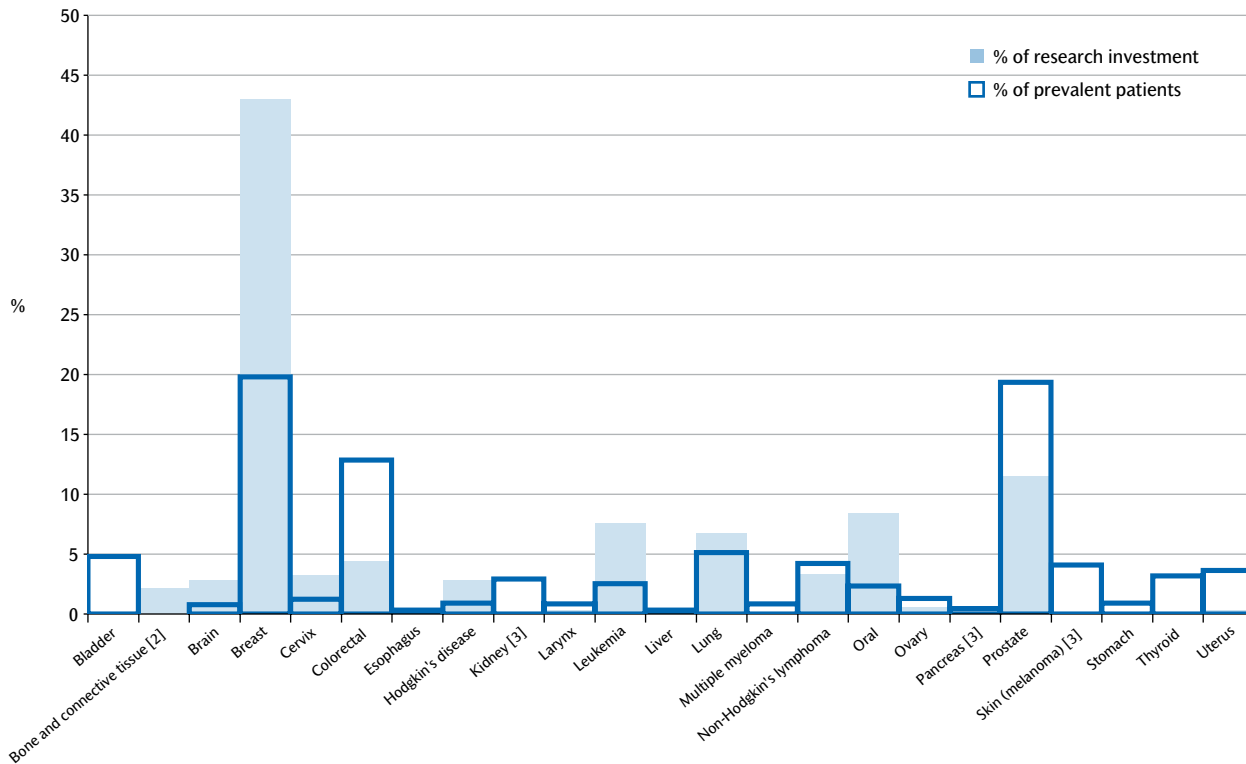
[2] There was no survivorship research investment in P.E.I.

[3] BC Cancer Agency data are not included so the figures may underestimate the investment in B.C.

[4] The average annual investment in survivorship research was less than \$10,000.

Figure 3.2.7 presents a comparison between site-specific investment and the proportion of prevalent cancer patients (patients diagnosed with cancer since 1997 who were still alive on January 1, 2007). More than half (55.3%) of the average annual investment in survivorship research was site-specific. This amount was more than the 48.2% found for the overall cancer research investment. For about half of the cancer types examined, the distribution of the research investment was close to or higher than the relative burden of illness as defined by cancer prevalence. For colorectal, prostate, and bladder cancers, however, the proportion of research investment fell well below the relative prevalence. There was no investment in survivorship projects focused on skin cancer (melanoma) or kidney and pancreatic cancers. Research focused on children and adolescents accounted for 78.0% of the brain cancer investment and 52.7% of the leukemia investment.

FIGURE 3.2.7
DISTRIBUTION OF SITE-SPECIFIC SURVIVORSHIP RESEARCH INVESTMENT AND 10-YEAR PREVALENCE [1]



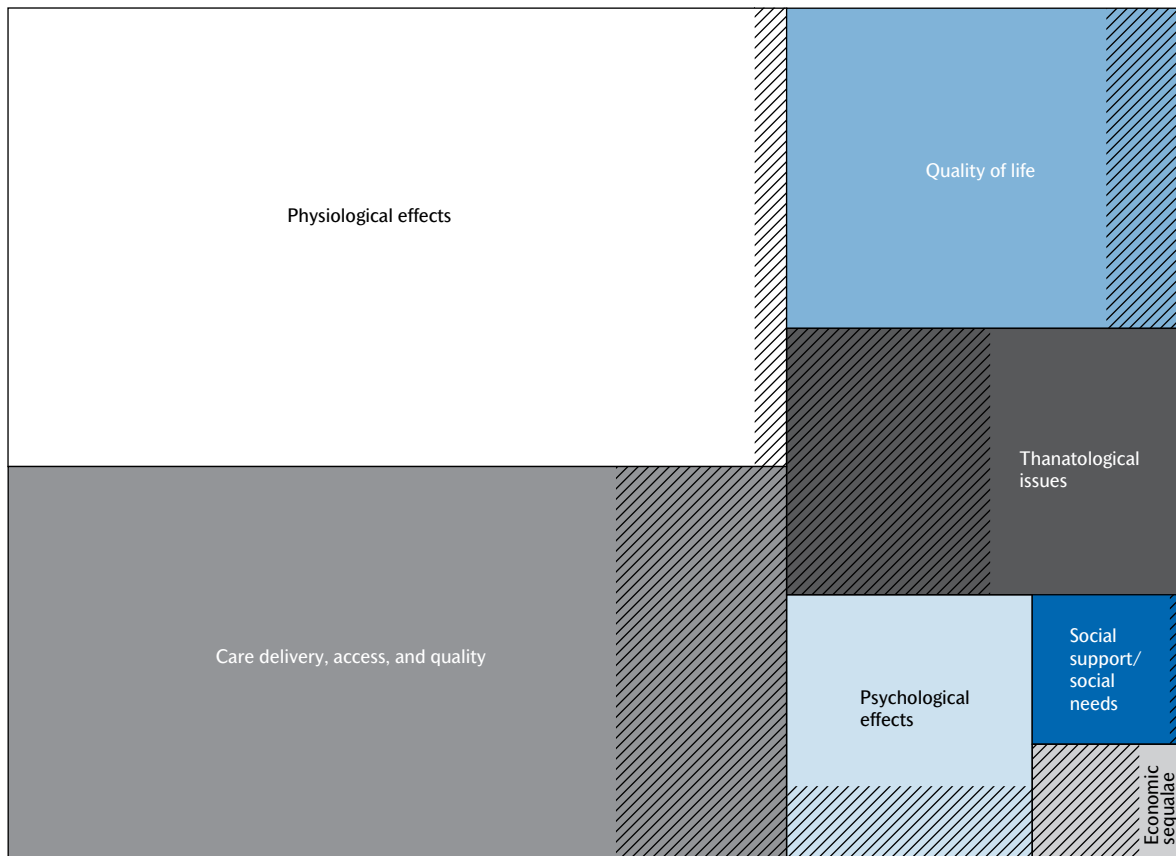
[1] The distribution represents site-specific prevalence for patients diagnosed with cancer since 1997 who were alive on January 1, 2007. Data were available from the Canadian Cancer Society's Steering Committee on Cancer Statistics, *Canadian Cancer Statistics 2011* (Toronto: Canadian Cancer Society, 2011).
 [2] Prevalence data were not available for bone and connective tissue cancers.
 [3] There was no investment in survivorship research focused on kidney cancer, pancreatic cancer, or skin cancer (melanoma).

3.3 INVESTMENT IN PALLIATIVE AND END-OF-LIFE RESEARCH

The treemap shown in Figure 3.3.1 summarizes the investment in palliative and end-of-life care research (\$6.4M). The investment was concentrated in two research areas: physiological effects (36.0%) and care delivery, access, and quality (31.0%). Research targeting family/caregivers (represented by the hatching) accounted for 19.3% (\$1.2M) of the average annual investment in palliative and end-of-life care, with the largest investments being in care delivery, access, and quality (36.2%) and thanatological issues (28.0%).

FIGURE 3.3.1

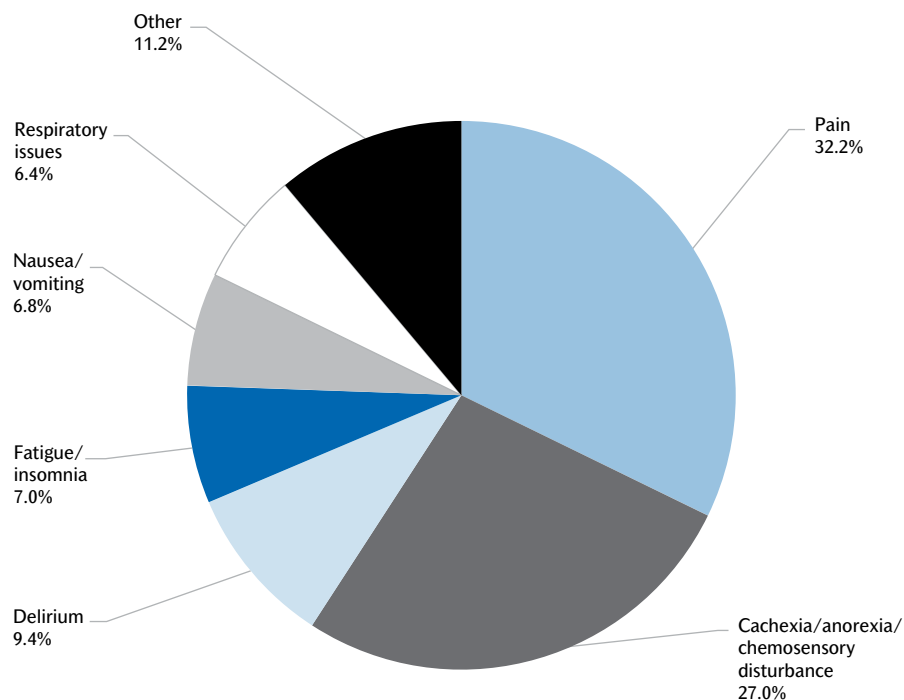
DISTRIBUTION OF AVERAGE ANNUAL RESEARCH INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE BY FOCUS AND TARGET POPULATION [1]



[1] This treemap was generated with the squarified tiling algorithm using Treemap 4.1 software (see <http://www.cs.umd.edu/hcil/treemap>).

The \$2.3M investment in physiological effects is further delineated in Figure 3.3.2. This pie chart includes those effects that individually represented at least 4% of the overall investment in physiological effects. Combined, the investments in research on pain and cachexia, anorexia, and chemosensory disturbance represented 59.2% of the overall investment in physiological effects.

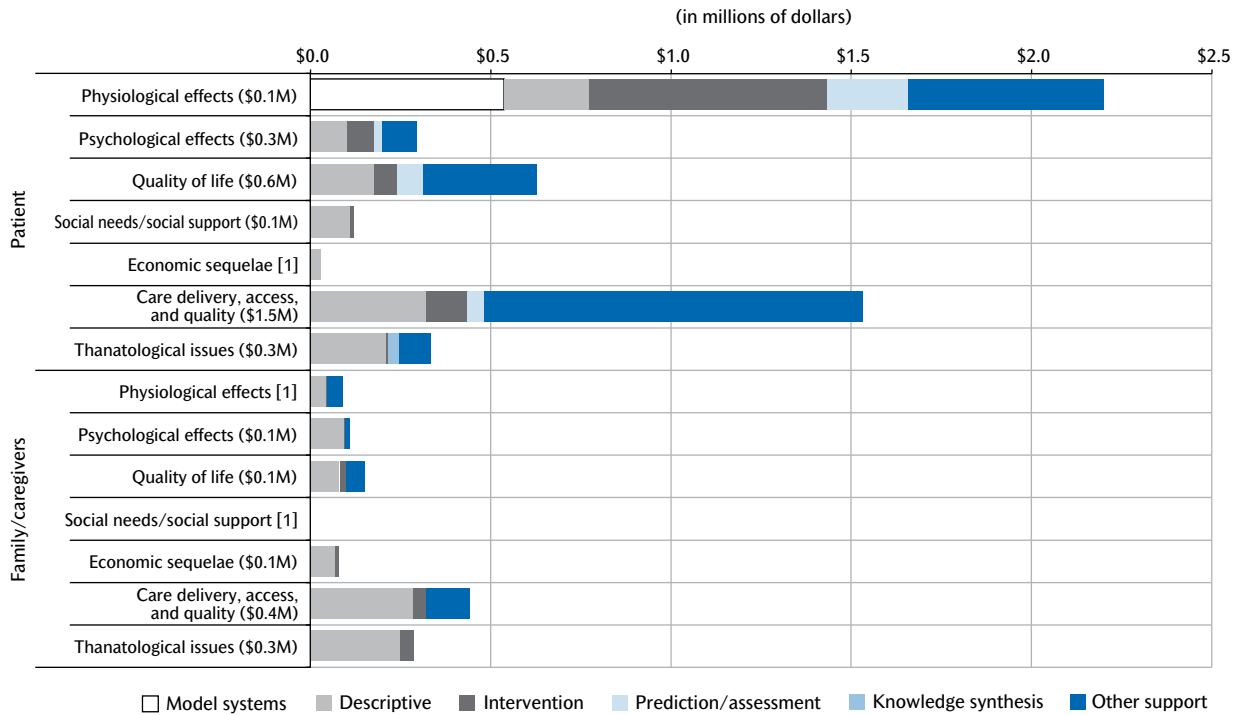
FIGURE 3.3.2
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH ON PHYSIOLOGICAL EFFECTS



Figures 3.3.3A and 3.3.3B show, respectively, investment in the entire classification system in dollar amounts and as a proportional breakdown. (For full details on the 2005–2008 investment, please refer to Appendix D.) The main research types – Other support (37.2%) and Descriptive (31.6%) – dominated most of the foci-specific investment. Investment in Model systems research was found only in research that focused on physiological effects and the investment in physiological effects was most varied in terms of research types.

FIGURE 3.3.3A

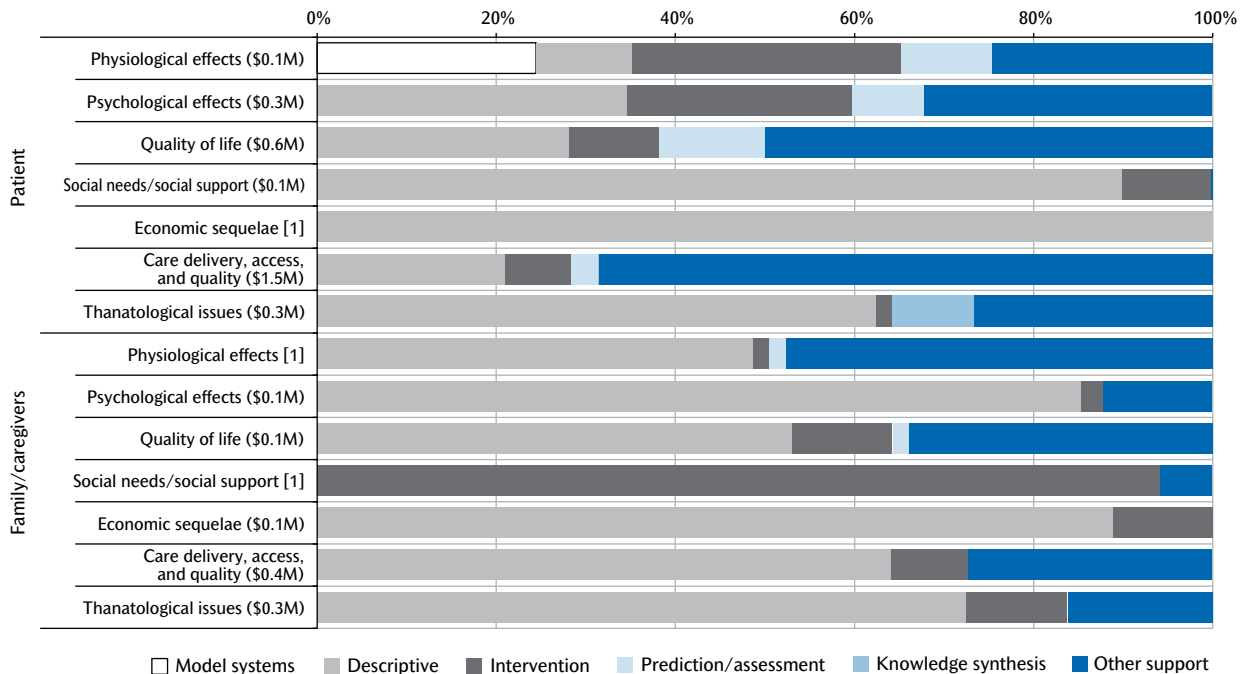
AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY TARGET POPULATION, RESEARCH FOCUS, AND RESEARCH TYPE



[1] The average annual investment was less than \$40,000.

FIGURE 3.3.3B

DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY TARGET POPULATION, RESEARCH FOCUS, AND RESEARCH TYPE



[1] The average annual investment was less than \$40,000.

Table 3.3.1 shows cancer research investment in palliative and end-of-life care by funding organizations. Twenty-three organizations had investments in this area. The Canadian Institutes of Health Research was the main funder and accounted for 63.0% of the investment, more than double what CIHR represented in terms of the overall cancer research investment. CIHR's investment at \$4.0M was less than 4% of its overall cancer research investment. A significant proportion of CIHR's investment (44.9%) was the result of the targeted initiatives previously described in section 3.1. The Canadian Cancer Society represented 14.1% of the overall investment (86.2% of the investment made by all organizations within the voluntary sector). At \$0.9M, this investment represented 2% of its overall cancer research investment.

TABLE 3.3.1

AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY ORGANIZATION

Sector [1]	Organization Type	Organization	Average Annual Investment in Palliative and End-of-life care Research, 2005–2008		% of Overall Average Annual Cancer Research Investment Represented by Palliative and End-of-life care Research for Each Organization	Distribution of Overall Average Annual Cancer Research Investment (%)
			\$	%		
GOVERNMENT \$5,336,427 80.5%	Federal \$4,403,790 65.2%	Canada Foundation for Innovation	\$44,995	0.7	0.1	21.3
		Canada Research Chairs Program	\$160,000	2.5	0.8	4.9
		Canadian Institutes of Health Research	\$4,019,821	63.0	3.6	27.8
		Health Canada/Public Health Agency of Canada [2]	\$19,465	0.3	0.6	0.8
		Natural Sciences and Engineering Research Council	\$25,074	0.4	0.4	1.6
		Social Sciences and Humanities Research Council [3]	\$134,436	2.1	21.3	0.2
	Provincial cancer agency [4] \$332,663 5.3%	Alberta Health Services – Cancer Care [5]	\$207,902	3.3	1.6	3.2
		CancerCare Manitoba	\$54,511	0.9	5.3	0.3
		Cancer Care Nova Scotia	\$2,500	less than 0.1	1.6	less than 0.1
		Cancer Care Ontario	\$67,750	1.1	0.9	1.8
	Provincial health research organization \$599,974 10.0%	Alberta Innovates – Health Solutions	\$198,938	3.1	3.5	1.4
		Fonds de la recherche en santé du Québec	\$54,254	0.9	0.6	2.4
		Manitoba Health Research Council	\$26,732	0.4	4.8	0.1
		Michael Smith Foundation for Health Research	\$128,237	2.0	1.9	1.7
		Nova Scotia Health Research Foundation	\$2,500	less than 0.1	0.7	0.1
		Ontario Institute for Cancer Research	\$158,347	2.5	0.8	4.8
	VOLUNTARY \$1,041,725 19.5%	Saskatchewan Health Research Foundation	\$30,966	0.5	9.4	0.1
		Brain Tumour Foundation of Canada	\$2,394	less than 0.1	1.3	less than 0.1
		Canadian Association of Radiation Oncology	\$5,151	0.1	2.5	0.1
Canadian Breast Cancer Foundation		\$97,390	1.5	1.1	2.2	
Canadian Cancer Society		\$897,968	14.1	2.0	11.3	
The Cancer Research Society		\$30,000	0.5	0.5	1.5	
Canadian Breast Cancer Research Alliance [6]		\$8,821	0.1	0.7	3.0	
TOTAL			\$6,378,151	100	1.6	91 [7]

[1] The sector refers to the kind of the organization that administered the funding program.

[2] This organization includes investment that flowed through the multi-funded initiatives but not funding programs that it administers directly.

[3] New guidelines regarding subject matter eligibility for health-related research came into effect in 2009. Social science or humanities research primarily intended to improve and/or increase knowledge of health, health care, and health-care systems is no longer eligible for support from SSHRC. This exclusion will affect investment figures for SSHRC in this area from 2009 onward.

[4] Data from BC Cancer Agency was not available for this report.

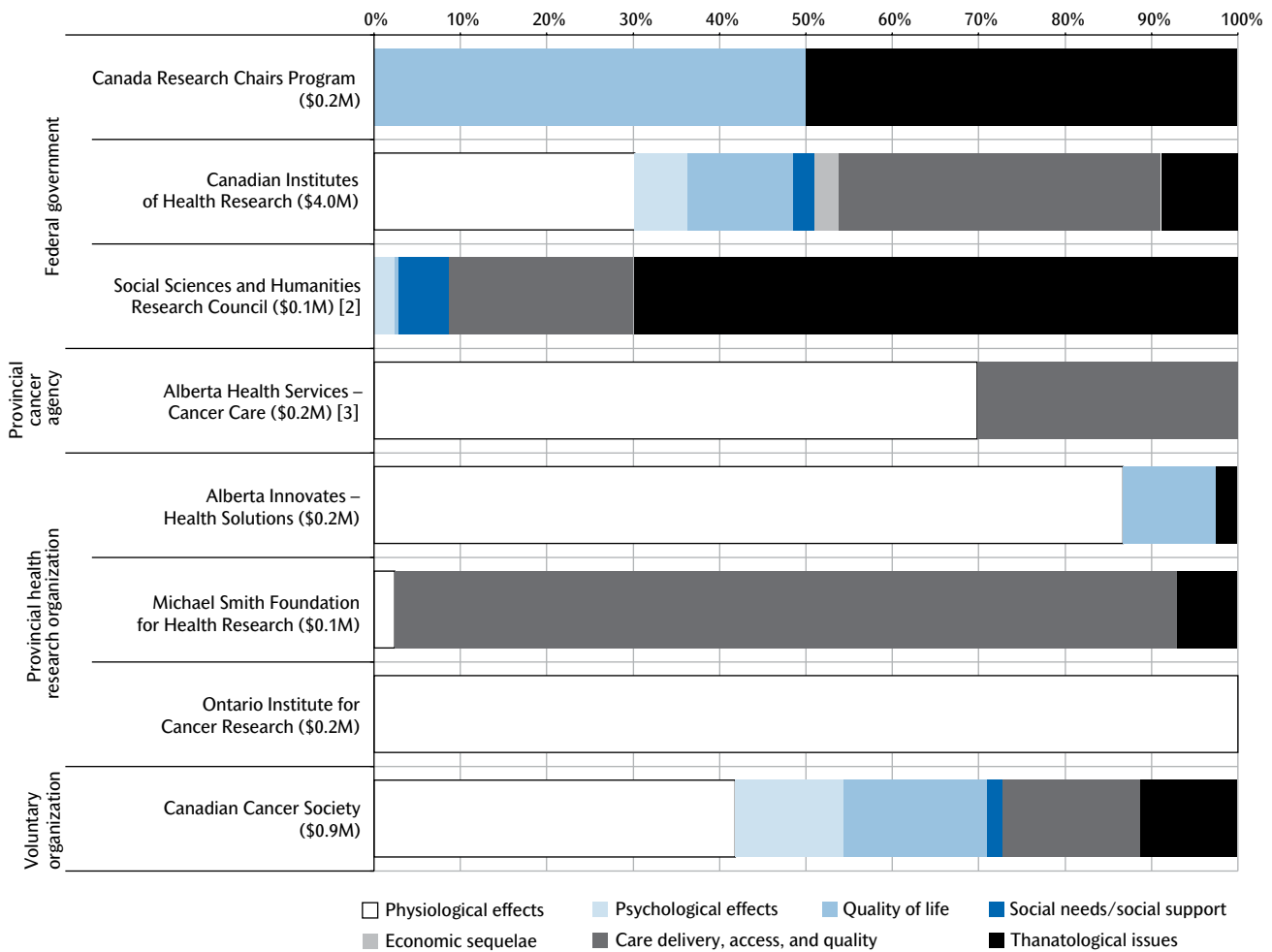
[5] As of April 1, 2009, the Alberta Cancer Board and 11 other provincial health authorities joined to form Alberta Health Services. The grants and awards program funded by both the Alberta Cancer Foundation and the Cancer Prevention Legacy endowment are included under this organization.

[6] This organization includes funders not already listed in the table.

[7] Organizations that did not invest in palliative and end-of-life care research represented 9% of the overall cancer research investment.

Figure 3.3.4 shows the distribution of the research foci for the eight organizations that had an average annual investment of at least \$100,000. (Combined, these organizations represented 92.6% of the overall survivorship research investment.) Only the Canadian Institutes of Health Research had some investment in all seven foci. For Alberta Health Services – Cancer Care, Alberta Innovates – Health Solutions, Ontario Institute for Cancer Research, and the Canadian Cancer Society, the highest proportion of their investments was in physiological effects. For the Michael Smith Foundation for Health Research and the Canadian Institutes of Health Research, the largest proportion of their investments was in care delivery, access, and quality. Thanatological issues formed the highest portion of the investment for the Social Sciences and Humanities Research Council.

FIGURE 3.3.4
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY RESEARCH FOCUS FOR SELECTED ORGANIZATIONS [1]



[1] These organizations have an annual average investment in survivorship research of at least \$100,000.

[2] New guidelines regarding subject matter eligibility for health-related research came into effect in 2009. Social science or humanities research primarily intended to improve and/or increase knowledge of health, health care, and health-care systems is no longer eligible for support from SSHRC. This exclusion will affect investment figures for SSHRC in this area from 2009 onward.

[3] As of April 1, 2009, the Alberta Cancer Board and 11 other provincial health authorities joined to form Alberta Health Services. The grants and awards program funded by both the Alberta Cancer Foundation and the Cancer Prevention Legacy endowment are included under this organization.

Table 3.3.2 breaks down the average annual investment in palliative and end-of-life research by the province of the principal investigator. The palliative and end-of-life investment is compared to the overall cancer research investment. The table also sets out the per capita investment. The proportion of the cancer research investment represented by palliative and end-of-life care research was highest in Manitoba and Alberta, at 4.2% and 3.4%, respectively. Although Ontario represented the largest proportion of the overall palliative and end-of-life care research investment, British Columbia and Alberta comprised 42.7% of the palliative and end-of-life care research investment versus 21.9% of the overall cancer research investment. On a per capita basis, the investment in Alberta was the highest, with British Columbia and Manitoba being a few cents lower.

TABLE 3.3.2

AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY PROVINCE OF PRINCIPAL INVESTIGATOR (\$6.3M) [1,2]

	Alta.	B.C. [3]	Man.	N.B.	N.L.	N.S.	Ont.	Que.	Sask.
Average annual investment in palliative/end-of-life care research	\$1.3M	\$1.4M	\$0.4M	less than \$10,000	less than \$40,000	\$0.2M	\$1.7M	\$1.3M	\$0.1M
Average annual investment in cancer research overall	\$39.3M	\$47.5M	\$8.5M	\$0.2M	\$1.1M	\$5.9M	\$191.1M	\$98.2M	\$4.7M
% of cancer research investment represented by palliative/end-of-life care research	3.4	2.9	4.2	0.8	2.9	2.7	0.9	1.3	2.1
Provincial distribution of the average annual palliative/end-of-life research investment (%)	21.0	21.7	5.6	0.0	0.5	2.5	26.5	20.6	1.5
Provincial distribution of the average annual cancer research investment (%)	9.9	12.0	2.1	0.1	0.3	1.5	48.2	24.8	1.2
Per capita investment for palliative/end-of-life care research [4]	\$0.37	\$0.31	\$0.29	less than 1 cent	\$0.07	\$0.17	\$0.13	\$0.17	\$0.10

[1] The total average annual investment of \$6.3M excludes \$41,483, which was dispersed to trainees who conducted their studies outside Canada.

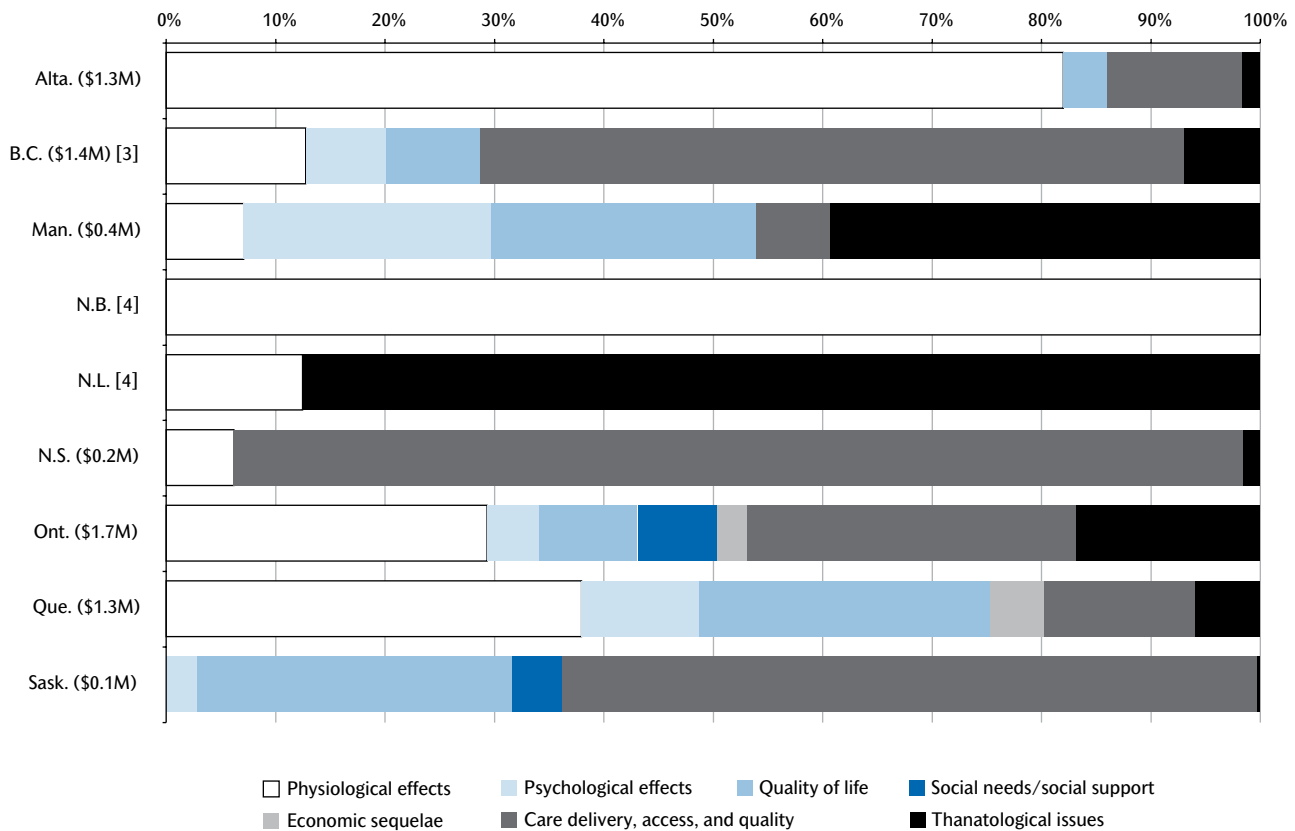
[2] There was no survivorship research investment in P.E.I.

[3] BC Cancer Agency data are not included so the figures may underestimate the investment in B.C.

[4] Provincial population figures based on July 1, 2008 estimates from Statistics Canada, CANSIM, table 051-0001, were used in the per capita investment calculation.

Figure 3.3.5 shows the distribution of palliative and end-of-life research investment by research focus for each province. Investments in care delivery, access, and quality dominated the distributions of Nova Scotia, British Columbia, and Saskatchewan. On the other hand, for research conducted in Alberta and New Brunswick, investment in physiological effects was the largest proportion. Investment in research projects headed by principal investigators from Ontario spanned all seven foci.

FIGURE 3.3.5
DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY PROVINCE OF PRINCIPAL INVESTIGATOR [1,2]



[1] The total average annual investment of \$6.3M excludes \$41,483, which was dispersed to trainees who conducted their studies outside Canada.

[2] There was no survivorship research investment in P.E.I.

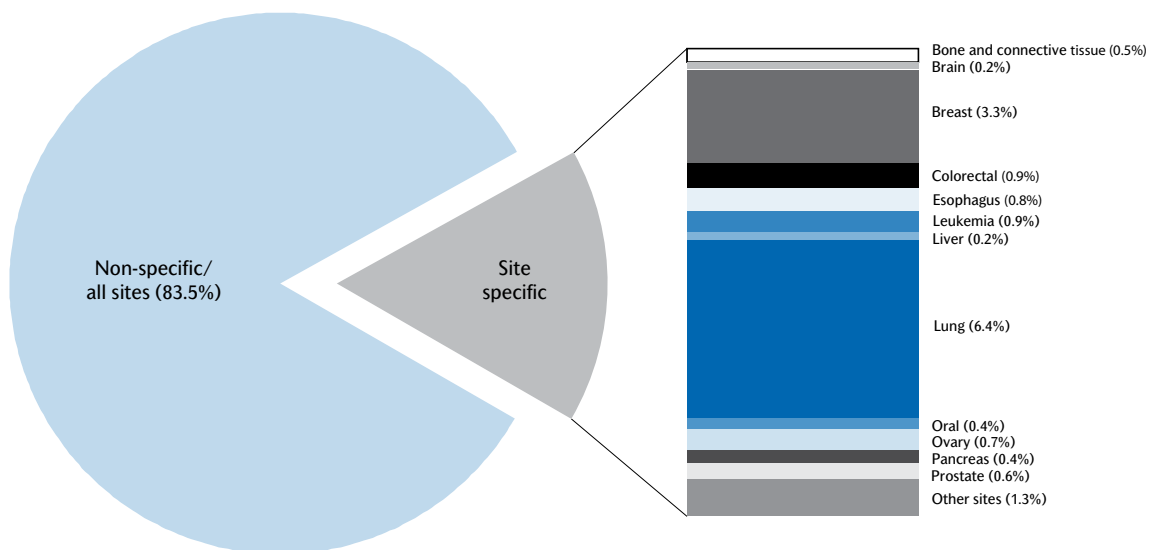
[3] BC Cancer Agency data are not included so the figures may underestimate the investment in B.C.

[4] The average annual investment in survivorship research was less than \$40,000.

Most (83.5%) of the investment in palliative and end-of-life research was in research that was not focused on specific cancer sites (see Figure 3.3.6). Of the site-specific research, most of the investment was focused on lung and breast cancers.

FIGURE 3.3.6

DISTRIBUTION OF AVERAGE ANNUAL INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH BY CANCER SITE



4. SUMMARY

4.1 KEY FINDINGS

The combined investment in survivorship and palliative and end-of-life care from 2005 to 2008 was less than 5% of the total cancer research investment over the same period.

We found that 4.6% of the average annual cancer research investment, or \$18.5M per year, focused on survivorship and palliative and end-of-life care. This is comparable to the U.S. National Cancer Institute, which reported about 4.1% of its overall budget on cancer survivorship for FY2007 and FY2008,³⁰ and higher than the 2.3% found by the National Cancer Research Institute (U.K.) in its recent report on research investment in survivorship after cancer and end-of-life care by members of its multi-organizational alliance.³¹ But is it enough? The number of cancer survivors in Canada is growing and is unlikely to abate. It is not merely numbers that should drive the research investment, but the nature, frequency, and complexity of symptoms and problems faced by survivors. On the palliative and end-of-life care side, awareness is growing of significant variations and gaps in care in Canada³² and of the need for research on models of palliative care delivery that will ultimately improve the quality of care received by patients and their family members.

The investment in survivorship research was on the upswing and cancer research funders within the voluntary sector played an important role in supporting this research.

We found a positive growth in survivorship research funding over the four years observed, with only a small proportion of the investment being attributable to strategic initiatives. While the Canadian Institutes of Health Research and the Canadian Cancer Society were the key funders, the voluntary sector as a whole played an important role in funding survivorship research, accounting for one-third of the research investment. Survivorship research is not only important in and of itself, but also for its potential to influence infrastructure systems (for example, databases), follow-up requirements for clinical practice and clinical trials, therapeutic approaches, and post-primary cancer treatment surveillance.³³

30. Cancer funding statistics were available through the NCI Funded Research Portfolio (see <http://fundedresearch.cancer.gov/>); FY2007 – \$191.4M on cancer survivorship out of a total budget of \$4,792.6M, FY2008 – \$198.8M on cancer survivorship out of a total budget of \$4,827.6M.

31. National Cancer Research Institute, *Rapid Review of Research in Survivorship and End of Life Care* (November 2010). (available at http://www.ncri.org.uk/includes/Publications/reports/rapid_review_seolc2010.pdf)

32. Canadian Cancer Society's Steering Committee on Cancer Statistics, *Canadian Cancer Statistics 2010* (Toronto: Canadian Cancer Society, 2010).

33. N.M. Aziz, "Cancer survivorship research: challenge and opportunity," *Journal of Nutrition* 132 (suppl) (2002):3494S–3503S.

The investment in survivorship research was commensurate with disease burden for all but a few types of cancer.

More than half of the survivorship research investment was site specific. For about half of the types of cancer examined in this report, the distribution of the research investment was close to or higher than the relative burden of illness as defined by cancer prevalence. For colorectal, prostate, and bladder cancers, however, the investment was well below the burden. This analysis is somewhat simplistic in that the challenges faced by survivors depend on many factors: the cancer site, the histology and stage of their disease, the treatment they receive, their age, their long-term prognosis, other health conditions, and their social or demographic circumstances.

The investment in palliative and end-of-life care research has not kept pace with cancer research funding overall.

While there was a net increase in the funding over the four years covered in the report for palliative and end-of-life care research, this increase did not keep pace with the increase in cancer research overall. About a third of the investment was for Other support, such as grants for capacity building, research networks, workshops, and equipment and infrastructure.

The research investment in palliative and end-of-life care relied on strategic funding initiatives offered by the Canadian Institutes of Health Research and those programs have now ended.

The Canadian Institutes of Health Research was the dominant funder of this research, with 45% of its funding in palliative and end-of-life care coming from strategic initiatives. It is unclear whether or not this investment could be sustained in the absence of continued strategic funding. As no other funding organization comes close in terms of level of research funding, CIHR's role in this area is vital.

On a relative basis the research investment in survivorship and palliative and end-of-life care research was highest in Alberta, suggesting that these are key areas of cancer research in the province.

Per capita investment was highest in Alberta for both areas of research and 16% of the investment in trainees awards went to trainees at universities in Alberta. The Psychosocial Resources Department at the Tom Baker Cancer Centre was one of the first interdisciplinary psychosocial oncology programs in Canada. The Behavioural Medicine Laboratory at University of Alberta has become a key centre for research on the link between physical activity and treatment recovery, and long-term survivorship.

Principal investigators in Quebec played a leadership role in training in the areas of survivorship and palliative and end-of-life care research.

Researchers from McGill University spearheaded two major training programs in survivorship and palliative and end-of-life care research during the reporting period. The Strategic Training Program in Palliative Care Research, which ran from April 2003 to March 2009, exposed students and new researchers to all aspects of palliative and end-of-life care and trained them to transfer their results to the frontline care providers. It involved investigators from University of Ottawa, Université Laval, and McGill University. The CIHR/ICR-funded Psychosocial Oncology Research Training (PORT) program (which started in April 2003 and will be ongoing until March 2015) has linked, and will continue to link, researchers from a variety of disciplines from universities in five provinces and provide training opportunities for young researchers.

4.2 RECENT DEVELOPMENTS

Since 2008 the need to support further research in survivorship has received more recognition, and the momentum is building. A number of workshops have looked at cancer survivorship research. These include:

- A pan-Canadian invitational workshop, “Towards an Agenda for Cancer Survivorship,” sponsored by the Cancer Journey Advisory Group of the Canadian Partnership Against Cancer, identified the promotion of survivorship research as a key priority for action.³⁴
- A pan-Canadian workshop, “Identifying Priorities for Cancer Survivorship Research,” sponsored by Canadian Institutes of Health Research in conjunction with the Partnership and others partners, identified five top priorities for survivorship research.³⁵ This workshop helped to inform the Pan-Canadian Cancer Research Strategy. The strategy³⁶ identifies the following three topics as key to addressing gaps in knowledge:
 1. Preventing and ameliorating (late) effects of cancer and its treatment
 2. Optimal models of follow-up care
 3. Interventions

34. Canadian Invitational Cancer Survivorship Workshop, *Creating an Agenda for Cancer Survivorship*, Toronto, March 25–26, 2008, available at http://www.partnershipagaincancer.ca/wp-content/uploads/2.4.0.2.6-CPAC_CJ_Survivorship_0308_Final_E.pdf.

35. Pan-Canadian Invitational Workshop, *Identifying Priorities for Cancer Survivorship Research*, Vancouver, November 21–22, 2008, available at <http://www.bccancer.bc.ca/NR/rdonlyres/E6F649B9-761C-4C51-89E0-C2F0834B8DCC/43097/CancerSurvivorshippriorities.pdf>.

36. Canadian Cancer Research Alliance, *Pan-Canadian Cancer Research Strategy: A plan for collaborative action by Canada's cancer research funders*, 2010, available at http://www.ccra-acrc.ca/PDF%20Files/Pan-Canadian%20Strategy%202010_EN.pdf.

- A Canadian Institutes of Health Research-sponsored meeting, “Paediatric/Adolescent/Young Adult Cancer: A Pan-Canadian Initiative,” promoted greater awareness of the specific challenges experienced by young cancer patients and sought advice and guidance in developing a multi-partnered strategic research initiative to be lead by the Institute of Cancer Research.³⁷
- A pan-Canadian invitational workshop, “Fostering Cancer Survivorship Research in Canada: Building Capacity,” sponsored by the Canadian Institutes of Health Research and LIVESTRONG, brought together researchers working in key areas of cancer survivorship to brainstorm and plan the development of a Canadian consortium of survivorship. Together, these researchers will create a research agenda to inform service delivery and advance priorities for cancer survivorship research.³⁸

The Canadian Task Force on Adolescents and Young Adults with Cancer, established in 2008 and supported by the Canadian Partnership Against Cancer and the C¹⁷ Council, recently published six broad recommendations, of which research is one.³⁹ Ten priority areas for research are identified. Among them are four related to survivorship and palliative and end-of-life care.

New research funding commitments include:

- In March 2009 the Canadian Institutes of Health Research announced 14 one-year projects focused on cancer survivorship, with a total investment of \$1,269,225, through its Catalyst Grant program, “Biomedical & Clinical Approaches to Improving Quality of Life.” In October 2010 the Canadian Institutes of Health Research, in conjunction with The Cancer Research Society, C¹⁷, the Canadian Partnerships for Tomorrow Project, and the Ontario Institute for Cancer Research, launched a team grant-funding opportunity to support for research focused on the prevention or mitigation of biological, long-term late effects of pediatric and adolescent cancer treatments. The total amount available for this funding opportunity is \$7,525,000.
- In 2010 the Pediatric Oncology Group of Ontario (POGO), in conjunction with the Canadian Cancer Society, Ontario Division, launched the Pediatric Cancer Outcomes Initiative to stimulate research on the outcomes and/or effects of pediatric cancer on the patient and/or family during the treatment and survivorship periods. Through this program, three two-year projects have been funded.

37. *Paediatric/Adolescent/Young Adult Cancer: A Pan-Canadian Initiative*, Meeting Report, Toronto, March 9, 2009, available at <http://www.cihr-irsc.gc.ca/e/40559.html>.

38. Pan-Canadian Invitational Workshop, *Fostering Cancer Survivorship Research in Canada: Building Capacity Through a Research Consortium*, Vancouver, May 6–7, 2010, available at http://www.bccancer.bc.ca/NR/rdonlyres/E6F649B9-761C-4C51-89E0-C2F0834B8DCC/49734/Consortium_Proceedings_FINAL.pdf.

39. C. Fernandez et al., “Principles and recommendations for the provision of healthcare in Canada to adolescent and young adult-aged cancer patients and survivors,” *Journal of Adolescent and Young Adult Oncology*, 1(1) (2011): 53–59.

- As part of its new redesigned research strategy, this year the Canadian Cancer Society's Research Institute will be developing a research program with funding dedicated to generating knowledge about how to enhance the quality of life for Canadians living with and beyond cancer. The initial focus will be on survivorship, supportive care, and end-of-life care. The program will provide a strong evidence base for the Canadian Cancer Society and other organizational programs/services to enhance the quality of life for cancer survivors and their families.

Recent developments on the palliative and end-of-life care research side include:

- In October 2009 the CIHR Institute of Cancer Research released an impact assessment of its palliative and end-of-life care initiative.⁴⁰ This report describes the projects funded, the lessons learned, and future opportunities.
- In August 2010 the CIHR Institute of Cancer Research announced a new funding opportunity to support a sustainable palliative and end-of-life care network to support this research community. The Institute will provide \$600,000 over three years to support networks.
- The Canadian Hospice Palliative End-of-Life Care Surveillance Team Network, as part of the Canadian Partnership Against Cancer, is in the process of creating a web-based end-of-life care surveillance system. It will provide important information about the characteristics of terminally ill cancer patients, their personal and family needs, and their resource use in the last year of life.

Given these developments, we expect to see dramatic changes in the investment landscape over the next few years. Tracking these changes will be part of our future reporting.

40. CIHR Institute of Cancer Research, *Palliative and End-of-Life Care Initiative: Impact Assessment*, October 2009 (Ottawa: CIHR Institute of Cancer Research). Available at: http://www.cihr-irsc.gc.ca/e/documents/icr_palliative_care_summary_e.pdf.

APPENDIX A. ABBREVIATIONS

AIHS	Alberta Innovates – Health Solutions
CBCF	Canadian Breast Cancer Foundation
CBCRA	Canadian Breast Cancer Research Alliance
CCRA	Canadian Cancer Research Alliance
CCRS	Canadian Cancer Research Survey
CCS	Canadian Cancer Society
CIHR	Canadian Institutes of Health Research
CSO	Common Scientific Outline
CTCRI	Canadian Tobacco Control Research Initiative
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Version 10
NCI	National Cancer Institute (U.S.)
NCRI	National Cancer Research Institute (U.K.)
PI	Principal Investigator
POGO	Pediatric Oncology Group of Ontario
SSHRC	Social Sciences and Humanities Research Council

APPENDIX B. INVESTMENT BY FUNDING MECHANISM, 2005 TO 2008**Survivorship**

RESEARCH FOCUS	FUNDING MECHANISM					TOTAL
	Operating grants	Equipment and infrastructure grants	Career awards	Trainee awards	Related support grants	
Physiological effects	\$14,833,031	\$1,410,563	\$3,345,734	\$2,035,827	\$40,250	\$21,665,405
% funding mechanism	56.0	18.4	40.7	33.7	22.6	
% research focus	68.5	6.5	15.4	9.4	0.2	
% total investment	30.5	2.9	6.9	4.2	0.1	
Psychological effects	\$4,310,004	\$10,000	\$1,324,396	\$2,495,763	\$24,813	\$8,164,975
% funding mechanism	16.3	0.1	16.1	41.3	13.9	
% research focus	52.8	0.1	16.2	30.6	0.3	
% total investment	8.9	less than 0.1	2.7	5.1	0.1	
Quality of life	\$3,691,588	\$5,117,998	\$2,399,437	\$787,372	\$55,725	\$12,052,119
% funding mechanism	13.9	66.7	29.2	13.0	31.3	
% research focus	30.6	42.5	19.9	6.5	0.5	
% total investment	7.6	10.5	4.9	1.6	0.1	
Social needs/social support	\$505,282	–	\$591,291	\$280,633	\$10,000	\$1,387,206
% funding mechanism	1.9	–	7.2	4.6	5.6	
% research focus	36.4	–	42.6	20.2	0.7	
% total investment	1.0	–	1.2	0.6	less than 0.1	
Economic sequelae	\$674,766	\$18,134	\$253,743	\$279,833	–	\$1,226,475
% funding mechanism	2.5	0.2	3.1	4.6	–	
% research focus	55.0	1.5	20.7	22.8	–	
% total investment	1.4	less than 0.1	0.5	0.6	–	
Care delivery, access, and quality	\$2,429,871	\$1,110,956	\$300,498	\$121,355	\$45,404	\$4,008,084
% funding mechanism	9.2	14.5	3.7	2.0	25.5	
% research focus	60.6	27.7	7.5	3.0	1.1	
% total investment	5.0	2.3	0.6	0.2	0.1	
Thanatological issues	\$63,437	–	–	\$46,737	\$2,000	\$112,174
% funding mechanism	0.2	–	–	0.8	1.1	
% research focus	56.6	–	–	41.7	1.8	
% total investment	0.1	–	–	0.1	less than 0.1	
TOTAL	\$26,507,978	\$7,667,651	\$8,215,098	\$6,047,520	\$178,191	\$48,616,438

Palliative and End-of-life care

RESEARCH FOCUS	FUNDING MECHANISM					TOTAL
	Operating grants	Equipment and infrastructure grants	Career awards	Trainee awards	Related support grants	
Physiological effects	\$7,479,976	\$118,725	\$1,346,734	\$225,902	\$3,250	\$9,174,586
% funding mechanism	40.5	14.0	47.0	7.0	3.4	
% research focus	81.5	1.3	14.7	2.5	less than 0.1	
% total investment	29.3	0.5	5.3	0.9	less than 0.1	
Psychological effects	\$1,281,893	\$105,438	\$30,000	\$206,692	\$2,000	\$1,626,023
% funding mechanism	6.9	12.5	1.0	6.4	2.1	
% research focus	78.8	6.5	1.8	12.7	0.1	
% total investment	5.0	0.4	0.1	0.8	less than 0.1	
Quality of life	\$1,203,681	\$24,933	\$401,301	\$1,470,167	\$29,250	\$3,129,332
% funding mechanism	6.5	2.9	14.0	45.6	31.0	
% research focus	38.5	0.8	12.8	47.0	0.9	
% total investment	4.7	0.1	1.6	5.8	0.1	
Social needs/social support	\$406,962	–	–	\$96,000	\$2,000	\$504,962
% funding mechanism	2.2	–	–	3.0	2.1	
% research focus	80.6	–	–	19.0	0.4	
% total investment	1.6	–	–	0.4	less than 0.1	
Economic sequelae	\$443,030	–	–	–	–	\$443,030
% funding mechanism	2.4	–	–	–	–	
% research focus	100.0	–	–	–	–	
% total investment	1.7	–	–	–	–	
Care delivery, access, and quality	\$5,948,736	\$466,469	\$648,426	\$791,667	\$53,681	\$7,908,979
% funding mechanism	32.2	55.1	22.6	24.5	56.8	
% research focus	75.2	5.9	8.2	10.0	0.7	
% total investment	23.3	1.8	2.5	3.1	0.2	
Thanatological issues	\$1,719,248	\$130,371	\$437,333	\$434,491	\$4,250	\$2,725,693
% funding mechanism	9.3	15.4	15.3	13.5	4.5	
% research focus	63.1	4.8	16.0	15.9	0.2	
% total investment	6.7	0.5	1.7	1.7	less than 0.1	
TOTAL	\$18,483,527	\$845,935	\$2,863,794	\$3,224,919	\$94,431	\$25,512,606

APPENDIX C. INVESTMENT IN SURVIVORSHIP RESEARCH, 2005 TO 2008

TARGET	RESEARCH FOCUS	RESEARCH TYPE						TOTAL
		Model systems	Descriptive	Intervention	Prediction/ assessment	Knowledge synthesis	Other support	
Patient	Physiological effects	\$5,665,416	\$7,439,968	\$5,136,618	\$1,247,562	\$41,416	\$1,449,813	\$20,980,793
	% research type	100.0	44.9	40.5	48.3	20.0	13.3	43.2
	% research focus	27.0	35.5	24.5	5.9	0.2	6.9	100.0
	% total investment	11.7	15.3	10.6	2.6	0.1	3.0	43.2
	Project equivalents [1]	39.0	75.8	46.6	19.5	0.5	8.3	189.7
	Psychological effects	–	\$2,108,849	\$2,394,200	\$1,033,392	–	\$1,278,050	\$6,814,491
	% research type	–	12.7	18.9	40.0	–	11.7	14.0
	% research focus	–	30.9	35.1	15.2	–	18.8	100.0
	% total investment	–	4.3	4.9	2.1	–	2.6	14.0
	Project equivalents [1]	–	31.5	19.8	6.8	–	4.6	62.7
	Quality of life	–	\$1,833,024	\$4,058,585	\$107,349	\$41,416	\$5,956,538	\$11,996,911
	% research type	–	11.1	32.0	4.2	20.0	54.6	24.7
	% research focus	–	15.3	33.8	0.9	0.3	49.7	100.0
	% total investment	–	3.8	8.3	0.2	0.1	12.3	24.7
	Project equivalents [1]	–	23.8	28.6	2.2	0.5	9.7	64.8
	Social needs/social support	–	\$764,481	\$170,853	\$115,833	–	\$73,680	\$1,124,847
	% research type	–	4.6	1.3	4.5	–	0.7	2.3
	% research focus	–	68.0	15.2	10.3	–	6.6	100.0
	% total investment	–	1.6	0.4	0.2	–	0.2	2.3
	Project equivalents [1]	–	10.8	3.3	2.0	–	2.1	18.1
	Economic sequelae	–	\$444,678	–	–	–	\$229,459	\$674,137
	% research type	–	2.7	–	–	–	2.1	1.4
	% research focus	–	66.0	–	–	–	34.0	100.0
	% total investment	–	0.9	–	–	–	0.5	1.4
	Project equivalents [1]	–	5.4	–	–	–	1.3	6.7
	Care delivery, access, and quality	–	\$1,337,604	\$542,335	\$44,683	\$100,832	\$1,899,163	\$3,924,618
	% research type	–	8.1	4.3	1.7	48.8	17.4	8.1
	% research focus	–	34.1	13.8	1.1	2.6	48.4	100.0
% total investment	–	2.8	1.1	0.1	0.2	3.9	8.1	
Project equivalents [1]	–	17.8	3.0	1.3	1.3	8.2	31.5	
Thanatological issues	–	\$40,060	\$63,437	–	–	\$1,000	\$104,497	
% research type	–	0.2	0.5	–	–	less than 0.1	0.2	
% research focus	–	38.3	60.7	–	–	1.0	100.0	
% total investment	–	0.1	0.1	–	–	less than 0.1	0.2	
Project equivalents [1]	–	1.0	1.0	–	–	0.1	2.1	
Family/caregivers	Physiological effects	–	\$666,884	\$16,727	–	–	\$1,000	\$684,612
	% research type	–	4.0	0.1	–	–	less than 0.1	1.4
	% research focus	–	97.4	2.4	–	–	0.1	100.0
	% total investment	–	1.4	less than 0.1	–	–	less than 0.1	1.4
	Project equivalents [1]	–	4.1	0.3	–	–	0.1	4.4
	Psychological effects	–	\$1,045,617	\$293,867	–	–	\$11,000	\$1,350,484
	% research type	–	6.3	2.3	–	–	0.1	2.8
	% research focus	–	77.4	21.8	–	–	0.8	100.0
	% total investment	–	2.2	0.6	–	–	less than 0.1	2.8
	Project equivalents [1]	–	15.2	2.8	–	–	0.6	18.5
	Quality of life	–	\$47,960	–	–	–	\$7,248	\$55,208
	% research type	–	0.3	–	–	–	0.1	0.1
	% research focus	–	86.9	–	–	–	13.1	100.0
	% total investment	–	0.1	–	–	–	less than 0.1	0.1
	Project equivalents [1]	–	1.3	–	–	–	0.4	1.6
	Social needs/social support	–	\$258,021	\$3,338	–	–	\$1,000	\$262,359
	% research type	–	1.6	less than 0.1	–	–	less than 0.1	0.5
	% research focus	–	98.3	1.3	–	–	0.4	100.0
	% total investment	–	0.5	less than 0.1	–	–	less than 0.1	0.5
	Project equivalents [1]	–	3.3	0.3	–	–	0.1	3.7
	Economic sequelae	–	\$552,338	–	–	–	–	\$552,338
	% research type	–	3.3	–	–	–	–	1.1
	% research focus	–	100.0	–	–	–	–	100.0
	% total investment	–	1.1	–	–	–	–	1.1
	Project equivalents [1]	–	3.3	–	–	–	–	3.3
	Care delivery, access, and quality	–	\$18,885	–	\$35,417	\$22,917	\$6,248	\$83,466
	% research type	–	0.1	–	1.4	11.1	0.1	0.2
	% research focus	–	22.6	–	42.4	27.5	7.5	100.0
% total investment	–	less than 0.1	–	0.1	less than 0.1	less than 0.1	0.2	
Project equivalents [1]	–	0.5	–	0.8	0.3	0.3	1.8	
Thanatological issues	–	\$3,338	\$3,338	–	–	\$1,000	\$7,677	
% research type	–	less than 0.1	less than 0.1	–	–	less than 0.1	less than 0.1	
% research focus	–	43.5	43.5	–	–	13.0	100.0	
% total investment	–	less than 0.1	less than 0.1	–	–	less than 0.1	less than 0.1	
Project equivalents [1]	–	0.3	0.3	–	–	0.1	0.6	
TOTAL		\$5,665,416	\$16,561,708	\$12,683,298	\$2,584,237	\$206,581	\$10,915,199	\$48,616,438

[1] Project equivalents are weighted counts of projects that take into consideration the project weighting and classification. Project equivalents, shown in the total column, will not always equal the sum of the project equivalents shown under the six research type columns because projects reflected under more than one research type are not double counted.

APPENDIX D. INVESTMENT IN PALLIATIVE AND END-OF-LIFE CARE RESEARCH, 2005 TO 2008

TARGET	RESEARCH FOCUS	RESEARCH TYPE						TOTAL
		Model systems	Descriptive	Intervention	Prediction/ assessment	Knowledge synthesis	Other support	
Patient	Physiological effects	\$2,150,199	\$948,402	\$2,639,816	\$895,716	–	\$2,171,312	\$8,805,446
	% research type	100.0	11.8	63.3	59.9	–	22.8	34.5
	% research focus	24.4	10.8	30.0	10.2	–	24.7	100.0
	% total investment	8.4	3.7	10.3	3.5	–	8.5	34.5
	Project equivalents [1]	10.3	10.3	40.6	8.9	–	4.0	74.2
	Psychological effects	–	\$410,056	\$299,353	\$94,283	–	\$381,818	\$1,185,510
	% research type	–	5.1	7.2	6.3	–	4.0	4.6
	% research focus	–	34.6	25.3	8.0	–	32.2	100.0
	% total investment	–	1.6	1.2	0.4	–	1.5	4.6
	Project equivalents [1]	–	4.5	2.2	1.5	–	0.7	8.9
	Quality of life	–	\$706,960	\$254,348	\$297,644	–	\$1,257,246	\$2,516,198
	% research type	–	8.8	6.1	19.9	–	13.2	9.9
	% research focus	–	28.1	10.1	11.8	–	50.0	100.0
	% total investment	–	2.8	1.0	1.2	–	4.9	9.9
	Project equivalents [1]	–	4.3	5.3	2.1	–	2.2	13.9
	Social needs/social support	–	\$438,462	\$48,375	–	–	\$1,000	\$487,837
	% research type	–	5.4	1.2	–	–	less than 0.1	1.9
	% research focus	–	89.9	9.9	–	–	0.2	100.0
	% total investment	–	1.7	0.2	–	–	less than 0.1	1.9
	Project equivalents [1]	–	2.6	2.0	–	–	0.1	4.7
	Economic sequelae	–	\$124,070	–	–	–	–	\$124,070
	% research type	–	1.5	–	–	–	–	0.5
	% research focus	–	100.0	–	–	–	–	100.0
	% total investment	–	0.5	–	–	–	–	0.5
Project equivalents [1]	–	0.7	–	–	–	–	0.7	
Care delivery, access, and quality	–	\$1,282,679	\$453,154	\$189,269	\$5,157	\$4,199,894	\$6,130,153	
% research type	–	15.9	10.9	12.7	4.0	44.1	24.0	
% research focus	–	20.9	7.4	3.1	0.1	68.5	100.0	
% total investment	–	5.0	1.8	0.7	less than 0.1	16.5	24.0	
Project equivalents [1]	–	17.7	3.0	1.9	0.4	9.6	32.6	
Thanatological issues	–	\$840,738	\$25,754	–	\$122,490	\$358,760	\$1,347,743	
% research type	–	10.4	0.6	–	96.0	3.8	5.3	
% research focus	–	62.4	1.9	–	9.1	26.6	100.0	
% total investment	–	3.3	0.1	–	0.5	1.4	5.3	
Project equivalents [1]	–	11.7	0.3	–	1.2	2.0	15.1	
Family/caregivers	Physiological effects	–	\$179,622	\$6,884	\$6,884	–	\$175,751	\$369,141
	% research type	–	2.2	0.2	0.5	–	1.8	1.4
	% research focus	–	48.7	1.9	1.9	–	47.6	100.0
	% total investment	–	0.7	less than 0.1	less than 0.1	–	0.7	1.4
	Project equivalents [1]	–	4.6	0.1	0.1	–	0.6	5.3
	Psychological effects	–	\$375,738	\$11,057	–	–	\$53,719	\$440,513
	% research type	–	4.7	0.3	–	–	0.6	1.7
	% research focus	–	85.3	2.5	–	–	12.2	100.0
	% total investment	–	1.5	less than 0.1	–	–	0.2	1.7
	Project equivalents [1]	–	4.5	0.5	–	–	0.4	5.4
	Quality of life	–	\$325,270	\$68,695	\$11,058	–	\$208,110	\$613,134
	% research type	–	4.0	1.6	0.7	–	2.2	2.4
	% research focus	–	53.1	11.2	1.8	–	33.9	100.0
	% total investment	–	1.3	0.3	less than 0.1	–	0.8	2.4
	Project equivalents [1]	–	1.6	1.8	0.6	–	0.3	4.3
	Social needs/social support	–	–	\$16,125	–	–	\$1,000	\$17,125
	% research type	–	–	0.4	–	–	less than 0.1	0.1
	% research focus	–	–	94.2	–	–	5.8	100.0
	% total investment	–	–	0.1	–	–	less than 0.1	0.1
	Project equivalents [1]	–	–	1.0	–	–	0.1	1.1
	Economic sequelae	–	\$283,369	\$35,591	–	–	–	\$318,960
	% research type	–	3.5	0.9	–	–	–	1.3
	% research focus	–	88.8	11.2	–	–	–	100.0
	% total investment	–	1.1	0.1	–	–	–	1.3
Project equivalents [1]	–	1.4	0.3	–	–	–	1.7	
Care delivery, access, and quality	–	\$1,140,401	\$152,890	–	–	\$485,535	\$1,778,826	
% research type	–	14.2	3.7	–	–	5.1	7.0	
% research focus	–	64.1	8.6	–	–	27.3	100.0	
% total investment	–	4.5	0.6	–	–	1.9	7.0	
Project equivalents [1]	–	9.6	0.8	–	–	1.7	12.1	
Thanatological issues	–	\$999,266	\$155,354	–	–	\$223,330	\$1,377,951	
% research type	–	12.4	3.7	–	–	2.3	5.4	
% research focus	–	72.5	11.3	–	–	16.2	100.0	
% total investment	–	3.9	0.6	–	–	0.9	5.4	
Project equivalents [1]	–	5.6	1.9	–	–	0.8	8.3	
TOTAL		\$2,150,199	\$8,055,032	\$4,167,396	\$1,494,854	\$127,647	\$9,517,477	\$25,512,606

[1] Project equivalents are weighted counts of projects that take into consideration the project weighting and classification. Project equivalents, shown in the total column, will not always equal the sum of the project equivalents shown under the six research type columns because projects reflected under more than one research type are not double counted.

OUR MEMBERS





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