Returning to Work after Cancer: Employee, Employer and Caregiver Perspectives

Person-Centred Perspective
Canadian Partnership Against Cancer

December 2012
PRESENTATION OBJECTIVE

To highlight the results of the following three studies commissioned by the Canadian Partnership Against Cancer (CPAC) – Cancer Journey Survivorship Task Group:

1) *Environmental scan of programs and resources to facilitate return to work for people with cancer and other chronic diseases*

2) *Literature review and consultations about return to work concerns faced by people dealing with cancer and caregivers*

3) *Workplace support for cancer survivors: perspectives of employers.*
A NOTE ABOUT THIS PRESENTATION

• In this slide presentation each of the three projects will be reviewed covering the methods, results and recommendations.
• The presentation will conclude by briefly highlighting the findings across projects and providing a link to information about future CPAC plans.
PROJECT #1: IDENTIFYING RETURN TO WORK RESOURCES

**Goal:** Create a comprehensive list of resources for employees returning to or managing at work that currently exist which address workplace issues for people living with cancer and other chronic diseases.
PROJECT #1: METHODS

• Created the framework for the web search.

• Implemented a web-based review of Canadian and International return to work resources related to cancer and chronic diseases.

• Conducted 16 in-depth interviews with representatives of 21 most relevant return to work programs for cancer, HIV and mental health.
• The most common web-based resources include programs, guides, information sheets, services, reports, publications and booklets
• Outside of cancer, most resources available were in the mental health field
• There is a relative absence of resources for health care professionals regarding return to work issues
Most programs were implemented in past decade

Across programs and across countries, return to work content focuses on financial and legal information, how to interact with the current and future employer, how to deal with stress and side effects

Most programs are offered to individuals who are finished treatment (not earlier in the cancer journey) and most focus on getting people back to work (not on what happens once they are back)
PROJECT #1: RECOMMENDATIONS

• Stakeholders develop and evaluate return to work projects that address return to work issues across the cancer trajectory.

• Support the creation of an expert panel of return to work professionals to inform and advise on best practices.

• Establish mechanisms for knowledge transfer among return to work program providers.

• Engage HIV and Mental Health organizations to determine how to share information/collaborate on projects.
PROJECT #2: SURVIVOR AND CAREGIVER PERSPECTIVES ABOUT RETURNING TO WORK

**Goal:** Conduct a literature review and consultations to determine the return to work challenges that people dealing with cancer and caregivers experience during or after treatment in Canada.
• Conduct a literature review and interviews to:
  ▪ identify available information concerning return to work
  ▪ inform on-line survey development
• Distribute a national on-line survey for people living with cancer and caregivers to identify return to work concerns, issues and challenges
• Conduct focus groups to delve more deeply into return to work experiences
Return to work issues are relevant to almost 60% of survivors

Conduct Most leave work at 6 months and return 12 to 18 months post diagnosis

Those living with breast, lung, or colorectal cancer are more likely to leave work for longer periods
• Particularly concerning side effects include physical and cognitive impairment, fatigue, emotional distress, lymphedema and incontinence

• Having chemotherapy negatively affects the ability to work

• Accommodation, flexibility in scheduling, support from employers and colleagues and services (i.e., retraining or counseling) assist return to work
PROJECT #2: RESULTS (SELECTED) - ON-LINE SURVEY/FOCUS GROUPS

- **Surveys**
  - Were completed by 410 individuals with cancer and 60 caregivers across Canada.
    - Individuals with cancer: 77% female, 25 to 64 years of age, 63% from Ontario
    - Caregivers: 88% were female, 25 to 64 years of age, 44% from Ontario

- **Focus Groups**
  - 16 individuals with cancer attended the two focus groups.
  - Participants ranged in age from 25 to 64 years.
For the most part, individuals with cancer were well supported by their employers, however...

- 60% experienced a decrease in income in the 12 months following diagnosis and 75% derived income from income supports (short term disability, long term disability, Employment Insurance)
- 40% left work for more than 6 months
- 50% returned gradually and 18% immediately returned to full time work
What cancer(s) were you diagnosed with (check all that apply)?

- Bladder
- Brain
- Breast (45.0%)
- Colorectal (10.0%)
- Head and Neck (20.0%)
- Kidney (0.0%)
- Leukemia (35.0%)
- Lung (5.0%)
- Melanoma (25.0%)
- Non-Hodgkin Lymphoma (15.0%)
- Prostate (5.0%)
- Thyroid (0.0%)
- Other (please specify) (10.0%)
What type of treatment did you have following your diagnosis (check all that apply)?

- Surgery
- Radiation
- Chemotherapy
- Medication (e.g. pain meds, hormonal therapies)
- No treatment
- Other
What was your return to work schedule like? (check all that apply):

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
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</thead>
<tbody>
<tr>
<td>I gradually returned to work in terms of the numbers of hours worked or the number of days worked per week</td>
<td>40.6%</td>
</tr>
<tr>
<td>I immediately went back to work full time</td>
<td>18.3%</td>
</tr>
<tr>
<td>I have not yet returned to work in any capacity</td>
<td>15.9%</td>
</tr>
<tr>
<td>I had flexible scheduling of hours worked each day or the location of work (e.g. work from home)</td>
<td>12.2%</td>
</tr>
<tr>
<td>I never stopped working during treatment</td>
<td>8.1%</td>
</tr>
<tr>
<td>I immediately returned to work on a part-time basis</td>
<td>6.6%</td>
</tr>
<tr>
<td>I retired after I was diagnosed</td>
<td>2.7%</td>
</tr>
<tr>
<td>I was dismissed from my job after I was diagnosed</td>
<td>2.0%</td>
</tr>
<tr>
<td>I quit after I was diagnosed</td>
<td>1.5%</td>
</tr>
<tr>
<td>Other</td>
<td>11.7%</td>
</tr>
</tbody>
</table>
Main work related issues included experiencing side effects at work and having difficulty managing them.

Main side effects included: Fatigue (74%), loss of energy (69%), cognitive problems (45%).

Those with side effects were more likely to report they were:
- Not able to work the same way as before,
- Unable to work full time now,
- Needed flexibility in work hours/workload/time off for appointments, and understanding from co-workers and manager/employer.
Which of the following cancer or health-related problems resulted in work-related issues, concerns or challenges following your diagnosis or treatment (check all that apply)?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>73.5%</td>
</tr>
<tr>
<td>Reduced energy</td>
<td>69.3%</td>
</tr>
<tr>
<td>Reduced physical ability</td>
<td>47.8%</td>
</tr>
<tr>
<td>Personal stress</td>
<td>47.3%</td>
</tr>
<tr>
<td>Reduced cognitive ability to manage work demands (e.g., poor memory, concentration)</td>
<td>45.3%</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>45.0%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>43.3%</td>
</tr>
</tbody>
</table>
Which of the following workplace accommodations or supports did you require following your cancer diagnosis or treatment and which did you receive?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>I required this accommodation or support</th>
<th>I received this accommodation or support</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support from supervisor and/or employer</td>
<td>166</td>
<td>162</td>
<td>212</td>
</tr>
<tr>
<td>Paid time off for medical appointments</td>
<td>155</td>
<td>137</td>
<td>180</td>
</tr>
<tr>
<td>Support from co-workers</td>
<td>148</td>
<td>171</td>
<td>205</td>
</tr>
<tr>
<td>Flexible scheduling of work hours</td>
<td>144</td>
<td>135</td>
<td>169</td>
</tr>
<tr>
<td>Gradual increase in work schedule</td>
<td>131</td>
<td>120</td>
<td>150</td>
</tr>
<tr>
<td>Gradual increase in workload</td>
<td>106</td>
<td>95</td>
<td>126</td>
</tr>
</tbody>
</table>
• 40% fulfilled this role over 6-month period

• They provided emotional support and tasks that required their physical presence/time away from their work

• 63% did not receive support or flexibility to leave work from their employer

• Caregivers experienced stress; needed time from work to care for patient but also to care for self
What cancer(s) was the individual you provided care for diagnosed with (check all that apply)?
What type of treatment did they have following this diagnosis (check all that apply)?

- Surgery: 58.3%
- Radiation: 36.7%
- Chemotherapy: 76.7%
- Medication: 38.3%
- No treatment: 1.7%
- Other: 18.3%
### What types of care do/did you provide (check all that apply)?

<table>
<thead>
<tr>
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<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support with activities of daily living</td>
<td>55.0%</td>
</tr>
<tr>
<td>Home management</td>
<td>93.3%</td>
</tr>
<tr>
<td>Skilled care</td>
<td>23.3%</td>
</tr>
<tr>
<td>Transportation to and from medical appointments</td>
<td>83.3%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>98.3%</td>
</tr>
<tr>
<td>Other</td>
<td>25.0%</td>
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</tbody>
</table>
### PROJECT #2: SURVIVORS’ RECOMMENDATIONS

What information or support would have helped you manage your work-related concerns and return to work experience following your cancer diagnosis (check all that apply)?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>What the impact of my cancer and treatment might have on my work</td>
<td>44.2%</td>
</tr>
<tr>
<td>Guidance on how much time I should have planned to take off from work</td>
<td>43.9%</td>
</tr>
<tr>
<td>Managing the pressure to meet work demands</td>
<td>39.5%</td>
</tr>
<tr>
<td>Knowing what my employment rights are</td>
<td>36.5%</td>
</tr>
<tr>
<td>Information on sources of income support</td>
<td>35.4%</td>
</tr>
<tr>
<td>How to manage my symptoms</td>
<td>31.8%</td>
</tr>
<tr>
<td>How to talk with my co-workers about my cancer diagnosis and treatment</td>
<td>30.7%</td>
</tr>
<tr>
<td>How to talk with my employer about my cancer diagnosis and treatment</td>
<td>28.7%</td>
</tr>
<tr>
<td>Access to income support (e.g. long term disability)</td>
<td>28.2%</td>
</tr>
</tbody>
</table>
What information or support would have helped you manage your work-related concerns while providing care for the individual with cancer (check all that apply)?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to manage caregiving and work demands</td>
<td>58.2%</td>
</tr>
<tr>
<td>What my employment rights were/are</td>
<td>52.7%</td>
</tr>
<tr>
<td>Information on potential sources of income support</td>
<td>49.1%</td>
</tr>
<tr>
<td>What the impact of providing care might be on my work</td>
<td>47.3%</td>
</tr>
<tr>
<td>How to talk with my employer about my caregiving role</td>
<td>45.5%</td>
</tr>
<tr>
<td>What workplace accommodations could be made</td>
<td>43.6%</td>
</tr>
<tr>
<td>Guidance on how much time I would likely need to provide care</td>
<td>41.8%</td>
</tr>
<tr>
<td>How to negotiate workplace accommodations with my employer</td>
<td>41.8%</td>
</tr>
<tr>
<td>How to talk with my co-workers about my caregiving role</td>
<td>40.0%</td>
</tr>
</tbody>
</table>
PROJECT #2: OVERALL RECOMMENDATIONS

• Create information about income supports for the employed and information about critical illness and/or disability insurance for the self-employed.

• Provide workplace accommodation information for employers in small companies and for employers of caregivers.

• For individuals with cancer and for employers/co-workers create information about the possible side effects that returning individuals might experience.

• Create rehabilitation resources (web-based or in-person) to address concerns about side effects.
Goal: Understand the perspectives of employers regarding the challenges faced by the workplace when an employee returns to work following cancer and identify programs and services that could be provided to the workplace to support working cancer survivors and their employers.
PROJECT #3: METHODS

• **Stage I**: In-depth interviews (N=41) with senior staff from workplace organizations
  • Recruiting considerations included size of firm, sector, level of the employee’s physical activity and geographic location.

• **Stage II**: Focus groups (3) with senior managers or human resource representatives where participants were from:
  • Large organizations (>500) where majority of employees were not physically active,
  • Large organizations (>500) where the majority of employees were physically active,
  • Medium-sized organizations (100-500) with a mix of physical activity among employees.
The incidence of actual, or known, employees with cancer is quite low in most organizations.

Most said this is not an human resource issue on which they are actively focusing.

There is variation in group benefit plans by size of organization.

There is low awareness of cancer support programs and services available outside their organizations, particularly among small and mid-sized organizations.
Many factors impact successful management of a situation where the employee’s capacity to work is affected by disease:

- Nature of the employee’s illness
- Nature of the work
- Size of the organization
- Flexibility of managers and employees
- Culture in the workplace
- Employee’s will to return
- Manager’s will to make things work
- Financial and organizational constraints of the employer
Level of employer support tends to:

- Increase with tenure and seniority, ease of replacement, strong performing employees
- Decrease with work that is physically demanding, hourly and part-time workers, and if management team is extremely cost driven
PROJECT #3: RESULTS - MAIN RETURN TO WORK CHALLENGES

- Challenges (in order of importance)
  - Managing employee workload and productivity
  - Accommodation restrictions/the employee’s diminished capacity
  - Confidentiality/co-worker stress
  - Managers lack of education & training
  - Costs incurred when employees capacity to work is diminished
  - Assessing return to work readiness
  - Lack of financial support for employees
  - Receiving timely and adequate information form physicians
• Challenges faced by employers do not change meaningfully by size of firm, nature of the work or by sector however, the ability to address these challenges, the difficulty of addressing them, and the tools and resources on hand to do so, do change significantly.

• For example, large employers will need to build on what they already do (more training, improved communication) and small employers will need to draw on external resources to create training and return to work policies.
PROJECT #3: RESULTS – FACTORS INCREASING SUCCESSFUL RETURN TO WORK MANAGEMENT

- Participants agreed that enhanced understanding to the employee’s situation, stronger communication between key stakeholders, an increased awareness of options/strategies available, and an improved toolkit would increase the likelihood of successfully managing such workplace situations.
PROJECT #3: RECOMMENDATIONS

- Create an awareness-raising program to raise profile of accommodating to chronic disease, like cancer.

- Build a toolkit of relevant resources.

- Develop educational material for managers.

- Provide training sessions about return to work issues for human resources managers.

- Provide access to external professionals.

- Compile an online list of community services.
OVERALL SIMILARITIES ACROSS PROJECTS

• The *Return to Work* projects shed light regarding gaps in available programs and resources.

• Other cross-project findings include that:
  • Employees and small and medium organizations require more education and information about workplace accommodation;
  • Key stakeholders must improve their communication (insurers, individuals with cancer, physicians, employers); and,
  • Employees with cancer and caregivers need increased financial support during the treatment and/or palliative period of time.
NEXT STEPS

• CPAC is looking to create resources and tools for patients, health care professionals and employers related to return to work issues after cancer

• Look for future developments on CPAC’s website at www.cancerview.ca

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