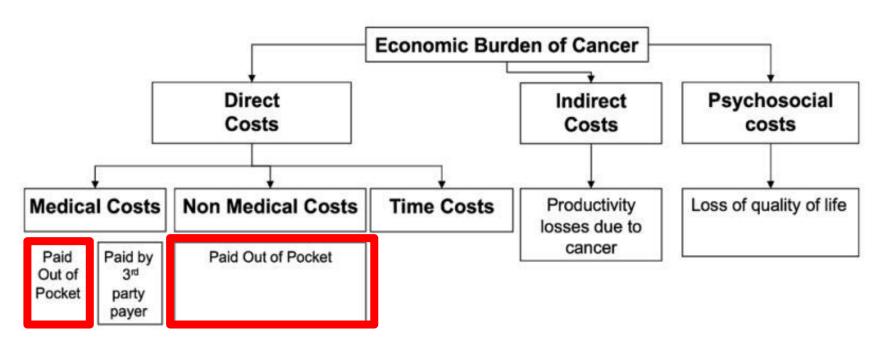


Economic Burden of Cancer: Out-of-Pocket Costs

Murray Krahn MD, MSc, FRCPC



Cost Components





OOP Costs for Ca Treatment

- drugs
- home/personal care
- parking/ travel
- complementary/alternative medicines
- vitamins and supplements
- natural, organic, or macrobiotic diets
- child care
- special pillows, beds, canes, and safety rails

- freezing eggs or sperm
- dog walking
- wheelchair rental
- wigs
- new clothing (as a result of weight loss)
- tutors (for students with Ca)
- Increase in take-out/restaurant/prepared food
- bucket list items



In Canada...

- Ca pts typically lack comprehensive cost coverage outside hospital setting
 - Once discharged, required to pay for prescription drugs, complementary and alternative medicine, home nursing
- Some costs for home or personal care of Ca pts are not funded by the public health care system

Impact of out-of-pocket costs on the quality of life of Canadian cancer patients (Fitch, Longo J Psy Onc 2018;36:582-596)

- Qualitative study n=14 breast, colorectal, prostate, lung cancer patients
- Financial changes add to an already difficult situation:
 - There's no sort of preparation for that aspect of a cancer diagnosis...you're thrown into this
 whirlpool and in addition to coping with a life threatening illness, you are all of a sudden faced
 with additional expenses...I don't think anyone ever made mention of that fact
 - Just because of the cancer, I am behind on everything. I was always on time for everything, never late with a payment...I don't have the finances to keep me going while I am healing...I am two months behind on my hydro...just waiting for the disconnection notice to come...it's been a really hard year



Impact of out-of-pocket costs on the quality of life of Canadian cancer patients (Fitch, Longo J Psy Onc 2018;36:582-596)

- > Financial changes add to an already difficult situation:
 - From a personal point of view, I just think that, that it's those kinds of things that tend to weigh anybody down when, when you're, like I said, when you're coping with a diagnosis that could end up in, could end in death. I mean, you don't know, at the time you are diagnosed. Ah, and then everyday you're faced with an additional expense, I mean, I would have to say that, that the diagnosis is devastating enough, but when you lose your income because of it, it's like being slapped when you are down.



Table 1 Average household out-of-pocket expenditures on health care (2009 dollars), by household income quintile, Canada excluding territories, 1997 to 2009

				Year				
Household income	1997	1999	2001	2003	2005	2007	2009	1997 to 2009
quintile				\$				% change
Q1 (lowest)	631	676	700	753	794	892	1,030	63*†
Q2	1,172	1,284	1,317	1,375	1,564	1,725	1,644	40*†
Q3	1,448	1,570	1,676	1,746	1,867	1,937	1,973	36*†
Q4	1,664	1,834	1,901	2,040	2,139	2,269	2,258	36*↑
Q5 (highest)	2,007	2,049	2,260	2,380	2,737	2,792	2,964	48*

^{*}significant change over time

Source: 1997 to 2009 Survey of Household Spending.



[†]significantly different from Q5 (highest income quintile)

In Canada...

LONGO C.J., DEBER R., FITCH M., WILLIAMS A.P. & D'SOUZA D. (2007) European Journal of Cancer Care 16, 500–507

An examination of cancer patients' monthly 'out-of-pocket' costs in Ontario, Canada

Ontario cancer patients' monthly out-of-pocket costs (OOPC) were assessed to determine whether these costs were problematic. A self-administered questionnaire was administered to breast (n=74), colorectal (n=70), lung (n=68) and prostate (n=70) cancer patients between October 2001 and April 2003. It measured categorical OOPC, which were analysed using linear regression modelling, to determine whether any of a variety of independent variables influenced OOPC. Monthly OOPC (mean, range) were: parking/fares (\$47, \$0–450), devices (\$46, \$0–2350), prescription drugs (\$45, \$0–1400), accommodation (\$43, \$0–1500), complementary and alternative medicine (\$29, \$0–5000), vitamins (\$25, \$0–400), homemaking (\$14, \$0–1000), family care (\$12, \$0–1200), homecare (\$2, \$0–330) and other (\$8, \$0–250), with the total averaging \$213 (\$0–5230). Imputed travel mileage costs added \$372 (\$0–6180). Most patients were well served by the current healthcare programmes. In multivariate analysis, variables influencing several OOPC categories were: tumour site, hospitalization, age, and number of clinic trips. Travel costs proved the most problematic, with patients under 65 years and without insurance more likely to have high OOPC. Education and income were not reliable predictors for high OOPC. Many of these costs were for items not traditionally covered by public healthcare financing systems, raising important issues around defining 'medically necessary' care and the role of government.

Methods

- > Self administered questionnaire
- > 5/8 cancer centers in Ontario
- > Breast/colorectal/lung/prostate
- On treatment for >30 days
- On ACTIVE treatment



In Canada...

	n	Mean (\$)	% with no costs	SD (\$)	Range (\$
Drugs	270	45.23	47.0	138.85	0-1400
Homecare	281	1.61	98.9	20.32	0-330
Homemaking	276	14.20	93.5	79.50	0-1000
CAM	279	29.10	93.4	306.49	0-5000
Vitamins/supplements	271	25.41	65.7	60.27	0-400
Family care	279	12.54	96.8	100.08	0-1200
Accommodation/meals	281	42.98	74.4	144.04	0-1500
Devices	277	45.55	85.9	241.92	0-2350
Other	275	7.63	86.9	29.38	0-250
Total	246	212.71	19.5	490.73	0-5230
Imputed travel cost	222	371.94	14.0	694.18	0-6180
Parking/fares	278	47.02	18.3	65.44	0-450

Longo CJ, Deber R, Fitch M, Williams AP, D'Souza D. An examination of cancer patients' monthly 'out-of-pocket' costs in Ontario, Canada. Eur J Cancer Care (Engl). 2007 Nov;16(6):500-7

\$630/month

Table 3. Univariate and multiple linear regression models (backward ste

	Univariate	Coefficient (SE)	P-value
Drugs	Coverage*	-63.73 (31.52)	0.044
	Age category	-37.59 (17.05)	0.028
	Hospitalization	79.22 (36.71)	0.032
Vitamins/supplements	Chemotherapy	20.56 (7.61)	0.007
	Age category	-26.60 (7.28)	0.000
Family care	Tumour [†]	35.16 (13.43)	0.009
Accommodation/meals	Clinic distance	0.47 (0.11)	0.000
Devices	Chemotherapy	65.58 (30.35)	0.032
	Sex [‡]	89.24 (28.81)	0.002
CAM	NS	_	_
Homecare, homemaking, other	NS	-	-
Total	Coverage*	-227.44 (111.92)	0.043
	Income	53.24 (19.19)	0.006
	Education	58.58 (21.30)	0.006
	Chemotherapy	139.61 (65.14)	0.033
	Age category	-172.29 (62.62)	0.006
	Sex [‡]	168.09 (61.98)	0.007
	Tumour [†]	243.12 (69.75)	0.001
	Hospitalization	421.82 (137.51)	0.002
Imputed travel cost	Clinic trips	27.37 (5.62)	0.000
	Radiation	529.08 (88.32)	0.000
	Clinic distance	5.34 (0.42)	0.000
Parking/fares	Tumour [†]	-20.64 (8.81)	0.020
	Radiation	28.33 (7.77)	0.000
	Clinic site	-7.25 (2.60)	0.006
	Clinic trips	3.33 (0.43)	0.000

-coverage, income

-radiation



Summary

- Results suggest that the current system is a qualified success
- > OOP costs are on average manageable and not strongly related to socioeconomic status



Summary

> Two warning signs

- Travel, esp rural and remote
- Extent to which costs are related to presence of private insurance



In Canada...

Out-of-Pocket Costs in the Year After Early Breast Cancer Among Canadian Women and Spouses

Sophie Lauzier, Pascale Lévesque, Myrto Mondor, Mélanie Drolet, Douglas Coyle, Jacques Brisson, Benoît Mâsse, Louise Provencher, André Robidoux, Elizabeth Maunsell

Manuscript received July 30, 2012; revised November 9, 2012; accepted November 12, 2012.

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Background We lack comprehensive information about the extent of out-of-pocket costs after diagnosis of early breast cancer and their effects on the family's financial situation.

Methods This longitudinal study assessed out-of-pocket costs and wage losses during the first year after diagnosis of early breast cancer among Canadian women and spouses. Out-of-pocket costs for treatments and follow-up, consulta-

tions with other practitioners, home help, clothing, and natural health products were estimated, with information collected from telephone interviews. Generalized linear models were used to identify women at risk of having

higher costs and the effects of out-of-pocket costs on perceptions of the family's financial situation.

Overall, 829 women (participation, 86,2%) and 391 spouses participated, Women's median net out-of-pocket costs during the year after diagnosis were \$1002 (2003 Canadian dollars; mean = \$1365; SD = \$1238), and 74.4% of these costs resulted from treatments and follow-up. Spouses' median costs were \$111 (mean = \$234; SD = \$320), or 9% of couples' total expenses. In multivariable analyses, the percentage of women with out-of-pocket costs of \$1773 or more (upper quartile) was statistically significantly associated with higher education, working at diagnosis, living more than 50 km from the hospital where surgery was performed, and having two and three different types of adjuvant treatment (all 2-sided P values ≤ .01). However, when considered simultaneously with wage losses, out-of-pocket costs were not associated with perceived deterioration in the family's financial situation; rather, wage losses were the driving factor.

Overall, out-of-pocket costs from breast cancer for the year after diagnosis are probably not unmanageable for most women. However, some women were at higher risk of experiencing financial burden resulting from these costs.

J Natl Cancer Inst:2013:105:280-292

Results

Conclusions

Methods

- Prospective cohort study, 2003
- Women receiving "first treatment" for breast cancer, and partners
- > 8 hospitals in Quebec
- > 1, 6, 12 months post diagnosis

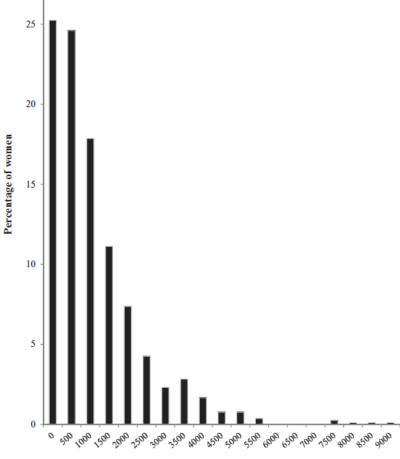


Table 2 (Continued).

Costs	No.	Mean ± SD
Child care (n = 17)	17	458±671
Clothing (n = 361)	361	154 ± 169
Vitamins and natural health products (n = 103)¶¶	98	263 ± 536
Total OOP net costs for other types of expenses (n = 486)	480	330 ± 527
Total OOP net costs (n = 800)	772	1365 ± 1238

^{*} IQR = interquartile range: PCT = percentile.





Total net out-of-pocket costs (2003 Canadian dollars)



Table 6. Prevalence of reporting a change for the worse in family financial situation over the year after diagnosis comparing women with different levels of out-of-pocket (OOP) costs and wage losses (N = 758)*

Change for the worse during the year after diagnosis in	No.	Prevalence	PR (95% CI)	P †	PR adjusted# (95% CI)	P †
Satisfaction with family financial situation						
Low OOP costs/low wage losses	456	11.2	1.00 (referent)	<.0001	1.00 (referent)	<.000
Low OOP costs/high wage losses	113	31.0	2.77 (1.90 to 4.04)		2.70 (1.77 to 4.11)	
High OOP costs/low wage losses	110	20.9	1.87 (1.20 to 2.92)		1.84 (1.17 to 2.91)	
High OOP costs/high wage losses	78	32.1	2.87 (1.89 to 4.34)		2.85 (1.81 to 4.48)	



Patient time and out-of-pocket costs for long-term prostate cancer survivors in Ontario, Canada

Claire de Oliveira • Karen E. Bremner • Andy Ni • Shabbir M. H. Alibhai • Audrey Laporte • Murray D. Krahn

- We estimated OOP costs for long-term PCa survivors
- N=585, 2-13 years since diagnosis, 3 geographic regions of Ontario



OOP Costs in PCa

		.		••		
	Patient time	costs (per year)	Out-of-po	cket costs (per year)	Total	costs (per year)
	Mean	95% CI	Mean	95% CI	Mean	95% CI
All patients (n=545)	\$838	\$442 -\$1233	\$200	\$109 - \$290	\$1037	\$622 - \$1453
Age (years)						
_<60 (n=44) 61-70 (n=155)	\$1514 \$834	\$95 – \$2932 \$180 – \$1489	\$588 \$182	\$55 - \$1121 \$106 - \$258	\$2102 \$1017	\$395 - \$3808 \$344 - \$1690
71-80 (n=273) >80 (n=73)	\$898 \$212	\$236 - \$1559 \$126 - \$298	\$112 \$334	\$73 - \$150 -\$232 - \$900	\$1009 \$546	\$338 - \$1680 - \$32 - \$1124
p-value for differences between groups	0.52		0.03		0.43	
Radical prostatectomy						
no (n=266) yes (n=279)	\$464 \$1194	\$69 - \$858 \$520 - \$1868	\$218 \$183	\$52 - \$385 \$104 - \$262	\$682 \$1377	\$245 - \$1119 \$680 - \$2074
p-value for differences between groups	0.70		0.10		0.07	
Radiation therapy						
no (n=351) yes (n= 194)	\$1152 \$270	\$542 - \$1761 \$162 - \$377	\$187 \$223	\$111 - \$264 \$7 - \$438	\$1339 \$492	\$710 - \$1968 \$240 - \$744
p-value for differences between groups	0.04		0.72	, , , = =	0.05	
Androgen deprivation therapy						
never (n=340) past (n= 112)	\$919 \$652	\$377 - \$1460 \$233 - \$1070	\$140 \$441	\$86 - \$194 \$34 - \$848	\$1059 \$1092	\$508 - \$1609 \$417 - \$1767
current (n=93)	\$765	-\$351 - \$1880	\$130	\$61 - \$199	\$894	- \$240 – \$2029
p-value for differences between groups	0.86		0.03		0.95	

Patient time and out-ofpocket costs for longterm prostate cancer survivors in Ontario, Canada. J Cancer Surviv. 2014 Mar;8(1):9-20.

Summary

- ➤ Mean OOP costs were \$200/year
- Although generally low, total costs (time and OOP) represented approximately 10 % of income for lower income patients
- Time and out-of-pocket costs are generally manageable for long-term PC survivors but can be a significant burden mainly for lower income patients. The effects of PC-specific, treatment-related dysfunctions on QoL can also represent sources of expense for patients



Approaches for Collecting OOP Costs Study-Specific Surveys

- Directly elicit OOP costs related to their treatment
- > Typically a self-administered questionnaire
 - Completed by pts or their care-giver



Approaches for Collecting OOP Costs

Study-Specific Surveys

- Over a particular time period
 - Typically over the last 30 days, or over a three/six month period
- Costs classified under type of expense:
 - Travel costs
 - 2) Prescription drugs
 - 3) In-home health care
 - 4) Homemaking services
 - 5) Alternative medicine
 - Vitamins and supplements
 - 7) Family care
 - 8) Accommodations/meals
 - 9) Devices/equipment
 - 10) Other

Study-Specific Cost Questionnaire

HEALTH CARE FOR PROSTATE CANCER

1. Health Professionals

We would like to know about the health professionals you saw during **the last 6 months BECAUSE OF YOUR PROSTATE CANCER**. It will be easier to answer if you refer to a calendar or appointment list on which you record your appointments. If you did not keep a record, try to remember if any appointments were on or near special days, such as your birthday, or the day of a social event, in the last 6 months.

Examples of health professionals who treat problems related to PROSTATE CANCER:

Family doctor/general practitioner

Urologist (treats prostate cancer and other prostate and urinary problems)

Radiation oncologist (treats prostate cancer with radiation)

Medical oncologist (treats prostate cancer when it has spread beyond the prostate)
Nurse

Dietitian or Nutritionist

Social Worker

Chiropractor

Acupuncturist

Physiotherapist or Occupational Therapist

Naturopath, Homeopath, or Herbalist

PLEASE THINK OF ALL THE HEALTH PROFESSIONALS YOU SAW IN THE LAST 6 MONTHS BECAUSE OF PROSTATE CANCER

Did you visit any of these, or any other health professionals, <u>in the last 6 months</u>, because of your <u>prostate cancer</u>?

☐ YES, I visited one or more hea	lth professionals because of prostate cancer i
the last 6 months	
 NO, I did <u>not visit</u> any health p 	professionals because of prostate cancer in
the last 6 months	GO to Question 3 on page 7

a) Health Professional #1 is a (please check	√one)
□ Family doctor/general practitioner □ Urologist □ Radiation oncologist □ Medical oncologist □ Nurse □ Dietitian / Nutritionist □ Other, please specify	□ Acupuncturist □ Physiotherapist □ Occupational Therapist □ Naturopath/ Homeopath/ Herbalist □ Social Worker
Location: Ontario Other City,]	province state and/or country
Number of visits to this person in the last 6	months:
<u>Procedures or treatments</u> you received at th	e visits:
<u>Diagnostic tests</u> associated with the visits (eg. X-ray, blood test, urine test, CT scan):
How much of your own money did you pa	ay for the visits and diagnostic tests?
☐ None OR enter amount: \$	
What other costs, in total, were associated parking, food, lodging), and paid by you or	
☐ None OR enter amount: \$	
How much time was associated with these	visits (include travel, waiting, etc.)?
hours in total	
IF YOU SAW <u>ANOTHER</u> HEALTH PRO CANCER IN THE LAST 6 MONTHS GO IF YOU <u>DID NOT</u> SEE ANOTHER HEAL OURSTION 2 ON PAGE 7	TO THE NEXT PAGE.

Study-Specific Cost Questionnaire

Service

4. Medications used in the last 6 months

Please record <u>all medications</u>, prescribed by a health professional or bought over-the-counter, that you used <u>DURING THE LAST 6 MONTHS FOR PROSTATE</u>

CANCER. Include medications taken for prostate cancer and its problems (e.g., pain), or problems caused by treatment (e.g. loss of sexual function after surgery). Write the dose used each time (e.g. two 5 mg pills=10 mg) and the number of times used each day. If you used it less than once per day (e.g., one injection every 4 weeks) please write this in the space after "Times taken/used per day".

We suggest that you put the <u>prostate cancer-related</u> medications you have at home in front of you while you answer these questions. Remember to include herbal medicine, skin creams, drops, needles, etc., as well as pills.

I used NO medications for prostate cancer in the last 6 months. Go to next page.

1. Medication:
Dose (each time taken/used): Times taken/used per day:
2. Medication:
Dose (each time taken/used): Times taken/used per day:
3. Medication:
Dose (each time taken/used): Times taken/used per day:
4. Medication:
Dose (each time taken/used) : Times taken/used per day:
5. Medication:
Dose (each time taken/used): Times taken/used per day:
How much <u>of your own money</u> did you spend in the last <u>6</u> months, with <u>no</u> <u>reimbursement</u> , for <u>all</u> of your prostate cancer medications?
IF YOU REQUIRE MORE SPACE FOR MEDICATIONS USED IN THE LAST 6 MONTHS FOR YOUR PROSTATE CANCER, PLEASE WRITE ON THE BACK

OF THIS PAGE PROVIDE THE SAME INFORMATION AS ABOVE

5. Equipment (aids, devices, household items) bought during the last 6 months Please list all items you bought during the last 6 months for a problem related to prostate cancer, and the amount of your own money, if any, that you paid for each. Examples of items include aids to help you bathe or dress, incontinence pads, etc. ☐ I bought NO equipment in the last 6 months because of prostate cancer. Please go to Question 6, below. 1. Item Cost to you: \$ 2. Item Cost to you: \$ 3. Item Cost to you: \$ 4. Item Cost to you: \$ 5. Item Cost to you: \$ 6. Item Cost to you: \$ 6. Community services used during the last 6 months Please list any community services (e.g., home care, meals-on-wheels, transportation) you used in the last 6 months because of a disability RELATED TO YOUR PROSTATE CANCER. Please record the number of times that you used each and how much you paid of your own money for each service. ☐ I used **NO** community services in the last 6 months because of prostate cancer. Please go to Ouestion 7 on the next page. OR list the services you used IN THE LAST 6 MONTHS below 1. Service Times used Total Cost to you: \$ 2. Service Times used Total Cost to you: \$ Times used Total Cost to you: \$ 3. Service Times used Total Cost to you: \$ 4. Service

Times used Total Cost to you: \$

Approaches for Collecting OOP Costs Generic Surveys

- Cancer survivors identified via national surveys
 - E.g. Medical Expenditure Panel Survey (MEPS), (NHEXS)
 - Collects detailed information on demographic characteristics, health status, income, health insurance, employment, access to care, and healthcare expenditures (including OOP expenditures)
 - Cancer survivors defined as any person who has ever been diagnosed with cancer based on the question: Has a doctor or other health provider ever told you that you have a cancer or malignancy of any kind?

Guy GP Jr, Yabroff KR, Ekwueme DU, Virgo KS, Han X, Banegas MP, Soni A, Zheng Z, Chawla N, Geiger AM. Healthcare Expenditure Burden Among Non-elderly Cancer Survivors, 2008-2012. Am J Prev Med. 2015 Dec;49(6 Suppl 5):S489-97



Table 2. Prevalence of High OOP Burden® Among Nonelderly Cancer Survivors and Individuals Without a History of Cancer: Medical Expenditure Panel Survey, 2008-2012 Cancer survivors. Individuals without a history of cancer.

Characteristics	Cancer survivors, % (95% CI) ^b (n=4,271)	Individuals without a history of cancer, % (95% CI) ^b (n=96,780)	p-value	
Total	4.3 (3.5-5.0)	3.4 (3.2-3.6)	0.009	
Age (years)				
18-39	3.8 (2.3-5.3)	2.8 (2.6-3.0)	0.13	
40-49	3.4 (2.1-4.6)	3.2 (2.9-3.6)	0.81	
50-64	5.7° (4.4-6.9)	4.3 (3.8-4.7)	0.02	
Sex				
Men	4.1 (2.9-5.3)	2.9 (2.8-3.1)	0.04	
Women	4.6 (3.8-5.5)	3.8 (3.5-4.0)	0.04	
Race/ethnicity				
Non-Hispanic white	4.2 (3.3-5.0)	3.4 (3.1-3.6)	0.046	
Non-Hispanic black	5.3 (3.5-7.1)	4.0 (3.6-4.4)	0.13	
Hispanic	4.3 (2.6-5.9)	3.0 (2.7-3.4)	0.11	
Non-Hispanic other	3.8 (1.1-6.5)	3.2 (2.6-3.8)	0.60	
Family income				
Poor (<100% FPL)	18.4 ^d (15.1-21.7)	19.3 (18.2-20.3)	0.63	
Near poor and low income (100%-200% FPL)	4.6 ^d (3.2-6.1)	3.2 (2.7-3.6)	0.02	
Middle and high income (> 200% FPL)	1.0 (0.5-1.5)	0.5 (0.4-0.6)	0.003	
Health insurance				Guy GP Jr, Yabroff KR,
Any private	3.2 (2.4-4.0)	1.9 (1.7-2.1)	<0.001	Ekwueme DU, Virgo KS, I
Public only	7.9 (5.9-9.8)	8.5 (7.8-9.2)	0.55	Banegas MP, Soni A, Zhe Chawla N, Geiger AM.
Uninsured	5.7 (4.1-7.3)	6.1 (5.6-6.6)	0.63	Healthcare Expenditure
Employment status				Burden Among Non-elde
Full time	1.7 (1.1-2.2)	1.1 (1.0-1.2)	0.02	Cancer Survivors, 2008-2 Am J Prev Med. 2015 Dec
Part time	4.2 (2.5-6.0)	3.1 (2.8-3.5)	0.19	Suppl 5):S489-97
Not working	10.2° (8.4-12.1)	10.5 (9.8-11.2)	0.77	

Issues

- Complexity
- Response burden
- > Recall
- Discriminating between Ca-related and non-Ca-related



Summary

- Household impact of a cancer diagnosis is often substantial
- But OOP costs, for the most part, are manageable
 - Share of costs paid by patients is rising
 - Not equally distributed- some pay much more
 - Travel- a burden for those who live far from cancer center



Research gaps

Comprehensive evaluation

- Across all provinces and territories
- All cancers
- All patients
- Validated instrument
- Tracked over time



Future Work...

- Develop standardized instruments by applying rigorous methodological approaches:
 - For collecting OOP costs
 - Develop a validated instrument to collect resource use, OOP costs from patients with Ca
 - ii. Patient/Caregiver Time
 - apply different methods to value the time of patients and caregivers and estimate time costs
- We then can
 - a. Conceptualize the important resources, costs, and time categories derived from an exhaustive literature search and focus groups with patients and caregivers
 - b. develop a core instrument for all cancer types with a module specific to prostate and bladder cancers
 - c. apply costing methods to estimate total OOP and time costs for patients and caregivers



Thank You!

