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A Pilot Study of Canadian Cancer Patients' Out-of-pocket Costs: A Qualitative analysis

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Intro

- Limited published research exploring patients' out-of-pocket costs (OOPC) has been undertaken in Canada. Especially absent are more in-depth investigations on the nature of these costs and the impacts they have on patient's overall QoL and insurance purchasing behavior.
- The indirect costs on patients can be substantial and there is literature that has examined impacts of cancer on patient OOPC (Longo et al., 2006; Longo et al., 2007; Longo et al., 2011; Mathews et al., 2009), lost income (Lauzier et al., 2008; Hopkins et al., 2010) or both (Longo et al., 2006).
- Previous research on patient costs , lost time from work /lost productivity are the most significant financial issues, then travel costs, and lastly medical costs not covered through the CHA nor by private insurers.
- Little investigation into whether this represents all aspects of patients financial burden in a Canadian context.
- First step, a more qualitative approach to determine whether previous work in this area had accurately captured the scope and impact of the financial burden to patients and families, including QoL and insurance perspectives.

Methods

- Undertook in-depth semi-structured interviews with breast, colorectal, lung and prostate cancer patients at the Odette Cancer Centre, Sunnybrook Health Sciences Centre, Toronto, Ontario (June 2011 and July 2012). A qualitative descriptive approach was used for analysis of the interview transcripts (Thorne, 2008).
- Participants were selected based on referrals from health professional within the participants circle of care.
- Members of the research team (CJL, MF, AM, JR) determined an initial coding framework based on the first 3 interviews. A secondary coding exercise was undertaken at completion of enrollment. Interviews continued until no new themes emerged (14 subjects).



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Results

- Subjects (descriptive)

	Breast	Colorectal	Lung	Prostate	TOTAL
Male	0	1	0	2	3
Female	7	2	2	0	11

- Age range: 37 to 78 years

- Enrollment: June 2011 - July 2012, 15 consented, 14 completed



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Results

- Major themes emerging
 - Financial management
 - Value of insurance, decisions to purchase
 - Residence changes/adjustments
 - Strong emphasis on parking fees
 - As identified in interim analysis
 - Food costs, healthy lifestyle, financial shock



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Results

- **Financial management** (ability/willingness to manage costs)
- #1 “Uh... I never look at money as my master, I’ll like if I have 10 dollars I spend 15”.
- #2 “well over say the last 12 years, 15 years since we got a mortgage, we kind of just have been spending as if um... we didn’t have one so um... there’s money that’s accumulated not that we can’t cover these cost and aren’t covering these costs” (pt 11)
- #3 “Well I mean certainly the, we got into ah.. unexpected ah.. financial ah.. expenses that was not in, within our ah.. resource” (pt 12)



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Results

- **Insurance purchase** (value & ability to purchase insurance)
- #1 “I checked the um, people from some ah, private insurance. It’s every expensive. I dunno if like as a normal, the normal guy like me who work like ah, can afford it for the family it cost a lot. I, I consider it but it cost too much” (pt 9)
- #2 “Also it’s my choice when I picked it out on my benefits statement. I could have had more but I didn’t expect to be sick. I never expected to be on long term disability” (pt 13)
- #3 “ If someone had tried to sell me disability insurance I don’t think I, wouldn’t have taken it I don’t think, because there is not history of cancer in my family.” (pt 7)



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Results

- **Insurance purchase** (value of insurance)
- #4 “ Well, I’m a believer in insurance. I think you can quite tell that. I think it’s important for everybody” (pt 6)
- #5 “critical care was with my mom was diagnosed I thought of it and then the long term care is ah, because since I’m not working, I’m going to be paying..you know ah like for medication with ah. So I thought you know ah maybe this would help” (pt 1)



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Results

- **Residence changes** (impact or consequence of expenses)
- #1 “so like bathroom expenses and those are not covered by anything. You know things like, I had to get the bathroom all set up for her, with the hand thing...they one that you put on the...on the tub for you to walk in and another hand one... I changed it. Now what I’ve done for me is that I’ve changed it to a hand shower so I had to pay for that.” (pt 1)
- #2 “All I have is my condominium and I’ve thought about selling it which I don’t want to. It’s the only thing I have”. (pt 3)
- #3 “Mostly her worriness about ah to find the accommodation to rent a room. Except its ah the financially..” (pt 2 caregiver)



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Results

- **Parking** (overall impact on expenses)
- #1 “my first appointment here until the end of, just the end of chemo, I would be here sixty to ninety times. Now sixty to ninety times at \$18 a day because it’s, you get to that to, to the maximum fee very, very quickly that, that would have been something in the order of, if you assume that ah, you know at \$18 a day um, how many times is that? How much money is that? About \$1000” (pt 14)
- #2 “and that was paying to park at [*hospital name*] then having the machine say do you wanna make a donation? I just made a donation with my parking expenses. That was adding insult to injury” (pt 8)



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Future analysis

- Themes not fully analyzed (separate publication effort)
 - Impact on Quality of Life (challenge in unpacking financial effects from diagnosis effects)
 - #1 “It’s just you know, you’re thrown into it this whirlpool and in addition of coping with a life threatening illness, you’re all of a sudden faced the with additional expenses. You know you’re gonna face, well in my situation I know I’m facing surgery, chemo, and radiation. But at the time is wasn’t the additional cost of every trip to the hospital is gonna involve parking. Who knows what drug your gonna be assigned and the impact. “ (pt 8)
 - more work (better exploratory questions) may be required on this dimension.



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Future analysis

- Themes not fully analyzed (separate publication effort)
 - Change
 - Expectations (health and financial)
 - Worry/Anxiety/Depression
 - Social/Lifestyle impact
 - Change in relationship with family



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Value/Use of research findings

- Quantitative
 - Revisit questions on categories of cost, and current behaviors for financial management
 - More detail on: parking, residence, food, lifestyle (fitness, etc)
 - Intend to incorporate added dimensions in newer survey instruments



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Future Directions

- Qualitative work
 - More exploration of emerging themes related to change, and its potential impact on support programs
 - Additional investigation into QoL may be needed to better unpack the QoL effects associated with financial challenges.



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