ARCC
Canadian Centre
for Applied Research
in Cancer Control

ARCC Program Area Webinar: Dr. Christopher J. Longo

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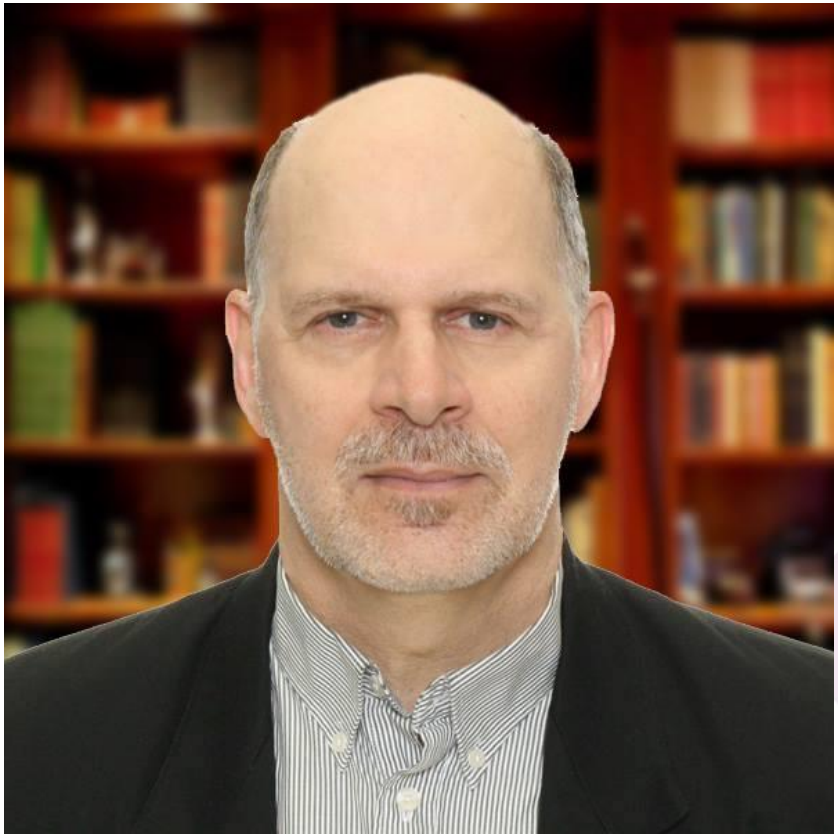
Dr. Christopher J. Longo



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Putting the pieces together: Creating a comprehensive picture of families' cancer related financial burden.

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Cancer patients' financial burden

- Topics for discussion
  - What does the burden look like?
  - Are there knowledge gaps in research?
  - Recent research, new information
  - An evolving tool: P-SAFE
  - Ongoing research
  - Looking forward

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What does the burden look like?

- Three broad components to patient costs: Medically related costs, travel related costs, lost income for patients and their caregivers.
- Existing Canadian literature on these topics (not comprehensive)
  - Longo et al, 2006 & 2007; OOPC, travel, lost income in breast, colorectal, lung, prostate
  - Lauzier et al, 2008; lost income in breast cancer
  - Grunfeld et al, 2004; OOPC, lost income in breast cancer
  - Miedema et al. 2008; OOPC, lost income in pediatric cancer
  - Mathews et al, 2009; Care provider perspectives to help manage patient financial challenges.

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What does the burden look like?

Lauzier et al, 2008

- Prospective cohort study, 8 hospitals in Quebec
- 962 breast cancer patients recruited, 800 completed (3 interviews), 489 with paying job one month before diagnosis
- Followed for 12 months to measure wage loss
- On average lost 27% of their wages (median 17%)
- Regression analysis showed higher loss with:
  - Lower education
  - Living 50km or more from hospital
  - Lower social support
  - Being self-employed; shorter tenure at job; part-time work
  - Having invasive disease; receiving chemotherapy

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What does the burden look like?

Grunfeld et al, 2004

- 89 patients with breast cancer, followed for up to 3 yrs. in Hamilton and Ottawa
- Series of questionnaires (SF-36, KPS, etc)
- Economic endpoints:
  - 69% had impact on work, 77% at terminal stage
  - Prescription drugs were most significant financial burden ($25/week; $1402/full observation period)
  - Total costs $106/week; $6582/observation period

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What does the burden look like?

Miedema et al. 2008

- 28 semi-structured interviews in Newfoundland and New Brunswick
- Details on OOPC, lost income, and assistance programs in pediatric cancers
- Main contributors to expenses were:
  - Necessary travel
  - Lost income (including quitting work)
  - Out of pocket treatment expenses
  - Inability to draw on assistance programs

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What does the burden look like?

Mathews et al. 2009

- Interviews with 21 care providers in Newfoundland and Labrador
- Findings included:
  - Patients minimizing costs by substituting or rationing medications
  - Choosing radical treatments
  - Lengthening the time between appointments
  - Choosing inpatient care
  - Working during treatment

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What does the burden look like?

Longo et al. (2006, 2007)

- Total of 306 enrolled and 282 evaluable patients
- Sampling technique – purposeful sampling
- Tumor types (lung, breast, colorectal & prostate)
- Response rate for eligible patients 83%
- Recruitment at Ottawa, London, Toronto, Hamilton, & Thunder Bay cancer centres, between Oct 2001 and April 2003.

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Longo et al. 2006

Average patient cost per month

Mean 30 day costs for travel, fares and aggregated – Combined sample

	N	Mean	Std. Dev.	Range
Imputed travel	222	**$371.94**	$694.18	$0-$6180
Parking/Fares	278	**$47.02**	$65.44	$0-$450
Total w/o travel (drugs, devices, homecare, CAM, etc)	246	**$212.71**	$490.73	$0-$5230
Total w/ imputed	193	**$645.75**	$833.91	$0-$5786

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Longo et al. 2006

Time off work - Patient

Mean days off work in last 30 days for patients indicating time off

Variable	N	Mean	Standard Deviation	Minimum	Maximum
Days off work	53	12.7	11.0	1	30

Time off work - Family/friends

Variable	N	% w/ lost time	Mean	Standard Deviation	Range
Family/Friend "time from work"	100	35.5%	7.0	8.2	0.2-30

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What are the knowledge gaps?

- A lot that we do understand from existing research, but still some knowledge gaps
  - Incomplete picture of lost time from work
  - Have we captured all the necessary cost categories?
  - If individuals don't spend out-of-pocket is that because they have no costs OR are foregoing care?
  - What do individuals understand about private health insurance and how are they using these products?

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Longo et al. Qualitative study

- Sunnybrook (Odette) Cancer Centre (2011-13)
  - 14 pts, range of issues covered
  - Accepted SCC (February 2016)
- Identified a number of items/issues
  - Financial literacy/ financial management
  - Limited knowledge and use of insurance
  - Cost category: Housing related changes
  - Services or essential needs foregone
  - History of being a primary caregiver
- Incorporated in latest version of P-SAFE

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P-SAFE (Patient Self Administered Financial Effects) Questionnaire

- "Financial effects" rather than OOPC
- In addition to OOPC includes
  - Travel costs, some of which is imputed
  - Lost income for patient and caregiver
  - Spillover effects on use of other services and consumables
  - Effects on insurance behavior

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P-SAFE Questionnaire

- Patient/caregiver completed questionnaire (previous 21-30 days)
- Categorical costs: medical, travel, lost work
- Insurance behavior
- Applied as point in time or longitudinally
- Analyses include descriptive, and regression analyses
- Identify gaps and/or populations at risk to inform policy making

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P-SAFE Questionnaire

- Opportunity to capture information not previously explored
  - In depth exploration of insurance behavior→
  - Better understanding of lost income (over previous work) →
  - Value of financial advise (ask 2nd question) →
  - Decisions to redirect savings, or forego treatments →
  - Inquiry about acting as primary caregiver →

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P-SAFE Questionnaire

- **In depth exploration of insurance behavior**
  - More detail on whether coverage is employer paid
  - More detail on CII insurance, and detail on ex-post regret
  - Detail on what patients expect the CII insurance funds would be used for

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P-SAFE Questionnaire

- **Better understanding of lost income (over previous work)**
  - Previous inquiries did not distinguish between “not working” and “quit because of illness”
  - More detail on level of paid leave if still working
  - More detail on multiple caregivers lost income

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P-SAFE Questionnaire

- **Value of financial advise (ask 2nd question)**
  - Qualitative work suggests that many do not have financial literacy
  - New questions seek to understand if they are "willing" to increase their financial literacy
  - As it is repeated measures we want to see if this answer changes over time
  - Policy implications in terms of supporting patients

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P-SAFE Questionnaire

- **Decisions to redirect savings, or forego treatments**
  - Previous work only looked as spending but ignored decisions to forego treatments
  - Current version attempts to better understand what tradeoffs were made to accommodate a reduction in disposable income.
  - Examples include: changes to home setting, foregoing treatments for self or family members.

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P-SAFE Questionnaire

- **Inquiry about acting as primary caregiver**
  - Qualitative work suggests that patient insurance behavior, and lifestyle behavior may be affected through caregiving of a family member or close friend.
  - Current questionnaire seeks to understand if those who have previous caregiving experience make different insurance and behavioral decisions.

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Putting the Pieces Together

- **"P-SAFE" strengths**
- In addition to examining the "OOPC", travel costs, and lost income…there is more detail allowing us to add more "pieces to the puzzle":
  - Better understand employment decisions by both patients and their caregivers
  - Better understand how insurance plays a role in patient's financial stability
  - Better understand what tradeoffs patients are making due to financial constraints (e.g. changing home setting)
  - Better understand what influence "being a caregiver to a cancer patient" has on patient decisions

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Caregiver Perspective (C-SAFE)

- Domains include:
  - Related medical costs (out-of-pocket)
  - Transportations costs
  - Lost work time & productivity
    - Absenteeism and Presenteeism
  - Applied as a longitudinal questionnaire (3-4 week intervals)
  - Application in cases where caregiver burden is high (e.g. pediatric cancers)

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Other Recent Work

- Caregiver Questionnaire (C-SAFE)
  - Applied in end-of-life care setting (McGill university, small sample pilot 2012-2013)
  - Applied in pediatric setting (Toronto Sick-Kids, Completion expected Q4 2016)
  - Sick-kids study includes a validation exercise (significant overlap with questions in P-SAFE)

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Looking forward

- 5 province P-SAFE study about to start. Ethics submission TODAY!!
- 3 time points (1-3 mo, +2 mo, + 4 mo)
- In addition to traditional data capture will more fully explore: lost work, insurance behavior/uses, financial management needs, housing issues
- Intended to aid policy making and help close existing gaps.

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Contributors (it takes a village)

- Qualitative
  - Marg Fitch, Michel Grignon, Alison McAndrew
- C-SAFE
  - Jason Pole, Lillian Sung, Aleks Zuc
- P-SAFE
  - Marg Fitch, Michel Grignon, Sue Bondy, Jolie Ringash, Jennifer Jones, Donna Turner, Winson Cheung, Arminee Kazanjian, Maria Mathews, Robin Urquhart, Young Jung, Fanor Balderrama, Kittie Pang

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QUESTIONS

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