

PERSPECTIVES OF CANCER SURVIVORS WITH LOW INCOME: CONCERNS, POSITIVE EXPERIENCES AND SUGGESTED IMPROVEMENTS IN SURVIVORSHIP CARE

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Introduction

- The number of cancer survivors in Canada has reached 1.5 million and is expected to continue to grow.
- Survivors frequently experience on-going physical, emotional and practical consequences as a result of having been diagnosed with cancer and treated (>80% in Canada).
- These consequences may have a profound impact on quality of life and well-being.
- Barriers exist which prevent access to screening, early diagnosis, treatment, rehabilitation, and palliative care, but little work has been done to understand barriers for cancer survivors into in accessing assistance and support after treatment is finished.
- Financial toxicity has been identified as a side effect of cancer treatment.
- Cancer survivors with low income (<25,000Cdn) experienced more physical, emotional and practical concerns and greater difficulty obtaining help for their concerns than did survivors in higher income groups (Fitch et al., XXXX).
- The Canadian health care system, is described as having universal coverage; however, this is defined as “medically necessary” care and leaves patients with having to pay out of pocket for items such as medications, equipment for home use, and supplies.
- It is important to understand the perspectives of cancer survivors as the basis for planning support and assistance programs.
- The purpose of this work was to explore major challenges, positive experiences, and suggestions for improvement in survivorship care from low-income Canadian cancer survivors one to three years following treatment.

Methods

Design

- Secondary analysis of data from the Canadian Transition Study: a cross-sectional survey mailed to >40,000 cancer survivors randomly selected from 10 provincial cancer registries; 13,2xx respondents returned the survey.
- 1708 respondents reported low annual household incomes of <25,000 Cdn.

Analysis

- Content analysis of responses to open-ended questions
- Questions focused on major challenges, positive experiences, and suggestions for improvement in survivorship care.
- Primary content topics were identified, followed by overall determination of frequencies determination for each

Results

Variable	Number(%)	Percentage
Sex		
- Male	685	40.1%
- Female	1,008	59.0%
Age		
- 18-29	55 (3.2%)	3.2%
- 30-64	445	26.1%
- 65 and older	1,198	70.1%
Marital Status		
- Single	254	14.9%
- Married/partnered	658	38.5%
- Separated/divorced/widowed	768	45.0%
Education		
- High School or less	1,331	77.9%
- Post-secondary degree (college/university)	276	16.2%
- University graduate degree	37	2.2%
Disease site*		
- Prostate	297	17.4%
- Colorectal	421	24.7%
- Breast	507	29.7%

Major Challenges n = 1,785		Sub-topics	Topic Total	Percentage of Topic		
PHYSICAL	1,085 (60.8%)	Capacity (fatigue/mobility)	394	36.3%		
		Pain/Numbness/Swelling	160	14.7%		
		Other Side Effects*	135	12.4%		
		Therapy Effects**	97	8.9%		
		Bowel Problems	91	8.4%		
		Urological Effects	51	4.7%		
		Body Image	45	4.1%		
		Post-Surgical Complications	40	3.7%		
		Sexual/Fertility Concerns	40	3.7%		
		Cognitive Effects	32	2.9%		
		EMOTIONAL	259 (14.5%)	Emotional issues, coping***	90	34.7%
				Fears (recurrence/death)	74	28.6%
				Depression/Anxiety	72	27.8%
Stress	23			8.9%		
PRACTICAL	119 (6.7%)	Chores/transportation help	52	43.7%		
		Return to work/school	38	31.9%		
		Financial concerns	29	24.4%		
LIFESTYLE ADJUSTMENTS	117 (6.6%)	Returning to normal	75	64.1%		
		Difficulty eating	33	28.2%		
SERVICE DELIVERY	92 (5.2%)	Information/Communication	32	34.8%		
		Follow-up Care	29	31.5%		
		Hospital/Clinic Services	20	21.7%		
		Healthcare Providers	11	12.0%		
RELATIONSHIPS, SUPPORT	51 (2.9%)	Family challenges/concerns	28	54.9%		
		Lack of emotional support	16	31.4%		
		Challenges with friends	7	13.7%		
NO CHALLENGES	26 (1.5%)	No challenges reported	26	100.0%		
OTHER	24 (1.3%)	No or still in treatment	24	100.0%		
POSITIVE	12 (0.7%)	Positive comments	12	100.0%		

Positive Experiences n = 1,171		Sub-topics	Topic Total (Percentage of Topic)
SUPPORT	293 (25.0%)	Support from family and friends	168(57.3)
		Peer and group support	60 (20.5)
		Help from others/HCPs	46 (15.7)
		Faith/spiritual support	11 (3.8)
		Practical support	8 (2.7)
		Stay positive, confident	104 (38.2)
SELF-CARE / ADVICE TO OTHERS	272 (23.2%)	Ask for help/trust HCPs	66 (24.3)
		Have faith/live each day	39 (14.3)
		Other (stay calm/healthy)	63 (23.2)
		Excellent/knowledgeable HCPs	120 (45.1)
HEALTHCARE PROVIDERS	266 (22.7%)	Support from HCPs, cancer centre	71 (26.7)
		Attentive, compassionate, caring HCPs	53 (19.9)
		Good access to HCPs, specialists	22 (8.3)
		Regular/timely follow-up	34 (37.8)
FOLLOW-UP CARE	90 (7.7%)	Care by doctors, oncologists, surgeons	34 (37.8)
		Routine tests/home visits	22 (24.4)
		Good communication with HCPs	36 (60.0)
INFORMATION AND COMMUNICATION	60 (5.1%)	Good information/answers to questions	24 (40.0)
		Good experience at centre	14 (100.0)
		Examples: meditation, yoga, naturopathy, art	12 (100.0)
SUPPORT THERAPIES POSITIVE	76 (6.5%)	Successful treatment	45 (59.2)
		Good experience	3 (6.5)
NO POSITIVE EXPERIENCES OTHER	51 (4.4%)	Nothing positive to report	51(100.0%)
		No follow-up care required	27 (73.0)
OTHER	37 (3.2%)	Other (still in treatment)	10 (27.0)

Discussion

- Study provided increased understanding of perspectives regarding concerns for cancer survivors with low income.
- Lack of information and lack of adequate follow-up care were described as unmet needs.
- The need for on-going financial aid programs for survivors was identified.
- Many survivors were unaware of existing financial support programs and how to access them.
- Health care professionals ought to be aware of the financial challenges experienced by survivors and monitor this challenge on a regular basis. Use of financial risk assessments and survivorship care plans, as well as informing survivors about existing financial support programs are recommended.

Suggested Improvements n = 1,140		Sub-topics	Topic Total (Percentage of total)
SUPPORT/SELF-CARE	297 (26.1%)	Practical	131 (44.1)
		Financial aid	63
		Help with chores/travel	37
		Return to work issues	31
		General	94 (31.6)
		Services/groups (plus peer)	59
		Family/friends support	30
		Other	5
		Emotional	52 (17.5)
		Personal/one on one	29
		Help with issues, coping	23
		SELF-CARE	20 (6.7)
		Be your own advocate	11
Other (faith, rest, healing)	9		
INFORMATION AND COMMUNICATIONS	236 (20.7%)	Information	189 (80.1)
		Self-care, recurrence, care plans, Other	80
		Side effects/post-treatment issues	74
		Programs/services/support groups	35
FOLLOW-UP CARE	213 (18.7%)	Communication With/among HCPs	47 (19.9)
		Timely/regular/care	109 (51.2)
		Access to/care by HCPs	49 (23.0)
		Post-treatment therapies	40 (18.8)
HEALTHCARE PROVIDERS	90 (7.9%)	Other	15 (7.0)
		Attentive, compassionate HCPs	41 (45.6)
		Good/knowledgeable HCPs	35 (18.9)
		Other (better access)	14 (15.6)
CLINICS/HOSPITAL SERVICES	70 (6.1%)	Improved services/facilities/closer to home	34 (48.6)
		Shorter wait times for results/appointments	31 (44.3)
		Other (e.g. address patient preferences)	5 (7.1)
POSITIVE COMMENTS	109 (9.6%)	Great care, satisfying experience	80 (73.4)
		No concerns, needs met	29 (26.6)
NO SUGGESTIONS	108 (9.5%)	No suggestions	108 (100.0)
NEGATIVE COMMENTS	17 (1.5%)	Negative comments	17 (100.0)

References

Nicoll, I., Lockwood, G., & Fitch M.I. (2023). Cancer survivors with low income: A qualitative exploration of concerns, positive experiences, and suggestions for improvement in survivorship care. *Current Oncology – Financial Toxicity Special Issue*. <https://doi.org/10.3390/curroncol30090590>

Fitch, M.I., Nicoll, I., & Lockwood, G. (2021). Physical emotional and practical concerns help-seeking and unmet needs of rural and urban dwelling adult cancer survivors. *European Journal Oncology Nursing*, 53, 101976