RESEARCH ARTICLE

Psychosocial Analysis of Cancer Survivors in Rural Australia: Focus on Demographics, Quality of Life and Financial Domains

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Abstract

Background: Cancer treatments can have long-term physical, psychological, financial, sexual and cognitive effects that may influence the quality of life. These can vary from urban to rural areas, survival period and according to the type of cancer. We here aimed to describe demographics and psychosocial analysis of cancer survivors three to five years post-treatment in rural Australia and also assess relationships with financial stress and quality of life domains. Materials and Methods: In this cross-sectional study, 65 participants visiting the outpatient oncology clinic were given a self-administered questionnaire. The inclusion criteria included three to five years post-treatment. Three domains were investigated using standardised and validated tools such as the Standard Quality of Life in Adult Cancer Survivors Scale (QLACS) and the Personal and Household Finances (HILDA) survey. Included were demographic parameters, quality of life, treatment information and well-being. Results: There was no evidence of associations between any demographic variable and either financial stress or cancer-specific quality of life domains. Financial stress was however significantly associated with the cancer-specific quality of life domains of appearance-related concerns, family related distress, and distress related to recurrence. Conclusions: This unique study effectively points to psychosocial aspects of cancer survivors in rural regions of Australia. Although the majority of demographic characteristics were not been found to be associated with financial stress, this latter itself is significantly associated with distress related to family and cancer recurrence. This finding may be of assistance in future studies and also considering plans to fulfil unmet needs.

Keywords: Cancer survivors - psychosocial factors - quality of life - financial distress - rural Australia

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Introduction

The psychosocial facet of cancer survival is an inadequately addressed problem in oncology practice. Several psychosocial issues concerning the physical, psychological, sexual and cognitive obscurity influence and determine the quality of life (QoL) of cancer survivors. The psychosocial aspects of the QoL, is a multidimensional, multi-disciplinary concept and hence, academic barriers isolate the studies and often based on either a 'single global rating' or 'multi-item instrument' with no 'Gold Standard' in place yet (Ganz et al., 1996).

Thus, there is a need to systematically address multidisciplinary health care needs of psychologically distressed cancer patients that are specific to gender, type of cancer, category of the psychosocial needs like fear of cancer recurrence and depression (Ram et al., 2013; Thewes et al., 2014).

The most important and intriguing aspect of these studies is that many of the cancer survivors have also been found to experience certain levels of unmet needs across the globe as substantiated by recent research on Australian and Canadian cancer survivors (Hall et al., 2013).

Hence, only those survey instruments that can effectively cut across these physical, physiological, psychological, social and geographical barriers can give the accurate research data required for analysis and inference.

The survey instruments at hand include the '(FLIC) Functional Living Index Cancer' (Schipper et al., 1984), '(CARES) Cancer Rehabilitation Evaluation System'(Schag and Heinrich, 1990), 'Health Related Quality of Life RAND–MOS' (Hays et al., 1993) and '(QLACS) Quality of Life in Adult Cancer Survivors Scale' (Avis et al., 2005; Avis et al., 2006).

Evaluation of the Quality of Life in Adult Cancer Survivors (QLACS) Scale for long-term cancer survivors (Avis et al., 2005; Avis et al., 2006) is a validated tool

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in health-related quality of life (HRQL) psychosocial assessment studies on cancer and hence, has been preferentially employed in this study. HILDA, Australia's nationally representative household-based panel survey is another tool used in this study in the areas of economic and subjective well-being. The present study utilised both these tools.

Materials and Methods

Objective

To describe the demographics of patients and psychosocial analysis of cancer survivors in rural Australia and assess the relationship of financial stress and quality of life domains.

Study Design

The research is a cross-sectional study. The study design has an inclusion criterion of cancer survivors aged above eighteen in their third, fourth and fifth year of follow-up since completion of treatment in a rural oncology clinic in the New England region, NSW, Australia. The study design excludes patients currently receiving active cancer treatment and those with cognitive impairment. The rural preponderance of the sample population was ascertained with the postal code provided.

The Quality of Life in Adult Cancer (QLACS) Survivors Scale (Avis et al., 2005; Avis et al., 2006) and Personal and Household Finances Questionnaire (HILDA, 2014) were used to survey demographic parameters, quality of life and treatment information and well-being. The QLACS scale contains 47 items and 12 categories, of which, 7 are generic and 5 cancer-specific. Generic domains include those of physical pain, negative feelings, positive feelings, cognitive problems, sexual problems, social avoidance, and fatigue. Cancer-specific domains relate specifically to cancer and include financial problems resulting from cancer, distress about family, distress about recurrence, appearance concerns, and benefits of cancer.

QLACS has been found effective in research studies that are based on follow-up data (Avis et al., 2006) such as this. HILDA survey questionnaire consists of a data study set released by the University of Melbourne every calendar year. Ethics committee approval and informed consent from the participants were obtained.

Sample population

The study was conducted in early 2013 to gauge quality of life of cancer survivors aged above eighteen in their third, fourth and fifth year of follow-up since completion of treatment in a rural oncology clinic in the New England region, NSW, Australia. Sixty-five survivors were given the questionnaire and 51 of them completed the survey. Patients are greater than five years (n=2) or less than three years (n=4) since last treatment were excluded.

Statistical analysis

Quality of life domains linked to cancer survival has been surveyed using the sum of three or four questions per domain (Avis et al., 2005). A five category frequency scale has been used for responses where 'one' represented "never" and 'five' represented "always". The four cancer-specific domains are: appearance related concerns (composed of four questions - max score 20), benefits of cancer (composed of four questions - max score 20), family related distress (composed of three questions - max score 15), distress related to recurrence (composed of four questions - max score 20). For the domains relating to appearance, family and recurrence a higher score represents a

worse quality of life for the domains, whereas, a higher score for benefits of cancer indicates a more positive outlook due to cancer. Missing items have been imputed using the average item score. Financial stress was measured using four items (on various scales from the best to the worst) sourced from the HILDA Self Completion Questionnaire, such that an increasing score represents increasing financial stress. The scores on each of the four items have been summed to give a total financial stress score (max score 26). Internal consistency of the financial stress items was assessed using Cronbach's alpha.

For regression modelling, some variables were recategorised for analysis due to small numbers. The highest level of education has been categorised as "No formal education and other", "High School" and "University or Vocational". Employment was classified as "Employed", "Retired" and "Not employed". Income has been categorised into "< $60000" and "> $60000", and "Don't know/No response" was set to missing. Private health insurance was categorised into any "health insurance" and "none". The country of birth has been described in "Australia" and "all others", and the marital status to "married" and "all others".

Simple linear regression of financial stress score on demographics was conducted to establish which demographics may confound the relationship between financial stress and quality of life. Demographics assessed included gender, age, birth country, marital status, number of children, education, employment, income, private health insurance, and number of cancer treatments. Crude estimates are provided with p-values, 95% confidence intervals, and R-squared values. Type 3 p- values for variables with greater than two categories indicate the significance of the variable across all categories. Simple linear regression was then used to assess the relationship between financial stress and quality of life domains. All statistical analyses were programmed using SAS v9.4 (SAS Institute, Cary, North Carolina, USA).

Results

There were 45 patients three to five years post-treatment who were included in the analysis. Patients' demographics are summarised in Table 1. A majority of the participants were under 65 years of age and women. There were total of 29 (64%) women and 16 (36%) men. Of the 45 responders, 40 (89%) were born in Australia and 36 (82%) of them were married or living together. Forty-four (98%) responders have had children and 32 (76%) had no children under their direct care. Only 2 (4.4%) of participants had no formal schooling, 19 (42%) had completed junior high school (or Grade 10), 6 (13%)

Table 1. Demographics of Cancer Survivors from Rural NSW Responding to Survey (N=45)

Parameter	Category	N (%)
Gender	Male	16 (36%)
	Female	29 (64%)
Are you of Aboriginal or Torres Strait Islander origin?	No	45 (100%)
Birth Country	Australia	40 (89%)
	New Zealand	1 (2.2%)
	United Kingdom	4 (8.9%)
Marital Status	Married/Living together	36 (82%)
	Divorced/Seperated	5 (11%)
	Widowed	3 (6.8%)
	Missing	1
Do you have children	Yes	44 (98%)
	No	1 (2.2%)
Number of children living in your care	0	32 (76%)
	1	2 (4.8%)
	2	5 (12%)
	3	1 (2.4%)
	4	1 (2.4%)
	5	1 (2.4%)
	Missing	3
Highest level of education completed	Have no formal schooling	2 (4.4%)
	Completed Junior High	19 (42%)
	Completed Senior High	6 (13%)
	Trade or technical	11 (24%)
	University or college	5 (11%)
	Other	2 (4.4%)
Current employment status	Employed full time	15 (33%)
	Employed part time or casual	4 (8.9%)
	Full time home duties/ home carer	6 (13%)
	Unemployed	1 (2.2%)
	Retired	15 (33%)
	Permanently ill / unable to work	3 (6.7%)
	Other	1 (2.2%)
Yearly household gross income	Less than $30,000	19 (43%)
	$30,001 to $60,000	12 (27%)
	$60,001 to $100,000	5 (11%)
	Over $100,000	6 (14%)
	Don't know / no response	2 (4.5%)
	Missing	1
Health insurance	No	21 (47%)
	Yes, Hospital	6 (13%)
	Yes, extras	1 (2.2%)
	Yes, hospital and extras	17 (38%)
Type of cancer	Breast	21 (47%)
	Colon/rectum/bowel	18 (40%)
	Lung	1 (2.2%)
	Oesophageal	1 (2.2%)
	Other	3 (6.7%)
	Breast and Ovarian	1 (2.2%)
Number of treatments	1	5 (11%)
	2	22 (49%)
	3	11 (24%)
	4	7 (16%)

had senior high school (or Grade 12), 11 (24%) completed trade or technical certificate or diploma, 5 (11%) finished university or college and 2 (4.4%) had various other types of education. Of the participants, 15 (33%) were employed full time and 15 (33%) retired. Nearly 31 (70%) participants yearly gross income was below $60,000.00. Twenty-one (47%) of the participants had no insurance cover at all.

There were 21 (47%) breast cancer survivors, 18 (40%) suffered colon/rectum/bowel cancer, 1 (2.2%) lung cancer, 1 (2%) oesophageal cancer, 1 (2%) breast and ovarian cancers, 3 (6.7%) suffered other types of cancers.

Internal consistency of the financial stress items was assessed using Cronbach's alpha score yielding 0.78. Table 2 summarises statistics of quality of life domains and financial stress. Financial stress score was regressed on each demographic variable that could plausibly confound the relationship of quality of life with financial stress. Effect estimates, p-values and confidence intervals are in Table 3. The majority of demographics were not associated with financial stress. Those with p-values less than 0.2 were investigated as confounders of the relationships between cancer-specific quality of life domains and financial stress. The demographics with crude p-values less than 0.2 were Age (P=0.09), Income (P=0.17), Health insurance (P=0.02) and categories of retired or not employed versus employed (type 3 p-value=0.08).

Crude estimates of effect of financial stress and demographic variables on cancer-specific quality of life domains (appearance, benefits of cancer, family related distress and recurrence related distress) are shown in Tables 4,5,6 & 7. These relationships did not appear to be confounded by demographic variables (p-values < 0.2 for both QoL domain and financial stress) so multivariable analyses were not conducted.

It was estimated that for each one point increase in financial stress, the average of appearance- related concerns increased by 0.37 of a point (P=0.015) and financial stress explained approximately 13.54% of the variation in the domain. Family related distress increased with increasing financial stress (P=0.0132) and approximately 14.07% of the variation in the domain was accounted for by financial stress. The effect on family related distress was estimated to be in the range (0.07, 0.53) for each point increase in financial stress. Distress of recurrence increased with increasing financial stress (P=0.001) and explained approximately 22.80% of the variation in the domain. The effect on distress of recurrence was estimated to be in the range (0.22, 0.82) for each point increase in financial stress. Family related distress has been shown to compound with an increase in financial stress (P=0.0132).

Crude analyses indicated that cancer type was associated with each of the quality of life domains. Those with colon or other cancers had less distress related to appearance, family and recurrence than those with breast cancer and perceived fewer benefits from cancer. It was also apparent that greater concern or distress associated with appearance, family and recurrence, and greater perceived benefits of cancer were observed in females compared to males.

Table 2. Summary Statistics of Quality of Life Domains and Financial Stress

	Financial stress score	QoL score appearance	QoL score benefits	QoL score distress family	QoL score distress recurrence
n	45	43	43	43	43
mean (SD)	8 (5)	9 (5)	15 (4)	9 (4)	12 (5)
median (min, max)	6 (0, 24)	8 (4, 18)	15 (4, 20)	9 (3, 15)	11 (4, 20)
median (Q1, Q3)	6 (5, 11)	8 (4, 12)	15 (13, 17)	9 (7, 11)	11 (8, 17)

Table 3. Crude Estimates of Effect of Demographic Variables on Financial Stress

	Parameter Estimate	Crude P	95% Confidence Interval	R squared	Type 3 p-value
Gender	-0.56897	0.6896	(-3.42, 2.28)	0.37%	
Age	-0.10889	0.0864	(-0.23, 0.02)	7.00%	
Birth Country	0.57895	0.6216	(-1.77, 2.93)	0.57%	
Marital Status	0.82456	0.4982	(-1.61, 3.26)	1.10%	
Number of children living in your care	0.70833	0.2295	(-0.46, 1.88)	3.59%	
Income	-2.15836	0.1736	(-5.31, 0.99)	4.58%	
Health insurance	-3.14286	0.0176	(-5.71, -0.58)	12.41%	
Number of treatments	-0.75949	0.3229	(-2.29, 0.77)	2.27%	
Employment - Retired (vs employed)	-0.40702	0.7874	(-3.43, 2.62)	11.15%	0.0836
Employment - Not employed (vs employed)	3.25359	0.0545	(-0.07, 6.57)		
No formal education & other (vs high school)	-2.69000	0.2775	(-7.62, 2.24)	2.84%	0.5463
University or Vocational (vs high school)	-0.19000	0.8966	(-3.12, 2.74)		
Cancer type - colon/rectum/bowel (vs breast)	-0.80303	0.5748	(-3.67, 2.06)	5.90%	0.2787
Cancer type - Other (vs breast)	2.86364	0.2029	(-1.60, 7.33)		

Table 4. Crude Estimates of Effect of Financial Stress and Demographic Variables on Cancer-Specific Quality of Life Domain - Appearance Concerns

	Parameter Estimate	Crude P	95% Confidence Interval	R squared	Type 3 p-value
Financial stress score	0.37406	0.0152	(0.08, 0.67)	13.54%	
Gender	3.11429	0.0330	(0.26, 5.96)	10.62%	
Age	-0.03675	0.5842	(-0.17, 0.10)	0.77%	
Birth Country	1.21385	0.3115	(-1.18, 3.61)	2.50%	
Marital Status	0.38636	0.7923	(-2.56, 3.33)	0.18%	
Number of children living in your care	-0.52174	0.4594	(-1.93, 0.89)	1.45%	
Income	1.37304	0.3929	(-1.84, 4.59)	1.93%	
Health insurance	0.14565	0.9191	(-2.73, 3.03)	0.03%	
Number of treatments	1.13037	0.1649	(-0.48, 2.74)	4.65%	
Employment - Retired (vs employed)	-0.49020	0.7708	(-3.87, 2.89)	0.23%	0.9548
Employment - Not employed (vs employed)	-0.09626	0.9582	(-3.79, 3.59)		
No formal education & other (vs high school)	-2.45652	0.3371	(-7.57, 2.65)	2.32%	0.6260
University or Vocational (vs high school)	-0.26902	0.8604	(-3.34, 2.80)		
Cancer type - colon/rectum/bowel (vs breast)	-4.32773	0.0027	(-7.06, -1.59)	22.87%	0.0055
Cancer type - Other (vs breast)	-4.45714	0.0368	(-8.63, -0.29)		

Table 5. Crude Estimates of Effect of Financial Stress and Demographic Variables on Cancer-Specific Quality of Life Domain - Benefits of Cancer

	Parameter Estimate	Crude P	95% Confidence Interval	R squared	Type 3 p-value
Financial stress score	-0.01757	0.8938	(-0.28, 0.25)	0.04%	
Gender	3.52381	0.0026	(1.30, 5.75)	20.01%	
Age	-0.02042	0.7091	(-0.13, 0.09)	0.36%	
Birth Country	-1.10154	0.2645	(-3.07, 0.87)	3.03%	
Marital Status	0.56818	0.6011	(-1.61, 2.75)	0.69%	
Number of children living in your care	-0.40217	0.4334	(-1.43, 0.63)	1.62%	
Income	2.36364	0.0726	(-0.23, 4.95)	8.23%	
Health insurance	0.89348	0.4484	(-1.46, 3.25)	1.41%	
Number of treatments	0.54513	0.4201	(-0.81, 1.90)	1.59%	
Employment - Retired (vs employed)	-2.26275	0.0961	(-4.95, 0.42)	7.26%	0.2217
Employment - Not employed (vs employed)	-0.43850	0.7640	(-3.37, 2.49)		
No formal education & other (vs high school)	-2.53261	0.2270	(-6.70, 1.64)	4.19%	0.4250
University or Vocational (vs high school)	0.21739	0.8618	(-2.29, 2.72)		
Cancer type - colon/rectum/bowel (vs breast)	-2.57703	0.0344	(-4.96, -0.20)	14.13%	0.0475
Cancer type - Other (vs breast)	-3.44762	0.0619	(-7.08, 0.18)		

Table 6. Crude Estimates of Effect of Financial Stress and Demographic Variables on Cancer-Specific Quality of Life Domain - Family Related Distress

	Parameter Estimate	Crude P	95% Confidence Interval	R squared	Type 3 p-value
Financial stress score	0.29858	0.0132	(0.07, 0.53)	14.07%	
Gender	2.18571	0.0574	(-0.07, 4.44)	8.53%	
Age	0.05363	0.2880	(-0.05, 0.15)	2.89%	
Birth Country	0.11846	0.9003	(-1.78, 2.02)	0.04%	
Marital Status	1.15000	0.3065	(-1.09, 3.39)	2.61%	
Number of children living in your care	-1.59783	0.0010	(-2.51, -0.69)	24.95%	
Income	-1.21944	0.3281	(-3.71, 1.27)	2.52%	
Health insurance	-0.42391	0.7057	(-2.68, 1.83)	0.35%	
Number of treatments	-0.59814	0.3511	(-1.88, 0.68)	2.12%	
Employment - Retired (vs employed)	0.85490	0.5133	(-1.76, 3.47)	2.08%	0.6567
Employment - Not employed (vs employed)	1.22460	0.3923	(-1.64, 4.09)		
No formal education & other (vs high school)	-1.06522	0.5929	(-5.06, 2.93)	2.66%	0.5827
University or Vocational (vs high school)	-1.19022	0.3223	(-3.59, 1.21)		
Cancer type - colon/rectum/bowel (vs breast)	-0.31373	0.7790	(-2.56, 1.93)	15.29%	0.0362
Cancer type - Other (vs breast)	-4.46667	0.0118	(-7.89, -1.04)		

Table 7. Crude Estimates of Effect of Financial Stress and Demographic Variables on Cancer-Specific Quality of Life Domain - Reurrence Related Distress

	Parameter Estimate	Crude P	95% Confidence Interval	R squared	Type 3 p-value
Financial stress score	0.51822	0.0012	(0.22, 0.82)	22.80%	
Gender	3.85238	0.0125	(0.87, 6.83)	14.26%	
Age	-0.05925	0.4060	(-0.20, 0.08)	1.78%	
Birth Country	0.66308	0.6063	(-1.91, 3.24)	0.65%	
Marital Status	0.30909	0.8403	(-2.77, 3.39)	0.10%	
Number of children living in your care	-0.66304	0.3591	(-2.11, 0.78)	2.22%	
Income	-0.15361	0.9302	(-3.68, 3.37)	0.02%	
Health insurance	0.82609	0.5890	(-2.24, 3.89)	0.72%	
Number of treatments	-0.18338	0.8347	(-1.95, 1.58)	0.11%	
Employment - Retired (vs employed)	-0.62745	0.7236	(-4.19, 2.93)	2.71%	0.5771
Employment - Not employed (vs employed)	1.43316	0.4607	(-2.46, 5.32)		
No formal education & other (vs high school)	-2.48913	0.3625	(-7.95, 2.97)	2.11%	0.6524
University or Vocational (vs high school)	-0.17663	0.9139	(-3.46, 3.11)		
Cancer type - colon/rectum/bowel (vs breast)	-2.07003	0.1800	(-5.14, 1.00)	14.94%	0.0393
Cancer type - Other (vs breast)	-5.95238	0.0139	(-10.63, -1.28)		

Discussion

Studies point out that psychosocial issues vary considerably with age, gender, type of cancer, treatment received, survival period, socioeconomic status and geographic niche. For instance, a psychosocial study of Iranian cancer survivors has shown that they receive high levels of social support and family members are the primary source of this support (Faghani et al., 2014). Whereas, studies to assess the QoL of Italian cancer survivors (Muzzatti et al., 2015) and the relationship between QoL and the socio-demographic characteristics have highlighted the need for multi- disciplinary follow-ups for long-term cancer survivors and the need to pay sufficient attention to the psycho-emotional long-term sequels of cancer. Investigations of the supportive care needs of cancer survivors in Japan has also demonstrated the need for expanded involvement of non-medical professionals and peer support, especially in the domains of medical-psychological, social-spiritual, financial and sexual needs (Umezawa et al., 2015).

As shown in our study, demographic variables of our patients didn't contribute for financial stress and it was also not affecting quality of life; Studies like Chambers et al. (2012) showed that some of demographic variables are associated with significantly lower QoL at long term such as no private health insurance or marital status. Chambers et al (2012) also mentioned that higher baseline optimism and higher perceived social support scores at baseline were associated with better social well-being and higher global at long term; we didn't carry out those aspects. In our study, not often survivors noticed trouble remembering things, bothered by having a short attention span and difficulty in doing activities that require concentration which affects their QoL. In contrary, Buchanan et al (2015) recorded high prevalence of cognitive concerns among breast cancer survivors after treatment. We also noted similarity on life satisfaction as stable phenomenon as described by Dunn et al. (2013). Positive outlook and QoL among cancer survivors has also been noted by Zucca et al. (2012).

High mean score for positive outlook on life, life enjoyed so far and feeling of happiness among cancer survivors in our study. Their concerns on cancer-specific domain such as family related distress, recurrence related distress, benefits of cancer and appearance-related

concerns affect their QoL. Strategies to focus these domains among cancer survivors would be the next step and challenge as well. This would certainly assist to uplift their QoL in an era where we are dealing with more and more cancer survivors.

We recognised need for further studies to focus on unmet need for cancer survivors and then to make strategies and interventions to support them along their survivorship journey. Furthermore, comparative studies of urban and rural cancer survivors to know their unmet needs and to know difference between them, would also be helpful.

Our study has few limitations such as small group of patients, cohort from rural Australia only which represent different demographics and difficult to compare with similar studies.

In conclusion, a psychosocial analysis of cancer survivors in rural regions of Australia shows that patients who had survived for more than two years after their last therapy has reasonably satisfactory quality of life. The majority of demographics have not been associated with financial stress and the studies point out a necessity for further investigations on some aspects of their unmet needs.

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