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Challenges of cancer survivorship care in Chile: a longitudinal study comparing the quality of care and quality of life for cancer survivors in a primary care network and a cancer centre in Chile

Klaus Puschel ,[1,2] Victor Arancibia,[2] Andrea Rioseco,[1,2] Sarah Paz,[2] María Gabriela Soto,[1,2] Javiera Martinez ,[2,3] Marcela Faundez,[2] Francisco Acevedo,[2,4] Felipe Di Biase,[2,5] Jon Emery ,[2,3] Augusto León,[6] Chandrakanth Are,[7] Beti Thompson[8]

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For numbered affiliations see end of article.

Correspondence to
Dr Klaus Puschel;
kpuschel@uc.cl

ABSTRACT

Objective The rapid growth in the cancer survivor population in Chile and Latin America raises new challenges in addressing their care needs. This study assesses the health status and compares the quality of care and quality of life in cancer survivors at a primary care network and a private cancer centre in Santiago, Chile.

Design Retrospective cohort study.

Setting Three primary care clinics and one cancer centre in Chile.

Participants All breast and colorectal cancer patients identified from a primary care retrospective cohort of 61 174 were followed from 2018 to 2023 and compared with an equivalent sample of patients from a university cancer centre identified during the same period.

Outcome measures Quality of care was assessed based on American Cancer Society standards, while quality of life was measured using the EuroQol 5 Dimensions-5 Levels survey instrument.

Results A total of 420 cancer survivors participated in the study; 208 from primary care and 212 from the cancer centre. All participants received substandard care. Patients in primary care had lower educational levels and higher rates of comorbidity. They reported a lower quality of life score (72.22 vs 78.43, p<0.001), a higher prevalence of chronic pain (37.02% vs 25.6%, p=0.016) and more severe mental health symptoms (19.89% vs 10.05%, p=0.03). Differences in educational level and cancer stage at diagnosis explained the observed disparities in chronic pain and mental health disorders between the two populations. Primary care patients received more psychosocial care (OR=2.29; 95% CI: 1.55 to 3.39), cardiovascular assessment (OR=2.66; 95% CI:2.17 to 3.26) and psychosocial evaluations (OR: 9.07; 95% CI:4.75 to 17.32).

Conclusion Cancer survivors face a significant disease burden and receive substandard care in Chile. As the primary source of care for this population, primary care is challenged to better integrate with speciality care to develop an effective shared care model for cancer survivors.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The sample of participants in this study represents a broad spectrum of cancer survivors in Chile.
- ⇒ The quality of life was assessed using standardised instruments through inperson interviews, and the quality of care was evaluated using standardised international indicators.
- ⇒ As an observational retrospective cohort design, it is not possible to evaluate intervention effects or causal associations.
- ⇒ Comparison groups differ in socioeconomic and clinical variables, and these differences influenced the primary study outcomes.

INTRODUCTION

The cancer population in Latin America is increasing rapidly.[1] Chile and Brazil have the highest projected increase in cancer incidence rates in Latin America, with an estimated change of 79.1% and 68.2%, respectively, for 2022–2044.[1] These estimates are higher than the 42.2% change projected for the USA or the 32.2% projected for the UK. Breast and colorectal cancers are among the most prevalent cancers in Latin America, accounting for 24% of all cancer cases.[2] Cancer survival trends are increasing in most Latin American countries, with the highest changes reported in Chile, Argentina and Brazil.[3] The change in incidence and the improvement in survival rates have led to a significant increase in the cancer survivor population and a new scenario in Latin American healthcare systems.

Cancer survivors experience several health conditions that are undetected or undertreated.[4 5] The prevalence of multiple chronic conditions, including heart disease, depressive disorders, respiratory diseases and diabetes, is higher than in the general population and affects about 55% of them.[5 6] There is also evidence showing that cancer survivors receive substandard care for their associated chronic diseases.[7] About half of the cancer survivors with depressive disorders remain undetected or are undertreated, and about 20% of them experienced pain related to cancer for many years after the initial diagnosis.[8] This population is also at a higher risk of preventable complications associated with diabetes.[4] Information about the health status, quality of life and quality of care for cancer survivors is scarce in Latin American countries.[2 9]

The significant growth in the cancer survivor population worldwide produces substantial stress in healthcare systems.[7] There is controversy on the appropriate model of care to address the many unmet needs of cancer survivors.[7] Most countries focusing on post-treatment survivorship care are high-income countries,[10] while this is an emergent topic in Latin America. The evidence indicates that in high-income countries, most survivorship care is provided in oncology units, following a traditional specialist-led care strategy, with fewer than 30% of centres adopting a shared care model that includes primary care.[7 11] In many Latin American countries, such as Chile, Brazil and Mexico, most patients, including cancer survivors, receive their care in the primary care system.[12–14] The limited evidence from Latin America suggests that primary care plays a more significant role in cancer survivorship care.[11] However, there are no organised programmes to address the needs of this population.[9] Traditional specialist-led care based on cancer centre models (oncology) appears insufficient and limited in providing the integrative and continuous care that cancer survivors need.[15 16] On the other hand, it is not clear whether models led by primary care providers could appropriately integrate the care of cancer survivors, given the multiple demands the teams faced already.[17] An integrative approach seems desirable, but it is unclear what the strengths and limitations of primary versus specialist-led care strategies are for developing a model that can effectively integrate both in clinical settings.[18]

This study applied a longitudinal design to compare the quality of care and quality of life of a primary care cohort of breast and colorectal cancer survivors with a cohort of cancer centre survivors in Chile. The study aimed to explore which dimensions are well addressed and which need to be improved to achieve a comprehensive and integrative cancer care model for cancer survivors, given the increasing demand and limited resources of the healthcare system.

MATERIALS AND METHODS

Study design and setting

A retrospective cohort study was conducted, gathering information from a reference population of patients registered at the Ancora Primary Care Network in Santiago, with breast and colorectal cancer diagnoses followed during the period 2018–2023. This reference population was compared with an equivalent sample of cancer survivors followed up at a private university cancer centre in Santiago. This study is part of the primary care cancer cohort study at the Chilean National Centre for Cancer Prevention and Control (CECAN).[19]

In Chile, cancer survivor patients treated in the public health system continue their regular care in the primary care network, while patients treated in the private system, such as the university cancer centre in this study, continue their follow-up care at the cancer centre given that there is no primary care network in the private health sector. This scenario is similar in many Latin American countries[20 21] and allows for comparing different survivorship care models. The Chilean National Health Plan, Plan Nacional de Salud (GES), provides full financial coverage for breast and colorectal cancer therapy once diagnosed (). There is no copayment for 80% of the population with public insurance and a maximum of 20% copayment for patients with private insurance. By law, once a diagnosis of breast or colorectal cancer is made in the public or private health system, providers are obliged to inform patients and register them in the National Registration Systems for Tracer Diseases (SIGGES). Patients must sign a form confirming that their provider informed them of their diagnoses.

The exposure variables of the cohort study were the site where the study population received their survivorship care, that is, the Ancora Primary Care Network or the university cancer centre. The Ancora Primary Care Network includes three primary care clinics located in an underserved area in Southeast Santiago with a total population of 60 000. The population registered at each Ancora Primary Care Clinic (20 000 for each clinic) is stable with a 3–5% turnover each year and is part of a national primary care cancer cohort that aims to study factors associated with cancer control and survivorship care over time.[19] All clinics have used electronic chart records (OMI-AP) since 2004. The national government funds the clinics based on a national capitation-based model and offers free services defined in the National Programme.[22] They include preventive care (eg, health check-ups, mammogram screening, cervical cancer screening, brief counselling for smoking cessation), clinical care (eg, medical care, physical therapy) and psychosocial services (eg, psychological support therapy, social worker services). After completing their treatment at the oncology unit at the Public Regional Hospital, patients continue their regular care at the primary care network. The referral public hospital has extensive experience in treating breast cancer patients. Clinical management of colorectal patients through the system is newer and has been better organised in recent years.

The university cancer centre is a private non-profit institution providing comprehensive cancer care to about 15 000 patients annually. Care services at the university cancer centre include biological therapy, chemotherapy, surgery and radiotherapy, in addition to palliative care and psychosocial support for cancer patients. Most survivor patients continue their follow-up care at the university cancer centre. The centre used electronic clinical records.

Sampling, instruments and variables

Cancer survivor cases in primary care were identified from the total population registered at the Ancora Primary Care Network, which included 61 174 patients in 2023. All patients with a diagnosis of breast or colorectal cancer from 1 January 2018 to 31 December 2023 who were registered in this network were included in the study. Cancer survivors were defined as all patients diagnosed with cancer from the time of diagnosis until the end of their lives.[23] The overall design of the cancer primary care cohort is described elsewhere.[19] For this study, several sources of information were used to identify cancer patients. First, SIGGES[24] that includes breast and colorectal cancer. Second, the cancer registry system at the Regional Public Hospital that concentrates the great majority of cancer diagnoses and therapy for patients in the catchment area and third, the electronic records of patients registered at the Ancora network clinics. Finally, we also reviewed death certificates from the National Civil Registry for Ancora patients with a diagnosis of breast and colorectal cancer during 2018–2023. An equivalent random stratified sample based on cancer type and survivorship time was obtained for patients with breast and colorectal cancer at the university cancer centre. The sample size of the comparison population at the cancer centre was based on the number of cases detected at the primary care network. Patients were eligible for the study if they had a breast or colorectal cancer diagnosis during the study period, were receiving care at one of the study centres and were able to communicate and provide consent at the time of the interview. Figure 1 summarises the sampling and recruitment processes.

A team of three nurses and two medical assistants conducted personal interviews through telephone contacts. They participated in a 3-hour training workshop and conducted pilot interviews, following a standard script, with a group of 10 participants who were not part of the sample. Survivors were contacted from January 2024 to May 2024 for the interviews. The interviews were based on a structured questionnaire comprising six dimensions: demographic information, health risk factors and non-oncologic chronic diseases, clinical care, quality of life perception, health status perception and social and family support. Demographic, health risk factors and non-oncological chronic disease dimensions included potential effect modifiers and potential confounding variables for quality of care and quality of life in cancer survivors.[21] Demographic information included age, ethnicity and education level. Health risk factors included smoking behaviour, alcohol drinking disorders, assessed through the Alcohol Use Disorders Identification Test scale[25]

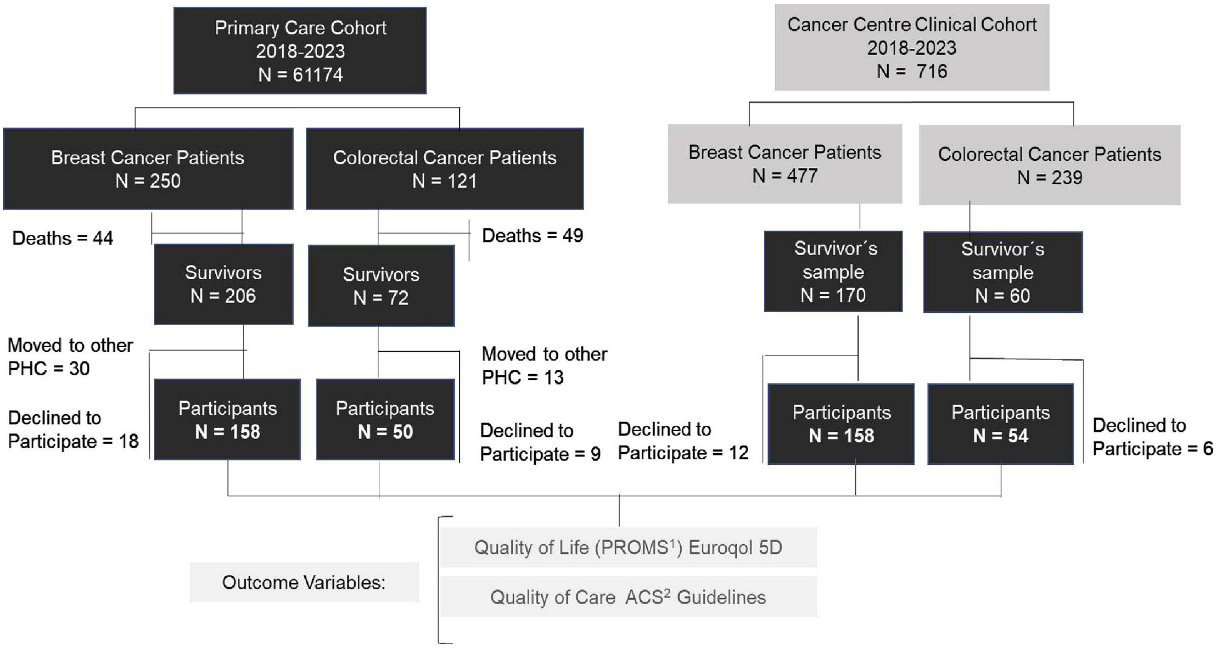

Figure 1 Study design. PROMS: Patient Reported Outcomes, ACS: American Cancer Society, PHC: Primary Health Centre. ¹ EuroQol Research Foundation. EQ-5DL User Guide 2019. https://euroqol.org/publications/user-guides ² American Cancer Society. Survivorship: During and after treatment. https://www.cancer.org/cancer/survivorship.html

and physical activity level. Depression was also evaluated through the Physical Health Questionnaire-version 9, which has been validated in Chile and used to estimate the general health status of patients.[26] Family and social support were estimated using the Salud Familiar instrument developed and validated for primary care in Chile.[27] All instruments used are included in the Chilean National Health Survey and approved for use in public-funded research in Chile.[28] Chronic disease assessment included diabetes mellitus, high blood pressure, asthma, chronic obstructive pulmonary disease, myocardial infarction and stroke. Participants were asked about the clinical care received, the type of treatment received and the type of health professionals (eg, physicians, nurses, psychologists, social workers, physical therapists, nutritionists) participating in their care.

The primary outcome variables of the study were quality of life and quality of care. Quality of life was assessed through the Euroqol 5 Dimensions- 5 Levels questionnaire, which required registration and approval for its use in this project. The instrument has been widely used in Chile.[29] Quality of care was assessed based on the American Cancer Society guideline indicators for breast and colorectal cancer survivors.[30 31] We used these guidelines as the gold standard for assessing the quality of survivorship care. The indicators were grouped in six dimensions that included patients' sociodemographic information, health professional speciality follow-up, risk factors and chronic disease assessment, cancer stage, screening and lab tests surveillance, type of treatment and psychosocial assessment and counselling. Electronic chart auditing during 2018–2023 was conducted at the Ancora Primary Care Network and UC Cancer Center to obtain information on the quality of care using the same standardised instrument. Figure 1 summarises the different stages of the project.

Analysis

The 5-year prevalence for breast and colorectal cancer was estimated for the primary care cohort population. It included all survival and death patients during the last 5 years of follow-up (2019–2023). The rate was obtained based on the total population exposed in the follow-up period adjusted by age according to the world health population standard.[32 33] This estimate was used to perform valid comparisons of the prevalence of this cancer cohort with national and international populations. A threshold of 10% or lower was defined as acceptable for handling missing data using case deletion analysis. An attrition rate exceeding 10% was identified as the criteria for applying imputation methods in the study's analysis.

Descriptive statistics were used to compare demographic and clinical characteristics between the primary care and cancer centre samples. χ^2 tests were employed to assess differences in the variables of interest between patients followed at the primary care network and those at the cancer centre. ORs were calculated to compare the likelihood of receiving specific types of care between the two populations. When evaluating differences between samples on the quality-of-life indicators, we also used multiple regression to control for potential confounders like cancer stage at diagnosis and educational level, which was considered a proxy for socioeconomic status in Chile. All statistical analyses were performed using R (V.4.3.0). A p value of <0.05 was considered statistically significant.

The study was reviewed and approved by the ethical committee of health sciences at Pontificia Universidad Católica de Chile (RN230710012). All participants read and signed an informed consent before entering the study.

Funding

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Competing interests

The authors declare no conflict of interest for this study.

Patient and public involvement statement

The public organisation 'Chile sin Cancer' (https://chilesincancer.cl/) participates as part of the CECAN Center, which sponsors the project and has encouraged the development of a cancer survivorship research line that explores the quality of life and the best model of care for this population in Chile. The Chilean National Cancer Agency informed research questions by highlighting the need to explore the role of primary care and cancer centres in survivorship care to include this topic in the future National Cancer Plan. No patient or public representative was involved in the design of the study. Participants of the study provided essential information on their quality of care. All participants read and signed informed consent prior to their participation. All participants were informed about the potential risks and benefits of participating in the study.

RESULTS

The total number of breast and colorectal cancer patients for the total 6-year follow-up period (2018–2023) was 250 and 121 cases, respectively (figure 1). The 5-year standardised (world) prevalence of breast cancer from our primary care cohort population was 278.79/100.000, and for colorectal cancer was 131.24/100.000.

The primary care survivor population was older than the cancer centre population (60.9. vs 55.37 years) and had a significantly lower educational level (9.73 vs 12.52 years of education). In general, the primary care survivor population had a higher prevalence of comorbidities than the survivor population at the UC Cancer Center. The primary care population had a higher prevalence of hypertension, diabetes and depressive disorders. Smoking behaviour was similar between the two populations, but alcohol consumption prevalence was higher in survivors

Table 1 Characteristics of the study population followed at the primary care network and cancer centre (n=420)

	Primary care population		Cancer centre population		Total population		Primary care compared with cancer Centre
No. of participants: N (%)	208	(49.52)	212	(50.48)	420	(100)	p=NS
Age: x (SD)	61.81	(14.09)	56.05	(14.93)	58.9	(14.79)	**p<0.001**
Gender: N (% female)	188	(90.38)	187	(88.21)	375	(89.29)	p=NS
Breast cancer: N (%)	157	(75.48)	158	(74.53)	315	(75.00)	p=NS
Colorectal cancer: N (%)	51	(24.52)	54	(25.47)	105	(25.00)	p=NS
Educational level (x-SD)	9.73	(3.09)	12.52	(3.11)	11.19	(3.40)	**p<0.001**
≤8 years : N (%)	55	(26.44)	13	(6.13)	68	(16.19)	**p<0.001**
9–12 years: N (%)	100	(48.08)	93	(43.87)	193	(45.95)	p=NS
>12 years: N (%)	27	(12.98)	87	(41.04)	114	(27.14)	**p<0.001**
Current smokers: N (%)	27	(12.98)	29	(13.68)	56	(13.33)	p=NS
Alcohol consumers: N (%)	54	(25.96)	92	(43.40)	146	(34.76)	**p<0.01**
Sedentarism: N (%)	92	(44.23)	97	(45.75)	189	(45.00)	p=NS
Hypertension: N (%)	101	(48.56)	65	(30.66)	166	(39.52)	**p<0.01**
Diabetes: N (%)	45	(21.63)	20	(9.43)	65	(15.48)	**p<0.01**
Chronic respiratory disease (asthma or COPD): N (%)	24	(11.54)	18	(8.49)	42	(10.00)	p=NS
Cardiovascular disease (coronary artery disease or cerebrovascular disease): N (%)	16	(7.69)	10	(4.72)	26	(6.19)	p=NS
Depressive disorders: N (%)	68	(32.69)	40	(18.87)	108	(25.71)	**p<0.01**
Anxiety disorders: N (%)	31	(14.90)	31	(14.62)	62	(14.76)	p=NS
Breast cancer stage at diagnosis							
0-I : N (%)	64	(40.76)	130	(82.28)	194	(61.59)	**p<0.001**
II: N (%)	45	(28.66)	24	(15.19)	69	(21.90)	**p=0.01**
III-IV N(%)	29	(18.47)	4	(2.53)	33	(10.48)	**p<0.001**
Colorectal cancer stage diagnosis							
0–I N (%)	19	(37.25)	27	(50.00)	46	(43.81)	p=NS
II N (%)	13	(25.49)	21	(38.89)	34	(32.38)	p=NS
III–IV N (%)	12	(23.53)	6	(11.11)	18	(17.14)	p=NS
Time since cancer diagnosis* (months) × (SD)	56.16	(46.84)	51.86	(28.44)	53.93	(38.43)	p=NS
≤12 months: N(%)	35	(16.83)	23	(10.85)	58	(13.81)	p=NS
13–36 months N (%)	60	(28.85)	54	(25.47)	114	(27.14)	p=NS
> 36 months N (%)	101	(48.56)	134	(63.21)	235	(55.95)	**p=0.03**

NS: p value>0.05.
Bold values indicate statistical significance at the p < 0.05 level
*Date of cancer diagnosis was based on the National Registration System of Tracer Diseases (SIGGES)
COPD, chronic obstructive pulmonary disease.

from the cancer care centre. Table 1 presents the characteristics of the study population.

There were significant differences in quality of care indicators between survivor patients in primary care and at the cancer centre. Almost all patients had an annual medical visit in the cancer centre compared with about half of the patients in primary care (table 2). In contrast, psychosocial care was provided to a larger proportion of survivors in the primary care network than in the cancer centre, and the likelihood of receiving psychosocial care in primary care was more than two times higher in primary care compared with the cancer centre (OR: 2.294; 95% CI: 0.734 to 1.261). Multidisciplinary care, that is, care provided by a nurse, nutritionist or physical therapist, was similar in both populations. For cardiovascular care, the expected standard was that each patient

Table 2 Quality of care Indicators in primary care and cancer centre

Indicators	Primary care (n=208)		Cancer Centre (n=212)		Total (n=420)		OR (95% CI)	P value
n=Number of patients **%** = Percentage of patients	**N**	**%**	**N**	**%**	**N**	**%**	Primary care versus cancer centre	
Medical Care								
Annual visits to MD in primary care (PCP) or Cancer centre (Oncologists)	**123**	**59.13**	**198**	**93.40**	**321**	**76.43**	**0.102 (0.055 to 0.188)**	**p<0.0001**
Psychosocial care:								
Annual visit to psych. or SW/year	**122**	**58.65**	**81**	**38.94**	**203**	**48.33**	**2.294 (1.551 to 3.392)**	**p<0.0001**
One or more psych. visit/year	83	39.90	65	30.66	148	35.24		p=NS
One or more SW visit/year	39	18.75	16	7.55	55	13.10		**p<0.01**
Multidisciplinary care:								
Annual visits to nurse, nutritionist or PT after cancer diagnosis	102	49.04	113	53.30	215	5.19		p=NS
One or more nurse visits	89	42.79	100	47.17	189	45.00		p=NS
One or more nutritionist visits	57	27.40	55	25.94	112	26.67		p=NS
One or more PT visits	58	27.88	71	33.49	129	30.71		p=NS
Cardiovascular risk factors assessment	**102**	**49.04**	**56**	**26.53**	**158**	**37.81**	**2.664 (2.172 to 3.268)**	**p<0.0001**
Smoking assessment	21	10.10	13	6.13	34	8.10		p=NS
High blood pressure assessment	180	86.54	34	16.04	214	50.95		**p<0.001**
Lipid disorder assessment	149	71.63	135	63.68	284	67.62		p=NS
Diabetes assessment	58	27.88	43	20.28	101	24.05		p=NS
Cancer surveillance								
Surveillance breast cancer annual mammography	79	65.29	70	63.64	149	64.50	1.078 (0.626 to 1.843)	p=NS
Surveillance colorectal cancer At least one colonoscopy in the past 3 year	19	54.29	27	65.85	46	60.53	0.615 (0.243 to 1.555)	p=NS
Psychosocial assessment	**81**	**19.47**	**11**	**2.59**	**92**	**10.95**	**9.078 (4.758 to 17.321)**	**p<0.0001**
Mental health disorders assessment	**59**	**28.37**	**8**	**3.77**	**67**	**15.95**		**p<0.001**
Socioeconomic status assessment	**22**	**10.58**	**3**	**1.42**	**25**	**5.95**		**p<0.001**

NS: p value>0.05.
Bold values indicate statistical significance at the p < 0.05 level
PCP, Primary Care Physician; PT, Physical Therapist; SW, Social Worker.

received at least one assessment on smoking status, blood pressure, lipid disorders or diabetes per year. Based on these standards, cardiovascular risk assessment was below 50% in both groups. However, it was better in primary care. Cancer survivor patients at the primary care network had a significantly higher assessment of cardiovascular risk factors compared with patients at the cancer centre (OR: 2.664 95%; CI: 2.172 to 3.268). Breast and colorectal cancer surveillance for recurrence was similar in both groups; however, about one-third of patients were not up to date in their cancer surveillance at the cancer centre. Finally, psychosocial assessment was relatively low in both groups compared with the desired gold standard and did not reach 20% of the population (table 2). In this scenario, however, psychosocial assessments were conducted more intensively in primary care than at the cancer centre. It was nine times more likely for patients in primary care to receive psychosocial assessment than those at the cancer centre.

Quality of life was assessed through personal interviews. The response rate of the personal interview survey was 90.5% (380/420 participants). This resulted in a missing data rate of 9.5% from the original sampled population. 23 participants did not complete the interview, and 17 were not available at the time set for the interview. Comparing quality of life perceptions between primary care and cancer centre patients appeared significantly different in various dimensions in univariate analysis (table 3). However, in multivariate analysis, differences remained significant only for self-health report and mobility. The self-reported health score was significantly lower among patients from primary care compared with patients from the cancer centre (72.22 vs 78.43, p<0.001) in univariate analysis. About 35% of patients from primary care reported a score below 69/100 compared with only 12% of patients from the cancer centre. After running

Table 3 Quality of life and social support perception in cancer survivors

	Primary care (n=181)	**Cancer Centre (n=199)**	**Univariate Analysis P value**	**Multivariate Analysis* β Coefficient, P value**
Global Self Report Health Score*			**p<0.001**	**–9.89, p<0.001**
Average (SD) (x̄, 0–100)	72.22 (23.03	78.43 (19.43)		
Median (Q1–Q3)	70 (60-90)	80 (70-90)		
No. participants score 70–100 n (%)	117 (64.64)	176 (88.44)	**p=0.001**	
No. participants score 0–69 n (%)	64 (35.36)	23 (11.56)	**p<0.001**	
Mobility*/N (%)				**0.18, p=0.02**
No problems to walk	130 (71.83)	173 (86.93)	**p=0.01***	
Some level of difficulty to walk	51 (28.7)	26 (13.07)	**p<0.001***	
Minimal problems to walk	38 (20.99)	14 (7.04)	**p<0.001***	
Moderate, severe or very severe problems	13 (7.18)	12 (6.03)	p=NS	
Selfcare*/N (%)				–0.04, p=NS
No problems to bathe or to get dressed	157 (86.7)	181 (90.96)	p=NS	
Minimal problems to bathe or to get dressed	14 (7.73)	9 (4.52)	p=NS	
Moderate, severe or very severe problems	9 (4.97)	9 (4.52)	p=NS	
Usual activities*/N (%)				0.03, p=NS
No problems for doing daily activities	151 (83.43)	180 (90.45)	p=NS	
Minimal problems for doing daily activities	20 (11.05)	10 (5.03)	p=NS	
Moderate, severe or very severe problems	10 (5.52)	9 (4.52)	p=NS	
Pain/discomfort*/N (%)				0.03, p=NS
No pain	114 (62.98)	148 (74.37)	**p=0.04**	
Some level of pain	67 (37.02)	51 (25.63)	**p=0.016**	
Mild pain	43 (23.76)	30 (15.08)	p=NS	
Moderate, severe or very severe pain	24 (13.26)	21 (10.55)	p=NS	
Anxiety/depression* / N (%)				0.19, p=NS
No anxiety or depressive symptoms	122 (67.40)	152 (76.38)	p=NS	
Some anxiety or depressive symptoms	59 (32.60)	47 (23.62)	p=NS	
Minimal anxiety or depressive symptoms	23 (12.71)	27 (13.57)	p=NS	
Moderate, severe or very severe symptoms	36 (19.89)	20 (10.05)	**p=0.03***	
Family and social support[2]/N (%)				–0.23, p=NS
Low support (score ≤3.7)	30 (16.57)	19 (9.55)	p=NS	
High support (score >3.7)	151 (83.43)	178 (89.45)	p=NS	

NS: p-value>0.05.
Bold values indicate statistical significance at the p < 0.05 level
*Multiple regression analysis: coefficients correspond to the effect of care centre type adjusted for patients' educational level and cancer stage at diagnosis.

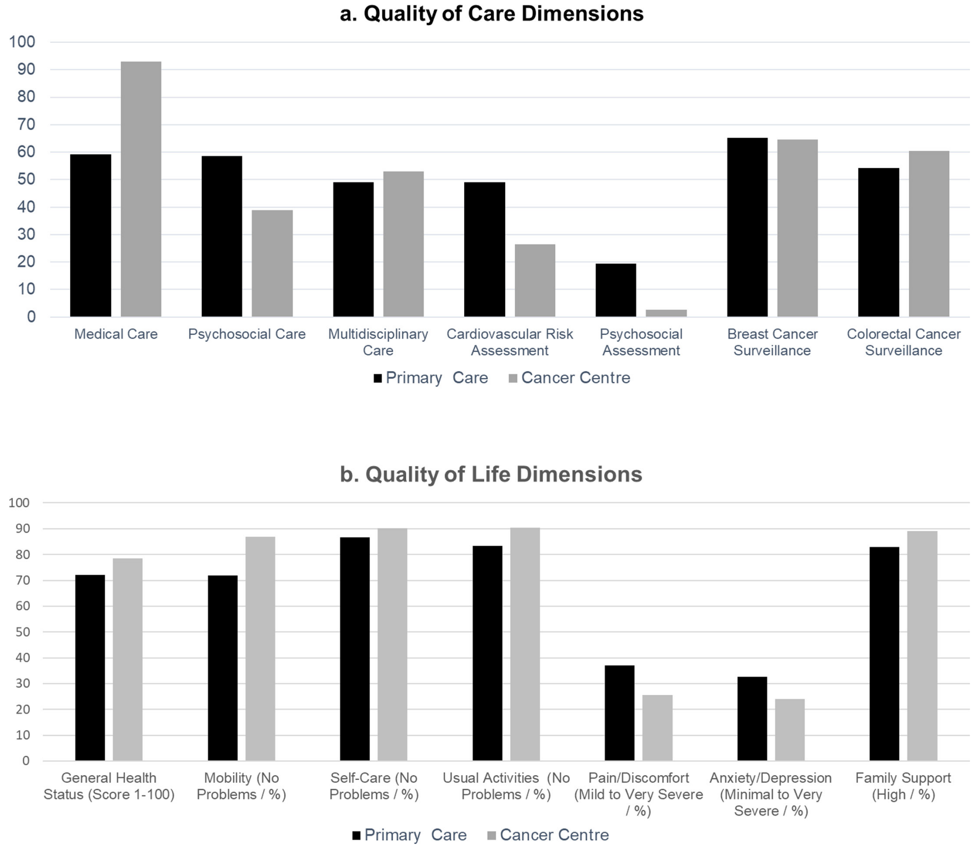

Figure 2 Quality of care and quality of life dimensions in cancer survivors at primary care and cancer centre.

multiple regression analysis, statistically significant differences remained even after adjusting for educational level and cancer stage at diagnosis (β=−9.89, t=−4.19, p<0.001). Similarly, differences in mobility problems between both populations remained statistically significant after multiple regression analysis (β=0.18, t=2.41, p=0.02). Chronic pain and discomfort appeared higher in the primary care population versus the cancer centre population (37.02% vs 25.63% p=0.016) in univariate analysis. However, in multiple regression analysis, after adjusting for cancer stage at diagnosis and cancer level, the differences reported in pain and discomfort between groups disappeared and were not statistically significant (β=0.03, t=0.24, p=0.74). In the same line, no statistical differences were found when comparing anxiety or depressive disorders between populations (table 3). Figure 2 summarises the differences in quality of care (a) and quality of life (b) dimensions between primary care patients and patients at the cancer centre.

DISCUSSION

This study shows that breast and colorectal cancer survivors received substandard care in both the primary care network and the cancer centre in Santiago, Chile. Our results also reveal that cancer survivors received more comprehensive care in primary care compared with the cancer centre. However, the primary care populations reported a higher disease burden and lower quality of life. The more socially vulnerable population served in primary care explained part of the differences observed in variables such as chronic pain or psychological distress. Evidence shows that low socioeconomic status and low education levels are significantly associated with lower quality of life and higher prevalence of chronic pain and depressive disorders in cancer survivors.[34 35] In Chile, as in many Latin American countries, the vast majority of cancer survivors are served through the public primary care system.[12–14] It is within this more vulnerable population that clinical outcomes should improve. Compared with speciality care, primary care provides more comprehensive care; however, the quality of their services should improve, for example, to better address the management of chronic pain or the early detection and management of depressive disorders.

Our study included a diverse group of cancer survivors in Chile, selected from a large cohort of primary care patients. This group was compared with an equivalent sample of cancer survivors from a cancer centre, representing the spectrum of care for cancer survivors in Chile. The age-adjusted prevalence rates for our primary care cohort, standardised by the WHO population, were similar to the national statistics reported by the WHO for Chile.[36] Specifically, the rates for breast cancer were 278.79 per 100 000 compared with the WHO's figure of 235.5 per 100 000, and for colorectal cancer, they were 131.24 per 100 000 versus the WHO's 107.0 per 100 000. The differences in these rates may be attributed to the higher cancer risks reported in urban populations in Chile.[32] These findings support the external validity of our study for the Chilean population.

Our results expose the challenges that primary care faces when addressing the care of the cancer survivor population and the essential collaboration needed from cancer speciality centres. The average overall health scores reported in our study ranged from 72 to 78 out of 100 and are similar to the score of 74 reported at a national level for the cancer survivor population in the UK using the same instrument.[33] Pain and discomfort were reported in 31.1% of our total population, and severe pain was reported in 11.8%. These estimates are similar to those published in a national survey in the USA, where 34.6% of cancer survivors reported pain and 16.1% referred to severe chronic pain.[37] The prevalence of pain was about 1.5 times higher in our socially disadvantaged primary care population compared with the cancer centre population. In the same line, the prevalence of anxiety and depression in our primary care population was three to four times higher than that reported at the national level in Chile.[38] Most of the variability observed in chronic pain and psychological distress could be attributed to differences in educational level between the two populations studied. However, these factors interact with each other. Chronic pain, multimorbidity and social vulnerability are well-known risk factors that increase the risk of developing depressive disorders between 2 and 6 times.[38–40] All these factors were present in our primary care population, highlighting the need to develop a more intense and comprehensive approach to improve the health status of this population.

The high comorbidity level found in our population is consistent with the evidence provided by several studies that have shown the high prevalence of multimorbidity and multiple risk factors in the cancer survivorship population.[5 21 41] Based on the US National Health Survey data, Jiang *et al*[5] found a prevalence of 40.6% for hypertension, 15.3% for diabetes, 10.3% for cardiovascular disease (stroke and ischaemic heart disease) and 17% for respiratory diseases (chronic obstructive pulmonary disease and asthma). Hoopes *et al*[41] reported similar findings in a primary care sample of more than 40 000 cancer survivor patients. These estimates are very similar to those found in our study and are also significantly higher than those reported for the general population in the Chilean National Health Survey.[28] Compared with the Chilean general population, we found a higher prevalence of hypertension (39.5% vs 27.6%), diabetes (15.4% vs 12.3%), severe cardiovascular disease (6.19% vs 5.9%) and chronic respiratory diseases (10.0% vs 5.3%). Our study confirms the higher comorbidity burden in the cancer survivor population. Based on our results of cardiovascular assessment, primary care seems to be in a better situation to provide an integrative model of care for this population. However, coverage for these services is still low even in primary care and will require reorganising the care model.

The best model of care for cancer survivors is currently a matter of debate. Most available studies that address this topic are from Europe, North America and Australia and do not include Latin American countries.[7 16] The available evidence shows that traditional specialist-led care for cancer survivors still predominates and tends to focus mainly on the detection of cancer recurrence, leaving other clinical, preventive and psychosocial dimensions in the background.[7 17] Our study aligns with the international evidence showing that cancer survivor patients followed in primary care received more comprehensive care, specifically more preventive, multidisciplinary and psychosocial care, compared with those followed in the cancer centre.[7 42] The reality in the Latin American healthcare system suggests that primary care should be a key player in cancer survivorship care. However, a survivor cancer care model based solely on primary care may not be sufficient to achieve high-quality care. Evidence suggests that oncologists and survivors may have limited confidence in primary care physicians and may prefer traditional, specialist-led models of care.[18 43] Shared care models have emerged as a more effective strategy for providing comprehensive care to cancer survivors. A national study conducted by Shakeel *et al* in Canada[44] found that a shared care model with intense involvement of general practitioners, combined with that of the oncologist, was associated with a significant improvement in physical and emotional symptoms among cancer survivors. A shared care model in Chile should require a more intense involvement of general practitioners and a better interaction with oncologists to improve critical outcomes such as quality of life, chronic pain or psychological distress.

LIMITATIONS

This study has some limitations that are important to address. The study is based on a retrospective cohort design that integrates electronic chart information records with personal interviews. Electronic records might contain non-systematic information over time, and registration differences between the two compared sites (primary care and cancer centre) may exist. In order to face this limitation, the same instrument, based on international standards, was used to review the information. In addition, different sources of information were compared (ie, electronic charts, patient interviews and hospital registries).

Non-registered information does not necessarily mean that an activity (eg, brief counselling) was not performed, but it lacks verifiability and expresses a lack of formal guidelines implementation. Recall bias is an important limitation in retrospective cohort studies. To address this limitation, we integrated the information from electronic chart records with information from personal interviews, having at least two sources of indicators.

Another limitation was the population differences between primary care and the cancer centre. In the Chilean context, there is a structural overlap between the type of healthcare centre and socioeconomic status, making it challenging to disentangle these factors. These populations differ in their educational level, which in Chile serves as a surrogate for socioeconomic status, and accordingly, also differ in their health insurance type (public in primary care; a mix of public and private in the cancer centre). They also differed in cancer stage at diagnosis and age. The variables of healthcare centre and socioeconomic status are intrinsically linked and cannot be fully separated, even with advanced statistical methods. We conducted multivariate regression analysis to adjust for these differences, especially in dependent variables associated with chronic pain, psychological distress and quality of life. We were careful not to over-adjust when analysing variables associated with quality of care, as some of the demographic differences present in the study reflect the reality of populations served in public versus private health systems and in primary versus speciality-led care.

CONCLUSION

This study shows that the cancer survivor population presents a high level of comorbidities and receives substandard care in both primary care and speciality care in Chile. Chronic pain, anxiety and depressive symptoms are dimensions that mainly affect the quality of life of cancer survivors. Differences in educational level and cancer stage at diagnosis between the populations were significantly associated with these dimensions. The disease burden was higher in the primary care population, where most cancer survivors receive their care. Patients in primary care received more comprehensive care; however, the services provided still did not achieve the required standards. As the main source of care for this population, primary care faces the challenge of better integrating with speciality care to develop an effective shared care model to respond appropriately to the multiple needs of cancer survivors.

Author affiliations

[1]Department of Family and Community Medicine, Pontificia Universidad Catolica De Chile School of Medicine, Santiago, Chile
[2]Center for Cancer Prevention and Control (CECAN), Santiago, Chile
[3]The University of Melbourne, Medical School, Melbourne, Victoria, Australia
[4]Department of Oncology, Pontificia Universidad Catolica De Chile School of Medicine, Santiago, Chile
[5]Universidad de los Andes, Santiago, Chile
[6]Department of Surgical Oncology, Pontificia Universidad Catolica de Chile, School of Medicine, Santiago, Chile
[7]Division of Surgical Oncology, University of Nebraska Medical Center, Omaha, Nebraska, USA
[8]Fred Hutchinson Cancer Research Center, Seattle, Washington, USA

X Javiera Martinez @jmartigu

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ORCID iDs

Klaus Puschel http://orcid.org/0000-0002-1362-1311
Javiera Martinez http://orcid.org/0000-0002-2493-9974
Jon Emery http://orcid.org/0000-0002-5274-6336

REFERENCES

1 Who.int. Cancer tomorrow. 2024. Available: https://gco.iarc.who.int/tomorrow/en/dataviz/bars?populations=152_826_76_840&key=percent&show_bar_mode_prop=0
2 Piñeros M, Laversanne M, Barrios E, *et al*. An updated profile of the cancer burden, patterns and trends in Latin America and the Caribbean. *Lancet Reg Health Am* 2022;13:100294.
3 Santucci C, Malvezzi M, Levi F, *et al*. Cancer mortality predictions for 2023 in Latin America with focus on stomach cancer. *Eur J Cancer Prev* 2023;32:310–21.
4 Worndl E, Fung K, Fischer HD, *et al*. Preventable Diabetic Complications After a Cancer Diagnosis in Patients With Diabetes: A Population-Based Cohort Study. *JNCI Cancer Spectrum* 2018;2:ky008.
5 Jiang C, Deng L, Karr MA, *et al*. Chronic comorbid conditions among adult cancer survivors in the United States: Results from the National Health Interview Survey, 2002-2018. *Cancer* 2022;128:828–38.

6 Ahmad TA, Dayem Ullah AZ, Chelala C. Prevalence of multimorbidity in survivors of 28 cancer sites: an English nationwide cross-sectional study. *Am J Cancer Res* 2024;14:880–96.
7 Jefford M, Howell D, Li Q, *et al*. Improved models of care for cancer survivors. *The Lancet* 2022;399:1551–60.
8 From cancer patient to cancer survivor: lost in transition. Washington, DC, 2005.
9 Anampa-Guzmán A, Acevedo F, Partridge AH, *et al*. Cancer Survivorship in Latin America: Current Status and Opportunities. *JCO Global Oncology* 2021;Available from:1472–9.
10 Romero Y, Trapani D, Johnson S, *et al*. National cancer control plans: a global analysis. *Lancet Oncol* 2018;19:e546–55.
11 Mollica MA, Mayer DK, Oeffinger KC, *et al*. Follow-Up Care for Breast and Colorectal Cancer Across the Globe: Survey Findings From 27 Countries. *JCO Glob Oncol* 2020;6:1394–411.
12 Croke K, Moshabela M, Kapoor NR, *et al*. Primary health care in practice: usual source of care and health system performance across 14 countries. *Lancet Glob Health* 2024;12:e134–44.
13 Cuadrado C, Fuentes-García A, Barros X, *et al*. Financing primary health care in chile: an assessment of the capitation mechanism for primary health. In: *Lancet Global Health Commission on Financing Primary Health Care*. 2022. Available: https://www.lshtm.ac.uk/media/59736
14 OECD. *Primary Health Care in Brazil, OECD Reviews of Health Systems*. Paris: OECD Publishing, 2021. Available: https://doi.org/10.1787/120e170e-en
15 Alfano CM, Jefford M, Maher J, *et al*. Building Personalized Cancer Follow-up Care Pathways in the United States: Lessons Learned From Implementation in England, Northern Ireland, and Australia. *American Society of Clinical Oncology Educational Book* 2019;625–39.
16 Høeg BL, Bidstrup PE, Karlsen RV, *et al*. Follow-up strategies following completion of primary cancer treatment in adult cancer survivors. *Cochrane Database of Systematic Reviews* 2019;2019.
17 Lewis RA, Neal RD, Hendry M, *et al*. Patients' and healthcare professionals' views of cancer follow-up: systematic review. *Br J Gen Pract* 2009;59:e248–59.
18 Vos JAM, Wieldraaijer T, Weert H, *et al*. Survivorship care for cancer patients in primary versus secondary care: a systematic review. *J Cancer Surviv* 2021;66–76.
19 Puschel K, Rioseco A, Soto M, *et al*. Implementation of cancer prevention practices in primary care: results of a cohort study in Chile 2018–2022. *Public Health (Fairfax)* 2024;236:168–74.
20 OCED. *Primary Health Care for Resilient Health Systems in Latin America, OECD Health Policy Studies*. Paris: OECD Publishing, 2022.
21 Leach CR, Weaver KE, Aziz NM, *et al*. The complex health profile of long-term cancer survivors: prevalence and predictors of comorbid conditions. *J Cancer Surviv* 2015;9:239–51.
22 Biblioteca del congreso nacional. 2022. Available: https://www.bcn.cl/leychile/navegar?i=1191575
23 Marzorati C, Riva S, Pravettoni G. Who Is a Cancer Survivor? A Systematic Review of Published Definitions. *J Canc Educ* 2017;32:228–37.
24 SIGGES. Página de inicio. FonasaCl. n.d. Available: https://siggestraining.fonasa.cl/
25 Alvarado ME, Garmendia ML, Acuña G, *et al*. Assessment of the alcohol use disorders identification test (AUDIT) to detect problem drinkers. *Rev Med Chil* 2010;1463–8.
26 Saldivia S, Aslan J, Cova F, *et al*. Psychometric characteristics of the Patient Health Questionnaire (PHQ-9). *Rev Med Chil* 2019;147:53–60.
27 Puschel K, Repetto P, Solar M, *et al*. Design and validation of an instrument to assess families at risk for health problems. *Rev Med Chile* 2012;140.
28 Primeros y segundos resultados de ens 2016-2017. citado el 01 de noviembre del 2024. 2018. Available: http://epi.minsal.cl/resultados-encuestas/
29 Rada I, Ortiz MS, Cabieses B. Calidad de vida relacionada con la salud en chilenos de comunas vulnerables [Health-related quality of life in Chileans from vulnerable communes. *Gac Sanit* 2023;37.
30 Runowicz CD, Leach CR, Henry NL, *et al*. American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline. *CA Cancer J Clin* 2016;66:43–73.
31 El-Shami K, Oeffinger KC, Erb NL, *et al*. American cancer society colorectal cancer survivorship care guidelines: American cancer society colorectal cancer survivorship care guidelines. *CA Cancer J Clin* 2015;428–55.
32 Villalobos C, Ferrer-Rosende P, Cavallera C, *et al*. Distribución geográfica de la incidencia de cáncer de beneficiarios de un convenio de atención oncológica en Chile.[Regional cancer incidence among beneficiaries of a private oncological insurance program in Chile]. *Rev Méd Chile* 2023;151:340–8.
33 Davies A, Waylen A, Leary S, *et al*. Assessing the validity of EQ-5D-5L in people with head & neck cancer: Does a generic quality of life measure perform as well as a disease-specific measure in a patient population? *Oral Oncol* 2020;101:104504.
34 Getie A, Ayalneh M, Bimerew M. Global prevalence and determinant factors of pain, depression, and anxiety among cancer patients: an umbrella review of systematic reviews and meta-analyses. *BMC Psychiatry* 2025;25:156.
35 Voskanyan V, Marzorati C, Sala D, *et al*. Psychosocial factors associated with quality of life in cancer survivors: umbrella review. *J Cancer Res Clin Oncol* 2024;150:249.
36 World Health Organization. International agency for research on cancer.global cancer observatory chile. n.d. Available: https://gco.iarc.who.int/media/globocan/factsheets/populations/152-chile-fact-sheet.pdf
37 Jiang C, Wang H, Wang Q, *et al*. Prevalence of Chronic Pain and High-Impact Chronic Pain in Cancer Survivors in the United States. *JAMA Oncol* 2019;5:1224.
38 Nazar G, Gatica-Saavedra M, Provoste A, *et al*. Factors associated with depression in Chilean adults. Results of the 2016-2017 National Health Survey. *Rev Med Chil* 2021;149:1430–9.
39 Read JR, Sharpe L, Modini M, *et al*. Multimorbidity and depression: A systematic review and meta-analysis. *J Affect Disord* 2017;221:36–46.
40 IsHak WW, Wen RY, Naghdechi L, *et al*. Pain and Depression: A Systematic Review. *Harv Rev Psychiatry* 2018;26:352–63.
41 Hoopes M, Schmidt T, Huguet N, *et al*. Identifying and characterizing cancer survivors in the US primary care safety net. *Cancer* 2019;125:3448–56.
42 Rubin G, Berendsen A, Crawford SM, *et al*. The expanding role of primary care in cancer control. *Lancet Oncol* 2015;16:1231–72.
43 Virgo KS, Lerro CC, Klabunde CN, *et al*. Barriers to Breast and Colorectal Cancer Survivorship Care: Perceptions of Primary Care Physicians and Medical Oncologists in the United States. *JCO* 2013;31:2322–36.
44 Shakeel S, Tung J, Rahal R, *et al*. Evaluation of Factors Associated With Unmet Needs in Adult Cancer Survivors in Canada. *JAMA Netw Open* 2020;3:e200506.