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Agnès Dumas,^{1,2} Rodrigue Allodji,^{1,2} Brice Fresneau,^{1,2,3} Dominique Valteau-Couanet,³ Chiraz El-Fayech,³ Hélène Pacquement,⁴ Anne Laprie,⁵ Tan Dat Nguyen,⁶ Pierre-Yves Bondiau,⁷ Ibrahima Diallo,^{1,2} Catherine Guibout,^{1,2} Carole Rubino,^{1,2} Nadia Haddy,^{1,2} Odile Oberlin,³ Gilles Vassal,² Florent de Vathaire.^{1,2}

¹ Centre for Research in Epidemiology and Population Health (CESP), Cancer and Radiation team, INSERM U1018, Université Paris-Sud, UVSQ, Université Paris-Saclay, 94807 Villejuif, France

² Department of Clinical Research, Gustave Roussy, 94805 Villejuif, France

³ Department of Paediatric and Adolescent Oncology, Gustave Roussy, 94805 Villejuif, France

⁴ Department of Paediatric Oncology, Institut Curie, 75005 Paris, France

⁵ Department of Radiation Oncology, Centre Claudius Regaud, 31059 Toulouse, France

⁶ Radiotherapy Department, Centre Jean Godinot, 51100 Reims, France

⁷ Department of Radiation Oncology, Centre Antoine Lacassagne, 06100 Nice, France

Correspondence to: Agnes Dumas, agnes.dumas@gustaveroussy.fr

Address: Gustave Roussy, U1018 INSERM, B2M, 114 Rue Edouard Vaillant, 94805 Villejuif, France

Tel: +331 42 11 66 26; Fax: +331 42 11 53 15

Running head: Insurance after childhood cancer

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Conflict of interest: None.

Abstract

Purpose

Access to insurance for a loan or a mortgage is an important issue for childhood cancer survivors. The aim of this study was to describe difficulties experienced by adult survivors.

Methods

A total of 1 920 survivors treated before the age of 18 in five French cancer centers responded to a questionnaire in 2010. Survivors who had tried to obtain a loan were asked if they had experienced difficulties, which were defined as experiencing rejection, higher premiums, or exclusions. The questionnaire investigated health problems related to the circulatory, respiratory, digestive, urinary, endocrine, hormonal, and nervous systems. Second tumors, diabetes mellitus, cardiac disease, and stroke were ascertained from a physician's report or medical records. Multivariable analyses were conducted to identify the characteristics of survivors reporting difficulties.

Results

Difficulties were experienced by 10.4% of those who had tried to obtain a small loan (n=787) and by 30.1% of those who had tried to obtain a home loan (n=909). Disclosure of childhood cancer to the insurer and amputation surgery were negatively associated with insurance accessibility, even when controlling for age, gender, education, health-related unemployment, familial situation, and severe or life-threatening conditions such as cardiovascular diseases, second cancers, or diabetes.

Conclusion

This study showed that the financial burden of cancer can extend decades after diagnosis.

Implications for Cancer Survivors

Thanks to a 2016 law, French cancer survivors no longer have to disclose their cancer to insurers after a fixed number of years. This law will probably lessen the socioeconomic burden of cancer.

Key words: Survivorship; Economic burden of disease; Discrimination; Long Term Adverse Effects; Quality of Life; Cohort studies.

INTRODUCTION

In Western countries about 80% of patients treated for childhood or adolescent cancer are disease-free after five years [1-2]. Seventeen years after diagnosis, 27% of survivors report severe or life-threatening chronic condition related to prior therapy [3]. The social consequences of childhood cancer and its late effects have been studied, whether they relate to employment [4], work ability [5-6], or income [7-8]. Despite the broad spectrum of late effects after childhood cancer, most survivors of childhood cancer tend to be employed, with the exception of brain tumor survivors, who are more often unemployed or economically inactive [4-6]. Access to insurance for loans and mortgages, because it can improve material living conditions and social well-being, is also an important issue for patients treated at a young age because they have their whole life ahead of them once treatment is over. Yet, the difficulties faced by adult survivors of childhood or adolescent cancer when trying to access loans have not been examined.

In France, there are two types of loans, namely 1) home loans, to buy a real estate property, or 2) loans (also called consumer credit or personal loans), for any other purpose. Insurance is systematically required to obtain a home loan and it can also be required for a personal loan above a certain amount. Mortgages are seldom used in France and thus covering a home loan with insurance is very important. However, even in countries using mortgages, insurance can be required to cover the mortgage.

In 2016, a law called “the right to be forgotten” was adopted in France. According to this law, survivors do not have to disclose their past history of cancer to the insurer after a fixed number of years post-treatment: five years for patients diagnosed under the age of 18 at time of diagnosis and ten years for patients aged 18 or above [9]. Before 2016 and the adoption of this law, insurers could impose higher premiums or warranty exclusions (e.g., lack of coverage in the case of cancer) or could refuse to insure survivors because of their past history

of pediatric cancer, even when they had no health problem at the time of the request for insurance. Nonetheless, past history of cancer was not systematically asked by insurance companies. For instance, questions about cancer could refer to “the five previous years” or to “any past radiotherapy or chemotherapy treatment”.

In this article, we describe the difficulties that survivors of pediatric cancer reported in accessing loans before the adoption of this law and we identify the characteristics of survivors experiencing difficulties.

PATIENTS AND METHODS

Study population

Patients were French members of the Euro2K international cohort study, which is aimed at studying the late effects of pediatric cancer and its psychosocial impact. The cohort study received approval from the French Data Protection Authority (CNIL) and from the ethics committee of the National Institute of Medical Research and Health (INSERM). Eligible patients were diagnosed between 1948 and 1985 with a solid tumor or a lymphoma and were treated before the age of 18 in five French centers. In 2005, according to the National Death Registration System, 2 647 patients were alive and therefore eligible (Figure 1, supplementary material). In 2010, 1 920 survivors returned an informed consent form and filled out a self-administered questionnaire (77.7% of persons contacted by mail).

Measures

Outcome measures

In the questionnaire, survivors were asked if they had ever tried to obtain 1) a personal loan or 2) a home loan and if they had experienced difficulties obtaining it or them. Experiencing

difficulties was defined as i) being rejected, ii) paying higher premiums, or iii) obtaining an insurance policy with warranty exclusions (Figure 1).

Clinical predictor variables

The questionnaire investigated health problems relating to the circulatory, respiratory, digestive, urinary, endocrine, hormonal, and nervous systems, as well as functional limitations and genetic diseases (the complete list is reported in Table 1). The participation agreement included an authorization form to access medical records. Records were requested from the physician(s) and hospital(s) listed by survivors in the questionnaire. The following events were ascertained from a physician's report or medical records: second malignant or benign tumors; diabetes mellitus; cardiac disease (myocardial infarction, angina, heart failure, valvular diseases, cardiac arrhythmia, conduction disorder, and pericardial disease); stroke; and amputation surgery (leg, arm, hand, or foot). The year of the onset of health problems (whether ascertained or self-reported) was recorded, as well as the year in which survivors tried to obtain a personal loan or a home loan. Health problems occurring after an insurance request were not taken into consideration in the analysis. The type of first cancer and treatment characteristics were extracted from the medical files of the cancer centers.

Socioeconomic predictor variables

Educational level was divided into three categories: 1) low (< high school), 2) intermediate (= high school) or 3) high (> high school). *Occupational class* was considered to be 1) low (corresponding to manual workers, farmers, craftsmen, shopkeepers, etc.); 2) intermediate (encompassing clerks and sales workers, technicians and associate professionals); or 3) high (corresponding to managers and professionals). *Health-related unemployment* referred to survivors who were not able to work because of health and who were dependent on disability benefit. Unemployment (referring to individuals in the workforce seeking work) was recorded

at the time of study, but not at the time of the request for insurance. Thus, unemployment was not used in the analysis since it was subject to variability across time.

Statistical analyses

First, we ran univariate analyses to identify the characteristics of survivors experiencing difficulties in accessing insurance, using t-tests for continuous variables and chi-square tests or Fisher exact tests for categorical variables. We considered the following predictor variables: age at diagnosis, type of first cancer, treatment (chemotherapy, radiotherapy, and cranial irradiation), amputation surgery, eye enucleation, and health problems (as listed in Table 1). Demographic and socioeconomic characteristics included: age when trying to obtain insurance, gender, whether living with a partner, level of education, occupational class, and health-related unemployment. Disclosure of childhood cancer to the insurer (yes/no) was considered as an independent variable since this question was not systematically asked by insurers.

Second, multivariable analyses were conducted using binary logistic regression. Odds ratios (OR) and their 95% confidence intervals were calculated. Health problems which were not significantly associated with the outcome variables in the univariate analyses were not included in the multivariable analyses. The models also excluded first primary cancer type to avoid multicollinearity with health problems.

Analyses were conducted using SAS 9.3 software (SAS Institute, Cary, NC). All *p*-values reported are two-sided; values below .05 were considered significant.

RESULTS

Responders were more often females, and had different distributions of year of diagnosis, primary cancer site, and treatment of primary cancer (Table 2). The mean follow-up time

since diagnosis of the 1 920 participants was 31.2 years (SD: 7.1) and their mean age at the time of the study was 36.3 years (SD: 8.0).

Survivors were 32 and 31 years old on average when they had tried to obtain a personal loan or a home loan, respectively. Difficulties were experienced by 10.4% of those who had tried to obtain a personal loan (n=787) and by 30.1% of those who had tried to obtain a home loan (n=909; Figure 1).

In univariate analyses, accessing insurance for a personal loan or a home loan was more difficult for survivors of bone or brain tumor or retinoblastoma, for patients who had received radiotherapy, who had undergone amputation surgery or eye enucleation, or who had cardiovascular diseases or health problems related to the respiratory, digestive, or nervous system (Table 1, Supplementary material). Being single and being unemployed for health reasons were associated with difficulties in accessing a personal loan. Disclosure of childhood cancer to the insurer was associated with difficulties in accessing both personal and home loans (Table 2, Supplementary material).

In multivariable analyses, disclosure of childhood cancer to the insurer was the strongest predictor associated with difficulties in obtaining both a personal loan (OR = 18.7; 95% CI = 10.0–35.0) and a home loan (OR = 11.1; 95% CI = 7.2–17.3). Amputation surgery also increased the likelihood of experiencing difficulties for obtaining both a personal loan (OR = 3.0; 95% CI = 1.2–7.8) or a home loan (OR = 5.3; 95% CI = 2.5–11.2).

In addition, difficulties with obtaining a personal loan increased with health-related unemployment (OR = 9.2; 95% CI = 2.6–32.7) while difficulties in obtaining a home loan increased with eye enucleation (OR = 3.6; 95% CI = 1.4–9.3), cardiovascular diseases (OR = 2.5; 95% CI = 1.1–5.7), and problems with the nervous system (OR = 2.4; 95% CI = 1.5–4.1) or the digestive system (OR = 1.7; 95% CI = 1.0–2.7) (Figure 2).

Approximately a third of the survivors who tried to obtain a personal loan (288/787) or a home loan (317/909) reported none of the health problems included in the analysis. In these two subsamples, 6.8% and 13.9% of survivors experienced difficulties with personal loans or home loans, respectively; difficulties with home loan were six times more likely to be reported by survivors who had disclosed their childhood cancer to the insurer as compared to those who had not (33.8% v. 4.6%; $P < .01$); the difference was even more important for personal loans (30.8% vs. 2.0%; $P < .01$).

DISCUSSION

Using data from a large cohort study, we found that 30% of adult survivors of childhood or adolescent cancer reported difficulties in accessing insurance for a home loan (including rejection, higher premiums, and exclusions), while 10% reported difficulties in accessing a personal loan.

This study showed that 30 years after diagnosis, the disclosure of childhood cancer to an insurer resulted in difficulties in accessing insurance, even for survivors with no health conditions when asking for a personal loan or a home loan. Furthermore, insurance accessibility decreased not only in the case of severe or life-threatening problems such as cardiovascular diseases, but also in the case of amputation surgery or eye enucleation, even when controlling for socioeconomic variables such as health-related unemployment, age, gender, education, and familial situation. This may be partly explained by the fact that survivors who had undergone amputation surgery or eye enucleation were more likely to disclose their childhood cancer, probably because these are visible consequences of cancer treatment.

To our knowledge, this is the first study to report the experience of pediatric patients. Difficulties in accessing insurance for a home loan have been previously reported for cancer

survivors who were treated as adults [10-14]. These studies only gave information on the proportion of survivors reporting problems in accessing personal or home loans (ranging from 10% to 31%) and did not provide information on the characteristics of survivors who experienced problems. Only one of these five studies included a large sample of patients treated for different types of cancer. In this Dutch study, of the 607 survivors who had tried to obtain a home loan, 55 (9%) experienced difficulties [11].

The strengths of the study include its long follow-up time and the ascertainment of severe health conditions by physicians or medical records. We used questions similar to those used by insurance companies to detect individuals at risk. The results are limited by the self-assessment and subsequent reduced accuracy of data on insurance and on certain medical conditions. Furthermore, this cohort is a multi-center study that does not fully represent adult survivors in France. Because leukemia was not treated at the participating centers, leukemia survivors were not included in the study, although it is the most common diagnosis in children [1]. Last, it is important to keep in mind that our data are based on the report of survivors and that our results are limited by both survival from childhood cancer and participation to the study. The study did not include a control group and we cannot control for the role of the right to be forgotten in access to loan-related insurance for survivors since its adoption.

CONCLUSION

France is the first country to enact an anti-discrimination law related to insurance's accessibility for the benefit of cancer survivors. This law will probably lessen the socioeconomic burden of cancer for survivors, in particular for those treated as they were children or adolescents.

Compliance with Ethical Standards

The authors declare no conflict of interest. The study received approval from the French Data Protection Authority (CNIL) and from the ethics committee of the National Institute of Medical Research and Health (INSERM). The investigators obtained informed consent from each participant.

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Figures and Tables

Figure 1. Overview of difficulties reported by adult survivors of childhood or adolescent cancer who have ever tried to obtain a personal loan or a home loan (France, 2010)

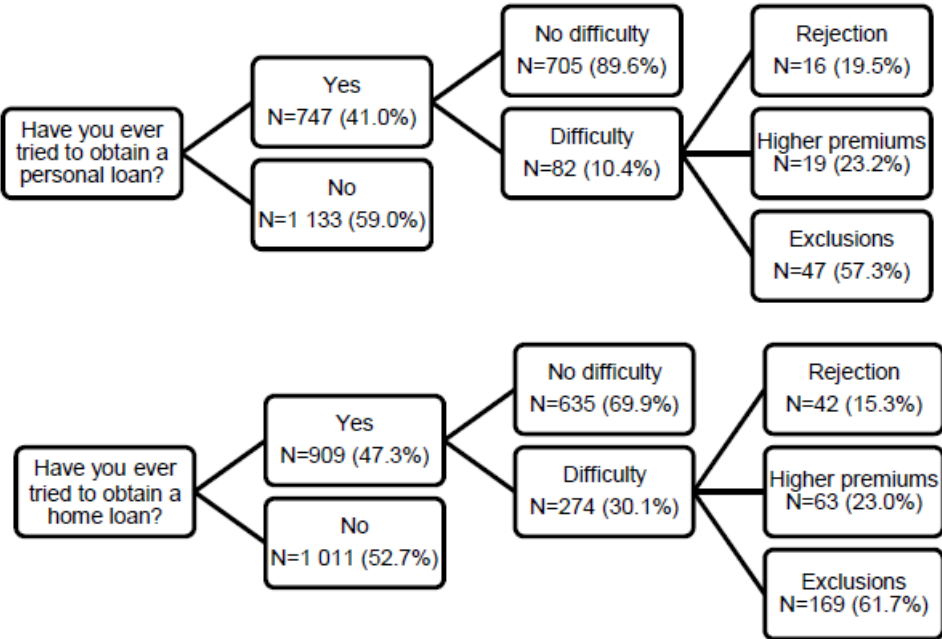
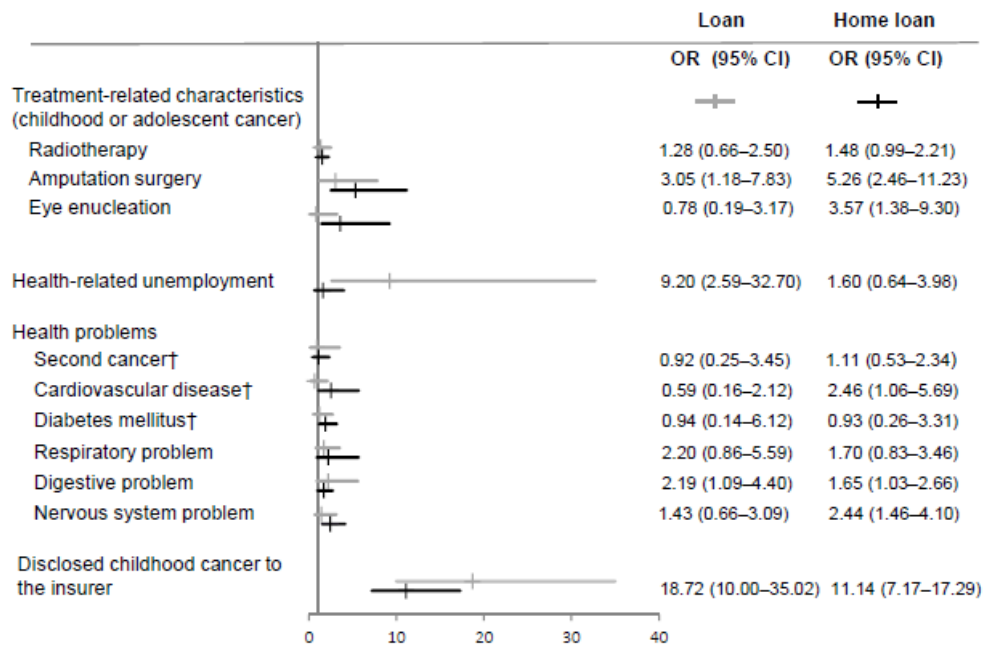


Figure 2. Characteristics of survivors reporting difficulties in accessing insurance for a loan or for a home loan; multivariable logistic regressions



OR: Odds Ratios adjusted for age at time of insurance request, sex, educational level, living with a partner, chemotherapy treatment, problems with the urinary system, and genetic disease, self-reported cardiovascular problems.

† Ascertained from a physician's report or medical records.

Ascertained cardiovascular diseases included myocardial infarction, angina, heart failure, valvular disease, cardiac arrhythmia, conduction disorder, pericardial disease, or stroke. Other self-reported cardiovascular problems included hypertension (either on medication or not), arterial problems, or blood clot (leg, brain).

Table 1. Health problems included in the analysis

Category of health problems	Health problems included in the category
Second tumour, ascertained from a physician or a medical record	Second malignant tumour Benign tumour
Diabetes, ascertained from a physician or a medical record	Diabetes mellitus
Cardiovascular disease ascertained from a physician or a medical record*	Myocardial infarction Angina Heart failure Valvular disease Cardiac arrhythmia Conduction disorder Pericardial disease Stroke
Other self-reported cardiovascular problem ^a	Hypertension (not on medication) Hypertension (on medication) Artery problem, including operation on artery Blood clot (leg, brain)
Respiratory system	Pleural effusion Repeated pneumonia Emphysema Lung fibrosis Need for extra oxygen
Digestive system	Gallstone Hepatitis Cirrhosis of the liver Jaundice Gastric or duodenal ulcer
Urinary system	Kidney stones Dialysis

Table 1. Continued

Category of health problems	Health problems included in the category
Problem with the thyroid	<p>Hyperthyroidism</p> <p>Hypothyroidism</p> <p>Thyroid nodules</p>
Nervous system	<p>Paralysis of any kind</p> <p>Epilepsy or repeated convulsions</p> <p>Epilepsy (on medication)</p> <p>Problems with balance or equilibrium</p> <p>Decreased ability to reach for or manipulate objects</p> <p>Tremors or problems with movements</p> <p>Decreased sense of touch or feeling in hands, fingers, arms, or legs</p>
Musculoskeletal	<p>Walks with a permanent limp</p> <p>Needs a walking stick</p> <p>Needs a wheelchair</p>
Hearing or vision	<p>Hearing loss, requiring hearing aid</p> <p>Blindness</p>
Genetic disease	<p>Ataxia-telangiectasia; Beckwith-Wiedemann syndrome; Neurofibromatosis type 1; Acoustic Neurofibromatosis; Bloom's syndrome; Down's syndrome; Fanconi's syndrome; Klinefelter's syndrome; Multiple exostoses; Polyposis Coli; Turcot syndrome; Turner's syndrome; Von Hippel-Lindau syndrome; Wiskott-Aldrich syndrome; Xeroderma pigmentosum</p>

^a Cardiac diseases were classified into two mutually exclusive categories; individuals who had a cardiac disease ascertained from a physician or a medical record were not included in the category of those who reported less severe self-reported cardiac diseases.

Table 2: Comparison of the characteristics of responders and non-responders

Characteristics	Responders (N=1 920)		Non-responders (N=631)		<i>P</i>
	N	(%)	N	(%)	
Sex					<.01
Women	908	47.3	239	37.9	
Men	1012	52.7	392	62.1	
Year of diagnosis					<.01
< 1970	364	19.0	101	16.0	
1970-1979	797	41.5	311	49.3	
≥ 1980	759	39.5	219	34.7	
Age at 1st cancer					.75
0–4	1041	54.2	329	52.1	
5–9	446	23.2	148	23.5	
10–14	366	19.1	132	20.9	
≥ 15	67	3.5	22	3.5	
First primary cancer type					<.01
Central nervous system tumour	192	10.0	71	11.3	
Hodgkin's lymphoma	114	5.9	34	5.4	
Non-Hodgkin's lymphoma	221	11.5	84	13.3	
Wilm's tumour	463	24.1	103	16.3	
Neuroblastoma	285	14.8	98	15.5	
Soft tissue sarcoma	227	11.8	84	13.3	
Bone tumour	140	7.3	40	6.3	
Retinoblastoma	82	4.3	36	5.7	
Other solid cancer ^a	196	10.2	81	12.8	
Treatment					.02
No radiotherapy. nor chemotherapy	135	7.0	58	9.2	
Radiotherapy only	320	16.7	131	20.8	
Chemotherapy only	489	25.5	150	23.8	
Chemotherapy and radiotherapy	976	50.8	292	46.3	
Year of birth					.44
1939-1969	808	42.1	283	44.8	
1970-1974	476	24.8	142	22.5	
1975-1979	393	20.5	120	19.0	

≥ 1985	243	12.7	86	13.6
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^a Retinoblastoma, gonadal tumour, thyroid tumour and other types of carcinoma

Supplementary material

Figure 1 (Supplementary material). Flow Diagram

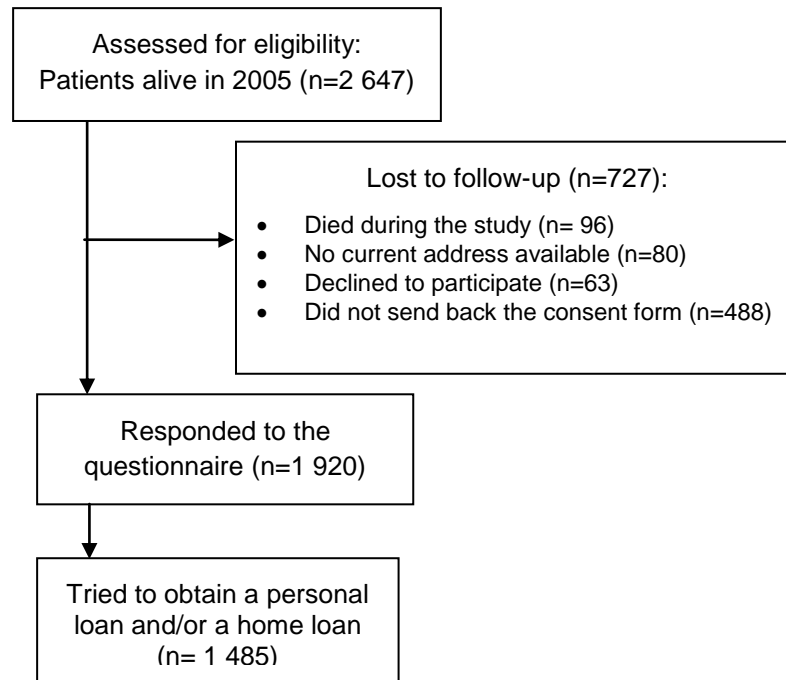


Table 1 (Supplementary material). Difficulties in accessing insurance for a mortgage or a loan among French childhood cancer survivors, according to treatment-related characteristics and health problems

Treatment-related characteristics and health problems	Loan		Mortgage		<i>P</i>
	Experiencing difficulty		Experiencing difficulty		
	Yes/Total (82/787)	% (10.4)	Yes/Total (274/909)	% (30.1)	
First primary cancer type					<.01
Central nervous system tumour	7/36	19.4	18/47	38.3	
Hodgkin	5/59	8.5	19/59	32.2	
Non-Hodgkin's lymphoma	8/105	7.6	28/107	26.2	
Wilm's tumour	12/193	6.2	61/238	25.6	
Neuroblastoma	13/104	12.5	28/111	25.2	
Soft tissue sarcoma	11/101	10.9	31/132	23.5	
Bone tumour	16/70	22.9	47/82	57.3	
Retinoblastoma	5/37	13.5	18/33	54.5	
Other diagnoses†	5/82	6.1	24/100	24.0	
Chemotherapy					.79
No	18/182	9.9	64/226	28.3	
Yes	64/605	10.6	210/683	30.7	
Radiotherapy					.06
No	21/275	7.6	71/309	23.0	
Yes	61/512	11.9	203/600	33.8	
Cranial radiotherapy					.27
No	67/675	9.9	231/791	29.2	
Yes	15/112	13.4	43/118	36.4	
Eye enucleation					.77
No	78/754	10.3	257/880	29.2	
Yes	4/33	12.1	17/29	58.6	
Amputation surgery: arm, leg, hand, foot*					<.01
No	70	9.4	239/858	27.9	
Yes	12	27.9	35/51	68.6	

Table 1 (Supplementary material), continued

Treatment-related characteristics and health problems	Loan		Mortgage			
	Experiencing difficulty		<i>P</i>	Experiencing difficulty		<i>P</i>
	Yes/Total	%		Yes/Total	%	
Secondary malignant neoplasm*			.53			.74
No	78/758	10.3		256/853	30.0	
Yes	4/29	13.8		18/56	32.1	
Second benign tumour*			.93			.60
No	71/679	10.5		227/762	29.8	
Yes	11/108	10.2		47/147	32.0	
Diabetes mellitus*			.36			.36
No	77/772	10.3		269/897	30.0	
Yes	5/15	16.7		5/12	41.7	
Any cardiovascular disease*			1.00			<.01
No	78/749	10.4		256/876	29.2	
Yes	4/38	10.5		18/33	54.5	
Any other cardiovascular problem**			.05			<.01
No	65/679	9.6		225/793	28.4	
Yes	17/108	15.7		49/116	42.2	
Any problem with the respiratory system			.02			.05
No	71/732	9.7		252/857	29.4	
Yes	11/55	20.0		22/52	42.3	
Any problem with the digestive system			.02			.04
No	61/657	9.3		220/765	28.8	
Yes	21/130	16.2		54/144	37.5	
Any problem with the urinary system			.12			.21
No	74/743	10.0		256/862	29.7	
Yes	8/44	18.2		18/47	38.3	
Any problem with the thyroid			.26			.79
No	71/709	10.0		247/823	30.0	
Yes	11/78	14.1		27/86	31.4	

Table 1 (Supplementary material), continued

Treatment-related characteristics and health problems	Loan			Mortgage		
	Experiencing difficulty		<i>P</i>	Experiencing difficulty		<i>P</i>
	Yes/Total	%		Yes/Total	%	
Any problem with the nervous system			.03		<.01	
No	65/685	9.5		220/800	27.5	
Yes	17/102	16.7		54/109	49.5	
Any musculoskeletal problem			<.01		<.01	
No	55/676	8.1		208/780	26.7	
Yes	27/111	24.3		66/129	51.2	
Any hearing or vision problem			.07		.72	
No	72/730	9.9		250/834	30.0	
Yes	10/57	17.5		24/75	32.0	
Any genetic disease			.37		.05	
No	77/755	10.2		259/876	29.6	
Yes	5/32	15.6		15/33	45.5	

Table 2 (Supplementary material). Difficulties in accessing insurance for a mortgage or a loan among French childhood cancer survivors, according to socioeconomic characteristics and disclosure of childhood cancer

Characteristics	Loan		<i>P</i>	Mortgage		<i>P</i>
	Experiencing difficulty			Experiencing difficulty		
	Yes/Total (82/787)	% (10.4)		Yes/Total (274/909)	% (30.1)	
Sex			.81			.99
Male	48/451	10.6		144/478	30.1	
Female	34/336	10.1		130/431	30.2	
Educational level			.35			.20
Low	34/311	10.9		82/316	25.9	
Intermediate	11/150	7.3		48/153	31.4	
High	35/299	11.7		127/398	31.9	
Occupational class			.50			.20
High	16/165	9.7		71/227	31.3	
Intermediate	32/380	8.4		138/432	31.9	
Low	22/192	11.5		50/199	25.1	
Lives with a partner			.03			.36
No	34/244	13.9		63/192	32.8	
Yes	48/543	8.8		211/717	29.4	
Health-related unemployment			<.01			.11
No	71/750	9.5		255/857	29.8	
Yes	10/24	41.7		13/30	43.3	
Disclosure of childhood cancer to the insurer			<.01			<.01
No	24/624	3.8		32/422	7.6	
Yes	55/150	36.7		236/470	50.2	