

Financial Distress in Testicular Cancer Survivors and Its Impact on Cancer Survivors' Quality of Life in the German Healthcare System

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Keywords

Cancer survivors · Financial stress · Quality of life · Distress · Testicular cancer

Abstract

Introduction: Testicular cancer accounts for the largest proportion of solid tumors in young adult men. With an average age of onset under 40 years and a relative 5-year survival of 97%, it is one of the prognostically favorable tumors. Little is known about the relationship between the financial burden and physical and emotional health of testicular cancer survivors. We examined the association between financial problems caused by cancer and the self-reported quality of life in a cohort-based sample of testicular cancer patients. **Methods:** A cross-sectional analysis of testicular cancer patients ($n = 87$, average age 39 years) was performed. Self-reported data were collected on demographics, income, wealth, cost-coping strategies, out-of-pocket costs, supportive medication compliance, quality of life, and perceived social isolation. A multivariable regression model was used to examine the relationship between the degree to which cancer caused financial burdens and the patients' reported quality of life. **Results:** The survey showed that, in addition to illness-related additional expenses, a disease-related loss of income can lead to severe financial disadvantages and impair quality of life. The study data show that concerns about the economic situation can increase the burden on patients which already results from cancer diagnosis and therapy. In this patient cohort, 32%

reported financial stress. **Conclusion:** Financial distress affects testicular cancer survivors in unique ways. To provide support, health professionals should consider survivors' developmental life stage to understand their financial stress, and ultimately, to improve quality of life.

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Introduction

Testicular cancer constitutes the largest proportion of solid tumors in young adult men. With an estimated incidence of >52,000 new cases worldwide per year, it accounts for only about 1% of all newly diagnosed cancers in men and 5% of genitourinary neoplasia. There has been a marked increase in its incidence throughout the world over the last decades, especially in European countries. With an average age at diagnosis of under 40 years and a relative 5-year survival rate of 97%, it is among the prognostically most favorable tumor entities. The highest age-specific incidence rate is found in men aged 30–34 years, with 90% of the cases diagnosed at T1 and T2 stage. Although the incidence is increasing, the mortality rate is low [1].

There is growing evidence that those diagnosed with cancer are at greater risk of financial distress than those who do not have cancer [2, 3]. The cost of cancer treatment has risen steadily in recent years, and even in countries with publicly funded healthcare, some of that burden falls on patients and their families. In addition, patients are often

unable to maintain full-time employment, causing them to reduce or quit work because of the disease, its treatment, or related consequences that limit their ability to work. In addition, cost-sharing for health insurers has increased through higher premiums, deductibles, co-payments, co-insurances, and other nonreimbursable expenses [2, 4, 5]. As a rule, income losses are only partially compensated for by continued payment of wages in the event of illness, sick pay, unemployment benefits, or pensions, or they only secure a subsistence level. Cancer can have financial consequences that can affect quality of life and perhaps survival. Financial consequences affect both loss of income and direct medical and nonmedical costs. While financial difficulties have long been a well-known problem for cancer and social counseling facilities, this has not yet been an issue for health and social politics. In Germany, this is mainly due to the fact that, under the conditions of the social insurance system, it is assumed that protection against disease and their immediate consequences is sufficient. However, financial consequences are becoming increasingly important for more and more cancer patients. With the continuous improvement in treatment with significantly better chances of survival, medium-term and long-term financial consequences are of great relevance. Another reason for the increasing interest in the topic is the psychosocial consequences that the financial implications have [6–8].

“Financial toxicity” is a relatively new field of research, which is reflected in the development of the number of publications. In recent years, financial burdens in countries with publicly funded healthcare systems have been recognized as a relevant problem for cancer survivors. Overall, however, the study situation for the German healthcare context is still very limited. In general, “financial toxicity” is understood to mean both the objective financial burden and the subjective distress that occurs as a result of the disease [9]. However, since both the terminology and the instruments for measuring financial toxicity differ greatly, study results have so far been difficult to summarize. This paper deals with the question of what financial effects a cancer diagnosis and therapy can have for affected testicular cancer patients and what possible socio-ethical and psychosocial consequences result from this.

Patients and Methods

Patients

Eligibility criteria included being a testicular cancer survivor who had been treated in the Department of Urology of University Rostock, 18 years of age and older, able to read and write in German, and able to provide

informed consent. We evaluated 87 testicular cancer patients with different tumor stages. Patients were recruited over a period of 8 years (June 1, 2014–December 31, 2023). Exclusion criteria included any current medical or psychiatric condition according to the treating physician’s report that made it impossible or unsafe for the patient to participate (e.g., acute illness or hospitalization).

Methods

Between June 2014 and December 2023, consecutive testicular cancer survivors at the Department of Urology at the Medical Center of Rostock University were asked to complete a written survey about cancer needs and concerns. Survivors could participate at any point during their disease course from the first diagnosis to after the completion of therapy. Patients provided written informed consent before completing the survey. The survey was completed by each participant. Medical variables were extracted from hospital and medical records. Standard questionnaires were used to collect socio-demographic data, validated instruments for health-related quality of life (HR-QoL), including the National Comprehensive Cancer Network distress thermometer and the Functional Assessment of Cancer Therapy – General (FACT-G). The distress thermometer is a visual Likert scale and measures subjective distress rates from 0 (no distress) to 10 (severe distress). HR-QoL was measured using the Functional Assessment of Cancer Therapy – General (FACT-G, Version 4). The FACT-G is comprised four subscales: physical well-being (seven items), social/family well-being (eight items), emotional well-being, and functional well-being (seven items). Total scores range from 0 to 100 with higher scores indicating better QoL. The FACT-G has established normative data from the general adult population and validated minimally important difference scores, defined as the smallest difference in scores that patients perceive as important and that would lead the clinician to consider a change in patient management. The Comprehensive Score for Financial Toxicity (COST; version 2) was used to assess financial toxicity [10]. It is a 12-item validated self-report measure of cancer-related financial distress. The study used a translation of an English questionnaire into German, which has not yet been validated for the German language. The COST assesses material and psychological aspects of financial hardship including direct costs related to cancer care (e.g., out-of-pocket expenses), indirect costs such as employment changes and loss of income, and psychological responses (e.g., financial worry and personal control over finances related to cancer). Items refer to the past 7 days and responses are on a five-point

Table 1. Sociodemographic and medical characteristics of included patients

Characteristic	Patients (n = 87)	No financial toxicity (n = 70)	Financial toxicity (n = 17)	p value
Age, mean (SD), years	38.65 (SD 11.18)	38.65 (SD 11.12)	37.42 (SD 10.88)	0.82
Educational level				0.01
Secondary school	10 (12%)	7 (10%)	4 (21%)	
High school	31 (36%)	26 (37%)	6 (33%)	
University	41 (48%)	34 (53%)	7 (46%)	
Income, annual household				<0.001
EUR <20,000	9 (11%)	4 (6%)	6 (34%)	
EUR 20,000 to 50,000	32 (37%)	26 (37%)	7 (40%)	
EUR 50,000 to 100,000	21 (24%)	20 (28%)	1 (5%)	
EUR >100,000	6 (7%)	5 (8%)	1 (5%)	
Declined to answer	17 (20%)	14 (20%)	3 (17%)	
Missing	2 (2%)	1 (1%)		
Employment				0.92
Employed	83 (95%)	65 (93%)	16 (93%)	
Not employed	4 (5%)	5 (7%)	1 (7%)	
Insurance				0.93
Legally insured	85 (98%)	68 (99%)	17 (100%)	
Privately insured	2 (2%)	2 (1%)		
Marital status				<0.001
Married	57 (65%)	48 (68%)	8 (49%)	
Single	30 (35%)	22 (32%)	9 (51%)	
Cancer stage				0.01
Localized	57 (65%)	50 (72%)	8 (45%)	
Metastasized	30 (35%)	20 (18%)	9 (55%)	

scale from “not at all” to “very much.” Total scores were calculated following guidelines (range 0–44) with lower scores representing worse financial outcomes (greater financial toxicity). An evidence-based grading score system for the COST was developed and validated based on differences in HR-QoL and odds ratio for a patient to have declared bankruptcy after cancer diagnosis. The grading system includes four categories: no financial toxicity (G0; COST scores >25), mild financial toxicity (G1, COST scores 14–25), moderate financial toxicity (G2, COST scores 1–13), and severe financial toxicity (G3, COST score of 0). This study was approved by the Rostock University Medical Centre’s Institutional Review Board and Committee (No. A 2021-0258). Written consent was obtained from participants.

Statistical Analysis

Descriptive statistics characterized the sample and study outcomes. Item-level analysis of the COST was used to better understand financial experiences. Bivariate relations between sociodemographic, medical factors, and financial toxicity were assessed using Pearson’s correlation for

continuous variables and independent samples *t* tests and analysis of variance for categorical variables. Factors significant at the $p < 0.001$ level were fitted to a multiple regression model with financial toxicity as the dependent variable to determine the strongest correlations of financial toxicity in the presence of other related factors. Two regression models were specified to examine the extent to which financial toxicity (independent variable) related to distress and QoL (dependent variables) taking into account income, level of education, and marital status, controlling for relevant sociodemographic and medical factors. The results were electronically collected (EXCEL) and statistically analyzed (IMB SPSS Statistics version 28).

Results

Sociodemographic and medical characteristics are reported in Table 1. 87 patients with an average age of 38.6 years old (SD 11.18; range: 20–52) took part. 65% had a partner, i.e., a relationship. 95% of them were working full-time/part-time and 5% unable to work due

Table 2. Financial toxicity in testicular survivors as reported on the COST measurement ($n = 87$); the mean financial toxicity score measured by the COST was 24.34 (SD = 10.12; mean = 28; range 5–44)

COST items	Not at all, %	A little bit, %	Somewhat, %	Quite a bit, %	Very much, %
I know that I have enough money in savings, retirement, or assets to cover the costs of my treatments and future healthcare needs	32	10	24	17	17
My out-of-pocket expenses are more than I thought they would be	39	16	23	13	9
I worry about the financial problems I will have in the future as a result of my illness or treatment	22	23	23	12	20
I feel I have no choice about the amount of money I spend on care	18	13	28	17	24
I am frustrated that I cannot work or contribute as much as I usually do	38	16	19	10	17
I am satisfied with my current financial situation	21	12	28	20	19
I am able to meet my money expenses	3	6	22	25	40
I feel financially stressed	31	30	18	10	11
I am concerned about keeping my job and income, including work at home	47	16	16	9	12
My cancer or treatment has reduced my satisfaction with my present financial situation	37	18	19	12	14
I feel in control of my financial situation	9	18	27	24	22
My illness has caused financial hardship to me and my family	40	22	19	7	12

to disability (4 of the 87 men unable to work reported that this was due to cancer with severe fatigue following intensive chemotherapy). 15% reported a change in employment status due to cancer. A wide range in annual household income was reported (from less than EUR 20,000 to more than EUR 100,000). 41% of patients reported incomes of EUR 50,000 or less. Most of the men had the obligatory German healthcare insurance (98%), and only 2 patients had private insurance. Lower school education was associated with financial toxicity ($p = 0.01$) as was a metastatic tumor stage ($p = 0.01$). Single patients had more financial burdens than those living in a partnership (<0.001). All patients had completed treatment and average time since diagnosis was 3.53 years (SD 5.40).

The mean financial toxicity score measured by the COST was 24.34 (SD = 10.12; mean = 28; range 5–44), indicating mild financial distress overall (Table 2). Based on the COST grading system, the majority of the sample indicated no financial toxicity (60%), 25% reported mild financial toxicity, 15% reported moderate financial toxicity. A third of the patients worried about financial problems as a result of cancer and most of the patients reported feeling financially stressed.

Compared with patients without financial toxicity, patients who reported financial toxicity were more likely

to report higher levels of distress (mean distress: 4.04 vs. 2.55, $p < 0.001$) and lower overall HR-QoL (mean FACT-G: 76.31 vs. 82.65, $p < 0.01$). In multivariate regression analysis, financial toxicity was associated with higher levels of distress and lower overall HR-QoL. Patients reporting financial toxicity scored a mean of 0.75 points (95% CI: 0.06–1.41 points) higher on the distress thermometer (indicating greater distress) and 5.50 points (95% CI: –8.88 to –1.81 points) lower on the FACT-G (indicating lower overall HR-QoL), a result that is clinically significant (Table 3).

Discussion

The financial impact of cancer is increasingly becoming a focus of research. “Financial toxicity” describes the impact costs that lead to significant financial burden for patients and their caregivers, resulting in increased psychosocial distress, diminished patient outcomes, and poorer quality of life. A distinction must be made between direct and indirect costs. The direct costs relate to the cost of cancer therapeutics and treatments. Most of these are covered by health insurance in Germany. However, the direct healthcare costs are not the only cause of financial toxicity for cancer patients who also

Table 3. Association of financial toxicity with distress and HR-QoL (β coefficient [95% CI])

Independent variable	Distress thermometer	Fact-G
Financial toxicity (vs. none)	0.75 (0.06 to 1.41), $p < 0.05$	5.50 (–8.88 to 1.81), $p < 0.01$
Educational level (vs. <high school)		
High school	–0.36 (–1.25 to 0.42)	–0.07 (–4.36 to 4.31)
University	–0.71 (–1.44 to 0.25)	1.79 (–2.31 to 7.12)
Marital status (vs. married)		
single	–0.09 (–0.54 to 0.51)	0.44 (–2.47 to 3.35)
Income (vs. EUR <20,000)		
EUR 20,000 to 50,000	–0.23 (–1.08 to 0.55)	2.24 (–2.23 to 6.77)
EUR 50,000 to 100,000	–0.05 (–1.01 to 0.88)	4.43 (–1.10 to 9.88)
EUR >100,000	–0.22 (–1.55 to 1.07)	–1.32 (–8.35 to 5.65)
Declined to answer	–0.55 (–1.44 to 0.44)	1.21 (–3.77 to 6.44)

experience loss of work productivity, which can include a reduction in work hours, missed days at work, or even loss of employment due to poor health. The most severe consequence, loss of employment, also limits access to employment-based benefits – including health insurance. Furthermore, job loss is associated with an increased risk of bankruptcy. The study by Ramsey et al. [11] showed that cancer patients were 2.65 times more likely to go into bankruptcy than healthy patients. In a follow-up study by Ramsey et al. [12], bankruptcy was associated with a higher risk of death among cancer patients.

Finally, financial toxicity describes not only the measurable financial impact in monetary terms but also the personal stress and financial worries experienced by cancer patients and their families. More financial distress can lead to increased psychological distress, especially among cancer patients already at risk of significant emotional distress, anxiety, and depression [13].

According to the published literature, this is only the second study examining the association between financial toxicity and quality of life in testicular cancer survivors. The study by Nezu et al. [14] also showed a correlation between financial toxicity and reduced quality of life. With severe financial distress, testicular cancer survivors had more treatment side effects, physical limitations, and anxiety concerning employment and future. The patients who reported low income were worried about their jobs and the future. The HR-QoL of the survivors with financial toxicity exhibited high impairment.

Not all patients are affected by the cost of cancer treatment in the same way and its impact depends very much on the healthcare system involved with great differences between different countries. Low-income

patients and uninsured patients are more likely to experience financial toxicity [15]. However, some patient populations are disproportionately affected, especially younger patients. Although cancer is traditionally thought to affect mostly the elderly, nearly half of new cancer cases are diagnosed in the working age population (20–65 years) [16] because younger patients may have less savings and fewer assets, as well as potentially more outstanding loans and financial responsibilities with younger families. In a study by Yabroff et al. [17], material financial hardship, including loans, debts, and inability to pay for care, was more common among cancer survivors under 65 years of age (28.4% vs. 13.8%). Also, cancer treatment, even for curable diseases, can result in employment effects that are particularly devastating for younger patients. Patients assumed that all costs of cancer treatment would be covered by either public or private health insurance. They also did not expect that costs would be incurred over a longer period of time, as they viewed cancer as an acute rather than a chronic disease. Furthermore, affected patients reported lower incomes because they could no longer work or could only work part-time. They also had problems with insufficient holiday entitlement and had to take unpaid holiday. Some patients did not perceive financial changes as a burden. Individuals were able to fall back on their savings or health insurance benefits or rely on their partner's income. Our study showed that 60% did not feel financially burdened. Other patients did not have sufficient financial resources to cope with side effects or to receive necessary help at home. In addition, financial constraints increased pressure to return to work earlier than those affected were ready, leading to emotional distress and existential concerns. Patients managed their

household expenses, adjusted their social or leisure activities, borrowed money from their employer, bank, family, and friends, or adjusted their working hours [18, 19].

Not only does the financial burden of cancer care affect a patient's personal finances and psychological well-being, it can also lead to delayed diagnosis and treatment. Wharam et al. [20] showed that employees with an insurance plan with high deductibles had significantly more delays in diagnosis and treatment than matched controls with an insurance scheme with low deductibles. In addition to delays in diagnosis and care, financial toxicity also affects treatment adherence. Patients with financial toxicity were more likely to report noncompliance with medication, indicating an inability to afford prescription drugs. The same patients reported forgoing mental health care, physician visits, and medical testing [21–23, 24].

Several limitations of this study should be taken into consideration. The participants were recruited from a single academic institution in Germany; the small cohort may be associated with a specific location or practice pattern.

Furthermore, a significant body of research has demonstrated that increased financial burden results in worse HR-QoL and increased symptom burden [25]. Study results from the USA must, however, be viewed differently to studies from Europe with different forms of state health care in different countries. However, if the results of our study can be reproduced in larger studies, the development of early counseling and targeted support measures would be required to compensate for the impairments of particularly disadvantaged patient groups. Health professionals should assess and recognize financial toxicity early in the cancer journey, be informed of available financial support resources and direct people to appropriate services. At an institutional level, the introduction of a financial support channel to provide assistance in applying for benefits, the integration of a welfare organization into oncology treatment programs and the provision of free transport and accommodation programs are recommended.

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Conclusions

The survival of testicular cancer is excellent. Long-term testicular cancer survivors, however, do face some degree of financial toxicity which can be severe in some cases. This problem has hitherto received little attention but should in future be considered in comprehensive cancer survivorship programs to ensure better long-term outcomes.

Statement of Ethics

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Institutional Ethics Committee of University Medical Center Rostock (No. A 2021-0258). Written informed consent was obtained from all study participants.

Conflict of Interest Statement

The authors declare that they have no competing interests.

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Author Contributions

D.L.D., J.N., and V.R. collected clinical data and analyzed the data. D.L.D. and O.W.H. wrote the manuscript. All authors provided critical feedback, helped shape the manuscript, and read and approved the final manuscript.

Data Availability Statement

The data that support the findings of this study are not publicly available as these are sensitive financial data and may contain information that could compromise the privacy of research participants but are available from the corresponding author (D.L.D.) upon reasonable request.

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