

Research Article

Financial Toxicity - A Relevant Adverse Effect for Curative Treated Long-Term NSCLC Survivors

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Received: November 27, 2020; **Accepted:** December 15, 2020; **Published:** December 22, 2020**Abstract**

Background: After receiving a cancer diagnosis, patients face many challenges. The association between return to work and financial problems caused by cancer has a substantial impact on Quality of Life (QoL) among cancer patients. Indeed, the QoL such as physical and mental health of cancer patients is lower when the risk of psychological disorders or distress increases, and chances for cancer cure are reduced. Progress in therapeutic intervention allows many cancer patients a social reintegration into their careers. About one third of cancer patients are younger than 65 years old, and with the constant increase in work life periods, a cancer diagnosis also presents a financial burden for those affected. The main objective of this study was to analyse the social QoL in the context of factors related to career and financial situation among patients diagnosed with Non-Small Cell Lung Cancer (NSCLC) I-IIIa.

Methods: A descriptive non-experimental research design was used to conduct a cross-sectional survey in collaboration with the German Pension Insurance Hessen (Deutsche Rentenversicherung: DRV Hessen)/Pension Fund. We analysed data of 46 Patients (pts) diagnosed with NSCLC I-IIIa using self-outcome questionnaires in combination with retirement insurance data from the date of first diagnosis up to two years afterwards. Out of 236 questionnaires, we received 46 completed forms. The remaining questionnaires of 46 patients were analysed according to self-determined outcomes and included a calculation of the financial changes caused by the disease. Only patients covered by pension insurance were included in the study.

Results: 46 patients (13 women) whose median age at first diagnosis was 56 years (range: 42-63 years) were included in the analysis. For 41% the employment situation changed after the period of cancer treatment. Twelve patients requested a retirement pension (reduced income insurance) and three patients reduced their weekly working hours and two patients lost their jobs due to complications of the disease. Eight pts (31%) changed their working place and had therefore a reduction in income. The data analysis revealed that, among these patients, two benefited from an income increase. In total, mean income has been reduced by around 23%. Considering only the patients who failed return to work resulted in an average loss of income of up to 94%.

Conclusion: Reduced ability to work may cause severe financial problems for those affected by the diagnosis of a NSCLC I-IIIa. We found an average income reduction of 23%, for those who failed return to work of 94%. This eventually relates to a higher risk of reduced wealth and may lower the patients' social standing.

Keywords: Non-small cell lung cancer; Cancer; Quality of life; Career and financial situation

Introduction

Worldwide, lung cancer occurred in approximately 2.1 million patients in 2018 and caused an estimated 1.7 million deaths [1]. In the United States, there will be approximately 230,000 new cases of lung cancer. Being diagnosed with NSCLC poses not only challenges for treatments and clinical decision-making or present health problems, but has also repercussions on the quality and professional life of the patients affected, as most of these patients not only have to cope with their therapies, but also face considerable financial burdens [2,3]. Thus, our motivation for the proposed research was based on the

lack of scientific knowledge about the career and financial situation following the diagnosis of NSCLC I-IIIa. The question if a NSCLC I-IIIa diagnosis could have an impact on the professional or financial situation in the short term or in the future depends on the type of cancer, its stage and size, the treatment and side effects, as well as the support provided [4]. However, with advances in medicine, more than one third of cancer patients are able to reintegrate into their professional careers, as most of them are less than 65 years old and still in work life. This negative impact of cancer on social life remains a big challenge and affects not only material but also

emotional well-being of patients and their families [5,6], as despite being in a fragile physical and psychological state, these patients have to work in order to cope with financial needs or daily demands [7,8]. In Germany, cancer patients are eligible within the social security system benefits and have special rights in the workplace. However, this legal and social regulation depends if the patient has a public or private insurance or if the patient is salaried or works as a public employee. Patients affiliated to the public health insurance receive sickness benefit for incapacity to work following interruption of employment-after 6 weeks of sick leave from employer's pay. This benefit represents 70% of the brutto income, but does not exceed 90% of the net income and is paid for a maximum of 78 weeks within three years [9]. Besides, there is possibility to receive an unemployment benefit type I (Arbeitslosengeld I: ALG 1), which is intended to cover unemployed persons who have paid regular contributions to the German social security system. ALG 1 is also given to patients who are still in work but have been on sick leave for more than 78 weeks. This provision (ALG 1) is proposed by the Federal Employment Agency (Bundesagentur für Arbeit) and is to ensure support during the job search process. Should a patient become unable to work for medical reasons, a disability or invalidity pension (pension based on reduced earning capacity: RECP) can be granted as income compensation as long as the retirement age has not been reached [10,11]. RECP depends on how able a patient can perform daily activities so this can be classified as partial and full earning capacity reduction (disability) and legally regulated. This requires appropriate medical and insurance conditions to be fulfilled.

1. Insurance legal conditions [12]:
 - Fulfilment a standard waiting period'
 - Three years Compulsory contributions in the last five years'
2. Benefit entitlement: reduction in earning capacity
 - Partial reduction in earning capacity (physical abilities (Leistungsvermögen: LV) of 3-6 h daily)
 - Full reduction in earning capacity (LV less than 3 hours a day)

*According to the German statutory Retirement Insurance (§ 43 SGB VI: Sozialgesetzbuch (SGB) VI- Gesetzliche Rentenversicherung) Derogations: Restricted waiting periods, transitory provisions and anticipated fulfilment of the waiting period under specific terms and conditions. The calculation of the pension is based on the pension clause: Earnings points x accession factor x 1.00 (regulatory retirement age). A flowchart describing how this system operates is included in (Figure 1).

For many patients, the loss of income or the inability to work remains an important burden, as many factors (such as flexible working hours, possibility to work from home, time off for doctor's appointments, change of duties due to work disability, interruption of work for medical care etc.) cannot be covered despite the efforts of the legal system.

Material and Methods

Objective of the study

Focusing on the question, "Did the diagnosis of NSCLC I-IIIa

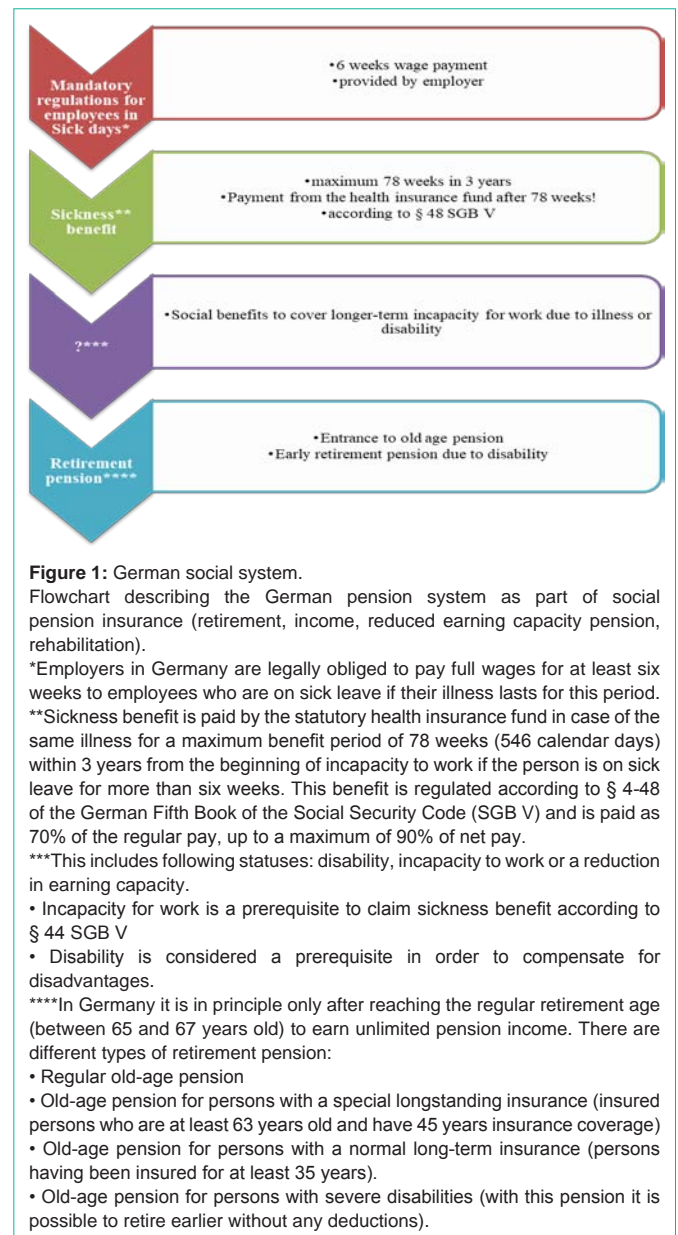


Figure 1: German social system.

Flowchart describing the German pension system as part of social pension insurance (retirement, income, reduced earning capacity pension, rehabilitation).

*Employers in Germany are legally obliged to pay full wages for at least six weeks to employees who are on sick leave if their illness lasts for this period.

**Sickness benefit is paid by the statutory health insurance fund in case of the same illness for a maximum benefit period of 78 weeks (546 calendar days) within 3 years from the beginning of incapacity to work if the person is on sick leave for more than six weeks. This benefit is regulated according to § 4-48 of the German Fifth Book of the Social Security Code (SGB V) and is paid as 70% of the regular pay, up to a maximum of 90% of net pay.

***This includes following statuses: disability, incapacity to work or a reduction in earning capacity.

• Incapacity for work is a prerequisite to claim sickness benefit according to § 44 SGB V

• Disability is considered a prerequisite in order to compensate for disadvantages.

****In Germany it is in principle only after reaching the regular retirement age (between 65 and 67 years old) to earn unlimited pension income. There are different types of retirement pension:

- Regular old-age pension
- Old-age pension for persons with a special longstanding insurance (insured persons who are at least 63 years old and have 45 years insurance coverage)
- Old-age pension for persons with a normal long-term insurance (persons having been insured for at least 35 years).
- Old-age pension for persons with severe disabilities (with this pension it is possible to retire earlier without any deductions).

affect your career or financial situation?" the objective of this study was to analyse the financial situation and return to work of patients diagnosed with NSCLC I-IIIa.

Research methods and description

Sample and data sources: This cross-sectional study was conducted on 46 patients over a period of 9 months, between March and December 2016, in collaboration with the Klinik Reinhardshöhe (Bad Wildungen, Germany), Klinik Sonnenblick (Marburg, Germany) and the German Social Insurance DRV Hessen/Pension Fund. The study was based on an analytical self-assessment questionnaire comparing patient data from the date of first diagnosis up to two years afterwards. Overall, 236 questionnaires were sent out to patients and 46 were completed. These 46 questionnaires were analysed according to data provided from patients and included a calculation of financial changes due to the disease. Data were collected from the German

retirement institution DRV Hessen (social insurance and pension fund) and thus objectively recorded. These data included economic aspects i.e. financial situation as well as socio-demographic aspects of patients.

Criteria for participation in the study

Inclusion criteria: Patients were included who are in their working age, pay into the retirement insurance, and signed the agreement allowing access information on their retirement financial situation. Patient has underwent an operation caused by a NSCLC Stad I-IIIa no longer than 12 month ago.

Exclusion criteria: Patients already retired at the time of their diagnosis, or patients without pension insurance at the time of diagnosis (such as parental leave, self-employment, receipt of social security benefits, etc.) were excluded. This also included self-employed persons and civil servants, as in Germany these people do not have to pay into an employment insurance scheme.

Process and data recruitment

The study covered a nine-month period. The data recruitment process started from the submission of the questionnaires up to the deadline according to the study schedule. Following patient consent and ethical approval from the ethic committee of the university clinic Marburg (AZ 96/14), detailed patient demographic information was documented in a compiled data sheet.

Data analysis and interpretation

We used qualitative data analysis method such as explicit and systematic inductive as well as deductive approaches. The self-assessment questionnaires were analysed with a deductive approach.

Results

Data collected from the retirement insurance were aggregated and evaluated. Following data processing, 46 questionnaires were selected from 236 pts (more than half of the patients were excluded due to missing selection criteria, mainly among patients who were already retired or not covered by pension insurance at the time of diagnosis, patients in parental leave, self-employment and social benefits). The response rate in participating in our study was 19%.

Participant characteristics

The sample included 46 NSCLC patients. Most of them (32; 70%) were men. Median age at first diagnosis was 56 years and ranged from 42 to 63 years. The majority had a school degree (91%) and only 15% of them had completed post-graduation degree (Table1).

Career situation

All patients (n=46) had a professional background. Based on employment status, 48% were still working, 11% received sickness benefit, 6% were unable to work, 33% had a temporary retirement pension and 2% were unemployed (Figure 2). However, more than 40% of the patients (41%) had to change their employment due to the illness, as many were no longer able to pursue their previous profession (Figure 3 and 4). 59% of the patients had no change in their professional career and maintained their regular activities. The following changes according to professional occupation as well as to the cancer diagnosis were reported by 41% (n=27):

- Twelve patients (44%) reported feeling unable to work and

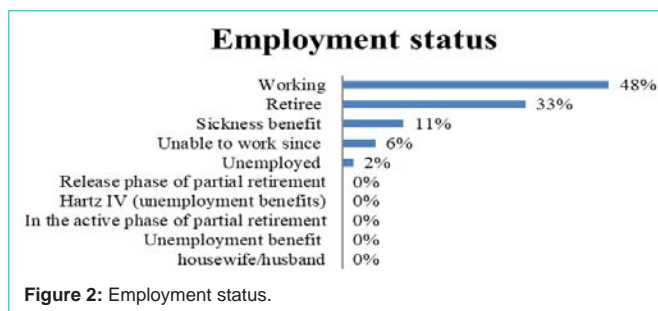


Figure 2: Employment status.

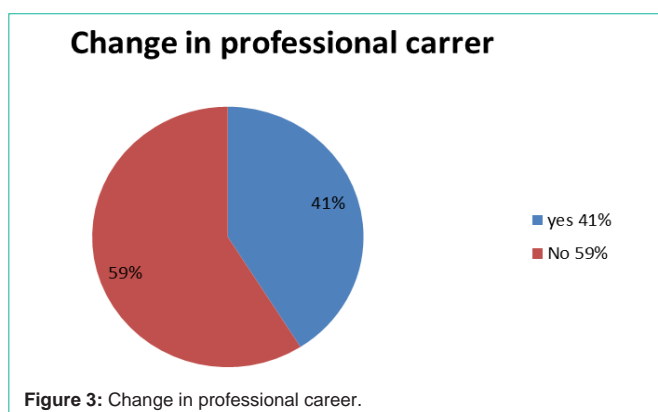


Figure 3: Change in professional career.

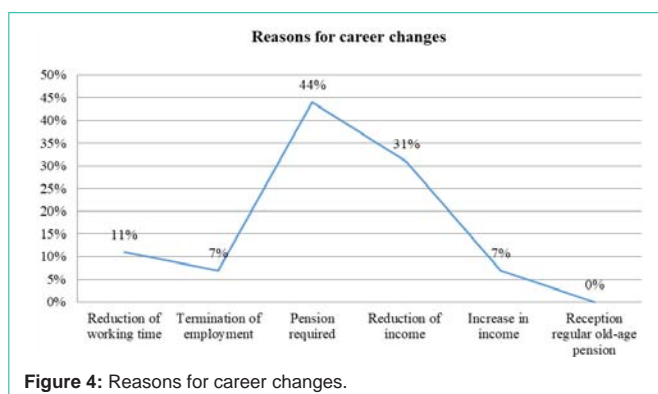


Figure 4: Reasons for career changes.

requested pension payments. Due to any effects of a cancer diagnosis, patients in Germany who have lost or restricted ability to work can receive a reduced earning capacity pension. However, this pension is only paid out to patients below retirement age and is managed from the German pension fund.

- Three patients (11%) claimed a reduction in working time and therefore a reduction in income, and two patients (7%) lost their employment due to the disease.
- Eight pts (31%) changed their working place and had therefore a reduction in income.
- 7% (2 pts) of all patients reported an increase in income due pay award or change of job (Figure 4).

The question about job satisfaction were reported by 82% (n=38), most of the patients (57%) stated that they were satisfied with their workplace (Figure 5); however, more than 80% reported having stress factors (Figure 6). 27% of the patients claimed to work physically

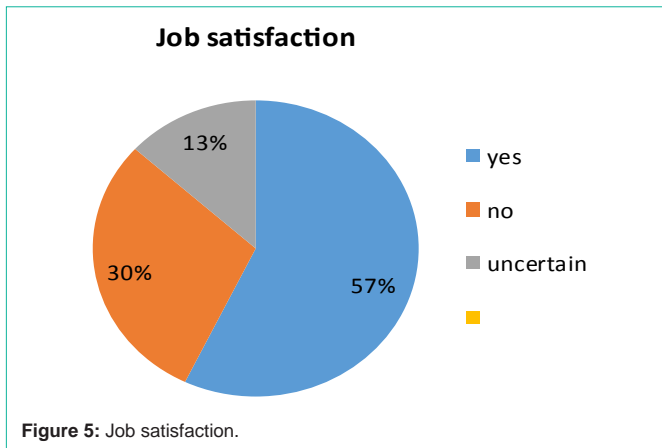


Figure 5: Job satisfaction.

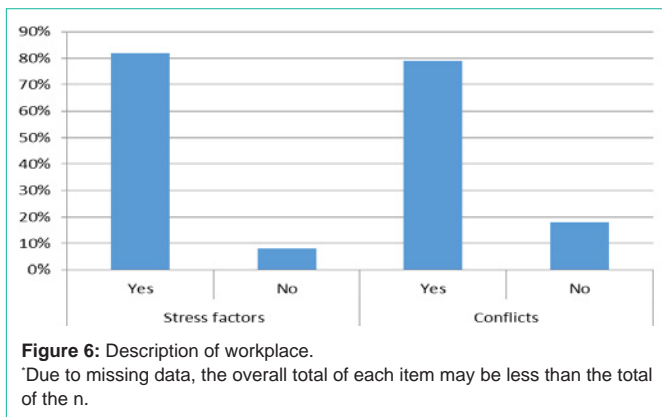


Figure 6: Description of workplace. Due to missing data, the overall total of each item may be less than the total of the n.

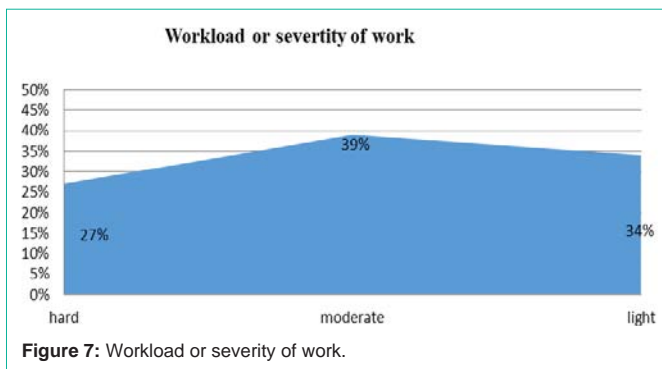


Figure 7: Workload or severity of work.

hard, while 39% stated that they had to do moderate and 34% do light physical work (Figure 7). 9 patients stated that they were still smoking after tumor treatment.

Financial situation

These results refer to data collected from the pension fund and were therefore objective-which makes this analysis different from most similar analyses, which often only focus on patients’ subjective perceptions. The average income among patients was reduced by about 23%. Analysing only the patients requesting pension payments, partial or full unemployment benefits led to an average loss of income of as high as 94%. Patients with a successful return to work led to an average loss of income of as high as 7%. It is important to note, however, that this financial burden was relative to patient income. There was no association between financial toxicity and tumor stage.

Table 1: Demographic characteristics of study participants (n=30)

Variables	Categories	n	%
Gender	Female	13	28%
	Male	33	72%
Tumor stage	I	19	41%
	II	16	35%
	IIIA	11	24%
Still smoking	Yes	31	67%
	no	15	33%
Level of education	No school degree	5	11%
	Primary/secondary school	34	74%
	Middle maturity certificate	0	0%
	Higher secondary certificate/post-secondary diploma	7	15%
	Others	0	0%

Results interpretation

Data resulting from this study were obtained by calculating mean values using simple averages. So, each income change was summed and then divided by the number of the study participants. The income reduction (23%) is also a mean value that reflects both the reduction of financial resources from pensions and reduced income. Accordingly, the loss of income (94%) is the average income variation from income earned before and after sickness period.

Discussion

The results of this study revealed that the diagnosis “NSCLC I-III A” has a major impact on the QoL of those affected and can significantly impact their financial as well as professional situation. According to statistics from the German Cancer Registry, nearly 500.000 new cases of cancer occur every year in Germany and due to the demographic situation, the incidence of new cancer cases in Germany is expected to rise around 23% between 2015 and 2030. This aspect refers mainly to patients in the employable age group (<65 years). There are few studies in Germany identifying the impact of cancer on work or employment, and almost none on early stage or locally advanced NSCLC. Such a thematic issue is particularly important as patients and physicians concur on the fact that work is an essential part of the QoL, as long as activity can be maintained [13].

Almost one-third of cancer patients experience financial difficulties due to their diagnosis or treatment [14], and these studies often proved that patients with financial instability complain about lower QoL [15], increased symptoms and more pain. Moreover, compared to healthy people with similar age groups, tumour patients are 37% more at risk of losing their jobs and have to work with reduced time or risk lower incomes [9]. Winkler et al., demonstrated that cancer can lead to a loss of income, associated with adverse psychological effects and thus cause financial distress [16]. The financial burden of cancer patients should be considered in the broader context of the patient’s individual situation and their experience with cancer diagnosis and treatment. Indeed, this reflects how oncologists have an essential role in managing cancer patients, independent of the quality of the treatment.

An investigation conducted in 2016 by French researchers on the impact of cancer on employment showed that patients face multiple difficulties in returning to work. Researchers point out that the first year after diagnosis corresponds to the time of treatment, which is generally characterised by increased periods of sick leave. [17]. A

Table 2: Financial situation of study participants (n=46).

Pts	Status	Gross salary before illness in €	Gross salary 2 years after diagnosis in €	Difference in €	Difference in %
1	return to work	208,3	243,07	34,77	14%
2	return to work	3471,75	3642,8	171,05	5%
3	return to work	5782,2	5932,2	150	3%
4	return to work	3998,1	3473	-525,1	-15%
5	return to work	3511,7	3775,3	263,6	7%
6	return to work	5390,2	5831,6	441,4	8%
7	return to work	3632	3815,5	183,5	5%
8	return to work	3801,5	3851,2	49,7	1%
9	return to work	1997	1997	0	0%
10	return to work	2300	2300	0	0%
11	return to work	1684,4	1734,7	50,3	3%
12	return to work	2333,4	2226,6	-106,8	-5%
13	return to work	1786	1786	0	0%
14	return to work	1184	1232,5	48,5	4%
15	return to work	1324	1324	0	0%
16	return to work	3397,7	3773,3	375,6	10%
17	return to work	573	573	0	0%
18	return to work	5754,2	5960	205,8	3%
19	return to work	3267	3267	0	0%
20	return to work	4118,7	4195,7	77	2%
21	return to work	3954	3954	0	0%
22	return to work	4596,8	4596,8	0	0%
23	no return to work	1283	1283	0	0%
24	no return to work	3803	1462,5	-2340,5	-160%
25	no return to work	1814,7	754,1	-1060,6	-141%
26	no return to work	2351,1	1874	-477,1	-25%
27	no return to work	1454,6	555,55	-899,05	-162%
28	no return to work	1129	853,7	-275,3	-32%
29	no return to work	1732,4	1995,97	263,57	13%
30	no return to work	570	775,62	205,62	27%
31	no return to work	1642,2	873,93	-768,27	-88%
32	no return to work	4393	3882	-511	-13%
33	no return to work	3028	1186,26	-1841,74	-155%
34	no return to work	2471	2471	0	0%
35	no return to work	692	692	0	0%
36	no return to work	3219,5	2752,5	-467	-17%
37	no return to work	1147,99	1147,99	0	0%
38	no return to work	2908,3	1940,6	-967,7	-50%
39	no return to work	1190,81	1210,7	19,89	2%
40	no return to work	823,89	823,89	0	0%
41	no return to work	753,47	766,05	12,58	2%
42	no return to work	3185	1494,97	-1690,03	-113%

43	no return to work	1074,99	1095,67	20,68	2%
44	no return to work	1206,06	1226,21	20,15	2%
45	no return to work	754,9	767,51	12,61	2%
46	no return to work	2550,1	1984	-566,1	-29%

^aIncreases and changes in pension rates.

French Monitoring Program for Social Action (DOPAS), studies the social impact of cancer every two years. This monitoring program collects patients' experiences and according to its results, 84% of the patients reported having a sick leave. Most of them also feel unable to work during treatment due to pain, fatigue and side effects. But, for some, working is a way to cope with the disease. Reconciling medical treatment and work is an economic necessity, as most patients are obliged to return to work in order to be able to manage daily expenses, especially for households with low income or the self-employed. Gilligan et al., showed the impact of cancer diagnosis on the financial situation of cancer patients [18]. They evaluated the variance in financial assets based on clinical data from 1998-2014 for cancer patients over 50 years old and the results revealed that:

There is significant financial burden associated with cancer treatment, and this is often reduced as prognosis worsens due to extended treatment periods; 42% of patients reported having spent all their income in less than two years after their diagnosis and 62% were indebted in order to finance cancer treatment costs.

According to Gilligan et al., there are subjective measures that include perceptions related to the financial burden as well as to the psychological impact of cancer. However, they also identified objective measures that focus on issues related to concrete strategies for facing financial burden, although these strategies were more focused on the common cancer types. The financial burdens are potentially more significant if a patient remains unable to work, as many cancer patients often have to take time off work upon diagnosis as well as during their treatment [19], but once returned to work, many report having challenges in managing their job due to health problems [20] and not receiving any medical benefits from their employer. So, for patients and their families, this could affect household income. The German health insurance has different regulations depending on the professional and life situation, e.g. health insurance funds do not have to pay sickness benefits if patients already have a reduced ability to work and can therefore claim pensions [21]. However, prior to receiving such a benefit, medical prescriptions must be checked or supportive measures must be taken to ensure a possible return to work [22], as the retirement age in Germany for the regular old-age pension is raised from 65 to 67 years starting in 2012. Following German legal regulations, all cancer patients can apply for a five-year handicapped pass and with this status it is also possible to retire two years earlier without any deductions [23]. In addition to this, patients in incapacity for employment are eligible for a disability pension as defined according to the German pension insurance. This disability pension is initially temporary, but afterwards unlimited. It covers only two years and is not much higher than the sickness benefit, which is about 70% of the regular salary. For patients who have been in care for more than one year, this can be compensated with a reduced earning capacity pension, which is paid up to legal retirement age [11,24,25]. There are many factors that influence the return or

reintegration in employment among cancer patients. In particular, socio-demographic factors (age, education level) and pathological factors (type of cancer, stage of the disease and treatments) constitute a major obstacle to the professional situation of patients.

Limitations and Perspective

As our study involved data collected from a cross-sectional survey, causal links between the financial situation and return to work of patients in relation to the diagnosis of NSCLC I-IIIa was not possible to identify. Indeed, many cancer patients as well as cancer survivors often face financial and emotional needs, so working can be an important step in helping them to overcome their situation. Nationally as internationally there is a significant lack of disease-related cost studies addressing this issue from the perspective of patients suffering from NSCLC especially in those a therapy regime with a curative intention is done.

Conclusion

This study has provided insights into the financial situation of patients diagnosed with NSCLC I-IIIa. Reduced ability to work may cause severe financial problems for those affected by the diagnosis of an early stage or locally advanced NSCLC. We found an average income reduction of 23%, for those who failed return to work of 94%. This eventually relates to a higher risk of reduced wealth and may lower the patients' social standing.

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