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ORIGINAL ARTICLE

Need for nursing care support in cancer patients: Registry-linkage study in Germany

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Abstract

Aim: In Germany, very little is known about the need for assistance and nursing care support among cancer patients after hospitalization. The aim of this study was to describe nursing care support for cancer patients and to analyse whether these patients need more care assistance than other persons in need for care.

Methods: This was a registry linkage study conducted in 2011. Cases were identified from the population-based cancer registry for the Muenster District in north-western Germany and in factually anonymised form linked by a semi-automatic probabilistic procedure (the standard procedure of the cancer registry) with medical examination records of patients applying for assistance and nursing care support from the regional statutory health insurance. The application records of 4,029 patients with colon, breast and prostate cancer were compared to a reference group of 13,104 non-cancer patients.

Results: In only 41.7% of colon, 45.8% of breast and 37.4% of prostate cancer patients was the malignancy the main underlying diagnostic cause for the application of assistance and nursing care. These patients were on average younger (mean age 71.1 vs. 76.8 years) than the non-cancer reference group, required higher levels of support (79.5 vs. 58.1% "considerable" or higher level care need) and their applications were less likely to be rejected (odds ratios [ORs] 0.26, 0.28, and 0.31, respectively). By contrast, the proportion of successful applications and the level of support granted did not differ between multimorbid cancer patients with other main diagnoses as compared to non-cancer applicants.

Conclusion: Patients with colon, breast or prostate cancer do not need per se more nursing care than non-cancer patients. Only if cancer is the main underlying diagnosis for nursing care support, higher levels of support are needed.

Keywords: cancer patients, Germany, nursing care.

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Introduction

The population in Germany, like in other industrialized countries, is ageing. Consequently, the burden of disease due to chronic conditions such as cancer is increasing.Improved early detection and medical care result in longer survival of cancer patients (1).Cancer survivors not only require in-hospital or ambulatory medical treatment but they may also need assistance and nursing care, either permanently or during certain periods in the course of their disease. Internationally the access to, the implication for and the coordination of care after treatment for cancer is a subject of research (2). Geriatric assessment (3), the use of care plans (4) and their improvement (5) as well as the use of multidisciplinary teams are discussed as ways to improve care (6). In Germany, depending on the individual need (determined by the type of disease, stage of disease and age of the patient) and on the personal financial resources, the patient or his/her family are entitled to apply for support from the statutory health insurances' nursing care provision program (gesetzliche Pflegeversicherung). This insurance covers about 70.5 million of the 80 million people residing in Germany (all those insured in the compulsory health insurance). After applying for support, the Medical Service of the Health Insurance (Medizinischer Dienst der Kranken-versicherung, MDK) will entrust trained medical personal with conducting a standardized assessment of the actual need of home nursing care in order to assess the eligibility for support and the type of support granted (financial, ambulatory nursing care, or institutional care) (7).The medical assessment results as well as information on the type of support granted are stored in regional databases maintained by the MDK. The MDK databases contain one main and one concomitant diagnosis underlying the need for nursing care support. Thus, older and multimorbid patients, even if they are cancer survivors and have been granted nursing care support, may not be registered as cancer cases in the MDK database. Hence, with this database alone, it is not possible to assess the level of nursing care support that cancer patients require relative to non-cancer patients. The complementing information may be retrieved from population-based cancer registries, which, however, usually do not contain information on nursing care (8). Therefore, very little is known about the need for nursing care support of cancer survivors after hospitalization in Germany. This study aims to describe nursing care support for cancer patients and to analyse whether these patients need more care assistance than other persons in need for care. All requirements of the German Data Protection Act and the responsible Ethical Committee were adhered to.

Methods

The study was conducted in the Muenster District in the north-west of Germany with a population of about 2.6 million persons in 2011. The Epidemiologic Cancer Registry for the Muenster District (EKR) registers all cancer cases, with a completeness of recording of more than 95% and a proportion of death certificate only cases of about 7% (9). The number of incident cancer diagnoses in the Muenster District is about 13,000 per year (10). Data of the regional MDK of Westphalia-Lippe (MDK-WL) were used to determine the need for and the type of nursing care support granted in the period of 2004 to 2008. The MDK-WL maintains a quasi-complete database of all claims for nursing care in Westphalia-Lippe (7). Westphalia-Lippe comprises three of the five districts of North Rhine-Westphalia (NRW), among them the district of Muenster. In this district, about 73,000 persons received support for nursing care in 2009, corresponding to 2,810 cases per 100,000 inhabitants (11).

As described elsewhere, records of the EKR and the MDK were pseudonymised and linked using a semi-automatic probabilistic procedure in accordance with the Cancer Registry Act of NRW (12). The resulting database contained detailed information about cancer cases (site, time of diagnosis, etc.) as well as their need for nursing care and the type of nursing care granted by the MDK.

About 18,900 cancer cases could be identified in the EKR who had at least one medical examination recorded in the MDK database. A reference group of patients with no records in the EKR was drawn from the MDK database for comparison (about 21,400 non-cancer patients). We used temporary record numbers to identify the patients not registered in the cancer registry and to draw the reference group.

In cases of changes in the need for nursing care (or appeals against the MDK's decision), a follow-up medical examination is conducted. Here, data of the first MDK follow-up examination is used to assess nursing care needs in relation to disease progress.

The analysis was restricted to cancer of the breast, colon and prostate (ICD10 C-18, ICD10 C-50, ICD10 C-61, total N= 4,029), the most frequent malignancies. A cancer record in the EKR and the main diagnosis leading to nursing care in the MDK database were used to define three subgroups:

i) Cancer according to EKR (yes) and to main diagnosis in the MDK (yes): n=1,707 patients;
ii) Cancer according to EKR (yes) but not to MDK (no): n=2,322 patients, and;
iii) EKR (no) and MDK (no): n=13,104 patients (reference group).

Due to the small number of patients (n=181) the fourth group (no/yes) was not considered. The age range was restricted to 38-95 years, so that groups of equal age are compared.

The outcome of interest was the "need for nursing care support" as assessed by MDK in the medical examination. It was defined according to the German Nursing Act in five levels (0 to 3+)[Box 1]. Descriptive analyses compared groups with regard to baseline characteristics and levels of need. Logistic regression models were used to adjust dichotomous outcomes for age (in years) and sex (colon cancer only). Analyses were performed with SAS 9.2.

Results

Age and sex distribution of patients who applied for nursing care are shown in Table 1, stratified by cancer case status in the EKR and the MDK database. Cancer patients with cancer as main diagnosis justifying nursing care (group 1) were about eight years younger than cancer patients whose need for nursing care was justified by another condition (group 2) and patients with main diagnoses other than cancer (group 3, reference). Differences by sex were fairly small, although statistically significant.

In more than 50% of MDK patients who suffered from colon, breast or prostate cancer, cancer was not the main diagnosis leading to nursing care (Table 2).

Nursing care level

Between 20.5% (group 1) and 41.9% (group 3) of MDK patients did not fulfil the criteria to receive nursing care support according to the first MDK medical examination.

Textbox 1: Levels of need for nursing care support adapted from [8]

-*Level 0:* No need of nursing care support
The need for nursing care is below the threshold of 90 minutes/day on average (see level 1 below), so no support is granted.

-*Level 1:* Considerable need for nursing care support
Need for assistance is required at least once a day and covers at least two activities in one or more areas of basic care (body care, feeding and mobility). In addition, domestic help is required several times a week.The weekly expenditure of time is at least 90minutes/day on average, with more than 45 minutes for basic care.

-*Level 2:* Extensive need for nursing care support
Need for assistance in basic care (body care, feeding and mobility) is required at least three times daily at different times of the day. In addition, domestic help is required several times a week.The weekly expenditure of time is at least 3 hours/day on average, with more than 2 hours for basic care.

-*Level 3:* Very extensive need for nursing care support
There is need for assistance in basic care around the clock, also at night. In addition, domestic help is required several times a week.The weekly expenditure of time is at least 5 hours/day on average, with more than 4 hours for basic care.

-*Level 3+:* "Härtefall"
If the conditions of level 3 are satisfied and there is an unusually high or intensive need of assistance, the hardship regulation with higher payments can be applied.

Nursing care support was more often granted (nursing care level 1 and higher) in MDK patients in whom cancer was the main diagnosis justifying nursing care support (group 1).

For cancer patients who had another main diagnosis that justified nursing care support (group 2), the rejection rate was considerably higher than in group 1, but similar to patients without cancer (group 3).

Table 1. Age and sex of MDK patients grouped by cancer case status in cancer registry (EKR) and MDK database (cancer cases in groups 1 and 2 restricted to colon, breast and prostate

Variable	Group 1 (EKR yes/ MDK yes)*	Group 2 (EKR yes/ MDK no)†	Group 3 (EKR no/ MDK no)‡	P
Age				
Mean ±SD	71.1±11.0	79.2±8.0	76.8±11.1	
Median	73	80	79	<0.001
Range	38-95	38-95	38-95	
Sex				
Male n, (%)	623 (36.5)	920 (39.6)	4.320 (33.0)	
Female n, (%)	1,084 (63.5)	1.402 (60.4)	8.784 (67.0)	<0.001
Total	1,707 (100)	2,322 (100)	13,104 (100)	

* cancer case in EKR + cancer is main diagnosis justifying nursing care - also if nursing care is not granted (level 0).
† cancer case in EKR + cancer is not main diagnosis justifying nursing care - also if nursing care is not granted (level 0).
‡ non-cancer case in EKR + cancer is not main diagnosis justifying nursing care - also if nursing care is not granted (level 0), reference.

Patients in group 1 also needed extensive nursing care of level 2 or level 3 (including level 3+) more frequently than patients in the other groups (Table 3).

Of all persons registered in the EKR applying for nursing care support (groups 1 and 2) a need for nursing care support (level 1 and higher) was confirmed at the first medical examination in 69.2 % of colon cancer patients (mean age: 77.1 years), 65.1 % of breast cancer patients (mean age: 73.4 years), and 72.4 % of prostate cancer patients (mean age 76.4 years) (Table 3).

Table 2. Age distribution of MDK patients stratified by cancer location, grouped by cancer case status in cancer registry (EKR) and MDK database

	Group 1 (EKR yes/ MDK yes)*	Group 2 (EKR yes/ MDK no)†	Group (EKR no/ MDK no)‡
ICD10 C-18: n, (%) (cancer of the colon)	483 (41.7)	675 (58.3)	
Mean(±SD) age females	75.1±10.0	82.0±7.0	78.6±10.3
Mean(±SD) age males	70.6±10.5	77.8±7.8	73.2±11.8
ICD10 C-50: n, (%) (female breast cancer)	811 (45.8)	958 (54.2)	
Mean(±SD) age females	68.4±12.2	79.1±8.9	78.6±10.3
ICD10 C-61: n, (%) (cancer of prostate)	413 (37.4)	689 (62.6)	
Mean(±SD) age males	73.8±7.7	77.9±6.9	73.2±11.8

*cancer case in EKR + cancer is main diagnosis justifying nursing care - also if nursing care is not granted (level 0).
† cancer case in EKR + cancer is not main diagnosis justifying nursing care - also if nursing care is not granted (level 0).
‡ non-cancer case in EKR + cancer is not main diagnosis justifying nursing care - also if nursing care is not granted (level 0), reference.

To assess what determines the chances of nursing care support being refused by MDK, we calculated odds ratios separately for the three cancer types (Table 4). The reference was group 3 (Table 4). The chance of receiving no support (level 0) was statistically significantly lower when cancer was the main diagnosis justifying nursing care, irrespective of the type of cancer (OR=0.26-0.31).

Table 3. Nursing care level of MDK patients as per first medical examination by cancer case status in cancer registry (EKR) and MDK database (cancer cases in groups 1 and 2 restricted to colon, breast and prostate cancer)

	Group 1 (EKR yes/ MDK yes)*	Group 2 (EKR yes/ MDK no)*	Group 3 (EKR no/ MDKno)*
	Nursing care level as per first medical opinion (n, %)		
Level 0 (no support)	350 (20.5)	928 (40.0)	5.492 (41.9)
Level 1 and higher	1.357 (79.5)	1.394 (60.0)	7.612 (58.1)
Level 1†	673 (49.6)	1.065 (76.4)	5.741 (75.4)
Level 2	614 (45.3)	310 (22.2)	1.711 (22.5)
Level 3‡	70 (5.1)	19 (1.4)	160 (2.1)

* see footnotes to Table 1.
†subgroups with level 1, 2 and 3 add up to 100% (as do Level 0 plus "Level 1 and higher").
‡ includes level 3+ cases.

By contrast, cancer patients who had another main diagnosis justifying their nursing care need (group 2) had equally high chances of refusal as the cancer-free reference group 3.

Table 4. Chance of receiving no nursing care support (Level 0) among MDK patients by type of cancer, adjusted for age (breast and prostate cancer) and for age and sex (colon cancer), by cancer case status in cancer registry (EKR) and MDK database

	Group 1 (EKR yes/ MDK yes)*		Group 2 (EKR yes/ MDK no)*		Group 3 (EKR no/ MDK no)*	
	N	OR [95% CI]	N	OR [95% CI]	N	OR
Cancer of colon						
Level 0	92	0.28 [0.22-0.36]	265	1.01 [0.86-1.18]	5,492	1.00 (Ref.)
Level 1 and higher	391		410		7,612	
Female breast cancer						
Level 0	201	0.31 [0.26-0.37]	416	1.00 [0.87-1.14]	3,848	1.00 (Ref.)
Level 1 and higher	610		542		4,936	
Cancer of prostate						
Level 0	57	0.26 [0.20-0.35]	247	1.12 [0.94-1.33]	1,644	1.00 (Ref.)
Level 1 and higher	356		442		2,676	

* see footnotes to Table 1.

Disease progression

The number of patients in our dataset with a second medical examination was limited (see numbers in Table 5). An increase in the need for nursing care support over time is evident, which is compatible with a progression of the malignancy. The strongest increment in terms of a need for level 2 or higher care was found in patients from group 1. For example, 11% of colon cancer patients were in level 2+ at the first examination. This increased to almost 52% at the second examination, a far larger increase than in the non-cancer reference group (12% to 39%). The difference between mean ages (as estimated from the mean ages in Table 5) is smallest in group 1, suggesting a shorter time-span between first and second medical examination.

Discussion

In this population of patients with colon, breast or prostate cancer who had applied for nursing care support (groups 1+2), the malignant disease was in less than half of the cases the underlying justification for support being granted (group 1). In other words, more than every second cancer patient (group 2) had another underlying diagnosis that was the main reason for nursing care support. The mean age of the cancer patients was high, so the combination of cancer with one or more other (presumably chronic) conditions reflects the well-known multimorbidity of the elderly in Germany (13-15). Studies analyzing German claims data indicate that the most common conditions in multimorbid patients are hypertension, lipid metabolism disorders, chronic low back pain diabetes

Table 5. Changes from first to second medical examination to establish level of nursing care support among MDK patients, by cancer case status in cancer registry (EKR) and MDK database

		Group 1 (EKR yes/ MDK yes)*		Group 2 (EKR yes/ MDK no)*		Group 3 (EKR no/ MDK no)*	
	Level	**N**	**%**	**N**	**%**	**N**	**%**
Cancer of colon				234		5,205	
First medical examination	0		23.8		32.9		32.9
	1		65.3		55.1		54.8
	2+		10.9		12.0		12.4
Mean age		*74.3*		*79.9*		*77.0*	
Second med. examination	0		20.8		26.5		25.6
	1		27.7		33.3		35.7
	2+		51.5		40.2		38.7
Mean age		*74.8*		*80.7*		*77.7*	
Female breast cancer		194		354		3,506	
First med. examination	0		22.7		39.8		34.3
First med. examination	1		88.0		87.8		82.7
	2+		12.0		12.2		17.3
Mean age		*69.9*		*79.5*		*78.6*	
Second med. examination	0		19.6		25.7		26.7
	1		39.7		49.1		47.8
	2+		60.3		51.0		52.2
Mean age		*70.4*		*80.2*		*79.4*	
Cancer of prostate		108		262		1699	
First med. examination	0		15.7		29.8		29.8
First med. examination	1		84.6		83.7		79.5
	2+		15.4		16.3		20.5
Mean age		*73.0*		*78.0*		*73.5*	
Second med. examination	0		13.0		21.0		24.3
	1		25.5		46.9		48.4
	2+		74.5		53.1		51.6
Mean age		*73.5*		*78.9*		*74.2*	

* see footnotes to Table 1.

mellitus, osteoarthritis and chronic ischemic heart disease (16,17). These often occur in dyads or triads together with cancer. Accordingly, diseases other than cancer are the major reasons for claiming nursing care support in Germany: Psychological and behavioural disorders take first place (18) while cancer ranges at the fifth rank (19). Our study shows, however, that if cancer was the diagnosis justifying nursing care support (patient group 1), then the probability of actually being granted support was significantly higher than in the reference group of non-cancer patients. Despite having greater need for care support, cancer patients in group 1 were significantly younger than patients in the other groups (more than 10 years in case of breast cancer). It can be concluded that there is a group of cancer patients who apparently is more severely ill and in need of nursing care support relatively early in life (group 1); and a second, older group of cancer

patients who is multimorbid and in whom cancer survivorship is a concomitant condition of less severity (group 2). The need for nursing care support of the latter group is not substantially different from that of non-cancer patients (group 3).

Our findings regarding the temporal development of the need for support seem to support this interpretation. Second medical examinations were conducted sooner in patients from group 1 than in the other two patient groups, indicating that the course of disease in this group was more severe requiring reassessment of the condition. Also, the proportion of patients being upgraded to higher levels of support was substantially higher in group 1 than in the other groups, despite younger age and earlier reassessment. While this might reflect a comparatively quick worsening of health among this group of cancer patients, differences in mean age could also partly be an effect of a higher case fatality rate in group 1.

Discussions in other countries highlight unmet needs of cancer patients, often calling for specialised oncology nursing in hospital and nursing home care (2,22-23). Hansen et al. (20) reported an association of unmet needs with health-related quality of live. According to Puts et al. (21) the most common needs are psychological and physical needs as well as needs for information. Another focus is on improvement and coordination of nursing care (2-6). Salz and Baxi (5) assume that patients with serious health problems will benefit most from care coordination. Though the system of nursing care support in Germany is different from systems in other countries, our findings confirm specific care needs among cancer patients. Comparative studies should establish how the different systems are performing, relative to each other.

-*Strengths:* Firstly, the medical examinations from MDK are performed by experts following highly standardized procedures, so information about need for nursing care and the underlying main diagnosis is reliable. Secondly, the completeness of data in the cancer registry and MDK databases is high. About 95% of cancer cases are registered. About 94% of persons in the study population are insured in the compulsory nursing care insurance, so all their claims for nursing care are registered by the MDK. Thirdly, the results of our study are representative for the study region of Muenster district. As Muenster is a typical West German district with rural and urban areas, the findings may be generally indicative of needs of the population in the western part of Germany. Fourthly, we could combine administrative with medical data, thus obtaining information that is not available in single databases such as claims data (16,17). To achieve this, we had to solve a methodological problem, namely linking routine data while maintaining data protection. There is no system of unique national identification numbers (24) that would allow a simple linkage of routine health data from different sources (25) in Germany, as in case of countries like Canada or the United Kingdom. We overcame this problem by developing an approach using pseudonymisation of personal identifiers, data encryption and probabilistic record linkage (17).

-*Limitations:* Only information available in the datasets of MDK and the cancer registry could be used. As complete data could only be obtained from one region, the number of cancer cases was sufficiently large to analyze only the three most common cancer diagnoses. Data on follow-up (second medical examination) was limited and this may compromise the interpretation of findings on the progression of nursing care needs. Also, deaths are documented in the cancer registry but not by the MDK database, which could bias comparisons between cancer and non-cancer patients. Studies with larger study populations and

preferably a prospective design could help to analyse the need for nursing care among other cancer diagnoses and to obtain more reliable data about the progression of nursing care needs of cancer patients. Enrolling incident cancer cases prospectively would also allow estimating the proportion of cancer patients applying for nursing care support. However, until sufficient patient-years among elderly people have been accrued in large cohort-studies, registry-based studies such as ours are needed to fill the gap.

Conclusion

Patients applying for nursing care support because of colon, breast or prostate cancer needed higher levels of support in spite of being younger than non-cancer patients (reference group). Also, their condition seems to deteriorate faster as they are re-examined after shorter time periods. Multimorbid cancer survivor patients, in whom cancer was not the main reason for their application for nursing care support, did not differ from the reference group in most parameters.

Conflict of interest: None.

Authors' contribution
JS and OR conceived the study. KK, WS, JB, and VK provided the data and prepared the datasets. JB, KK, VK and JS performed the data analysis. JB, JS and OR wrote the first draft of the manuscript. All authors contributed to discussion of the results and revised the manuscript. All authors have read and approved the final manuscript.

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