

Utilisation of psychosocial and informational services in immigrant and non-immigrant German cancer survivors

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Abstract

Objective: We examined psychosocial and informational services used by long-term survivors of breast, colon and prostate cancer in immigrants versus non-immigrants.

Methods: Patients were sampled from population-based cancer registries in Germany. They completed a questionnaire assessing immigration biography, service use and socio-demographic characteristics.

Results: Data of 6143 cancer survivors were collected of whom 383 (6%) were immigrants. There was no evidence of an association between immigration status and service use. However, immigration biography played a role when patients' and their parents' birthplace were taken into account. When parents were born outside Europe, survivors less frequently used information from the Internet (OR_{adj} 0.4, 95% CI 0.2; 0.8). Web-based information (OR_{adj} 0.7, 95% CI 0.5; 0.9) was less frequently used when the participant was born outside Germany.

Conclusion: The differences in the use of psychosocial and informational services between immigrants and non-immigrants seem to be generally small. Acculturation may play a role in service uptake. In survey-based health services research, investigators should not stratify by census-defined immigration status, but rather by cultural background.

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Introduction

This study set out to identify whether immigrant cancer patients differ from the native population in Germany in their use of psychosocial and informational services.

Evidence suggests that cancer survival depends on patients' ethnicity. In the USA, for example, black breast cancer patients have worse overall survival than other ethnic groups [1], whereas Asian women tend to have better survival [2,3].

The mechanisms of this relationship are still not entirely clear. It seems that intersections between lifestyle, perceived discrimination and structural factors such as access to healthcare play a major role in health disparities [4]. In a setting where equal access to health care was possible, no differences in colon cancer survival were observed [5]. Hence, there must be factors other than the availability of health care contributing to the survival gap between

immigrants and non-immigrants. One explanation might be the different use of health care when it is available to all. It is therefore of interest how immigrants make use of healthcare services.

This applies to mental health care even more: In some countries, mental health diseases are severely stigmatised, resulting in the concealment of such problems and denial of the need to seek professional help [6]. It is therefore possible that immigrant cancer patients with mental health problems suffer from triple stigmatisation: being a member of an ethnic minority, having cancer and suffering mentally; this may result in a reduced use of psychosocial services [7]. However, little is known about help-seeking behaviour of immigrants with cancer, especially in Europe.

In Germany, 16.3 million inhabitants are immigrants, 20% of the entire population [8]. However, research on immigrants' health and their healthcare use is still sparse. Results from other countries cannot be generalised

directly to the situation in Germany as the healthcare system and the immigrant population differ. Many immigrants in Germany are ethnic Germans coming from the Russian Federation. They are Germans by nationality, but a considerable number of them have only a basic command of the German language, and often their cultural background is closer to Russian than to German traditions [9,10]. The predominant countries of origin among people with a non-German nationality are Turkey, Yugoslavia and Italy [11]. The countries where most people migrate from to Germany are Poland, Romania and Bulgaria [12], that is, the majority of immigrants originated from Europe. We can assume that their cultural traditions and experiences with healthcare services are more similar to those who were born in Germany than to people who were born and raised in non-European countries.

The National Cancer Plan of Germany declares that each cancer patient is entitled to receive psychosocial support and disease-related information [13]. Psychosocial and informational services should be tailored to the needs of immigrants, as they may have specific needs regarding, for example, the involvement of family, the disclosure of information, spiritual support, translators and knowledge about the healthcare system [14–19].

In Germany, the main psychosocial services for cancer patients are consultation–liaison services at the hospital and counselling centres in outpatient settings. These services offer information, practical support and counselling in acute crises, both for patients and relatives, free of charge. Key informational services in Germany are provided free of charge via telephone, email, web pages and brochures.

Methods

Study design

The study population was derived from the multi-regional population-based CAESAR study. Cancer survivors were approached via regional epidemiological cancer registries from six German federal states (Schleswig-Holstein, Saarland, North Rhine-Westphalia, Rhineland-Palatinate, Hamburg and Bremen). Inclusion criteria were a diagnosis of breast, colon or prostate cancer between 1994 and 2004 and age at diagnosis between 20 and 75 years. They ($n=15\ 195$) received a mailed questionnaire together with a stamped envelope. If the survivor did not reply, up to two reminders were sent. Written informed consent was obtained from all participants, and ethical approval was given by all relevant institutions [20].

Assessment

Immigration status and demographic information were collected as suggested by Schenk for epidemiological studies [21]. Participants indicated their nationality, whether

German was their mother tongue, whether they were born in Germany (and if not, the year of immigration) and where their parents were born.

The use of psychosocial services was assessed by asking whether participants had talked to a psycho-oncologist in the hospital or in a community-based service centre since their cancer diagnosis, and whether they had visited a patient support group. The use of informational services was defined as having used any informational service via telephone, internet or brochures. We further assessed age, sex, education, income and community size. Information on the date of diagnosis, tumour site and stage of disease was obtained from the cancer registries.

Data analysis

According to the German census, a person is classified as an immigrant if he or she (a) immigrated to Germany after 1955, or (b) was born in Germany but of non-German nationality, or (c) was born in Germany with German nationality, but both parents were not born in Germany [8].

Participants' nationality as the parents' birthplace were grouped into Germany, Europe EU-15 (Member States of the European Union as of 2004), Europe not EU-15, Africa, Asia and America/Australia/Oceania.

A combined variable was created containing the parents' birthplace: both parents born in Germany, both in Europe EU-15, both in Europe but not EU-15, both outside Europe, one in Germany and the other in another country, both not in Germany and from different areas ('mixed, Germany & other'). If only one parent's birthplace was known, it was treated as if both parents came from this place.

Equivalence income was defined taking into account the number and age of people in the household [22].

Cultural differences in the use of these services were evaluated by logistic regressions comparing immigrants versus non-immigrants, adjusting for age, sex, income, education, size of community and stage of disease. Potential effect modifications were assessed prior to the regression analyses via Mantel–Haenszel tests. All statistical tests were done using STATA (STATA Corp, College Station, TX).

Results

Sample

Of all contacted survivors ($n=15\ 195$), a total of 6143 (40%) completed the questionnaire. Of the survivors, 7403 did not reply; 827 returned the questionnaire uncompleted or expressed their unwillingness to participate. In 155 cases, the current address could not be traced, 617 were deceased and 50 were excluded.

Compared with non-participants, participants were on average one year younger at the time of diagnosis and were more frequently men.

At the time of survey, participants were 34 to 89 years old (69 years on average). Cancer diagnosis dated 5 to 16 years back (8 years on average). Participants who had breast cancer are 44%, 20% had colon cancer and 36% had prostate cancer (Table 1).

According to the definition of the German census, 383 were immigrants and 5666 were non-immigrants. Immigrants were on average younger, better educated, worse paid, lived in bigger communities and were more frequently women than non-immigrants.

Use of psychosocial services

Hospital-based psychological services were used by 9% of non-immigrants and 10% of immigrants, community services by 3% and patient support groups by 6% in both groups. There was no evidence of an association between immigration status as defined by the census and the use of psychosocial services (Table 2).

The use of hospital services seemed to have decreased among survivors whose parents were born outside of Europe; however, this was not statistically significant (OR_{adj} 0.4, 95% CI 0.1; 1.2). The same was true for the use of community services (OR_{adj} 0.2, 95% CI 0.0; 1.8) and patient support groups (OR_{adj} 0.3, 95% CI 0.1; 1.2).

Use of informational services

Telephone information services were used by 3% of both non-immigrants and immigrants. Web-based information services were utilised by 15% and 16%, respectively, and printed information (brochures, leaflets, etc.) by 32% and 33%, respectively. There was no evidence for an effect of immigration status on the use of informational services (Table 3).

If the parents were born outside Europe, survivors used information from the Internet less frequently (OR_{adj} 0.4, 95% CI 0.2; 0.8). There was, however, no evidence for an effect of parents' birthplace on information searches via telephone and printed information. Web-based information

Table 1. Sample characteristics by immigration status

	N (%)	Non-immigrants		Immigrants		P*
		5666 (92.2%)		383 (6.2%)		
		N	Percent	N	Percent	
Sex						
Female		2927	51.7	229	59.8	0.002
Male		2739	48.3	154	40.2	
Age						
<55 years		464	8.2	53	13.8	<0.001
55–74 years		3569	63.0	256	66.8	
75+ years		1632	28.8	74	19.3	
Unknown		1	0.0	0	0.0	
Education						
<10 years		3002	53.0	152	39.7	<0.001
10+ years		2555	45.1	220	57.4	
Unknown		109	1.9	11	2.9	
Income						
Euro <500		207	3.7	36	9.4	<0.001
Euro 500–999		1059	18.7	109	28.5	
Euro 1000 to 1499		1410	24.9	92	24.0	
Euro >1500		2526	44.6	120	31.3	
Unknown		464	8.2	26	6.8	
Community size						
<10 000 inhabitants		1735	30.6	97	25.3	0.03
10 000 to 100 000		1935	34.2	125	32.6	
>100 000		1846	32.6	151	39.4	
Unknown		150	2.6	10	2.6	
Tumour site						
Breast		2456	43.3	198	51.7	<0.001
Colon		1131	20.0	82	21.4	
Prostate		2079	36.7	103	26.9	
Stage of disease						
Local		3242	57.2	223	58.2	0.52
Regional		1476	26.1	106	27.7	
Distant		114	2.0	5	1.3	
Unknown		834	14.7	49	12.8	

Immigration status unknown in $n=94$ (1.6%) cases.

*Chi-square tests.

Table 2. Use of psychosocial services by immigration biography, adjusted for sex, age, education, community size and stage of disease

	Total N	Hospital services				Community services				Patient support groups			
		N	%	OR	95%CI	N	%	OR	95%CI	N	%	OR	95%CI
Immigration background													
Non-immigrants	<i>5666</i>	501	9	1		168	3	1		357	6	1	
Immigrants	383	39	10	1.0	(0.7; 1.4)	11	3	0.7	(0.4; 1.3)	23	6	0.8	(0.5; 1.3)
Unknown	94	7	7	0.9	(0.4; 2.0)	4	4	1.5	(0.5; 4.2)	4	4	0.7	(0.3; 2.0)
Birthplace													
Germany	<i>5715</i>	509	9	1		172	3	1		362	6	1	
Not Germany	300	26	9	0.9	(0.6; 1.3)	7	2	0.6	(0.3; 1.3)	16	5	0.7	(0.4; 1.3)
Unknown	128	12	9	1.2	(0.7; 2.3)	4	3	1.1	(0.4; 3.2)	6	5	0.8	(0.4; 1.9)
Mother tongue													
German	<i>5907</i>	526	9	1.0		174	3	1		372	6	1	
Not German	142	14	10	0.8	(0.5; 1.5)	5	4	0.7	(0.3; 1.7)	8	6	0.7	(0.3; 1.5)
Unknown	94	7	7	0.9	(0.4; 1.9)	4	4	1.4	(0.5; 4.0)	4	4	0.7	(0.3; 2.0)
Birthplace of mother													
Germany	<i>5786</i>	516	9	1		169	3	1		364	6	1	
Europe, EU-15	76	6	8	0.8	(0.3; 1.8)	4	5	1.5	(0.5; 4.2)	6	8	1.1	(0.5; 2.6)
Europe, not EU-15	99	13	13	1.3	(0.7; 2.4)	5	5	1.4	(0.5; 3.5)	6	6	0.8	(0.4; 2.0)
Not Europe	72	5	7	0.5	(0.2; 1.3)	1	1	0.2	(0.0; 1.7)	3	4	0.5	(0.1; 1.5)
Unknown	110	7	6	0.7	(0.3; 1.6)	4	4	1.3	(0.4; 3.5)	5	5	0.8	(0.3; 1.9)
Birthplace of father													
Germany	<i>5496</i>	487	9	1		161	3	1		362	7	1	
Europe, EU-15	90	8	9	0.9	(0.4; 1.9)	3	3	1.0	(0.3; 3.1)	6	7	0.9	(0.4; 2.1)
Europe, not EU-15	99	12	12	1.2	(0.7; 2.3)	6	6	1.5	(0.6; 3.7)	3	3	0.4	(0.1; 1.2)
Not Europe	76	5	7	0.5	(0.2; 1.3)	1	1	0.2	(0.0; 1.7)	3	4	0.4	(0.1; 1.4)
Unknown	382	35	9	1.1	(0.7; 1.5)	12	3	1.2	(0.6; 2.2)	10	3	0.4	(0.2; 0.7)
Birthplace of parents													
Both Germany	<i>5739</i>	508	9	1		166	3	1		361	6	1	
Both Europe EU-15	47	4	9	0.8	(0.3; 2.3)	2	4	1.1	(0.2; 4.8)	4	9	1.2	(0.4; 3.5)
Both Europe, not EU-15	74	9	12	1.2	(0.6; 2.5)	5	7	1.9	(0.7; 4.9)	2	3	0.4	(0.1; 1.5)
Both not Europe	74	4	5	0.4	(0.1; 1.2)	1	1	0.2	(0.0; 1.8)	2	3	0.3	(0.1; 1.2)
Mixed, Germany & others	128	15	12	1.2	(0.7; 2.0)	5	4	1.1	(0.4; 2.7)	11	9	1.2	(0.6; 2.3)
Both unknown	105	7	7	0.8	(0.4; 1.7)	4	4	1.3	(0.5; 3.7)	4	4	0.6	(0.2; 1.7)

Values in italics indicate the total number of participants.

EU-15, European Union member states as of 2004; OR, odds ratio, CI, confidence interval; N, number.

(OR_{adj} 0.7, 95% CI 0.5; 0.9) was less frequently used when the participant was born outside of Germany.

Discussion

This study aimed to assess whether immigrant and non-immigrant cancer survivors differ in their use of psychosocial and informational services. Although this was a large population-based study, investigating this question was not easy because it turned out that (a) the percentage of survivors having used such services in general was small (except for the use of brochures) and (b) the percentage of participating immigrants was relatively low. According to the 2011 German census, 20% of the population in Germany are immigrants. In our study, in contrast, only 6% had an immigration background. One could argue that this was due to the advanced age of this sample, typical for cancer survivors, whereas the immigrant population usually is younger. However, when we stratified by age, we found that in almost every age group immigrants are underrepresented in the CAESAR sample. There are three possible explanations for this: either immigrants returned

the questionnaire less often, for example, because of language problems or perhaps doctors notify the cancer registry less frequently if the patient is an immigrant or cancer is less common among immigrants than in the general population. This could be due to diverse health behaviours [23] or due to the fact that migration from one country to another requires good health per se [24]. Immigrants more often lived in big cities where community services for cancer patients are more frequent [25]. Therefore, these factors were taken into account in the regression models.

One aspect that we would like to highlight is that 'migration status' as defined by the German census was not at all related to service use in CAESAR, and it is likely that this will not be informative in future studies either. Immigrants from European and especially from EU countries are obviously similar to the native population in their healthcare use. European countries are the major source of immigration to Germany [11]. Based on the fact that having a non-European background (indicated by the parents' birthplace) was related to poor service use, we believe that the cultural background may influence service use more than the fact that someone has changed the country of residence.

Table 3. Use of informational services by immigration biography, adjusted for sex, age, education, community size and stage of disease

	Total N	Information via phone				Information via web				Information via brochures			
		N	%	OR	95%CI	N	%	OR	95%CI	N	%	OR	95%CI
Immigration background													
Non-immigrants	5666	152	3	1		846	15	1		1809	32	1	
Immigrants	383	10	3	0.7	(0.4; 1.4)	62	16	0.8	(0.6; 1.1)	126	33	0.9	(0.7; 1.1)
Unknown	94	0	0	--		9	10	0.7	(0.3; 1.4)	30	32	1.1	(0.7; 1.7)
Birthplace													
Germany	5715	154	3	1		868	15	1		1844	32	1	
Not Germany	300	7	2	0.7	(0.3; 1.5)	39	13	0.7	(0.5; 0.9)	86	29	0.7	(0.6; 1.0)
Unknown	128	1	1	0.3	(0.0; 2.2)	10	8	0.6	(0.3; 1.1)	35	27	0.9	(0.6; 1.4)
Mother tongue													
German	5907	158	3	1		883	15	1		1888	32	1	
Not German	142	4	3	0.7	(0.2; 1.9)	23	16	0.7	(0.4; 1.1)	47	33	0.8	(0.5; 1.1)
Unknown	94	0	0	--		11	12	0.8	(0.4; 1.6)	30	32	1.1	(0.7; 1.7)
Birthplace of mother													
Germany	5786	152	3	1		861	15	1		1841	32	1	
Europe, EU-15	76	2	3	0.8	(0.2; 3.5)	15	20	1.2	(0.7; 2.2)	28	37	1.1	(0.7; 1.7)
Europe, not EU-15	99	4	4	1.3	(0.5; 3.6)	20	20	1.2	(0.7; 2.0)	38	38	1.1	(0.7; 1.7)
Not Europe	72	4	6	1.4	(0.5; 3.9)	10	14	0.5	(0.2; 0.9)	25	35	0.8	(0.5; 1.4)
Unknown	110	0	0	--		11	10	0.7	(0.4; 1.3)	33	30	1.0	(0.6; 1.5)
Birthplace of father													
Germany	5496	146	3	1		819	15	1		1765	32	1	
Europe, EU-15	90	0	0	--		13	14	0.8	(0.4; 1.5)	28	31	0.8	(0.5; 1.3)
Europe, not EU-15	99	4	4	1.2	(0.4; 3.5)	21	21	1.2	(0.7; 2.0)	34	34	0.9	(0.6; 1.5)
Not Europe	76	3	4	0.9	(0.3; 3.0)	11	14	0.5	(0.3; 1.0)	26	34	0.8	(0.5; 1.4)
Unknown	382	9	2	0.9	(0.5; 1.8)	53	14	0.9	(0.7; 1.3)	112	29	0.9	(0.7; 1.1)
Birthplace of parents													
Both Germany	5739	151	3	1		847	15	1		1823	32	1	
Both Europe EU-15	47	0	0	--		8	17	0.9	(0.4; 2.1)	18	38	1.1	(0.6; 2.0)
Both Europe, not EU-15	74	4	5	1.8	(0.6; 5.1)	15	20	1.2	(0.6; 2.2)	28	38	1.1	(0.7; 1.9)
Both not Europe	74	2	3	0.6	(0.2; 2.7)	9	12	0.4	(0.2; 0.8)	23	31	0.7	(0.4; 1.2)
Mixed, Germany & other	128	5	4	1.2	(0.5; 3.1)	27	21	1.3	(0.8; 2.1)	42	33	0.9	(0.6; 1.3)
Both unknown	105	0	0	--		11	10	0.7	(0.8; 1.4)	31	30	0.9	(0.6; 1.5)

Values in italics indicate the total number of participants.

Significant associations are marked with bold printing.

EU-15, European Union member states as of 2004; OR, odds ratio; CI, confidence interval; N, number.

Another point that may warrant further research is that this effect diminished when one parent was German. This underlines the notion that acculturation may play a role in service use. Acculturation is usually understood as a process through which individuals acquire the behaviours, attitudes and values prevalent within the society they now live in [26]. It is a core concept of understanding immigrants' health and may help explain our finding that cancer survivors whose parents were bi-national (one from Germany, one from another country) had fewer obstacles in using informational services.

Regarding the effect of language, all CAESAR participants are likely to have a good command of German language as they were all able to complete a comprehensive questionnaire. Although other studies have shown that the ability to understand the language of the ethnic majority was not related to immigrants' use of patient support groups [27], and likewise not with their mental health [28], we cannot rule out the effect of language problems as potential barriers to seeking psychosocial and informational support. Patients from non-Western cultures seem to

have different informational needs [29]. If survivors with a poor command of German language were less likely to participate in the CAESAR study, which is likely, and if they also tend to use services less often, which is also likely, the relationship between immigration status and service use found in our study is an underestimation of the true association.

There are some other limitations in our study. Although mental health was measured in our study, it was not possible to find out how the patients felt throughout the disease trajectory, which would have been necessary to know, as service use was assessed cumulatively for the entire period, from diagnosis until the time of survey. Some studies suggest that immigrants have worse mental health than non-immigrants [30]; however, others have found no differences [31]. Our study did not assess the reasons why participants used these services nor the frequency of visits, which limits conclusions about the extent to which mental health problems played a role in the initial contact or whether they were adequately treated. It should be noted, though, that psychosocial services are not only provided for emotional problems, but also if social problems occur.

Another shortcoming is that survivors only reported their use of hospital and community services, whereas consultations with psychiatrists or psychotherapists in the outpatient setting were not assessed. Although we know from other studies that cancer patients in Germany are rarely treated in psychotherapeutic practices [32], future studies should investigate the use of these services as well.

Finally, the low prevalence of psychosocial service used in the overall sample was unexpected. To date, there are no representative data for Germany to which we could compare our results with, neither for survivors nor for patients. A single-centre study from the University Hospital in Leipzig reported service use in 11% of patients with active cancer [33], higher than in our study. One possible explanation for this discrepancy is that the Leipzig study was performed in a large city with well-established service structures, whereas CAESAR included patients from different areas including small communities with poor availability of services.

In conclusion, this study can help create hypotheses and tailor methods for future research on immigrant cancer patients' service use. Lessons learnt are (a) differences in the use of psychosocial and informational services between immigrants with good language capacities and non-immigrants are generally small, (b) the largest differences in service use were seen in the use of web-based information, (c) parental birth place may be more important for

service use than the census-defined 'migrant status' and (d) if the cultural background of the receiving country differs strongly from the country of origin, this may hinder help seeking.

Discrimination against people with mental health problems is widespread throughout the world, but especially common in resource-poor countries [6,34]. There, mental health services are not only especially scarce, but they are also particularly unequally distributed [6]. In people emigrating from such areas to high-income countries, this experience may lead to an attitude that psychosocial services are just not an option for them. They may also have different ideas on where to seek help, for example, in asking ghosts [30] or talking to religious leaders [35,36]. It may therefore be worthwhile to focus on those non-European cancer patient and survivor groups in future studies investigating immigrant service use in Europe.

Clinicians should try to identify subgroups whose needs for culturally appropriate services and/or more intensive outreach efforts may have not yet been met, so that all cancer patients have equal access to services, as it is the aim of the National Cancer Plan.

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