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Original Research

The gap between rare and common cancers still exists: Results from a population-based study in the Netherlands

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Abstract ***Introduction:*** Epidemiological discrepancies exist between rare and common cancers. The aim of this population-based study was to compare rare versus common adult solid cancers in the Netherlands, by providing incidence, prevalence and survival rates, evaluating trends in survival and comparing individual entities within domains and families.
Methods: All adult patients with malignant solid cancers in the Netherlands between 1995 and 2019 were identified from the Netherlands Cancer Registry. Data on patient, tumour and treatment characteristics were collected, and relative survival and survival trends were analysed.
Results: A total of 170,628 patients with rare adult solid cancers and 806,023 patients with common adult solid cancers were included. Rare cancers accounted for 18% of all cancer diagnoses (mean incidence), and 15% of the total ten-year cancer prevalence during 2010–2019. Overall 5-year survival was worse for rare cancers than for common cancers (52.0% versus 68.7%). Between 1995–1999 and 2015–2019, 5-year survival rates for rare cancers increased to a lesser extent (from 46.2% to 52.6%, i.e. 6.4%) than for common cancers (56.9%

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–70.1%, i.e. 13.2%), and for most rare cancer domains compared to common cancer domains. The majority of rare cancer entities did not show an improvement in 5-year survival. Differences for individual entities between domains and families were found.
Conclusion: Differences in survival between rare and common cancers indicate major challenges for rare cancer care and emphasise that improvement is highly needed. Observed inequalities need to be overcome by investing in early diagnosis, novel therapies, scientific research and in establishing centres of expertise.

1. Introduction

In the Netherlands, the incidence of cancer has increased over the past 30 years to an annual number of 124,000 new cases in 2021 [1]. Approximately 25,000 of these new cases are identified as rare cancers (RCs) [2], and defined as those with an incidence of <6/100,000 people per year, according to the Surveillance of Rare Cancers in Europe (RARECARE) project [3].

RCs pose challenges within health care for both clinicians and patients [4]. That is, knowledge and expertise are not widely available, and information regarding RC is limited, due to the lack of scientific studies and the small number of patients available for inclusion in these studies. Limited knowledge and expertise may lead to misdiagnosis and delay in diagnosis. Further, the lack of access for patients to appropriate therapies may be a consequence of deficient concentration in healthcare and expertise [5]. Consequently, disease outcomes for patients with RC are worse than for patients with common cancer (CC) [3,6].

Nowadays, more than 5.0 million people with a diagnosis of RC are living in the European Union (EU), as reported by RARECARE and RARECARENet [3,7]. The RARECARENet project showed that RCs represent 24% of all cancers diagnosed in the EU in 2000–2007, and that the 5-year relative survival for RCs is 49% compared to 63% for CCs [6]. Because of these high incidence rates and adverse outcomes, priority should be given to improving such outcomes and healthcare in general for patients with RC.

In the European Reference Network called EURACAN, established in 2017, adult solid RC entities were grouped into ten 'domains'. In 2020, the Joint Action on Rare Cancers (JARC) published a consensus article in which RC entities were partitioned into RC 'families' [8], comparable to the EURACAN domains. Yet, while the EURACAN domains correspond to the RARECARENet list, in which RCs are defined upon Tier 2 entities (i.e. relevant for clinical decision making and research), JARC families are defined upon Tier 1 entities[1] (i.e. relevant for health care organisation). Potential implications of the adjusted partitioning and whether there will be widespread adherence to the modification still has to be explored. A comparison of RC entities as grouped within the EURACAN domains and within the JARC families is needed as the first step.

So far, no overview has been given over the past 25 years, regarding epidemiological measurements (incidence and prevalence) and outcomes (survival), between adult solid RCs and CCs in the Netherlands, and a comparison between entities within domains and families has not been made. Therefore, the aim of this study was to present population-based data on the incidence, prevalence and survival for adult solid RC versus CC entities in the Netherlands from 2010 to 2019, to evaluate trends in survival from 1995–1999 to 2015–2019 and to compare individual entities within domains and families.

2. Methods

2.1. Study population and quality control

Patients in this population-based study were selected from the Netherlands Cancer Registry (NCR). The NCR is a nationwide registry including all newly diagnosed malignant cancer cases within the Netherlands (i.e. 17.4 million inhabitants) [9]. Specially trained registrars routinely collect patient information from medical records in all Dutch hospitals. Data quality is assured due to thorough training of the registrars and systematic consistency checks [10]. The NCR registers topography and morphology codes according to the International Classification of Diseases for Oncology version 3 (ICD-O-3) [11]. The International Agency for Research on Cancer multiple primary coding rules have been applied for reporting data on cancer incidence and survival [12]. Cancer stage is based on the tumour-node-metastasis (TNM) Classification of Malignant Tumours [13–15] and is converted to the Extent of Disease (EoD) [16] classification, distinguishing localised (TNM stage I-II), regional (TNM stage III) and metastatic disease (TNM stage IV).

For the current study, all Dutch patients aged ≥18 years diagnosed with solid malignant tumours during

[1] ICD-O-3 entities are grouped into categories (Tier 2) of cancers, considered to require similar clinical management and research. These categories are further grouped into general categories of tumours (Tier 1), considered to involve the same clinical expertise and patient referral structure.

Table 1
Patient, tumour and treatment characteristics of patients aged ≥18 years, diagnosed with rare and common solid cancer entities in the Netherlands between 2010 and 2019.

	Domains (EURACAN)[a]		Families (JARC)[a]	
	Rare cancers (n = 170,628)	Common cancers (n = 806,023)	Rare cancers (n = 118,504)	Common cancers (n = 859,002)
Age at diagnosis (median years, IQR)	64 (55–75)	68 (61–77)	65 (54–75)	69 (60–77)
Age at diagnosis (%)				
18–34 years	5.9	0.9	7.1	1.1
35–49 years	11.7	7.0	12.0	7.3
50–64 years	28.5	27.0	28.6	27.0
65–79 years	39.3	46.3	38.0	46.1
>80 years	14.5	18.8	14.3	18.3
Gender (%)				
Male	48.4	52.6	58.4	51.0
Female	51.7	47.4	41.6	49.1
Extent of disease (%)				
Localised	45.2	55.0	45.2	54.5
Regional	17.7	16.0	14.0	16.6
Metastatic	22.7	20.4	21.2	20.8
Unknown	14.4	8.5	19.6	8.1
Treatment[b] (%)				
Surgery (+/− PPT)	58.7	62.2	60.6	61.7
Systemic[c] (+/− RT)	14.9	16.3	12.1	16.5
RT	9.0	4.7	10.5	4.7
Other	2.3	1.8	2.6	1.8
None	15.2	15.1	14.2	15.2
Hospital type[d] (%)				
Academic[e]	41.4	11.4	44.3	12.8
Top clinical[f]	39.5	52.6	37.9	52.0
General	19.0	34.8	17.6	34.0
Other	0.2	1.3	0.2	1.2

IQR, interquartile range; PPT, pretreatment or post-treatment; RT, radiation therapy.
[a] All P < 0.001. Chi-square test.
[b] In case of multiple treatments, treatment is presented in the order of surgery (+/− pre- or posttreatment), systemic therapy (+/− radiotherapy), radiotherapy and other.
[c] Systemic treatment includes chemotherapy, targeted therapy, hormonal therapy and immune therapy.
[d] Hospital type has been classified according to the Dutch health care system and cancer care is given in all hospitals.
[e] Including all eight academic teaching hospitals, affiliated to universities, and the Antoni van Leeuwenhoek hospital (specialised in oncology).
[f] Top clinical hospitals are non-academic teaching hospitals that provide complex care in addition to basic care.

2010–2019 were selected from the NCR to obtain incidence, prevalence and survival rates. A 10-year period was chosen to account for fluctuations in incidence over time. In addition, patients diagnosed during 1995–2019 (25-year period) were selected to evaluate survival trends (1995–1999 versus 2015–2019). Population data and cancer mortality data (i.e. date of death) were accessed by linkage to the Dutch Municipal Personal Records Database.

Systematic data checks were routinely performed, and standard data quality indicators (e.g. percentage of microscopically verified cases, percentage of topography codes not otherwise specified (NOS)) were calculated to assess the quality of the NCR data (Supplementary Table 1).

2.2. Cancer list, definition, and classification

In this study, Tier 1 and Tier 2 cancer entities are presented and based on the ICD-O-3 topography and morphology codes in concordance with the updated version (February 2019) of the RARECARENet cancer list [17]. Furthermore, RCs are defined as those Tier 2 entities with an annual incidence rate of <6/100.000 according to the RARECARE definition [18], and this definition has been applied to the Dutch situation. The heterogeneous group of adult solid RC and CC entities are primarily presented according to the EURACAN domains [19]. Breast cancer has been added as an additional domain due to the high incidence of breast cancer in the Netherlands [20], in accordance with the national organisation of cancer care.

In addition to the EURACAN domains, entities within the JARC families are presented as a comparison. Within the JARC families, RCs are defined as those Tier 1 entities with an annual incidence rate of <6/100,000 according to the JARC partitioning [8]. In Appendix A, all estimates of incidence, prevalence and survival for Tier 1 and Tier 2 entities are shown.

2.3. Statistical analyses

For this study, patient, tumour and treatment characteristics were described, and differences in characteristics, both within domains and families, were tested using Chi-square tests. Incidence, prevalence and survival (trends) were calculated for both domains and families. Incidence rates of RCs and CCs were calculated as the annual number of new cases arising in 2010–2019, divided by the total person-years in the general Dutch population (both male and female). Further, the number of prevalent cases in 2019 and the 10-year prevalence per 100,000 at the index date of 1st January 2020 were calculated. Relative 5-year survival was calculated using the Ederer II method [21]. To establish differences in relative survival (RS) by domain for RCs and CCs and to evaluate trends in survival by domain, family and for RC entities, a generalised linear model adjusted for age, sex and year of diagnosis was used. The model assumed that the observed number of deaths were Poisson-distributed and produced the excess risks of death [22]. Trends in survival were evaluated for the Tier 2 RC entities whose survival rates changed significantly over time and were evaluated by log-rank tests. Differences were considered statistically significant at $P < 0.05$. All statistical analyses were performed using STATA (version 14.2, Stator LP, College Station, TX).

3. Results

3.1. Sample characteristics

Between 2010 and 2019, 170,628 newly diagnosed patients with RC and 806,023 with CC (domain categorisation) were registered by the NCR. Patient, tumour and treatment characteristics by domain and family are presented in Table 1.

Compared to patients with CC, patients with RC (domain categorisation) were more often diagnosed at a younger age (median 64 years versus 68 years; $P < 0.001$). Most cancers in patients up to 34 years were RCs, and CCs became increasingly prominent in patients aged 35 and older. Further, RC patients were less often diagnosed with a localised EoD (45.2 versus 55.0%; $P < 0.001$), but more often with an unknown EoD (14.4 versus 8.5%; $P < 0.001$) than CC patients. Patients with RC were also more often treated in an academic hospital (41.4% versus 11.4%; $P < 0.001$), and received more often radiotherapy (9.0% versus 4.7%; $P < 0.001$) than patients with CC. Within the families, patients with RC were more often

Table 2
Estimates of incidence, prevalence and survival for rare and common adult solid cancers in the Netherlands by domain and family, 2010–2019.

		Entities	Crude incidence per 100,000 people per year	SE	10-year prevalence per 100,000	SE	5-year relative survival (%, 95% CI)[a]	SE
Digestive cancers	Domain	RC	16.1	0.6	46.2	1.0	24.0 (23.4–24.6)	0.3
		CC	115.2	2.2	553.7	5.8	51.7 (51.5–52.0)	0.1
	Family	RC	7.1	0.2	22.3	0.4	27.6 (26.7–28.6)	0.5
		CC	124.3	2.4	578.3	6.4	49.5 (49.3–49.8)	0.1
Thoracic cancers	Domain	RC	6.9	0.4	11.9	0.3	13.7 (13.0–14.4)	0.4
		CC	72.2	1.6	181.6	4.7	20.6 (20.3–20.8)	0.1
	Family	RC	3.7	0.0	6.9	0.2	12.1 (11.1–13.0)	0.5
		CC	75.3	1.2	187.0	4.8	20.4 (20.1–20.6)	0.1
Breast cancer	Domain	RC	4.2	0.1	34.8	0.1	92.8 (91.7–94.0)	0.6
		CC	81.2	0.6	678.3	2.8	90.2 (89.9–90.4)	0.1
	Family	RC	–	–	–	–	-	–
		CC	85.4	0.6	713.0	2.9	90.3 (90.1–90.5)	0.1
Female genital cancers	Domain	RC	16.8	0.3	92.5	1.1	53.8 (53.1–54.5)	0.4
		CC	9.7	0.1	75.7	0.3	85.9 (85.2–86.7)	0.4
	Family	RC	2.9	0.1	19.2	0.2	72.8 (71.0–74.5)	0.9
		CC	23.6	0.2	127.3	0.8	64.8 (64.2–65.3)	0.3
Male genital and urogenital cancers	Domain	RC	9.0	0.2	63.1	0.4	72.6 (71.8–73.5)	0.4
		CC	99.2	1.8	698.3	5.6	80.3 (80.0–80.6)	0.2
	Family	RC	8.4	0.2	61.1	0.4	75.4 (74.5–76.2)	0.4
		CC	100.0	1.9	701.3	5.6	80.0 (79.7–80.3)	0.2
Skin cancers and non-cutaneous melanoma	Domain	RC	2.6	0.0	17.8	0.1	76.8 (75.0–78.6)	0.9
		CC	98.1	6.2	771.0	9.2	93.4 (93.1–93.7)	0.2
	Family	RC	2.6	0.0	18.0	0.1	76.9 (75.0–78.7)	0.9
		CC	98.2	6.3	772.2	9.3	93.4 (93.1–93.7)	0.2
All cancers	Domain	RC	100.7	1.2	516.5	5.2	52.0 (51.7–52.3)	0.1
		CC	475.6	10.0	2958.6	27.7	68.7 (68.6–68.9)	0.1
	Family	RC	69.9	1.0	378.4	3.6	55.7 (55.3–56.0)	0.2
		CC	506.8	10.3	3079.1	29.2	67.2 (67.1–67.3)	0.1

SE, standard error; CI, confidence interval; RC, rare cancer; CC, common cancer.
[a] Bold numbers indicate statistical significance ($P < 0.05$).

male and diagnosed with an unknown EoD than patients with RC within the domains.

3.2. Incidence

In Table 2, incidence, prevalence and survival rates of adult solid RCs and CCs by domain and family are shown. The crude incidence of all RCs (domain categorisation) was 100.7 patients per 100,000 per year (SE 1.2), compared with 475.6 patients per 100,000 per year (SE 10.0) for all CCs. Overall, RCs accounted for 18% of all adult solid cancers diagnosed in the Netherlands during 2010–2019. RCs constituted 63% of incident female genital cancers and 12% of incident digestive cancers. RCs were <10% of incident cancers within other domains (in those domains in which CCs were present as well). Within the families, RCs accounted for 12% of all cancer diagnoses. In addition, RC entities within the families comprised 11% of incident female genital cancers and <10% in all other families.

3.3. Prevalence

The 10-year prevalence of all adult solid RCs (domain categorisation) was 516.5 patients per 100,000 (SE 5.2), compared with 2958.6 patients per 100,000 (SE 27.7) for all adult solid CCs. In total, RCs were 15% of the total cancer prevalence in the Netherlands during 2010–2019. The prevalence estimates of RCs were higher than those of CCs for the female genital tract (92.5 per 100.000 versus 75.7 per 100.000). The prevalence rates of RCs were lower than those of CCs for all other domains (in those domains in which CCs were present as well). Within the families, RC entities were 12% of the total cancer prevalence (Table 2).

3.4. Relative survival

The 5-year RS of all adult solid RCs (domain categorisation) was 52.0% (95% CI 51.7–52.3), compared with 68.7% (95% CI 68.6–68.9) for all adult solid CCs ($P < 0.001$) (Table 2). Compared to patients with CC, higher survival rates were found in RC patients with breast cancer (92.8% (95% CI 91.7–94.0) versus 90.2% (95% CI 89.9–90.4)) ($P < 0.001$). The survival rates of RCs were lower than those of CCs for all other domains ($P < 0.001$). Site-specific RS differences for RCs and CCs can be found in Appendix 1 (e.g. within female genital cancers, RS for rare Tier 2 entities of epithelial tumours of corpus uteri is lower than for CC entities). Domains including RC only had a 5-year RS ranging from high (>75%), for cancers of the endocrine organs

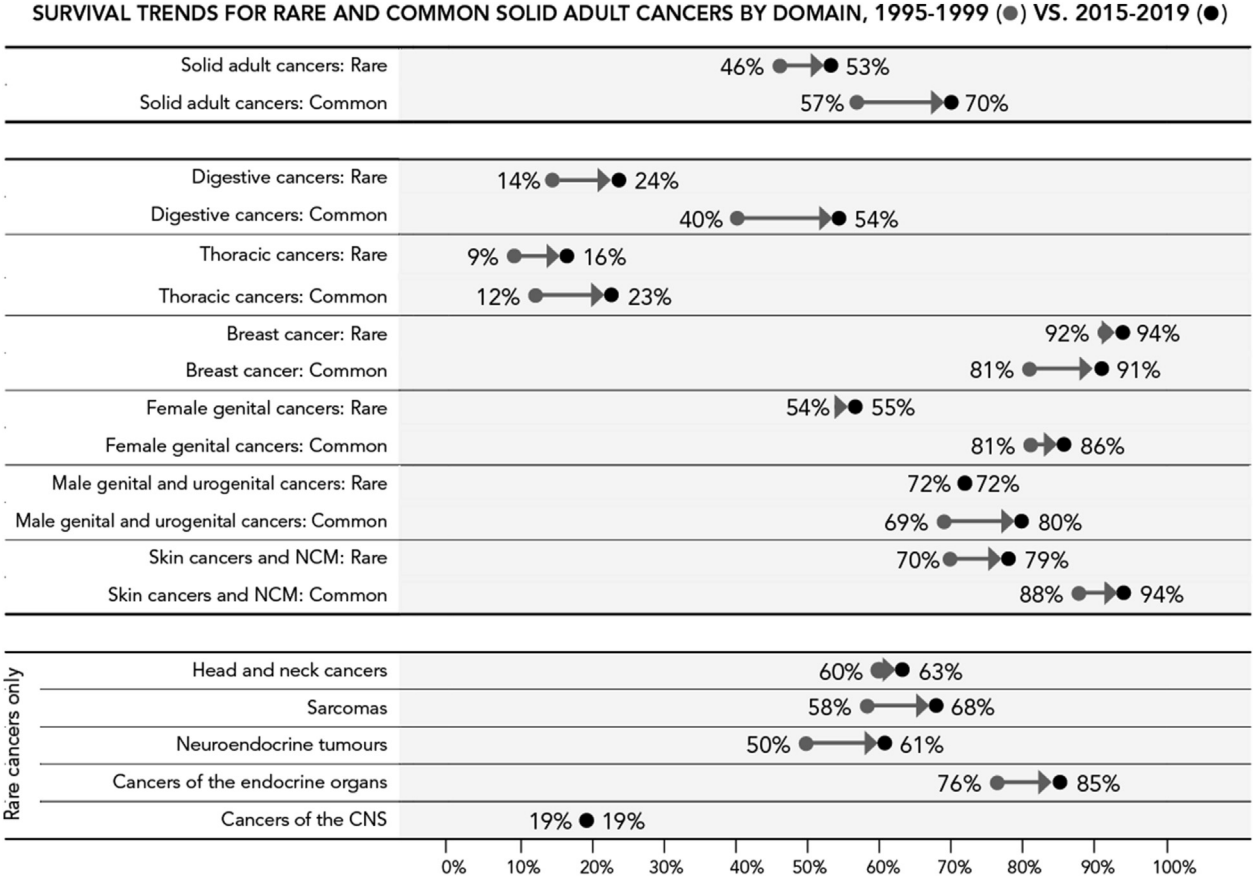

Fig. 1. **Survival trends for rare and common adult solid cancers by domain, 1995–1999.** versus 2015–2019. NCM, non-cutaneous melanoma; CNS, central nervous system.

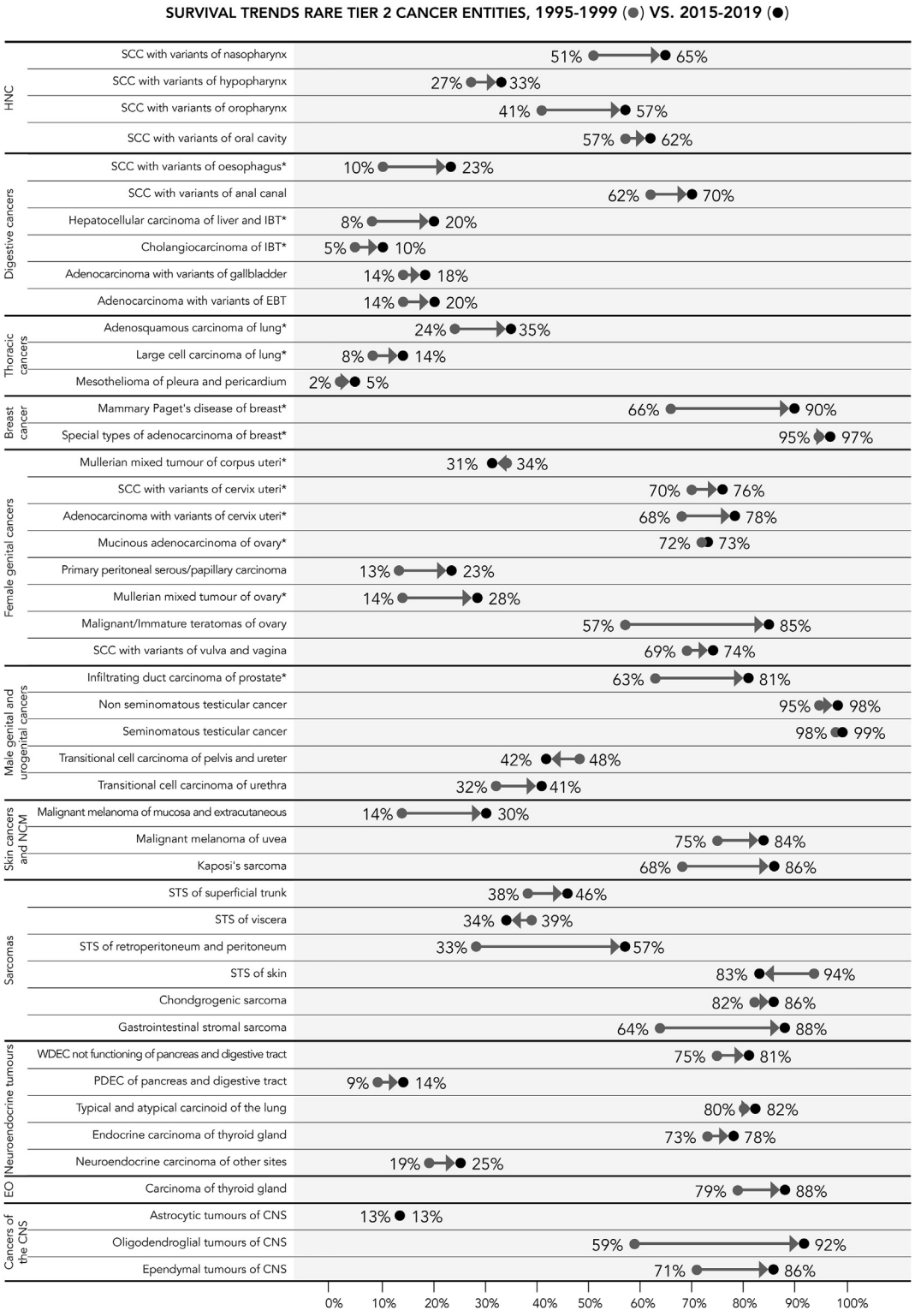

Fig. 2. **Statistically significant survival trends for rare Tier 2 cancer entities, 1995–1999.** versus 2015–2019. HNC, head and neck cancer; SCC, squamous cell carcinoma; IBT, intrahepatic bile tract; EBT, extrahepatic bile tract; NCM, non-cutaneous melanoma; STS, soft tissue sarcoma; WDEC, well differentiated endocrine carcinoma; PDEC, poorly differentiated endocrine carcinoma; EO, endocrine organs; CNS, central nervous system. Log rank test. A P-value < 0.05 was considered statistically significant. * Considered common according to the rare cancer 'families' from the Joint Action on Rare Cancers (JARC), based on the Tier 1 entities with incidence rate >6/100,000.

(84.7% (95% CI 83.6–85.8)), to intermediate (50–75%), for sarcomas (66.9% (95% CI 65.9–67.9)), cancers of head and neck (62.9% (95% CI 61.5–62.9)), and neuroendocrine tumours (60.1% (95% CI 59.1–61.1)), and low (<50%) for cancers of the central nervous system (20.0% (95% CI 19.3–20.9)) (data not shown). The 5-year RS of all RC entities within the families were higher than those within the domains, except for thoracic cancers (12.1% versus 13.7%, respectively) and breast cancer (i.e. not considered rare within the family). Comparing RC entities within the families to the domains, a major difference in 5-year RS was seen for female genital cancers (72.8% versus 53.8%, respectively).

3.5. Trends in survival

The 5-year RS of all adult solid RCs (domain categorisation) increased from 46.2% (95% CI 45.8–46.7) in 1995–1999 to 52.6% (95% CI 52.1–53.0) in 2015–2019 (i.e. 6.4%), compared to an increase from 56.9% (95% CI 56.7–57.2) in 1995–1999 to 70.1% (95% CI 69.9–70.3) in 2015–2019 (i.e. 13.2%) for CCs (Fig. 1). Smaller or no survival improvements were found for all RC domains in comparison to CC domains, except for skin cancers and non-cutaneous melanoma, in which a larger survival improvement was found for patients with RC versus CC (from 70.3% to 78.5% versus from 88.4% to 94.0%). From 1995–1999 to 2015–2019, the 5-year survival rates increased for all domains including RC only. Similar results were found for RC entities within families, although the 5-year RS rates were higher than the domains. In addition, a deterioration in 5-year RS was seen for RC entities within the family male genital and urogenital cancers (from 77.7% to 74.8%) (data not shown).

In Fig. 2, the survival trends for statistically significant Tier 2 RC entities (domain categorisation) diagnosed in 1995–1999 versus 2015–2019 are presented. Although large improvements in 5-year RS (≥20%) were seen for five entities (i.e. Mammary Paget's disease of breast, malignant/immature teratomas of ovary, soft tissue sarcoma of retroperitoneum and peritoneum, gastrointestinal stromal sarcoma, and oligodendroglial tumours of central nervous system), the improvement in 5-year RS was small (≤10%) in 63% of the RC entities. A decrease in 5-year RS was observed in four entities (i.e. Mullerian mixed tumour of corpus uteri, transitional cell carcinoma of pelvis and ureter, soft tissue sarcoma of viscera and soft tissue sarcoma of skin).

4. Discussion

In this population-based study, we have shown that adult solid RCs were 18% of the total solid cancer incidence and 15% of the total solid cancer prevalence in the Netherlands during 2010–2019. This finding on incidence is partly in line with previous studies using the RARECARE definition, demonstrating that RCs represent 24% of cancer diagnoses in Europe (period: 2000–2007), 20% of cancers in the United States (period: 2009–2013), 16–24% of cancers in Asia (period: 2011–2015) and 17% of cancers in Canada (period: 2006–2016) [6,23–25]. If haematological and childhood cancers had been included in our study, as those previous studies all did, RCs would have accounted for 21% of the total cancer incidence in the Netherlands (period: 2010–2019) (data not shown). Our finding on prevalence contrasts with previous findings from a study by Gatta *et al.* (2011), in which RCs were estimated at 24% of the total cancer prevalence in Europe [3]. However, contrary to our study, complete prevalence was used, and haematological cancers were included here as well, pushing up the prevalence rates of RC. Still, our findings on incidence and prevalence indicate that solid RCs comprise a large proportion of the cancer burden in the Netherlands.

As previously reported in studies in Europe and the United States [6,23], it has been confirmed in our study that overall 5-year survival for solid RCs was worse than for solid CCs in adults (52.0% versus 68.7%). This survival gap might be explained by differences in biological tumour behaviour and inadequacies of care or treatment for RCs, including lack of expertise, diagnostic delays, lack of adequate treatments and lack of evidence-based clinical guidelines [3,26]. A general consensus emerged that care for patients with RC should be centralised within Centres of Expertise (CoE) to ensure multidisciplinary expertise and patients' access to clinical studies [27]. It has been suggested that centralisation of care, including networking and establishing international ERNs and national CoE for all patients with RC, will improve disease outcomes for RCs [28]. Up to now, the centralisation of care for RCs is still suboptimal in Europe [6], while centralisation seems crucial to reduce the disparities between RC and CC.

Over a 25-year period, 5-year survival increased to a lesser extent for adult solid RCs (from 46.2% to 52.6%) than for adult solid CCs (from 56.9% to 70.1%), and for all RC domains compared with CC domains, except for skin cancers and non-cutaneous melanoma. Similar findings on survival improvements in RCs versus CCs were found in Europe [6], implying that investments regarding, e.g. diagnostic approaches, treatment and scientific studies, were predominantly aimed at CCs. No previous studies have assessed the survival trends by domain. The larger survival improvement for patients with RC versus CC with skin cancers and non-cutaneous melanoma can largely be explained by the survival improvement for Kaposi sarcoma (+19%) due to the more effective treatment for HIV and decline of AIDS-related Kaposi sarcoma incidence rates [29].

Regarding the survival trends for RC entities, it has been shown that improvements in survival rates were large (≥20%) for a number of RC entities, but this degree of improvement was not visible for the majority of the RC entities. Besides, only statistically significant

survival trends for RC entities have been presented here, and for more than two-thirds of the RC entities, we were unable to show significant results due to the low number of cases. These large improvements in 5-year RS can be explained by the introduction of new and effective treatment (for malignant/immature teratomas of ovary and gastrointestinal stromal sarcomas (GIST) [30,31]), improved diagnosis and centralisation of care (for GIST and soft tissue sarcoma of retroperitoneum and peritoneum [32]) and a possible reduced diagnostic delay due to improved detection and early diagnosis (for Mammary Paget's disease of breast and malignant/immature teratomas of ovary). The developments in these particular RC entities can serve as an example for other RCs, aiming at investments within diagnostics, treatment, scientific research and organisation of care.

With regard to the partitioning of adult solid RC entities, differences were found between the grouping within the EURACAN domains and within the JARC families. In our study, RCs accounted for 18% of all cancers as grouped within EURACAN domains (i.e. defined upon Tier 2 entities), while RCs correspond to 12% within the partitioning of the JARC families (i.e. defined upon Tier 1 entities). These findings are in line with the JARC consensus article [8]. Consequently, certain rare Tier 2 entities are partitioned as 'common' within the JARC families in contrast to the EURACAN domains, resulting in a shift in gender, EoD, and RC estimates.

Main strengths of this study are the analysis of trends in survival by domain and for Tier 2 RC entities, the use of population-based nationwide data with high national coverage and the extensive study period, resulting in a representative and recent study population. Limitations include the changes within the ICD-O classification over time and the lack of specificity of morphology NOS codes which might have led to an underestimation of the true incidence and prevalence of Tier 2 entities. For this study, 6% of the patients with RC had missing morphology codes (i.e. M8000-M8001) and could only be classified to a Tier 1 category. A possible explanation for this might be the difficulty of obtaining an accurate histological diagnosis by pathologists because of the rarity and heterogeneity of these tumours.

Future research should examine more in-depth comparisons between solid RCs and CCs, e.g. taking into account trends and patterns in incidence and prevalence, stage and/or grade, tumour biology, hospital type, type of treatment, treatment volumes and degree of centralisation of care. Furthermore, the clinical impact of the adjusted partitioning of RC entities into families instead of domains should be explored into further detail. Regarding clinical practice, (inter)national collaboration should be further stimulated by, e.g. establishing CoE, accessible to all patients with RC. Those CoE should be part of clinical networks to stimulate knowledge sharing and research development (e.g. interventions for prevention, early diagnosis and treatment) in the field of RC. In the Netherlands, the initiation of the Dutch Rare Cancer Platform ensures national and multidisciplinary collaboration for optimal diagnostics, increased participation in clinical studies and timely treatment. In addition, although grouping RC entities into families would be relevant for health care organisation and patient referral, certain patients with RC will be at disadvantage in terms of medical expertise.

5. Conclusion

To our knowledge, this is the first study, in which a comparison between adult solid RCs and CCs in the Netherlands has been made, regarding data on incidence, prevalence, survival (trends) and the partitioning of entities within domains and families. RC survival improvements are still lagging behind CC. Although some progress in 5-year survival rates was seen for most RC domains and several RC entities, further improvement in diagnosis, treatment and management of solid RCs is urgently needed to offer the best possible care for all patients with RC.

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Credit author statement

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Conflict of interest statement

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejca.2022.03.001.

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