



The impact of parental cancer on preadolescent children (0–11 years) in Western Australia: a longitudinal population study

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Abstract

Purpose Australian population data regarding the number and sociodemographic characteristics of children affected by a parent's cancer are not currently available. Moreover, predictions that this population is increasing have not been tested. This study provides data on the number and sociodemographic characteristics of parents with cancer and their young children (aged 0–11 years) in the state of Western Australia, and investigates whether long-term trends in this population have increased over time.

Methods Linked administrative data were used to describe parents with malignant cancer and their children aged 0–11 years at the time of diagnosis between 1982 and 2015 in Western Australia. Parents and children were described overall and by year of diagnosis and sociodemographic characteristics. A Poisson regression was used to investigate trends in the number of children affected, accounting for population growth. Incidence counts of parental cancer characteristics were included.

Results Between 1982 and 2015, 15,938 parents were diagnosed with a malignant cancer, affecting 25,901 children. In 2015, 0.28% of children in Western Australia experienced a parent's diagnosis. The number of children affected increased over time; however, this was accounted for by population growth. The majority of families lived in regional areas and were of high socioeconomic status. Older children and older parents most frequently experienced parental cancer. Skin and breast cancer were the most common diagnoses.

Conclusions A substantial number of families are affected by parental cancer. Results can guide intervention development and delivery to children of different developmental stages, and inform decisions regarding resource allocation and health service accessibility.

Keywords Parental cancer · Children · Incidence · Australia · Cancer

Introduction

When a parent is diagnosed with cancer, it affects the entire family. Treatment and hospitalisation of the diagnosed parent can introduce periods of separation and disrupt family roles, daily routines, and family communication [1–4]. Preadolescent

children (0–11 years) may be especially vulnerable to a parent's cancer, as they depend on their parents to meet their basic needs, lack the ability to adjust to sudden change in routine and have fewer developmental resources to cope [5]. Although most children adjust to the challenges presented by their parents' cancer [6, 7], research that has included preadolescent children indicates that a substantial cohort exhibit heightened levels of stress and distress [8–10], and experience more emotional and behavioural problems compared to norms [9, 11, 12]. Children may also experience increased somatic symptoms and difficulties at school [7, 13]. While many symptoms dissipate over time, children who initially experience more emotional and behavioural problems may remain vulnerable [14].

Families impacted by parental cancer need support [15]. Many best practice guidelines embed support for families that experience a cancer diagnosis into healthcare frameworks (e.g., National Institute for Clinical Excellence (NICE) guidelines

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[16]). However, research has identified a lack of professional support for families affected by parental cancer [17], concerns among healthcare professionals about their competence to provide support [18], and difficulty identifying support services [19]. The provision of adequate support services and interventions for those affected by parental cancer may be aided by determining the prevalence and sociodemographic characteristics of the families impacted.

Currently, there are no such data available for Australia, although international estimates imply that a significant number of Australian families may be impacted. Population-based prevalence rates estimate that parental cancer has impacted 6.6% of Finnish offspring (0–21 years) born in 1987 [20], 3.1% of minors (0–18 years) in Norway [21], and approximately 0.38% of 0–18-year olds in Japan [22]. Further, 14% of US cancer survivors report living with a minor child (0–18 years) [23], and it is estimated that 0.30% of families with a 0–18 year old in Norway experience a parent's cancer diagnosis annually [21].

In order to meet the needs of Australian families affected by a parent's cancer with preadolescent children, they too must be enumerated and described in terms of sociodemographic and other key characteristics. Global estimates indicate that Australia has one of the highest national incidences of cancer in the Organisation for Economic Co-operation and Development (OECD) [24]. Thus, making comparisons using the aforementioned global figures of parental cancer may underestimate the extent of the problem in Australia. Moreover, secular trends in fertility rates show that families are having fewer children [25], which implies that while an increasing number of families may be affected by a parent's cancer, the composition of these families may also be changing. Limited understanding of how these factors combine to influence the number of families affected and their sociodemographic profiles undercuts attempts to respond adequately to the needs of this population.

This study utilised longitudinal population-level data to address the current lack of knowledge regarding the incidence and prevalence of parental cancer in the state of Western Australia, and to examine long-term trends in these numbers. To facilitate research considering the specific challenges faced by young children with a parent with cancer, this study examined the impact of parent cancer on families with preadolescent children (aged 0–11 years).

Methods

Study design

This study was a longitudinal, retrospective cohort study based on anonymised administrative linked data for the Western Australian (WA) population between 1982 and

2015. To determine the prevalence and incidence of families with a 0–11-year-old child impacted by parental cancer, as well as the characteristics of this population, two cohorts were identified using individual-level data linkage: parents with cancer and a child aged 11 years or younger at the time of their incident cancer diagnosis (parent cohort); and their children (0–11 years) (child cohort). Ethics approval to conduct this study was obtained from the WA Department of Health Human Research Ethics Committee and the University of Western Australia Human Research Ethics Committee.

Identification of parent and child cohorts

Parent cohort

Parents were identified using the Western Australian Cancer Registry (WACR). Data were extracted from the WACR for individuals with a first cancer diagnosis (except basal cell carcinoma (BCC) and squamous cell carcinoma (SCC)) between 1 January 1982 and 31 December 2015. Data on parent mortalities were linked using the WACR and WA death registrations.

Child cohort

Individuals with a first recorded cancer during the 34-year period were linked to offspring aged 0–11 years at the time of parents' diagnosis using genealogy databases: Western Australian Data Linkage System (WADLS) Family Connections, Midwives Notification System (MNS) and Birth Registrations.

Data analysis

The population of parents and children who experienced parental cancer were described overall and separately by sociodemographic characteristics (sex, parent and child age at parent's diagnosis, socioeconomic status (SES), and remoteness). For children with a parent with cancer, descriptive incidence analyses were undertaken to identify the number of sons and daughters impacted by a mother's and/or father's cancer.

SES was estimated using the *Index of Relative Socio-economic Disadvantage* (IRSD) provided by Australia's national statistical agency as part of the broader *Socio-Economic Indexes for Areas* (SEIFA) framework [26]. The IRSD collates a range of area-level indicators of social (e.g., proportion of secondary school completion) and economic (e.g., proportion earning < \$20,799 per year) disadvantage to provide a broad measure of the relative SES of an area. It is often used to investigate the relationship between SES and health outcomes, in part, to inform decisions regarding funding allocation [26]. The index ranks areas on a continuum of

disadvantage; for the present study, IRSDs were grouped into ‘low’, ‘middle’ and ‘high’ SES.

Given the need to consider service accessibility in planning the provision of support services, remoteness area (RA)—a measure of geographic remoteness produced by Australia’s national statistical agency—was included [27]. RA calculations are based on geographic distance to service towns, which allows for the categorisation of areas according to the degree of accessibility to goods, services and opportunities for social interaction into: major cities, inner regional, outer regional, remote and very remote [27].

Descriptive analyses were used to report on parent’s cancer site. To investigate the impact of child age and provide relevant developmental information for service planning, children were grouped into pre-school (aged 0–3), early school (aged 4–7) and late school (8–11) groups. Long-term trends in the incidence of families impacted by parental cancer were described by incidence counts of maternal and paternal cancer cases by year of diagnosis during the period 1982–2015, and the number of children who experienced the cancer diagnosis of at least one parent by year of parent’s diagnosis over the same period. Poisson regression was used to determine whether the number of children who experienced a parent’s diagnosis had increased over the 34-year period when controlling for state-level population growth. Generalised linear modelling was conducted to investigate whether the upward trend in the incidence of children impacted by parental cancer was accounted for by state-level population growth. A negative binomial model was used to correct for data over dispersion (i.e., that there was greater variability than expected). The natural logarithm of the Western Australian population of 0–11-year olds between 1982 and 2015 was derived from ABS census data and added into the model as an offset variable.

Results

Sociodemographic characteristics

There were 15,938 parents (52.7% mothers) of 25,901 children (51.7% boys) aged 0–11 years with an incident cancer diagnosis in WA between 1982 and 2015. See Table 1 for prevalence counts for parents with cancer and their children by sex, parent and child age at the parent’s diagnosis, number of children, SES, and RA.

Parents’ age at diagnosis spanned 16 to 86 years ($M = 39.9$ years, $SD = 8.2$ years; Table 1), with the majority of parents (79.7%) aged 31–50 years. On average, parents had 1.6 children ($SD = 0.79$) at the time of diagnosis; over half (51.5%) had just one child at diagnosis, with approximately a third (36.0%) having two children.

At the time of diagnosis, most parents (46.3%) resided in high SES areas and were regionally located (58.5%).

Table 1 Distribution of sociodemographic characteristics of parents diagnosed with cancer from 1982 to 2015 and their offspring at time of parent’s diagnosis

Variable	Parents <i>N</i> (%)	Children <i>N</i> (%)
Sex		
Male	7531 (47.3)	13,379 (51.7)
Female	8407 (52.7)	12,522 (48.3)
Parent’s age at diagnosis		
≤20	45 (0.3)	N/A
21–30	1764 (11.1)	N/A
31–40	6974 (43.8)	N/A
41–50	5726 (35.9)	N/A
51–60	1161 (7.3)	N/A
61–70	226 (1.4)	N/A
>70	42 (0.3)	N/A
Child’s age at diagnosis		
0–3	N/A	7648 (29.5)
4–7	N/A	8123 (31.4)
8–11	N/A	10,130 (39.1)
Number of children		
1	8209 (51.5)	
2	5744 (36.0)	
3	1597 (10.0)	
≥4	388 (2.4)	
SES ^a		
Low	3558 (22.3)	5876 (22.7)
Middle	4925 (30.9)	8061 (31.1)
High	7376 (46.3)	11,835 (45.7)
Unknown ^b	79 (0.5)	129 (0.5)
Remoteness area ^a		
Major cities	5379 (33.7)	8498 (32.8)
Inner regional	7668 (48.1)	12,438 (48.0)
Outer regional	1654 (10.4)	2833 (10.9)
Remote	208 (1.3)	371 (1.4)
Very remote	950 (6.0)	1632 (6.3)
Unknown ^b	79 (0.5)	129 (0.5)

^a SES and RA for children and parents based on parent’s postcode at diagnosis. If a child had two parents with cancer, SES and RA were based on the mother’s postcode. If a child had two parents of the same sex, SES and RA were based on earlier diagnosis postcode

^b No fixed address or not recorded

Estimates of offspring SES and RA roughly correspond to those for parents with cancer. Like parents, the majority of children lived in inner and outer regional areas (59.0%) and about a third (32.8%) in major cities, although a slightly higher proportion of children resided in outer regional (10.9%), remote (1.4%) and very remote (6.3%) areas compared to parents.

Of the children, more sons (51.7%) than daughters (48.3%) were affected by parental cancer, although this reflects the population sex distribution [28]. The mean child age at the time of parent's diagnosis was 5.9 years ($SD = 3.5$ years). Of these children, 29.5% were infants and toddlers (0–3 years), 31.4% were in early childhood (4–7 years), and 39.1% were in late childhood (8–11 years). Offspring aged 11 years (10.3%) were most commonly affected by a parental cancer diagnosis; however, the number of children aged 0 years ($n = 2518$, 9.7%) at a parent's diagnosis was comparable to the number affected in late childhood. More sons (52.4%) and daughters (53.2%) had a mother with cancer (see Table 2). A minority (0.9%) experienced a cancer diagnosis of *both* parents; of these, there was an average of 3.4 years ($SD = 3.0$ years) between the diagnosis of the first and second parent: 53.8% (68 sons, 61 daughters) affected by the cancer of both parents first experienced the mother's diagnosis, and 46.3% (60 sons, 51 daughters) first experienced the father's diagnosis.

Parental cancer characteristics

Among the most common parental cancer diagnoses were skin cancer (26.2%), breast cancer (18.3%), cancer of the digestive organs (11.2%) and cancer of the genital organs (7.5%). Skin cancer was most common in fathers (29.9%), and breast cancer was most common in mothers (34.7%). See Table 3.

Long-term trends in the impact of parental cancer on parents and children

There was an upward trend in the diagnosis of parent cancer across the 34-year period (see Fig. 1). The annual incidence of maternal cancer cases increased from 161 in 1982 to 402 in 2015; the lowest number of new cases of maternal cancer for a given year was recorded in 1984 (134 additional cases). The incidence of paternal cancer increased from 107 in 1982 to a high of 342 in 2015. An upward trend was also observed in the number of children who experienced a parent's diagnosis between the years 1982 and 2015 (Fig. 1). Whereas 453 children (1.7%) experienced a mother's or father's diagnosis in 1982, 1149 children (4.4%) experienced a parent's diagnosis in

2015. No statistically significant association was found between the number of offspring and year, adjusting for the offset (logarithm of WA population) ($\chi^2(1) = 1.4$, $p = .285$). Thus, annual growth in the number of children affected by a parent's cancer diagnosis was accounted for by population growth.

In 2015, 744 parents (45.9% fathers) of 1149 children received a cancer diagnosis. By June 2015, the state population of children aged 11 years or younger was estimated at 405,461 [29]; thus, approximately 0.28% of 0–11-year olds in Western Australia experienced the diagnosis of at least one parent in 2015. Over the period June 1982 to June 2015, approximately 0.24% of 10,859,477 [29] children aged 0–11 years in WA experienced a parent's diagnosis.

Discussion

Using linked administrative data from Western Australia over a 34-year period, the proportion of 0–11-year olds with a parent with cancer was estimated at 0.24%. In 2015, the proportion of children affected in Western Australia was estimated at 0.28%. Children in late childhood (8–11 years) and parents aged 31–40 years were most frequently affected. The most common types of cancer in parents were skin and breast cancers. The number of parents and children affected by cancer increased during the study period (1982–2015). Some have proposed that such trends indicate that the population of children affected by parental cancer is increasing as individuals delay childbearing [22, 23]. Our data did not support this hypothesis, as growth in the number of children affected by parental cancer was accounted for by state-level population growth. Australian trends in the increasing age of parents at childbirth are comparable to those in other countries in the Organisation for Economic Co-operation and Development (OECD) [25], so it may be that this effect is not yet evident for parents with *young* children, whereas it may emerge at later offspring ages. Whereas age is a risk factor for many common cancers, parents older than 50 years comprised a minority of this population. As Western Australia is considered to be representative of the wider Australia population in terms of sociodemographic and health economic indicators, these results can be considered generalizable to the Australian population [30].

The prevalence and incidence of parental cancer

One in every 352.9 children aged 0–11 years (0.28%) in Western Australia experienced the incident diagnosis of at least one parent in 2015. This estimate is slightly lower than annual estimates of the number of minors affected in Norway

Table 2 Distribution of children experiencing parental cancer by sex and parent sex

Parent with cancer	Sons (%)	Daughters (%)	All children (%)
Father	6241 (46.6)	5752 (45.9)	11,993 (46.3)
Mother	7010 (52.4)	6658 (53.2)	13,668 (52.8)
Father and mother	128 (1.0)	112 (0.9)	240 (0.9)
Total	13,379 (51.7)	12,522 (48.3)	25,901 (100.0)

Table 3 Distribution of maternal and paternal cancer by cancer characteristics between the years 1982–2014 and 2015

Variable	ICD-10 code	Cancer in mother		Cancer in father	
		1982–2014 prevalence (%)	2015 incidence (%)	1982–2014 prevalence (%)	2015 incidence (%)
Cancer site					
Melanoma and skin	C43–C44	1832 (22.9)	89 (22.1)	2152 (29.9)	99 (28.9)
Breast	C50	2776 (34.7)	149 (37.1)	4 (0.1)	2 (0.6)
Digestive organs	C15–C25	637 (8.0)	49 (12.2)	1068 (14.9)	65 (19.0)
Male genital organs	C60–C63	–	–	1144 (15.9)	62 (18.1)
Female genital organs	C51–C54; C56–C58	917 (11.5)	29 (7.2)	–	–
Thyroid and other endocrine glands	C73–C75	628 (7.8)	34 (8.5)	201 (2.8)	12 (3.5)
Lip, oral cavity, and pharynx	C00–C12; C14	151 (1.9)	1 (0.2)	583 (8.1)	21 (6.1)
Non-Hodgkin lymphoma	C82–C86	189 (2.4)	8 (2.0)	375 (5.2)	20 (5.8)
Respiratory and intrathoracic organs	C30–C34; C37–C38	134 (1.7)	10 (2.5)	349 (4.9)	10 (2.9)
Urinary tract	C64–C68	120 (1.5)	4 (1.0)	316 (4.4)	15 (4.4)
Eye, brain, and other parts of central nervous system	C69–C72	175 (2.2)	6 (1.5)	268 (3.7)	12 (3.5)
Leukaemia	C91–C95	122 (1.5)	11 (2.7)	215 (3.0)	6 (1.8)
Hodgkin lymphoma	C81	105 (1.3)	1 (0.2)	132 (1.8)	2 (0.6)
Mesothelial and soft tissue	C45–C49	54 (0.7)	4 (1.0)	125 (1.7)	5 (1.5)
Unknown primary site	C80	65 (0.8)	2 (0.5)	101 (1.4)	5 (1.5)
Multiple myeloma and malignant plasma cell neoplasms	C90	32 (0.4)	0 (0.0)	54 (0.8)	4 (1.2)
Bone and articular cartilage	C40–C41	26 (0.3)	2 (0.5)	36 (0.5)	0 (0.0)
Lymphoid, haematopoietic, and related tissue	D47	18 (0.2)	3 (0.7)	25 (0.3)	1 (0.3)
Myelodysplastic syndromes	D46	13 (0.2)	0 (0.0)	16 (0.2)	0 (0.0)
Polycythaemia vera	D45	5 (0.1)	0 (0.0)	14 (0.2)	1 (0.3)
Other and unspecified malignant neoplasms of lymphoid, haematopoietic, and related tissue	C96	5 (0.1)	0 (0.0)	6 (0.1)	0 (0.0)
Malignant immunoproliferative diseases	C88	1 (0.0)	0 (0.0)	5 (0.1)	0 (0.0)
Total		8005 (100.0)	402 (100.0)	7189 (100.0)	342 (100.0)

ICD-10 International Classification of Diseases, 10th edition

(0.30%) [21] and Japan (0.38%) [22]. However, these previous studies included a broader age range (0–18-year olds) than the present study. The proportion of children who experience parental cancer increases with child age in our sample and in others [21, 22]. Consequently, we would have expected the proportion of 0–11-year olds impacted by a parent's cancer in our study to be smaller than previous estimates that include both younger and older age groups. Taking this into account, to the extent that our estimate is relatively similar to this previous research likely reflects the high incidence of cancer in Australia relative to other OECD countries and suggests a pressing need for Australia to address services for this population. To this end, the findings on socio-demographic characteristics summarised below should help to develop and provide services.

Characteristics of parents with cancer and their children

Most families resided in regional and remote areas, with approximately one third residing in cities. Further, almost one fifth of parents and children resided in outer regional and remote areas, which increases the likelihood that the parent will need to spend time away from or temporarily move the family to receive treatment. Thus, establishing support services for families that consider this population dispersion and relevant needs is essential (e.g., using *online* modalities to circumvent service gaps) [31, 32]. Nearly half of parents diagnosed with cancer and their children resided in high SES areas. The proportion of low SES families is at odds with typical cancer incidence, which indicates highest incidence

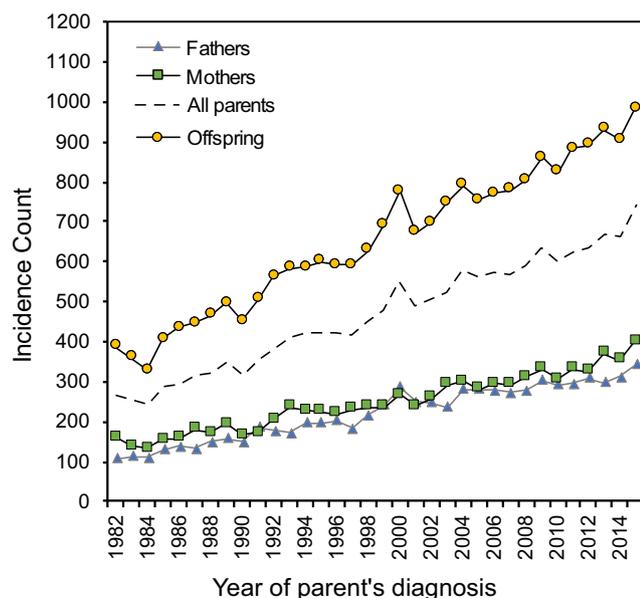


Fig. 1 Long-term trends in the incidence of parental cancer between 1982 and 2015. This figure does not account for annual growth in the population of 0–11-year olds; when state population growth is accounted for, the upward trend in the number of children affected by a parent's diagnosis is not significant

rates in the lowest SES areas [33]. This may be because a large majority of parents in this population were diagnosed with localised cancers, whereas low SES is a risk factor for advanced stage of cancer at diagnosis [34]. In this case, children may have higher unmet needs due to prolonged treatment, more life-threatening forms of cancer and/or more limited funds for supportive care.

More mothers experienced a cancer diagnosis than fathers, which is consistent with findings from Norway, Japan, Finland and the USA [20–23]. Sons and older children, as expected [21, 22], were most commonly affected. The majority of children had one or no siblings, perhaps because many parents of young children have not yet completed childbearing. These sociodemographic characteristics may place children at psychosocial risk because children have more difficulties adjusting to a mother's than a father's cancer [8, 35, 36] and sons report more problems than daughters [37, 38]. Moreover, households with fewer children and being firstborn have been linked to more emotional and behavioural problems in children [39]. Taken together, this buttresses the urgent need to provide family support.

This study identified that parents were most affected by skin and breast cancers. These cancers are commonly treated using surgical procedures and adjuvant therapies [40], and place considerable burden on parents, limiting their capacity to respond to children's needs [41]. Even after initial treatment has ended, a patient's diminished quality of life can impact the psychosocial functioning of their children [42]. Although prognoses for common cancer are typically good [40],

younger age at diagnosis (as seen in this population) is associated with poorer prognosis for some common cancers (e.g., breast, prostate) [43, 44], which is linked to worse child adjustment [37]. Thus, in addition to experiencing initial treatment, young children may also face a parent's cancer recurrence and continued uncertainty about prognosis.

The impact on Australian families

Children and their families articulate a need for *timely* and *flexible* support to cope with a parent's cancer [15]. However, many of these needs remain unmet [45]. These suggestions—together with results regarding the considerable impact of parental cancer on Australian families—should expedite the provision of family support. To fulfil the needs of families necessitates the development of support tailored to the distinct sociodemographic profiles of young children. To ensure this support is effective, it must be aided by research on challenges unique to children of different developmental stages. The wide geographic dispersion of families means that intervention developers and service providers must think creatively to address large service gaps.

Limitations

This study has limitations. First, our method of data linkage meant that we could not identify non-biological children of parents with cancer, whether children resided with the parent with cancer or estimate the number of children in single versus two parent families. Second, our data included information only for parents' incident diagnosis; thus, we were unable to explore the impact of cancer recurrence on families. Third, our study was limited to malignant cases and excluded benign and in situ cancers.

Conclusion

The potential for a parent's cancer to interfere with healthy child development is clear [6, 37, 38]. To our knowledge, this study is the first to investigate long-term trends in the number of children (0–11 years) and their parents with cancer in Australia. This evidence highlights that a substantial number of Australian families experience a parent's cancer diagnosis each year. This study has provided knowledge to guide the sensitive, effective, and efficient development and delivery of interventions, as well as decisions regarding resource allocation and health service accessibility.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval Approval for the project was received from the Western Australia Department of Health (WADoH) (no. 2016/31), Western Australia Data Linkage Branch (no. 201604.07) and University of Western Australia Human Research Ethics Council (HREC) (RA/4/1/8660).

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