

A longitudinal investigation of Western Australian families impacted by parental cancer with adolescent and young adult offspring

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A parent's cancer is the cause of considerable distress for their children.¹ Offspring of parents with cancer experience a variety of psychological and physical health problems.²⁻⁶ For example, compared to the norm, these children access more psychiatric services⁵ and have an increased rate of death.² Parents with cancer not only endure the physical and emotional strain of the disease and its treatment, but are burdened with feelings of guilt about the impact that their illness has on their children.⁷ Research has demonstrated that offspring respond differently to parental cancer depending on their age,⁸ with older offspring experiencing greater disruption as a result of parental cancer than younger children. Compared to children of healthy parents, adolescent and young adult offspring of ill parents are tasked with more household and caregiver responsibilities^{9,10} that impede on their leisure activities, and impair their academic achievement⁹ and normative development.¹¹ Research also shows that compared to preadolescents who experience parental cancer, adolescent and young adult offspring experience higher levels of anxiety and depression.¹² Recent findings have demonstrated that adolescent and young adult offspring facing a family member's cancer experience levels of distress comparable to those experienced by young people seeking treatment for mental health issues.¹⁰ Additionally, adolescents and young adults report higher levels of distress and higher levels of unmet needs if they have a

Abstract

Objective: Parental cancer is a significant problem for adolescent and young adult offspring. To understand the extent of the problem of parental cancer for Australian offspring, data regarding those impacted are required. The aim of this study was to enumerate and describe the characteristics of Western Australian adolescent and young adult offspring (12–24 years) and their parents with cancer using linked population data.

Methods: A retrospective cohort study was conducted using data from the Western Australia Data Linkage System, which provided results generalisable at a national level.

Results: Between 1982 and 2015, 57,708 offspring were impacted by 34,600 parents' incident malignant cancer diagnoses. The most common diagnosis was breast cancer. Of the 36.4% of parents who died, this was mostly a result of cancer. Most families resided in regional areas and were of high or middle socioeconomic status. Significant predictors of earlier parent death included low socioeconomic status, remoteness, age, having more children and having older children.

Conclusion: A considerable number of adolescent and young adult offspring are impacted by parental cancer at a potentially vulnerable age. This research provides knowledge to better understand who is affected by parental cancer in Australia.

Implications for public health: These results may be useful for planning and implementation of Australian supportive services.

Key words: parental cancer, cancer, data linkage, offspring

parent with cancer, compared to those with a sibling with cancer.¹⁰

Support for families experiencing a parent's cancer is essential to offspring development and parent coping.^{13,14} However, there are large service gaps in the provision of support for this group.^{15,16} Offspring affected by parental cancer may be overlooked by supportive care services¹⁷ as they themselves are not the patient. For offspring in their adolescence and young adulthood, this is particularly problematic. These offspring possess a unique vulnerability in that their

developing cognitive and empathetic capacities mean they are more aware of a parent's physical and emotional pain than younger children.¹⁸ Further, these young people are contending with the developmental challenges and milestones that accompany adolescence and young adulthood. It is imperative that adolescents and young adults experiencing a parent's cancer diagnosis are appropriately supported. A step in achieving this aim is to seek to better understand the prevalence of parent cancer in households with adolescent and

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Submitted: July 2018; Revision requested: November 2018; Accepted: January 2019

The authors have stated they have no conflict of interest.

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Aust NZ J Public Health. 2019; 43:261-6; doi: 10.1111/1753-6405.12885

young adult children, as well as identify factors which are contributing to poorer outcomes in relation to cancer to better identify at-risk groups.

Outside of Australia, parental cancer has been quantified in an effort to understand the extent of this problem. Parental cancer is estimated to affect 6.6% of Finnish offspring (0–21 years);⁵ 1.4% of Norwegian offspring (0–25 years);¹⁹ and 0.38% of Japanese offspring (0–18 years).²⁰ In Sweden, 4.0% of children (<18 years) followed between 1991 and 2009 ($n=2,871,242$) had a parent diagnosed with cancer.² Further, United States based estimates indicated that in 2007, 562,000 dependent children (<18 years) lived with a parent in the early phases of cancer²¹ and 200,000 children were newly impacted by a parent's incident cancer diagnosis.²²

It is estimated that every year in Australia, 10,000 parents are diagnosed with cancer,²³ affecting 21,000 adolescents and young adults (12–24 years).²⁴ Besides these projections, there is a dearth of evidence that identifies the number of Australian offspring affected by parental cancer and characterises these families in terms of demographics and other key variables. Identifying the number and characteristics of Australian families with adolescent and young adult offspring affected by parental cancer is essential to appropriately respond to this vulnerable population by providing evidence essential to service development and implementation. Therefore, the purpose of this study was to enumerate and describe the characteristics of adolescent and young adult offspring (12–24 years) and their parents with cancer in Western Australia (WA) using whole-population linked administrative health data.

Ethics

Approval for the project was received from the WA Department of Health (WADoH) (#2016/31); WA Data Linkage Branch (#201604.07); University of WA Human Research Ethics Council (HREC) (RA/4/1/8660) and University of Adelaide HREC (#32198).

Methods

Definitions of offspring and parents

For the purpose of this project, adolescents and young adults were defined as young people aged 12–24 years. This age range closely aligns with the World Health Organization's definition of adolescents and young adults (10–24 years);²⁵ while

encompassing developmental perspectives of age 12 years constituting the start of adolescence,²⁶ and adopting the same age delineation for adolescent and young adults as provided by Australian government²⁷ and cancer support organisations (i.e. CanTeen).

In this project, parents were defined as biological mothers and fathers as current data linkage is limited in its capacity to link family members outside of biological relationships.

Data sources

A retrospective cohort study was conducted using routinely-collected linked whole-population data from the WA Data Linkage System (WADLS). Data were obtained between 01 January 1982 and 31 December 2015 to coincide with the earliest record available in the WA Cancer Registry (WACR) and latest date available at the time of data extraction for this study. Parents were identified in the WACR as having an incident malignant cancer diagnosis (excluding benign or in-situ cancers; and according to WACR definitions of malignancy,²⁸ excluding basal cell carcinoma (BCC) and squamous cell carcinoma (SCC)) between 1 January 1982 and 31 December 2015; and at least one child aged 12–24 years and alive at the time of diagnosis. Offspring (12–24 years) were identified via Family Connections (a system that genealogically links individuals) through the Midwives Notification System, Birth Registrations, and Mortality Registry. WACR records provided demographic information (sex, date of birth, residential postcode at diagnosis), cancer information (date of diagnosis, tumour topography) and cancer-related death data (date of death, cause of death). Birth Registrations and Midwives Notification System data provided further demographic information on the parent and offspring cohorts (sex, age, birth place, postcode of residence). The Mortality Registry provided death data (date of death, cause of death). Cause of death and tumour topography were classified according to the International Classification of Diseases (ICD-10). Socioeconomic status (SES) was assigned based on parent postcode at diagnosis or Local Government Area at diagnosis where postcode was unavailable, using the Socioeconomic Index for Areas (SEIFA) Index of Relative Socioeconomic Disadvantage.²⁹ SEIFA was assigned according to the most recent Census to time of diagnosis. Parents were categorised into one of three SEIFA groups (low, middle and high SES) depending

on their SEIFA score relative to the state-wide tertiles for that Census period. Remoteness was assigned based on parent postcode at diagnosis using the Australian Statistical Geography Standard Remoteness Area (RA) structure.³⁰ RA was assigned on the basis of relative access to services and categorises areas into one of five classes of increasing remoteness: metropolitan, inner regional, outer regional, remote, and very remote.³⁰ Offspring were assigned their mother's SEIFA and RA scores. In the case of offspring having two mothers in the dataset, offspring were assigned SEIFA and RA scores of the parent with the earlier cancer diagnosis.

Data analysis

Data analysis was conducted using SPSS (version 24).³¹ Descriptive statistics were used to report offspring and parent cohort demographics and characteristics, specifically: age, sex, ethnicity, country of birth, family relations (number of parents per offspring; number of children per parent), SES (SEIFA), place of residence (remoteness), and date and cause of death. If a child had more than one parent who experienced an incident cancer diagnosis in the WACR, their age was calculated at the date of earliest diagnosis. Descriptive statistics were also used to report on parent's cancer data, specifically: year of diagnosis, age at diagnosis, and tumour information (behaviour, morphology, topography).

Negative binomial regression analysis was used to determine whether the number of offspring impacted by parental cancer changed from 1982 to 2015, and whether the number of offspring experiencing parental cancer varied in terms of their age. The adolescent and young adult (12–24 years) WA population from 1982 to 2015 was derived from ABS Census data and added to the model as the offset variable.

Multivariate Cox Proportional Hazards regression modelling was used to determine the characteristics associated with earlier parent cancer-related death, thus establishing the rate at which offspring were bereaved. Covariates included parent's Indigenous status, age at diagnosis, total offspring at incident diagnosis, mean age of offspring (categorised as early adolescence (12–24 years), late adolescence (15–19 years), or young adulthood (20–24 years)),³² SES, and remoteness. Hazard ratios (HRs) with 95% confidence intervals were adjusted for the covariates. The start of follow-up was the

date of the parent's cancer diagnosis; and follow-up ended at the date of parent's cancer related death; or censored at the date of non-cancer related death or at 31 December 2015. Cancer type was not added as a covariate to the model due to unbalanced distribution across cancers (i.e. low frequency of some cancer types), thus producing unreliable parameter estimates and limiting meaningful interpretation.³³

Results

Offspring & parents

Between 1982 and 2015, 57,708 adolescent and young adult offspring (51.3% male; 48.7% female) experienced their 34,600 parents' (52.8% male; 47.2% female) incident cancer diagnosis in WA. The cumulative proportion of offspring affected by parental cancer was estimated to be 0.47%, corresponding to an average of 0.46% of offspring newly affected each year (95%CI: 0.43, 0.49). The mean age of offspring at their parents diagnosis was 18.8 years (SD=3.7), and the mean age of parents was 51.3 years (SD=7.9). Visual inspection of the data indicated that older offspring were more affected by parental cancer, but this difference was not statistically significant ($X^2(1)=0.50, p=0.48$). The mean number of offspring per parent at their diagnoses was 1.71 (SD=0.85), with the range of offspring per parent varying from 1 to 9.

Cancer incidence and thus the number of offspring impacted by parental cancer increased between 1982 and 2015 (Table 1). However, negative binomial regression modelling demonstrated no significant association between the number of offspring and time, adjusting for the WA population aged 12–24 years ($X^2(1)=1.36, p=0.24$). Most offspring (97.5%) had only one parent diagnosed with cancer. The remaining 2.5% of offspring encountered both parents' diagnoses between 1982 and 2015. Among this latter group, the mean time between parent's cancer diagnoses for this group was 3.4 years (SD=3.0), and mothers were generally diagnosed earlier than fathers (52.5% vs 47.5%). Of the 2.5% of offspring who had both parents diagnosed, 0.14% ($n=2$) had same-sex parents.

Socioeconomic status and geographic remoteness

Most families (parents and offspring) resided in Inner (48.2%) or Outer Regional (11.3%) areas (Table 2). More families were of high

(44.5%) or middle SES (31.8%). The majority of offspring (99.9%) and parents (69.1%) were born in WA. The remaining parents were born in the United Kingdom (13.3%), or New Zealand, Europe, Asia, Africa, the Americas, and Antarctica (14.3% combined). An additional 2.3% had no place of birth record.

Cancer information

Parent's incident diagnoses included invasive and lymphohaematopoietic malignancies (Table S1). The most common diagnoses among mothers was breast (40.7%) and among fathers, cancer of the male genital organs (22.4%). Melanoma and skin cancers (excluding BCC and SCC) were the second most common cancer for mothers and fathers (16.3% and 21.1%, respectively).

Deaths

Between 1982 and 2015, 1.1% of offspring died at a mean age of 34 years (SD=9.6), and mean time to death from their parent's diagnosis of 13 years (SD=8.7). In the study period, 36.4% of parents died, at a mean age of 58.3 years (SD=10.7), and mean time to death from diagnosis of 4.6 years (SD=6.6).

More fathers died overall (60.5%) and more fathers died of both cancer-related (58.8%) and non-cancer related or unknown causes (71.0%) than mothers. Among parents who died, more died of cancer-related deaths (86.4%) than non-cancer deaths (13.6%).

Rate of offspring bereavement due to parent's cancer-related death

Cox Proportional Hazards Regression models revealed a statistically significant relationship between a parent's age at diagnosis and time to death, ($p<0.001$, Table 3), where parents aged 50 years and younger had a hazard of dying 34% lower than parents aged 51–94 years. Fewer children in the family was also associated with lower hazard of dying ($p<0.01$); and parents with four or more children had the lowest survival rate. A statistically significant association was found between child's age and time to parent's death ($p<0.05$). Parents with offspring in their early or late adolescence had a lower hazard of dying than parents with young adult offspring. A statistically significant association was found between SES and time to death ($p<0.001$). Compared

Table 1: Parent cancer diagnoses and offspring affected between 1982 and 2015.

Year of parent diagnosis	Parent diagnoses	%	Offspring affected	%	Total	%
1982–1985	2,272	6.6	4,164	7.2	6,436	7
1986–1990	3,358	9.7	5,824	10.1	9,182	9.9
1991–1995	4,309	12.5	7,056	12.2	11,365	12.3
1996–2000	4,522	13.1	7,399	12.8	11,921	12.9
2001–2005	5,790	16.7	9,625	16.7	15,415	16.7
2006–2010	6,740	19.5	11,103	19.2	17,843	19.3
2011–2015	7,609	22	12,537	21.7	20,146	21.8
Total	34,600	100	57,708	100	92,308	100

Note:

For offspring with two parents with cancer, count was considered at the earliest diagnosis.

Table 2: Socioeconomic status and remoteness areas.

	Offspring	%	Parents	%	Total	%
Total	57,708		34,600		92,308	
SES^a						
Low	13,562	23.5	8,068	23.3	21,630	23.4
Mid	18,410	31.9	10,931	31.6	29,341	31.8
High	25,579	44.3	15,512	44.8	41,091	44.5
NFA ^b	157	0.3	89	0.3	246	0.3
Remoteness Area						
Major cities	19,550	33.9	12,128	35.1	31,678	34.3
Inner Regional	27,902	48.4	16,626	48.1	44,528	48.2
Outer Regional	6,619	11.5	3,774	10.9	10,393	11.3
Remote	891	1.5	4,894	1.4	1,380	1.5
Very Remote	2,589	4.5	1,494	4.3	4,083	4.4
NFA ^b	157	0.3	89	0.3	246	0.3

Notes:

a: 'Low' indicates relatively greater disadvantage and a lack of advantage; 'high' indicates relatively greater advantage and a lack of disadvantage.

b: NFA=No fixed address.

to those of high SES, parents of low SES had a 49% increased rate of dying, and parents of moderate SES had a 30% increased rate. Lastly, there was a statistically significant association between remoteness and time to death ($p < 0.05$), with parents living in major cities and regional areas having a 9% lower risk of death than parents living in remote areas.

Discussion

To our knowledge, this is the first study to describe the Australian population of adolescent and young adult offspring (12–24 years) impacted by parental cancer and adds to the international research regarding parental cancer in other jurisdictions.^{2,5,19,20} WA has been shown to be representative of the wider Australia population in terms of sociodemographic and health economic indicators.³⁴ As such, findings are likely generalisable at a national level. Results demonstrated that an estimated 0.47% (equating to 57,708) of adolescents and

young adults experienced their parent's incident cancer diagnosis between 1982 and 2015 in WA. Importantly, this percentage reflects *incident* parent diagnoses over the 33-year period as opposed to overall prevalence of parental cancer and so likely underestimates the true burden from parental cancer. Regardless, this study confirms that on average, approximately 1,697 adolescents and young adults are impacted by a parent's incident cancer diagnosis each year.

Although these results provide a reference point for the extent of incident parental cancer diagnoses in Australia, drawing comparisons between countries is complicated by methodological variations in the published literature. Where our study excluded first record cancer diagnoses of BCC and SCC (due to WACR definitions of malignancy),²⁸ other studies did not comment on such exclusion criteria. Further, our study was limited to malignant diagnoses and excluded benign or in-situ records. This criteria was consistent with that of Niemelä et al.⁵ but different to other population-based studies that focused on malignant and in-situ diagnoses,² malignant and benign neoplasms of the brain,¹⁹ or one study that mentioned exclusion of in-situ cases, but did not specify their inclusion criteria.²⁰ Our study focused on adolescents and young adults defined as 12–24 years, where others have focused on dependent offspring (0–8 years)^{2,20} or children and young adults (0–25 years).¹⁹ Other variations relate to differences in observation periods ranging from 4 years,²⁰ 18 years,² 21 years⁵ and 48 years.¹⁹ These methodological differences mean that comparisons between countries should be attempted with caution, both in regard to the number of families affected by parental cancer and in terms of comparing the extent of the problem that is parental cancer. For example, by focusing on malignant cancers, we do not imply that in-situ or benign diagnoses are less distressing. In fact, research has demonstrated that false-positive cancer diagnoses are experienced as psychologically distressing.³⁵ Thus, while this research is a necessary contribution elucidating the number of offspring affected by parental cancer in Australia, the nuances of each study of this nature must be considered for global estimates or national comparisons.

Across the sample, most cancer diagnoses were among mothers for breast cancer. Daughters experience their mother's cancer as particularly distressing.³⁶ In response to a mother's breast cancer diagnosis, daughters

report increased concerns about their body image, sexual functioning,³⁷ future health and their genetic susceptibility to the disease.³⁸ Healthcare professionals should be prepared to support offspring of newly diagnosed patients, as well as offer support relevant to the disease, such as genetic counselling in the case of a parent's breast cancer diagnosis.³⁸

Notably, most of the families in this study resided in regional areas, which is higher than the general WA population, the majority of whom reside in major cities.³⁹ Furthermore, a substantial proportion of families (23.4%) were of low socioeconomic status, although this is consistent with population norms.³⁴ In Australia, people with cancer who are socioeconomically disadvantaged or geographically isolated are less able to access care; both in terms of screening and treatment.^{40,41} Rurality and socioeconomic disadvantage is consistently linked to poorer cancer survival in Australia,⁴² a finding echoed in this study where parents characterised by these demographics had an increased rate of death. In other words, offspring were parentally bereaved at a faster rate if their family was socioeconomically disadvantaged or geographically isolated. Socioeconomic disadvantage and geographic isolation are factors consistently linked to under-utilisation of mental health services in Australia due to inadequate service provision.^{43,44} Results indicated that offspring most at risk of bereavement due to parental cancer were also the least likely to access psychosocial support because of their sociodemographic profile. As most parent deaths were cancer-related there is a clear need for effective bereavement support regardless of offspring's socioeconomic or geographic position.

Offspring experienced parental cancer at a mean age of 18 years. In most Australian States, this age corresponds to the final year of secondary school, and represents a major transitional point in children's lives characterised by greater independence and responsibilities. Plausibly, this age is a time of acute vulnerability triggered by the disappearance of structure they have received through formal schooling. If the young person is in school or university at the time of their parent's diagnosis, they may struggle academically,⁹ or even be at risk of withdrawal.⁴⁵ Besides academic obligations, the older a child is at their parent's cancer diagnosis, the more responsibilities they likely adopt.^{9,10} This includes adopting the role of caregiver,¹⁰ which may disrupt their

Table 3: Characteristics influencing rate to parent's cancer related death.

Variable	Hazard Ratios		
	Adj. HR	(95% CI)	p-value
Parent age at diagnosis (26–50)	0.66	(0.63–0.69)	<0.000
Parent age at diagnosis (51–94)			
Total offspring			
1 offspring	0.87	(0.79–0.97)	0.01
2 offspring	0.80	(0.72–0.89)	<0.000
3 offspring	0.81	(0.73–0.90)	<0.000
4 or more offspring			
Mean offspring age^a			
Early adolescence (12–14)	0.88	(0.82–0.93)	<0.000
Late adolescence (15–19)	0.95	(0.91–0.99)	0.02
Young adulthood (20–24)			
SEIFA			
Low	1.49	(1.42–1.56)	<0.000
Middle	1.30	(1.24–1.36)	<0.000
High			
Remoteness^b			
Major cities	0.91	(0.84–0.99)	0.02
Regional	0.92	(0.85–0.99)	0.03
Remote			

Notes:

a: Offspring age categorised according to Patton et al. definitions of adolescent and young adult age

b: Remoteness collapsed into Major Cities, Regional (Inner and Outer Regional) and Remote (Remote and Very Remote)

Parents excluded if missing a date of death record ($n=69$), date of birth record ($n=3$), or postcode at diagnosis ($n=89$).

developmental trajectory. To counteract this, families must be mindful of balancing offspring's needs with the needs of the parent with cancer¹⁰ and it is important that healthcare professionals support families to achieve such a balance. In addition, support strategies should consider the age of offspring at the time of their parent's diagnosis and the offspring's needs.

In this sample, 2.5% of offspring who experienced parental cancer had both parents diagnosed with cancer. Although a minority, this cohort are potentially at significant risk. A parent's illness may compromise the quality of the parent-child relationship as the ability to fulfil parenting obligations is challenged.¹¹ If offspring have two parents with cancer, it follows that they may endure the deterioration of two essential relationships and supports. In response to parental illness, families endure a redistribution of roles that see offspring adopting the role of a parent¹¹ or caregiver.¹⁰ Such responsibilities would be exacerbated for offspring if both their parents were affected by cancer. Long-term parental illness (e.g. those with lasting side effects) may significantly disrupt the family structure and as a result compromise the family's capacity to meet their children's developmental needs.³⁴ Plausibly, this may also be the case if parents are diagnosed sequentially across the child's life.

Strengths and limitations

A strength of this study was that it involved whole-population routinely-collected data linked through the WADLS, thereby increasing statistical power and reducing reporting bias. This method identified people otherwise under-represented in cancer research, as focus is predominately placed on mothers with cancer, coupled parents, those belonging to an ethnic majority and those who are neither socioeconomically disadvantaged or geographically isolated. Current data linkage has no capacity to link to adoptive, step or surrogate offspring, as Family Connections data are limited to biological relationships as recorded on birth certificates. Therefore, there was under-representation of non-traditional families in this study; and no method of discerning the nature of the relationship for the ($n=2$) same-sex parent families. No staging information is currently available in the WACR, which meant the acuity of offspring's experience of their parent's cancer was not thoroughly

understood in terms of disease severity or treatments received. Offspring cause of death was provided by the Cancer Registry, and therefore only available for offspring who had a cancer diagnosis and subsequently died within WA. Also, there were no data that described the relationships between offspring and their parents. In other words, some offspring may be estranged from their parents and potentially not affected by their parent's cancer, but this would not be represented in the data.

Conclusion

Results show a considerable number of offspring and their parents were impacted annually. Offspring would be sooner parentally bereaved if their parent was older, of low socioeconomic status, or residing in non-metropolitan regions. The considerable number of parental deaths due to cancer identified in this study and factors associated with time to death highlights the need for greater attention to be placed on bereavement support for offspring affected by parental cancer. Adolescent and young adult offspring are affected by parental cancer at an age that makes them vulnerable, given other challenges they are facing as part of their developmental trajectory. This research brings to attention the significant number of offspring affected by a parent's cancer. More attention must be given to these offspring and in particular, those affected by both parent's cancer and those experiencing bereavement due to parental cancer.

Implications for public health

Parental cancer is a problem in Australia, as family members who encounter the burden of illness are often overlooked by support services. This study is the first to report the number of adolescents and young adults (12–24 years) affected by a parent's incident cancer diagnosis in an Australian setting. These results are useful for the planning and implementation of supportive care services for these families, whose offspring are potentially at risk due to their developmental vulnerabilities.

Acknowledgements

This research was supported by grant funding from the University of WA School of Population and Global Health and CanTeen

Australia; and an Australian Government Research Training Program Scholarship.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary Table 1: Topography of parent's incident malignant cancer diagnosis.