Palliative and Supportive Care

cambridge.org/pax

Neuroblastoma survivors' self-reported late effects, quality of life, health-care use, and risk perceptions

Jessica Tan [1,2], Jordana K. McLoone, PH.D. [1,2], Claire E. Wakefield, PH.D. [1,2], Natasha Nassar, PH.D. [3,4], Richard J. Cohn, F.R.A.C.P. [1,2], Christina Signorelli, PH.D. [1,2] and on behalf of the ANZCHOG Survivorship Study Group

[1]Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW, Australia; [2]Discipline of Paediatrics & Child Health, School of Clinical Medicine, UNSW Medicine & Health, Randwick Clinical Campus, UNSW Sydney, Sydney, NSW, Australia; [3]Sydney School of Public Health, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia and [4]Children's Hospital at Westmead Clinical School, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

Original Article

Cite this article: Tan J, McLoone JK, Wakefield CE, Nassar N, Cohn RJ, Signorelli C (2024). Neuroblastoma survivors' self-reported late effects, quality of life, health-care use, and risk perceptions. *Palliative and Supportive Care* **22**, 296–305. https://doi.org/10.1017/S1478951523000615

Received: 23 May 2022
Revised: 18 December 2022
Accepted: 02 May 2023

Keywords:
Childhood cancer; Survivorship; Neuroblastoma; Late effects; Health-care use; Quality of life

Corresponding author: Christina Signorelli; Email: c.signorelli@unsw.edu.au

Abstract

Background. Survivors of childhood neuroblastoma are at risk of multiple treatment-related health problems (late effects), impacting their quality of life. While late effects and quality of life among Australia and New Zealand (ANZ) childhood cancer survivors have been reported, the outcomes of neuroblastoma survivors specifically have not been reported, limiting critical information to inform treatment and care.

Methods. Young neuroblastoma survivors or their parents (as proxy for survivors <16 years) were invited to complete a survey and optional telephone interview. Survivors' late effects, risk perceptions, health-care use, and health-related quality of life were surveyed and analyzed using descriptive statistics and linear regression analyses. In-depth interviews explored participants' experiences, knowledge, and perception of late effects and information needs. Thematic content analysis was used to summarize the data.

Results. Thirty-nine neuroblastoma survivors or parents completed questionnaires (median age = 16 years, 39% male), with 13 also completing interviews. Thirty-two participants (82%) reported experiencing at least 1 late effect, most commonly dental problems (56%), vision/hearing problems (47%), and fatigue (44%). Participants reported high overall quality of life (index = 0.9, range = 0.2–1.0); however, more participants experienced anxiety/depression compared to the population norm (50% met criteria versus 25%, $\chi^2 = 13$, $p < 0.001$). Approximately half of participants (53%) believed they were at risk of developing further late effects. Qualitatively, participants reported knowledge gaps in understanding their risk of developing late effects.

Conclusion. Many neuroblastoma survivors appear to experience late effects, anxiety/depression and have unmet cancer-related information needs. This study highlights important areas for intervention to reduce the impact of neuroblastoma and its treatment in childhood and young adulthood.

Introduction

Neuroblastoma is a neural crest cell malignancy affecting 14.6 per million children aged 0–5 years in a 10-year period since 2003 in Oceania (Hubbard et al. 2019). Compared to other childhood cancer survivors, neuroblastoma survivors have 1 of the lowest 5-year and 20-year relative survival rates (Baade et al. 2010). Unlike other childhood cancer survivors, the late mortality rates for neuroblastoma survivors have increased, partly attributable to increased survival among high-risk neuroblastoma patients that has also led to higher incidence of chronic disease (Armstrong et al. 2016). Late mortality in survivors is primarily due to disease recurrence, external or unknown causes, followed by long-term toxic side effects of neuroblastoma treatment, including second malignant neoplasms, pulmonary and cardiac complications (Laverdière et al. 2009).

Treatment-related chronic conditions (i.e. late effects) can appear years after treatment and are associated with poorer general health and psychosocial difficulties that can greatly reduce survivors' health-related quality of life (HRQoL) (Elzembely et al. 2019; Laverdière et al. 2009; Wilson et al. 2020). International studies have characterized the development of multiple late effects and their outcomes in neuroblastoma survivors (Laverdière et al. 2005; Wilson et al. 2020). Late effects are understudied in Australia and New Zealand (ANZ), where large

geographical areas serviced by few childhood cancer treatment centers (Ballantine et al. 2017; Jackson et al. 2020) may impact cancer-specific survivorship care and late-effects management (Barakat et al. 2012).

ANZ neuroblastoma survivors have been included in cancer survivorship studies exploring the prevalence of specific late effects, such as second malignancies (Wilson et al. 2009), pain and fatigue (Kelada et al. 2019), dental problems (Hsieh et al. 2011), primary gonadal insufficiency (Gunn et al. 2016), and psychological problems (Roberts et al. 2014; Yallop et al. 2013). Only a single institution study in ANZ has reported a range of late effects in neuroblastoma survivors treated with autologous stem cell transplantation (Trahair et al. 2007). A nation-wide data linkage study has described the incidence, survival, and recurrence of neuroblastoma in the past 3 decades and explored the incidence of secondary malignancies (Youlden et al. 2020). However, neuroblastoma survivors have significant risks for developing a range of severe late effects and are among the highest risk for hospitalization compared to other childhood cancer survivors due to the intensity of the treatment they receive and the young age at which they are treated (de Fine Licht et al. 2017). Thus, the needs of this group should be considered carefully to understand their unique health issues, which may be masked by inclusion in larger childhood cancer survivor studies.

Previous studies have shown that childhood cancer survivors' knowledge of late effects and understanding of their risk of developing late effects is poor (Lee et al. 2019; Syed et al. 2016; Vetsch et al. 2017). These showed that a substantial proportion of survivors who were exposed to toxic treatment were not concerned about their risk of developing late effects (Gibson et al. 2018). Inaccurate risk perceptions can dissuade survivors from engaging with follow-up care and positive health behaviors (Signorelli et al. 2019b), which can delay the detection of late effects and result in poorer health outcomes (Signorelli et al. 2017a). Determining neuroblastoma survivors' risk perceptions is therefore vital to understand potential barriers to engagement in follow-up care.

Characterizing the broad range of late effects experienced by ANZ neuroblastoma survivors may inform the design of interventions to minimize morbidity and mortality and provide care that meets neuroblastoma survivors' needs. In this study, we aimed to describe neuroblastoma survivors' self or proxy-reported late effects, HRQoL, health-care use (e.g. hospitalizations and health professional visits), and risk perception for future health problems (including late effects and cancer recurrence).

Methods

Participants

We recruited neuroblastoma survivors as a part of the Australian and New Zealand Childhood Cancer Survivorship Study (Signorelli et al. 2019a). We obtained ethics approval from the South Eastern Sydney Local Health District and each participating site. All participants provided written consent. We identified survivors using the electronic medical records of each of the 11 hospitals in ANZ that treat pediatric oncology cases. Survivors were eligible if they were diagnosed with neuroblastoma before the age of 16 years, had completed active treatment, and were at least 5 years post-diagnosis at study participation. If survivors were <16 years, their parents completed the questionnaire on their behalf.

Data collection

A hard copy and online link to the questionnaire and consent form were sent to participants, with nonrespondents followed up by telephone after 4 weeks. Within the questionnaire, participants were invited to take part in an optional telephone interview to discuss their experiences and perceptions of late effects in more depth. Those who agreed were mailed a second consent form, and a suitable interview time was arranged. We conducted semi-structured interviews over the phone and transcribed the interviews verbatim.

Study outcomes and measures

Study outcomes collected included survivor or proxy-reported late effects, HRQoL, perceived risk and worry about cancer recurrence and the development of late effects, previous hospitalizations, and health professional visits for self-perceived cancer-related reasons since finishing cancer treatment. We asked participants to indicate from a list of 19 late effects (listed in Fig. 1; response options "yes/no") which conditions survivors experienced and which they believed were related to their cancer treatment (i.e. conditions which predated their diagnosis) based on commonly experienced late effects reported by survivors. Survivors' HRQoL was measured using the EQ-5D instrument, and each health state was measured on a 5-point scale (1 = "no problems" and 5 = "I am unable to") and then weighted using England EQ-5D-5L value set (Devlin et al. 2018) to calculate the index value from 0 to 1 (0 = the health state equivalent to dead and 1 = the value of full health). These values were compared to a large adult community sample reflecting Australian norms (McCaffrey et al. 2016). In interviews, we asked survivors or their parents about the survivor's experience of late effects, their knowledge of and perceived risk for developing future late effects, and their need for information about late effects. A full list of measures and the interview schedule can be found in Supplementary Table S1.

The study questionnaires collected survivors' self-reported demographic, diagnostic, and clinical information (Table 1). Clinical information such as treatment intensity was measured according to the Intensity of Treatment Rating Scale (ITR-3) (Kazak et al. 2012), which uses treatment modality and disease stage at diagnosis to categorize treatment from least intensive (e.g. received surgery only) to most intensive (e.g. received transplant) across 4 categories. Survivors were grouped into 3 treatment regimen eras (<1984, 1984–2004, and >2005) based on the different treatment protocols used at hospital in their year of diagnosis.

Data analysis

We summed self-reported late effects to indicate a cumulative burden, which we described using descriptive statistics. We used chi-squared tests to understand potential group differences in outcomes. Using linear regressions, we analyzed the association between clinical information (e.g. treatment type) and demographic factors (e.g. age) on the total number of self-reported late effects. We used SPSS26.0 (IBM Corp 2019) to perform quantitative analysis. Results were considered significant when $p < 0.05$ for 2-tailed tests.

We analyzed interview data using thematic content analysis guided by Miles and Huberman (1994). After deciding on an initial coding tree, 2 researchers coded and compared 30% of interviews (J.T. and C.S.) to ensure consistency. One researcher (J.T.)

https://doi.org/10.1017/S1478951523000615 Published online by Cambridge University Press

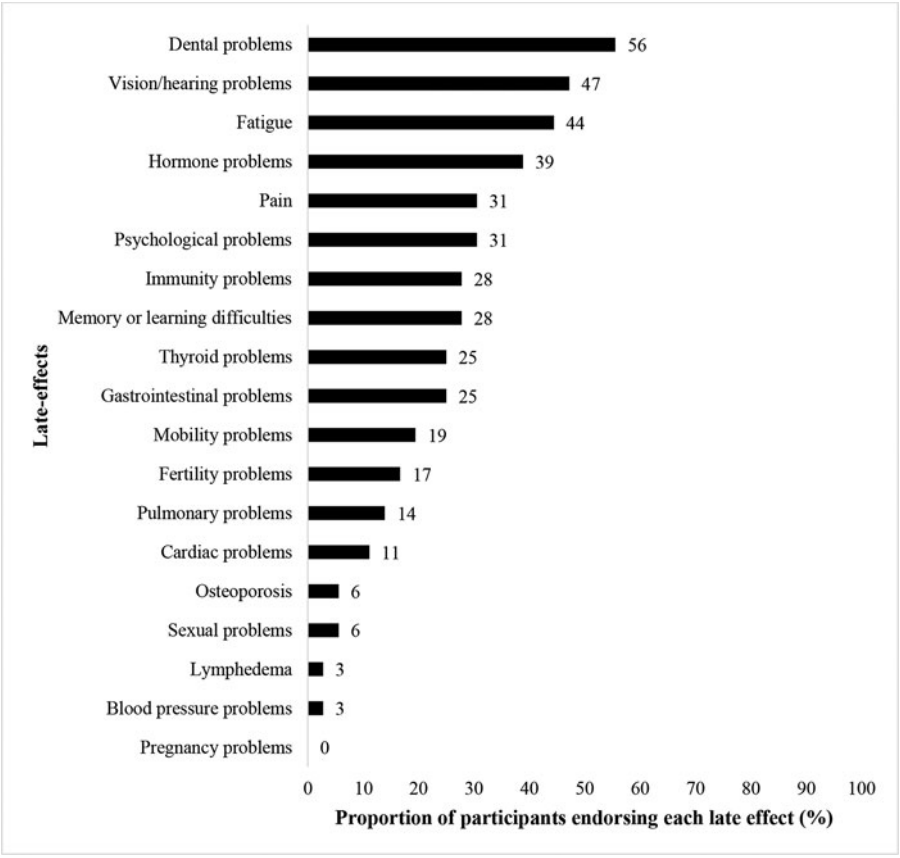

Figure 1. Self or proxy-reported late effects experienced by neuroblastoma survivors.

coded the remainder of interviews line-by-line using NVivo12 (QSR International Pty Ltd 2018). We established codes using a combination of predetermined themes based on our research questions (e.g. for perceived risk of developing future late effects: decreasing, increasing, or unsure) and themes arising inductively from the data (e.g. unique experiences of late effects).

Results

Sample characteristics

Of the 634 childhood cancer survivors who completed questionnaires from 11 hospitals in ANZ as part of the ANZCHOG Survivorship Study, 39 were neuroblastoma survivors ($n = 39/69$, 57% response rate), including 20 survivors aged 16 and over and 19 parents representing survivors aged under 16 years (Table 1). We did not observe any differences between participating and nonrespondent neuroblastoma survivors in terms of age ($p = 0.840$) or sex ($p = 0/059$). Of these, 13 participants also completed interviews (4 survivors and 9 parents). Although 39 participants completed the survey, 3 reported incomplete diagnosis and/or treatment information, meaning that we could not categorize their treatment intensity.

The median age of neuroblastoma survivors at the time of survey completion was 16 years (IQR = 11.0–20.5 years) and 39% were male. Most participants identified as Australian or New Zealand citizens (73%) and lived in metropolitan areas (78%). The median age of survivors at diagnosis was 9 months (IQR = 3.0–27.5) and most were diagnosed between 1984 and 2004 (69%). Most participants reported being diagnosed with high-risk disease (72%). Survivors were treated with surgery (92%), chemotherapy (85%), bone marrow transplant (47%), and radiotherapy (39%). Most survivors received the highest level of treatment intensity on the ITR-3 (52%).

Late effects

Self-reported late effects (n = 39)

The median number of late effects reported by participants from the provided list was 3.5 (IQR = 2.0–6.0). Of the 19 late effects studied, the most common reported late effects were dental problems (56%), followed by vision/hearing problems (47%) and fatigue (44%; Fig. 1). Thirty-two participants (89%) reported experiencing at least 1 late effect since finishing cancer treatment. Eleven participants (31%) indicated more than 5 late effects (Fig. 2), 8 of whom were diagnosed with high-risk disease (89%). The highest average number of late effects was reported by those diagnosed before 1984 (6) followed by 1984–2004 (4.3) and after 2005 (3.6; Fig. 3).

In univariate regression analyses, compared with survivors with few late effects, those who reported experiencing a greater number of cancer-related late effects reported high-risk disease ($b = 3.69$, $p = 0.04$, CI 95% = 0.23–7.16), had received radiation therapy ($b = 4.00$, $p = 0.001$, CI 95% = 1.78–6.23), and had received a bone marrow transplant ($b = 4.59$, $p < 0.001$, CI 95% = 2.67, 6.51). Survivors with few late effects also reported attending survivorship clinic ($b = 2.95$, $p = 0.02$, CI 95% = 0.60–5.31), were unemployed ($b = -2.70$, $p = 0.05$, CI 95% = −5.37 to −0.03), and had poorer self-reported overall health ($b = -4.68$, $p = 0.001$, CI 95% = −7.36 to −2.00; Supplementary Table S2). There was no difference in the number of late effects by any other factors, including treatment regimen era.

https://doi.org/10.1017/S1478951523000615 Published online by Cambridge University Press

Table 1. Survivor and parent demographics and clinical characteristics ($n = 39$)

Characteristic	*N* (%) Survivors $n = 20$ (51%)	*N* (%) Parents $n = 19$ (49%)
Survivor gender		
Male	15 (39)	–
Female	24 (62)	–
Survivor age (median, IQR)	16, 11–25.5	–
<16	16 (43)	–
16–20	12 (32)	–
21–30	5 (14)	–
31–40	4 (11)	–
Relationship to the survivor		
Father	–	4 (22)
Mother	–	14 (78)
Self-reported ethnic background*[,b]	–	–
Australian or New Zealander	16 (80)	11 (65)
Not Australian or New Zealander	4 (20)	6 (35)
Religion*		
No religion	5 (26)	8 (44)
Christian	13 (69)	10 (56)
Buddhism	1 (5)	0 (0)
Area of residence*[,a]		
Metro	16 (80)	13 (77)
Regional or remote	4 (20)	4 (23)
Education*		
High school or apprenticeship	13 (62)	5 (28)
Post school education (e.g. TAFE or university)	8 (38)	13 (72)
Income*[,c]		
Less than $60,000AUD	12 (67)	3 (18)
More than $60,000 AUD	6 (33)	14 (82)
Employment*		
Not currently employed	6 (29)	3 (17)
Currently employed	15 (71)	15 (83)
Marital status*	–	–
Not currently married or de facto	17 (81)	1 (6)
Currently married or de facto	4 (19)	16 (94)
Age at diagnosis (median, IQR) (months)	9, 9–27.5	–
<18 months	24 (65)	–
>18 months	13 (35)	–
Era of diagnosis (based on treatment regimen)		
<1984	1 (3)	–
1984–2004	24 (69)	–
>2005	10 (28)	–
Self or proxy-reported level of risk	–	–
Low	3 (10)	–
Intermediate	5 (17)	–
High	21 (73)	–
Treated with surgery	–	–
Yes	35 (92)	–
No	3 (8)	–
Treated with chemotherapy	–	–
Yes	33 (85)	–
No	6 (15)	–
Treated with radiotherapy	–	–
Yes	13 (39)	–
No	20 (61)	–
Received bone marrow transplant	–	–
Yes	17 (47)	–
No	19 (53)	–
Treatment intensity (according to ITR-3)	–	–
Least intensive treatments	3 (9)	–
Moderately intensive treatments	2 (6)	–
Very intensive treatments	11 (33)	–
Most intensive treatments	17 (52)	–
Years since diagnosis (median, IQR)	13, 9–18	–
Years since treatment completion (median, IQR)	12, 12–17	–
Number of late effects experienced (median, IQR)	3, 2–6	–
Currently attends a survivorship clinic	–	–
Yes	24 (63)	–
No	14 (37)	–

–, not applicable; ITR-3, Intensity of Treatment Rating scale; IQR, interquartile range; AUD, Australian Dollar.
Study population ($N = 39$). Numbers may not add up due to missing values.
*These factors referred to the survivor's parent if the survivor was under 16 years of age.
[a]According to the Area of Remoteness Index Australia classifications.
[b]Not Australian or New Zealander included ethnicities such as European, Vietnamese, and Cuban.
[c]Based on the median personal income in Australia.

https://doi.org/10.1017/S1478951523000615 Published online by Cambridge University Press

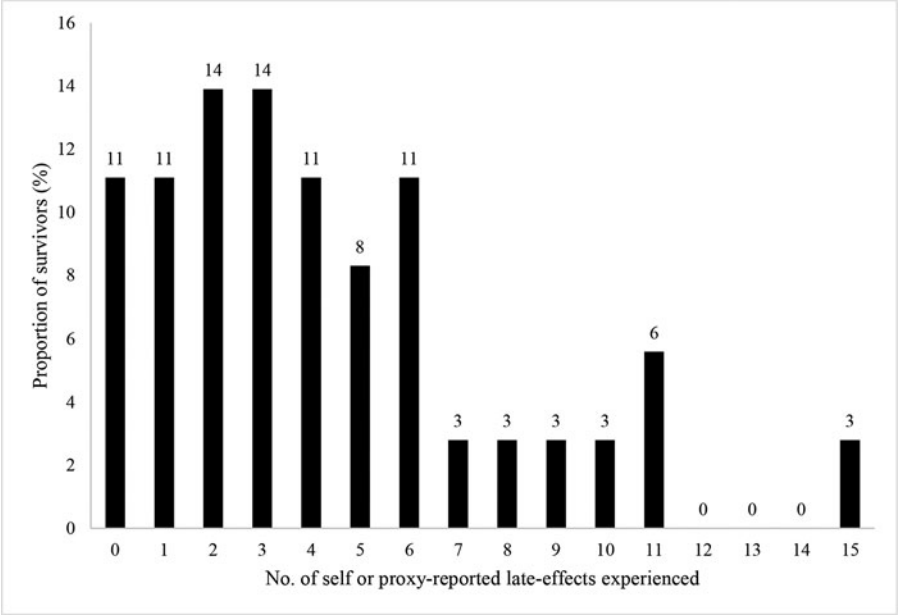

Figure 2. The frequency of self or proxy-reported late effects experienced by neuroblastoma survivors.

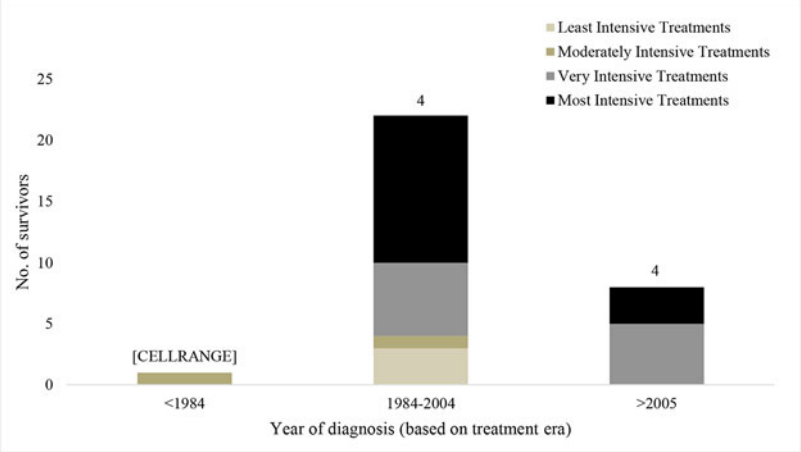

Figure 3. Number of participants reporting the survivor's experienced late effects, by treatment era and treatment intensity (based on the ITR-3); the average number of total late effects reported is labeled above each column.

Perceived risk of late effects

Less than half of participants (40%) believed that the survivor was at risk of cancer recurrence and 50% of the sample reported that they worried about the possibility of cancer recurrence. Approximately half (53%) of all participants believed that they were at risk of developing future late effects and 50% reported that they worried about the survivors' risk of developing late effects in the future. Of those who did not believe that the survivor was at risk of developing future late effects, 17% still reported worrying about the survivor's risk.

Survivors' health-related quality of life (n = 39)

Most participants (62%) reported deficits in an average of 1.3 dimensions (range = 0–5) in any of the 5 quality of life dimensions. Participants (50%) reported significantly more problems with anxiety/depression than the general population (4.7%; $\chi^2 = 13.1$, $p < 0.001$) (McCaffrey et al. 2016). We did not observe any differences between survivors and the general population in any other dimensions (all $p < 0.05$; Fig. 4) (McCaffrey et al. 2016).

The mean quality of life index score for survivors was high (0.9, SD = 0.1, range = 0.2–1). There was no difference in the mean quality of life index scores compared to population norms ($t(37) = -0.68$, $p = 0.50$). Participants generally rated survivors' overall health to be good in the past 4 weeks (81%). The mean overall self or proxy-reported health score was 77 (SD = 16, range = 30–100). There was no difference between the overall self or proxy-reported health of our survivor population and population norms ($t(37) = -0.44$, $p = 0.66$).

Health-care use (n = 39)

Hospitalizations

Almost half of all participants reported that the survivor had been hospitalized on one or more occasions since their cancer treatment had finished (49%). The median number of days hospitalized was 4 (IQR = 2–9). The most common reasons for hospitalization

https://doi.org/10.1017/S1478951523000615 Published online by Cambridge University Press

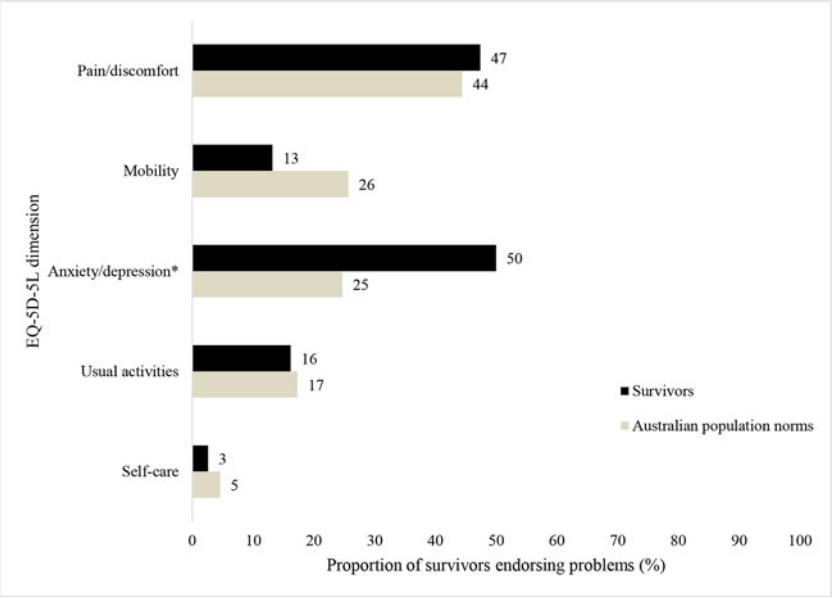

Figure 4. Proportion of neuroblastoma survivors or parent proxies endorsing problems in each 5 level EQ-5D (EQ-5D-5L) dimension compared to Australian population norms (McCaffrey et al. 2016). *$p < 0.001$.

included surgical procedures (e.g. oral surgery; 30%), other reasons (e.g. management of benign tumors; 20%), appendectomy (15%), infections (15%), and accidents and injuries (15%).

Health professional visits

Almost all participants reported that survivors had seen at least one health professional (97%) for any cancer-related care since treatment completion. The median number of health professionals seen since cancer treatment completion was 3.5 (IQR = 2–7). The most visited health professionals since cancer treatment were oncologists (68%), followed by general practitioners (GP; 62%), ears/eyes specialists (47%), and dentists (46%; Supplementary Fig. S1). Two-thirds of survivors (63%) reported that they attended survivorship clinic at a tertiary center.

Interview on survivors' perceptions regarding late effects and their future health (n = 13 interviews)

During interviews, some participants reported that late effects greatly impacted the survivor's life, years after treatment completion (Supplementary Table S3), "all the side effects and things [from often having surgery] … it still to this day does cause issues in the way … I bond with my family" (female survivor aged 19 years). Many survivors and their parents expressed emotional impacts resulting from bullying from peers due to short physical stature, scars from surgery, hormone-induced puberty, and distressing memories of their treatment. These were reported to manifest emotionally as mood swings, anger, distress, disassociation, and anxiety associated with undergoing medical procedures. Others expressed notable physical impacts such as abnormal bowel movements and exercise intolerance, which were described as problematic and difficult to overcome.

Six survivors or their parents could not recall hearing of the term "late effects" or had very limited understanding of survivors' risk of developing late effects. In general, most parents recalled receiving information regarding late effects during treatment; however, the effects of treatment may not have been understood at that time. One parent attending a cancer survivorship clinic expressed a knowledge gap in understanding the relationship between treatment and dental problems: "His adult teeth are smaller than his children's teeth but again you say well that was his teeth, [treatment] was done all on his tummy" (mother of survivor aged 13). Another parent attending a cancer survivorship clinic expressed uncertainty regarding the cause of the survivor's short stature: "He's quite a bit smaller than his peers. We think some of that is to do with the radiation" (mother of survivor aged 16).

Participants had mixed preferences for receiving ongoing personalized information about their risk of developing late effects. While some valued the idea of receiving information about their personal late effects risk, others expressed a desire not to receive any further information. One parent described balancing the desire to be "informed about what possibly is around the corner," with understanding that receiving information is "a two-edged sword," which may induce anxiety and "scares us" (mother of survivor aged 11). Another parent described that at present she had received "more than enough information," accepting that her child's future health was ultimately "a wide unknown" (mother of survivor aged 13 years).

Some participants could not recall receiving lifestyle information, and therefore expressed an unmet need for information regarding preventative interventions and identifying warning signs for developing late effects or recurrent cancers. One parent expressed a desire to know how dietary factors could be managed in the present to improve survivors' quality of life in the future. Another parent suggested that information relating to "[not] smoking and what he eats" be communicated to survivors from "a young guy of his age … rather than hearing it from parents" (father of survivor aged 13) as survivors mature and take responsibility for their own health.

Discussion

Our study measured self or proxy-reported health conditions in a cohort of ANZ neuroblastoma survivors to understand the burden of late effects, survivors' health-care use, HRQoL, and participants' knowledge of late effects and future health. Participants generally

https://doi.org/10.1017/S1478951523000615 Published online by Cambridge University Press

reported good overall health. Eighty-nine percent of participants reported survivors experiencing at least one late effect, most commonly dental problems (56%), vision/hearing problems (47%), and fatigue (44%). A larger proportion of participants reported problems with anxiety/depression compared to the general population and half reported worrying about their future health. In interviews, many participants described that they had poor knowledge of late effects and were uncertain of the survivor's risk of developing late effects, despite the perceived benefits of attending a survivorship clinic.

The proportion of neuroblastoma survivors in our study experiencing at least one late effect (89%) is comparable to that found in stage 4 or high-risk neuroblastoma survivors in other studies (80–100%; median age = 10–15 years) (Hobbie et al. 2008; Laverdière et al. 2005; Moreno et al. 2013). Although the prevalence of late effects is known to increase with time (Oeffinger et al. 2006), our study found no difference in the number of late effects experienced and the treatment era of diagnosis. This could possibly be explained by escalating treatment intensity in recent decades (Armstrong et al. 2016) or by better awareness of late effects among more recently diagnosed survivors who are likely to still be engaged in survivorship care (Klosky et al. 2008). Alternatively, survivors with more severe late effects from earlier treatment periods may have died prior to this study. Considering our cohort is young (median age = 16), continued follow-up is needed to understand the changes to the frequency of late effects as neuroblastoma survivors age and the incidence of late effects grows (Hudson et al. 2013; Oeffinger et al. 2006).

Our study drew attention to the high proportion of neuroblastoma survivors experiencing dental problems, which was more prevalent than other high-risk neuroblastoma studies (56% versus 13–51%) (Cohen et al. 2014; Laverdière et al. 2005; Perwein et al. 2011). Known dental problems in neuroblastoma survivors include caries, microdontia, and root stunting (Kaste et al. 1998) and are often not life-threatening and may be overlooked or neglected in follow-up care. However, these problems can significantly affect quality of life and morbidity through pain, functional deficits (e.g. poor nutrition and speech difficulties), ongoing financial toxicity, and cosmetic concerns precipitating psychosocial challenges (Carneiro et al. 2017; Meaney et al. 2011; Noronha and Macdonald 2016). Furthermore, periodontal disease has been found to be significantly associated with cardiovascular disease in the general community (Mozos and Stoian 2019), which may be more deleterious in neuroblastoma survivors who are already at a heightened risk of dyslipidemia, insulin resistance, and cardiac late effects (Meacham et al. 2010; Neville et al. 2006). Since dental problems in survivors are associated with younger age at diagnosis and treatment (Gawade et al. 2014), which is common in neuroblastoma (London et al. 2005), oral care education, thorough examination and documentation of dental problems, and financial support for dental care are paramount in preventing complications and improving quality of life.

While fatigue has not been specifically studied in neuroblastoma survivors, the proportion reporting fatigue in our cohort is higher than in survivors of other childhood cancers (44% versus 19–30%) (Mulrooney et al. 2008). Taking into account the median time since diagnosis of our cohort (13 years versus 20–24 years (Mulrooney et al. 2008)), this may be explained by "response-shift," where those diagnosed more recently have not yet adapted to a new internal standard of measurement for fatigue (Visser et al. 2000). However, fatigue is a complex symptom, and understanding its mechanisms, including determining the trends of fatigue symptoms over time and whether levels of fatigue differ significantly from the general population, is still to be elucidated (Frederick et al. 2016; Jóhannsdóttir et al. 2012; Karimi et al. 2020; Langeveld et al. 2003; Mört et al. 2011; Mulrooney et al. 2008; Rach et al. 2017; Zeltzer et al. 1997). Since fatigue has been found to be the most powerful predictor of functional status and HRQoL in a cohort of childhood cancer survivors (Meeske et al. 2007) and was the third most commonly reported late effect experienced in our cohort, further study on the nature of fatigue in neuroblastoma survivors is needed.

Our findings echo previous studies reporting poorer emotional health among survivors compared to the general population (Nathan et al. 2007; Wilson et al. 2020). Poor psychological health can promote risky health behaviors and exacerbate health conditions (Brinkman et al. 2018; Karimi et al. 2020). For example, higher levels of depression and social withdrawal are associated with reduced exercise and obesity, which can increase survivors' already heightened risk of metabolic syndrome and cardiac conditions (Krull et al. 2010). The compounding nature of late effects and poor emotional health, and their risk to future health and HRQoL, call for further investigation and careful intervention.

Many neuroblastoma survivors reported visiting their GP for cancer-related care, a higher proportion than childhood cancer survivors in a similar study (62% versus 23%) (Signorelli et al. 2019c). High proportion of GP visits may be explained by the young median age of this cohort (16 years) who were treated with aggressive treatment (52% receiving the most intensive treatment), given those treated more recently and with high-risk treatment are more likely to visit for cancer-related care (Oeffinger et al. 2004). Since we did not collect the reason for these visits, further study is needed to assess increased primary health-care use in neuroblastoma survivors.

Our participants reported modest survivorship clinic engagement compared to other childhood cancer survivors in a UK study (63% versus 15%–82%) (Knighting et al. 2020). Perceived susceptibility to developing late effects may be important in survivors' ability to learn about their risk and seek recommended surveillance (Cherven et al. 2014; Gibson et al. 2018; Signorelli et al. 2019a, 2019b). In our cohort, only 53% of our cohort believed they were at risk of developing further late effects, despite 85% receiving very/most intensive treatment according to ITR-3.

Facilitating access to more information about late effects may empower survivors to make informed decisions about their health, promote health protective behaviors, lower distress, and improve quality of life (Gianinazzi et al. 2014; Landier et al. 2006). Many parents recalled receiving late effects information but were uncertain or unsure of the survivor's future health risks, which may suggest that late effects information is not understood or not perceived as salient at the time of treatment and is thus misremembered or may not be passed from parent to survivor as they mature if attendance at the survivorship clinic is stopped (Gianinazzi et al. 2014). Since information needs can be addressed in a survivorship clinic (Signorelli et al. 2017b), which has other demonstrated benefits (Signorelli et al. 2017a; Sutradhar et al. 2015), a greater focus on improving both survivors' attendance at survivorship clinic and information delivery is needed. Although most interviewees in this study were parents who may have different or more unmet information needs than survivors themselves (Knijnenburg et al. 2010; Vetsch et al. 2017), our findings reinforce the need for more effective and consistent information delivery tailored to each survivor's personal wishes and circumstances (Gianinazzi et al. 2014).

https://doi.org/10.1017/S1478951523000615 Published online by Cambridge University Press

We examined a wide variety of somatic and psychological late effects in neuroblastoma survivors, using validated tools and interviews that provided rich insight into the personal impacts of late effects and cancer treatment. Our study relied on self or proxy-reported data, which is vulnerable to participants' perceptions of their condition, or knowledge/understanding of the listed late effects, and may underrepresent the true incidence of late effects that require clinical testing such as pulmonary conditions (Hudson et al. 2013; Stone et al. 2017), or are present but currently undiagnosed. Since vision/hearing issues were asked together in the survey, we were unable to determine the exact proportion experiencing each late effect or compare these to other studies. Due to our small sample size ($n = 39$), our study is vulnerable to type 1 and 2 errors. Thus, care must be taken when extrapolating our findings to the general neuroblastoma survivor population.

The high burden of late effects and gaps in survivors' knowledge of late effects pose risks to the future health and quality of life of ANZ neuroblastoma survivors. This study draws attention to the high rates of dental problems, the poor emotional health in neuroblastoma survivors compared to the general population, and their specific information needs. More effective ways of educating and engaging survivors' families in follow-up care is needed to prevent, screen for, and manage late effects and improve survivors' quality of life.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951523000615.

Data availability statement. The data that support the findings of this study are not publicly available due to privacy or ethical restrictions, and the full dataset is not able to be released due to ethical restrictions. Requests may be made to the authors.

Acknowledgments. We would like to thank Dr Kate Hetherington, Brittany McGill, and Mary-Ellen Brierley who helped to conduct interviews. We would also like to thank the families who participated and each of the recruiting sites for this study, including Sydney Children's Hospital Randwick, the Children's Hospital at Westmead, John Hunter Children's Hospital, the Royal Children's Hospital Melbourne, Monash Children's Hospital Melbourne, Royal Children's Hospital Brisbane, Princess Margaret Children's Hospital, Women's and Children's Hospital Adelaide, and in New Zealand, Starship Children's Health, Wellington Hospital, and Christchurch Hospital.

The members of the ANZCHOG Survivorship Study Group in alphabetical order: Dr Frank Alvaro, Prof Richard Cohn, Dr Rob Corbett, Dr Peter Downie, Ms Karen Egan, Ms Sarah Ellis, Prof Jon Emery, Dr Joanna Fardell, Ms Tali Foreman, Dr Melissa Gabriel, Prof Afaf Girgis, Ms Kerrie Graham, Ms Karen Johnston, Dr Janelle Jones, Dr Liane Lockwood, Dr Ann Maguire, Dr Maria McCarthy, Dr Jordana McLoone, Dr Francoise Mechinaud, Ms Sinead Molloy, Ms Lyndal Moore, Dr Michael Osborn, Dr Christina Signorelli, Dr Jane Skeen, Dr Heather Tapp, Ms Tracy Till, Ms Jo Truscott, Ms Kate Turpin, Prof Claire Wakefield, Ms Jane Williamson, Dr Thomas Walwyn, and Ms Kathy Yallop.

Funding. Dr Christina Signorelli is supported by Neuroblastoma Australia and a Cancer Institute NSW Fellowship (2020/ECF1144). Prof Claire E. Wakefield is supported by a Career Development Fellowship from the National Health and Medical Research Council (NHMRC) of Australia (APP1143767 and APP2008300). Dr Natasha Nassar is supported by Financial Markets foundation for Children and NHMRC Investigator Fellowship (APP1197940). This study was funded by Neuroblastoma Australia and the Kids Cancer Alliance. The Behavioural Sciences Unit (BSU) is proudly supported by the Kids with Cancer Foundation. The BSU's survivorship research program is funded by The Kids' Cancer Project and a Cancer Council NSW Program Grant PG16-02 with the support of the Estate of the Late Harry McPaul. These funding bodies did not have any role in the study, nor did they have a role in the writing of the manuscript or the decision to submit it for publication.

Competing interests. No author has any conflicts of interest to disclose in relation to this manuscript.

References

Armstrong GT, Chen Y, Yasui Y, *et al.* (2016) Reduction in late mortality among 5-year survivors of childhood cancer. *New England Journal of Medicine* **374**(9), 833–842. doi:10.1056/NEJMoa1510795

Baade PD, Youlden DR, Valery PC, *et al.* (2010) Population-based survival estimates for childhood cancer in Australia during the period 1997–2006. *British Journal of Cancer* **103**(11), 1663–1670. doi:10.1038/sj.bjc.6605985

Ballantine KR, Watson H, Macfarlane S, *et al.* (2017) Small numbers, big challenges: Adolescent and young adult cancer incidence and survival in New Zealand. *Journal of Adolescent and Young Adult Oncology* **6**(2), 277–285. doi:10.1089/jayao.2016.0074

Barakat LP, Schwartz LA, Szabo MM, *et al.* (2012) Factors that contribute to post-treatment follow-up care for survivors of childhood cancer. *Journal of Cancer Survivorship* **6**(2), 155–162. doi:10.1007/s11764-011-0206-6

Brinkman TM, Recklitis CJ, Michel G, *et al.* (2018) Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood cancer: Current state of the literature. *Journal of Clinical Oncology* **36**(21), 2190–2197. doi:10.1200/JCO.2017.76.5552

Carneiro TV, Ribeiro ILA, Alves CV, *et al.* (2017) Factors associated with health-related quality of life among children with cancer from the standpoint of patients and caregivers. *Journal of Public Health* **25**(4), 371–377. doi:10.1007/s10389-017-0791-6

Cherven B, Mertens A, Meacham LR, *et al.* (2014) Knowledge and risk perception of late effects among childhood cancer survivors and parents before and after visiting a childhood cancer survivor clinic. *Journal of Pediatric Oncology Nursing* **31**(6), 339–349. doi:10.1177/1043454214532022

Cohen L, Gordon J, Popovsky E, *et al.* (2014) Late effects in children treated with intensive multimodal therapy for high-risk neuroblastoma: High incidence of endocrine and growth problems. *Bone Marrow Transplantation* **49**(4), 502–508. doi:10.1038/bmt.2013.218

de Fine Licht S, Rugbjerg K, Gudmundsdottir T, *et al.* (2017) Long-term inpatient disease burden in the Adult Life after Childhood Cancer in Scandinavia (ALiCCS) study: A cohort study of 21,297 childhood cancer survivors. *PLoS Medicine* **14**(5), e1002296. doi:10.1371/journal.pmed.1002296

Devlin NJ, Shah KK, Feng Y, *et al.* (2018) Valuing health-related quality of life: An EQ-5D-5L value set for England. *Health Economics* **27**(1), 7–22. doi:10.1002/hec.3564

Elzembely MM, Dahlberg AE, Pinto N, *et al.* (2019) Late effects in high-risk neuroblastoma survivors treated with high-dose chemotherapy and stem cell rescue. *Pediatric Blood & Cancer* **66**(1), e27421. doi:10.1002/pbc.27421

Frederick NN, Kenney L, Vrooman L, *et al.* (2016) Fatigue in adolescent and adult survivors of non-CNS childhood cancer: A report from project REACH. *Supportive Care in Cancer* **24**(9), 3951–3959. doi:10.1007/s00520-016-3230-2

Gawade PL, Hudson MM, Kaste SC, *et al.* (2014) A systematic review of dental late effects in survivors of childhood cancer. *Pediatric Blood & Cancer* **61**(3), 407–416. doi:10.1002/pbc.24842

Gianinazzi ME, Essig S, Rueegg CS, *et al.* Swiss Paediatric Oncology Group (SPOG) (2014) Information provision and information needs in adult survivors of childhood cancer. *Pediatric Blood & Cancer* **61**(2), 312–318. doi:10.1002/pbc.24762

Gibson TM, Li C, Armstrong GT, *et al.* (2018) Perceptions of future health and cancer risk in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer* **124**(16), 3436–3444. doi:10.1002/cncr.31397

Gunn HM, Rinne I, Emilsson H, *et al.* (2016) Primary gonadal insufficiency in male and female childhood cancer survivors in a long-term follow-up clinic. *Journal of Adolescent and Young Adult Oncology* **5**(4), 344–350. doi:10.1089/jayao.2016.0007

Hobbie WL, Moshang T, Carlson CA, *et al.* (2008) Late effects in survivors of tandem peripheral blood stem cell transplant for high-risk neuroblastoma. *Pediatric Blood & Cancer* **51**(5), 679–683. doi:10.1002/pbc.21683

Hsieh SG-S, Hibbert S, Shaw P, *et al.* (2011) Association of cyclophosphamide use with dental developmental defects and salivary gland dysfunction in recipients of childhood antineoplastic therapy. *Cancer* **117**(10), 2219–2227. doi:10.1002/cncr.25704

Hubbard AK, Spector LG, Fortuna G, *et al.* (2019) Trends in international incidence of pediatric cancers in children under 5 years of age: 1988–2012. *JNCI Cancer Spectrum* **3**(1). doi:10.1093/jncics/pkz007

Hudson MM, Ness KK, Gurney JG, *et al.* (2013) Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA* **309**(22), 2371–2381. doi:10.1001/jama.2013.6296

IBM Corp (2019) IBM SPSS statistics for windows [Software]. Armonk (NY): IBM Corp.

Jackson CGCA, Bissett I, Macfarlane S, *et al.* (2020) Improving cancer services and survival in New Zealand. *Journal of Cancer Policy* **23**, 100216. doi:10.1016/j.jcpo.2020.100216

Jóhannsdóttir IMR, Hjermstad MJ, Moum T, *et al.* (2012) Increased prevalence of chronic fatigue among survivors of childhood cancers: A population-based study. *Pediatric Blood & Cancer* **58**(3), 415–420. doi:10.1002/pbc.23111

Karimi M, Cox AD, White SV, *et al.* (2020) Fatigue, physical and functional mobility, and obesity in pediatric cancer survivors. *Cancer nursing* **43**(4), E239–e245. doi:10.1097/NCC.0000000000000712

Kaste SC, Hopkins KP, Bowman LC, *et al.* (1998) Dental abnormalities in children treated for neuroblastoma. *Medical and Pediatric Oncology* **30**(1), 22–27. doi:10.1002/(SICI)1096-911X(199801)30:1<22::AID-MPO8>3.0.CO;2-2

Kazak AE, Hocking MC, Ittenbach RF, *et al.* (2012) A revision of the intensity of treatment rating scale: Classifying the intensity of pediatric cancer treatment. *Pediatric Blood & Cancer* **59**(1), 96–99. doi:10.1002/pbc.23320

Kelada L, Wakefield CE, Heathcote LC, *et al.* (2019) Perceived cancer-related pain and fatigue, information needs, and fear of cancer recurrence among adult survivors of childhood cancer. *Patient Education and Counseling* **102**(12), 2270–2278. doi:10.1016/j.pec.2019.06.022

Klosky JL, Cash DK, Buscemi J, *et al.* (2008) Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. *Journal of Cancer Survivorship* **2**(4), 225. doi:10.1007/s11764-008-0063-0

Knighting K, Kirton JA, Thorp N, *et al.* (2020) A study of childhood cancer survivors' engagement with long-term follow-up care: 'To attend or not to attend, that is the question.' *European Journal of Oncology Nursing* **45**, 101728. doi:10.1016/j.ejon.2020.101728

Knijnenburg SL, Kremer LC, van den Bos C, *et al.* (2010) Health information needs of childhood cancer survivors and their family. *Pediatric Blood & Cancer* **54**(1), 123–127. doi:10.1002/pbc.22207

Krull KR, Huang S, Gurney JG, *et al.* (2010) Adolescent behavior and adult health status in childhood cancer survivors. *Journal of Cancer Survivorship: Research and Practice* **4**(3), 210–217. doi:10.1007/s11764-010-0123-0

Landier W, Wallace WHB and Hudson MM (2006) Long-term follow-up of pediatric cancer survivors: Education, surveillance, and screening. *Pediatric Blood & Cancer* **46**(2), 149–158. doi:10.1002/pbc.20612

Langeveld NE, Grootenhuis MA, Voûte PA, *et al.* (2003) No excess fatigue in young adult survivors of childhood cancer. *European Journal of Cancer* **39**(2), 204–214. doi:10.1016/S0959-8049(02)00629-9

Laverdière C, Cheung NKV, Kushner BH, *et al.* (2005) Long-term complications in survivors of advanced stage neuroblastoma. *Pediatric Blood & Cancer* **45**(3), 324–332. doi:10.1002/pbc.20331

Laverdière C, Liu Q, Yasui Y, *et al.* (2009) Long-term outcomes in survivors of neuroblastoma: A report from the Childhood Cancer Survivor Study. *Journal of the National Cancer Institute* **101**(16), 1131–1140. doi:10.1093/jnci/djp230

Lee JL, Gutierrez-Colina A, Williamson Lewis R, *et al.* (2019) Knowledge of late effects risks and healthcare responsibility in adolescents and young adults treated for childhood cancer. *Journal of Pediatric Psychology* **44**(5), 557–566. doi:10.1093/jpepsy/jsy102

London WB, Castleberry RP, Matthay KK, *et al.* (2005) Evidence for an age cutoff greater than 365 days for neuroblastoma risk group stratification in the Children's Oncology Group. *Journal of Clinical Oncology* **23**(27), 6459–6465. doi:10.1200/JCO.2005.05.571

McCaffrey N, Kaambwa B, Currow DC, *et al.* (2016) Health-related quality of life measured using the EQ-5D-5L: South Australian population norms. *Health and Quality of Life Outcomes* **14**(1), 133. doi:10.1186/s12955-016-0537-0

Meacham LR, Chow EJ, Ness KK, *et al.* (2010) Cardiovascular risk factors in adult survivors of pediatric cancer – A report from the childhood cancer survivor study. *Cancer epidemiology, Biomarkers & Prevention* **19**(1), 170–181. doi:10.1158/1055-9965.EPI-09-0555

Meaney S, Anweigi L, Ziada H, *et al.* (2011) The impact of hypodontia: A qualitative study on the experiences of patients. *The European Journal of Orthodontics* **34**(5), 547–552. doi:10.1093/ejo/cjr061

Meeske KA, Patel SK, Palmer SN, *et al.* (2007) Factors associated with health-related quality of life in pediatric cancer survivors. *Pediatric Blood & Cancer* **49**(3), 298–305. doi:10.1002/pbc.20923

Miles MB and Huberman AM (1994) *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks, California: Sage.

Moreno L, Vaidya SJ, Pinkerton CR, *et al.* (2013) Long-term follow-up of children with high-risk neuroblastoma: The ENSG5 trial experience. *Pediatric Blood & Cancer* **60**(7), 1135–1140. doi:10.1002/pbc.24452

Mört S, Lähteenmäki PM, Matomäki J, *et al.* (2011) Fatigue in young survivors of extracranial childhood cancer: A Finnish nationwide survey. *Oncology Nursing Forum* **38**(6), E445–E454. doi:10.1188/11.ONF.E445-E454

Mozos I and Stoian D (2019) Oral health and cardiovascular disorders. In *Crosstalk in Biological Processes*. IntechOpen.

Mulrooney DA, Ness KK, Neglia JP, *et al.* (2008) Fatigue and sleep disturbance in adult survivors of childhood cancer: A report from the childhood cancer survivor study (CCSS). *Sleep* **31**(2), 271–281. doi:10.1093/sleep/31.2.271

Nathan PC, Ness KK, Greenberg ML, *et al.* (2007) Health-related quality of life in adult survivors of childhood Wilms tumor or neuroblastoma: A report from the childhood cancer survivor study. *Pediatric Blood & Cancer* **49**(5), 704–715. doi:10.1002/pbc.20949

Neville KA, Cohn RJ, Steinbeck KS, *et al.* (2006) Hyperinsulinemia, impaired glucose tolerance, and diabetes mellitus in survivors of childhood cancer: Prevalence and risk factors. *The Journal of Clinical Endocrinology and Metabolism* **91**(11), 4401–4407. doi:10.1210/jc.2006-0128

Noronha C and Macdonald ME (2016) Oral health issues and quality of life among pediatric cancer survivors. In Fitzpatrick TR (ed.), *Treating Vulnerable Populations of Cancer Survivors: A Biopsychosocial Approach*. Cham: Springer International Publishing, 111–125.

Oeffinger KC, Mertens AC, Hudson MM, *et al.* (2004) Health care of young adult survivors of childhood cancer: A report from the childhood cancer survivor study. *The Annals of Family Medicine* **2**(1), 61. doi:10.1370/afm.26

Oeffinger KC, Mertens AC, Sklar CA, *et al.* (2006) Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine* **355**(15), 1572–1582. doi:10.1056/NEJMsa060185

Perwein T, Lackner H, Sovinz P, *et al.* (2011) Survival and late effects in children with stage 4 neuroblastoma. *Pediatric Blood & Cancer* **57**(4), 629–635. doi:10.1002/pbc.23036

QSR International Pty Ltd (2018). NVivo [Software].

Rach AM, Crabtree VM, Brinkman TM, *et al.* (2017) Predictors of fatigue and poor sleep in adult survivors of childhood Hodgkin's lymphoma: A report from the Childhood Cancer Survivor Study. *Journal of Cancer Survivorship* **11**(2), 256–263. doi:10.1007/s11764-016-0583-y

Roberts RM, Robins T, Gannoni AF, *et al.* (2014) Survivors of childhood cancer in South Australia attending a late-effects clinic: A descriptive report of psychological, cognitive, and academic late-effects. *Journal of Psychosocial Oncology* **32**(2), 152–166. doi:10.1080/07347332.2013.873998

Signorelli C, Wakefield CE, Fardell JE, *et al.* (2017a) The impact of long-term follow-up care for childhood cancer survivors: A systematic review. *Critical Reviews in Oncology/Hematology* **114**, 131–138. doi:10.1016/j.critrevonc.2017.04.007

Signorelli C, Wakefield CE, Fardell JE, *et al.* (2019b) Perceptions of future health and cancer risk in adult survivors of childhood cancer: Implications for engagement in follow-up care. *Cancer* **125**(6), 1008–1009. doi:10.1002/cncr.31934

Signorelli C, Wakefield CE, Fardell JE, *et al.* (2019c) The role of primary care physicians in childhood cancer survivorship care: Multiperspective interviews. *The Oncologist* **24**(5), 710–719. doi:10.1634/theoncologist.2018-0103

Signorelli C, Wakefield CE, McLoone JK, ***et al.*** (2017b) Models of childhood cancer survivorship care in Australia and New Zealand: Strengths and challenges. *Asia-Pacific Journal of Clinical Oncology* **13**(6), 407–415. doi:10.1111/ajco.12700

Signorelli C, Wakefield C, McLoone JK, ***et al.*** (2019a) Childhood cancer survivorship: Barriers and preferences. *BMJ Supportive & Palliative Care* **12**(e5), e687–e695.

Stone A, Novetsky Friedman D, Worgall S, ***et al.*** (2017) Long-term pulmonary outcomes in pediatric survivors of high-risk neuroblastoma. *Journal of Pediatric Hematology/oncology* **39**(7), 547–554. doi:10.1097/MPH.0000000000000883

Sutradhar R, Agha M, Pole JD, ***et al.*** (2015) Specialized survivor clinic attendance is associated with decreased rates of emergency department visits in adult survivors of childhood cancer. *Cancer* **121**(24), 4389–4397. doi:10.1002/cncr.29679

Syed IA, Klassen AF, Barr R, ***et al.*** (2016) Factors associated with childhood cancer survivors' knowledge about their diagnosis, treatment, and risk for late effects. *Journal of Cancer Survivorship* **10**(2), 363–374. doi:10.1007/s11764-015-0482-7

Trahair TN, Vowels MR, Johnston K, ***et al.*** (2007) Long-term outcomes in children with high-risk neuroblastoma treated with autologous stem cell transplantation. *Bone Marrow Transplantation* **40**(8), 741–746. doi:10.1038/sj.bmt.1705809

Vetsch J, Fardell JE, Wakefield CE, ***et al.*** (2017) "Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care. *Patient Education and Counseling* **100**(2), 355–363. doi:10.1016/j.pec.2016.09.013

Visser MRM, Smets EMA, Sprangers MAG, ***et al.*** (2000) How response shift may affect the measurement of change in fatigue. *Journal of Pain and Symptom Management* **20**(1), 12–18. doi:10.1016/S0885-3924(00)00148-2

Wilson CL, Brinkman TM, Cook C, ***et al.*** (2020) Clinically ascertained health outcomes, quality of life, and social attainment among adult survivors of neuroblastoma: A report from the St. Jude Lifetime Cohort. *Cancer* **126**(6), 1330–1338. doi:10.1002/cncr.32678

Wilson CL, Cohn RJ, Johnson KA, ***et al.*** (2009) Tracing survivors of childhood cancer in Australia. *Pediatric Blood & Cancer* **52**(4), 510–515. doi:10.1002/pbc.21907

Yallop K, McDowell H, Koziol-mclain J, ***et al.*** (2013) Self-reported psychosocial wellbeing of adolescent childhood cancer survivors. *European Journal of Oncology Nursing* **17**(6), 711–719. doi:10.1016/j.ejon.2013.06.007

Youlden DR, Jones BC, Cundy TP, ***et al.*** (2020) Incidence and outcomes of neuroblastoma in Australian children: A population-based study (1983–2015). *Journal of Paediatrics and Child Health* **56**, 1046–1052. doi:10.1111/jpc.14810

Zeltzer LK, Chen E, Weiss R, ***et al.*** (1997) Comparison of psychologic outcome in adult survivors of childhood acute lymphoblastic leukemia versus sibling controls: A cooperative Children's Cancer Group and National Institutes of Health study. *Journal of Clinical Oncology* **15**(2), 547–556. doi:10.1200/JCO.1997.15.2.547