NCIN
national cancer
intelligence network
Using information to improve quality & choice

Shared Care & Survival

CTYA SSCRG
(Childhood Cancer Research Group)

January 2013

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.

The National Cancer Intelligence Unit will be part of Public Health England from 1st April 2013

Our aims and objectives cover five core areas to improve the quality and availability of cancer data from its collection to use:

- **Promoting efficient and effective data collection throughout the cancer journey**
- **Providing a common national repository for cancer datasets**
- **Producing expert analyses, to monitor patterns of cancer care**
- **Exploiting information to drive improvements in cancer care and clinical outcomes**
- **Enabling use of cancer information to support audit and research programmes**

Shared Care and Survival from Childhood Cancer in the UK 1997-2009

A questionnaire was sent to all paediatric oncology principal treatment centres (PTCs) in the UK, asking for information about their practice of shared care during 1997-2009.

Level of shared care was defined as follows:

Little or none	Care shared with no more than one paediatric oncology shared care unit (POSCU)
Moderate	Several associated POSCUs, but without full coverage of catchment area
Extensive	Comprehensive network of POSCUs throughout the catchment area

Table 1 shows the numbers of PTCs at each level of shared care during 1997-2000, 2001-2004 and 2005-2009. Eight PTCs practised extensive shared care throughout the study period. There was a steady increase in the number of PTCs, with a moderate level of shared care and a corresponding decrease in the number with little or none.

The analyses that follow are based on all cases of childhood cancer other than retinoblastoma with a registration at diagnosis from any PTC in the UK except Barts/Royal London. Retinoblastoma was excluded because supraregional referral is standard practice for this tumour. Barts/Royal London was excluded because it ceased to be a paediatric oncology PTC during the study period. Table 2 shows the numbers of children registered from a PTC with any cancer except retinoblastoma (groups I-IV, VI-XII in the International Classification of Childhood Cancer, Third Edition (ICCC-3)) before age 15, classified by shared care level at their PTC during 1997-2000, 2001-2004 and 2005-2009. Between 1997-2000 and 2005-2009 the proportion of children registered from PTCs with extensive shared care increased from 50% to 58% and the proportion registered from PTCs with little or no shared care decreased from 39% to 17%.

Survival was analysed by PTC level of shared care for all children combined, by broad diagnostic group and by prognostic group. The broad diagnostic groups were leukaemias and lymphomas

(ICCC-3 I and II), CNS tumours including CNS germ-cell tumours (ICCC-3 III and Xa) and all other solid tumours (ICCC-3 IV, VI-IX, Xb-Xe, XI and XII). Prognostic groups were defined according to five-year survival rate during the study period as a whole. The definitions were based on type of cancer, but acute lymphoblastic leukaemia was subdivided by age at diagnosis and Down syndrome status, and medulloblastoma and neuroblastoma were both subdivided by age. The composition of the prognostic groups is shown in Table 3. Finally, survival was analysed by PTC level of shared care for non-Down syndrome children aged 1-14 years with ALL. This group was analysed separately because, whereas most children with cancer receive virtually all their chemotherapy at their PTC and shared care is largely limited to supportive care, children with ALL can also receive a substantial proportion of their chemotherapy at a POSCU. It was also the diagnostic group with the largest of patients in the study series.

Five-year survival for all children by period of diagnosis and PTC shared care level is shown in Table 4. Survival did not vary significantly by shared care level in any of the three calendar periods for all cancers combined or for any of the three broad diagnostic groups (log-rank $p>0.05$ throughout).

Five-year survival by period of diagnosis, prognostic group and PTC shared care level is shown in Table 5. Survival did not vary significantly by shared care level for any combination of calendar period and prognostic group (log-rank $p>0.05$ throughout).

Five-year survival by period of diagnosis and PTC shared care level for non-Down syndrome children aged 1-14 years with ALL is shown in Table 6. Survival did not vary significantly by shared care level in any of the three calendar periods (log-rank $p>0.05$ throughout).

One-year survival was also analysed by PTC shared care level for all combinations of period of diagnosis and diagnostic group covered in Tables 4-6. Survival did not vary significantly by shared care level in any of the three calendar periods for all cancers combined or for any of the diagnostic groups (log-rank $p>0.05$ throughout; data not shown).

In conclusion, the analyses presented here found no evidence of variation in survival for children with cancer diagnosed during 1997-2009 in relation to the level of shared care at their PTC.

Table 1 Number of paediatric oncology PTCs by level of shared care, UK, 1997-2009

	1997-2000	2001-2004	2005-2009
Little or none	10	8	5
Moderate	2	4	7
Extensive	8	8	8
Total	20	20	20

Leicester and Nottingham now operate as a single East Midlands centre but were separate centres during the study period and are counted separately here.

Barts/Royal London ceased to be a paediatric oncology PTC during the study period and is not included here.

Table 2 Number of newly diagnosed childhood cancer patients by level of shared care at PTC, UK, 1997-2009

	1997-2000	2001-2004	2005-2009	Total
Little or none	2174 (39%)	1552 (26%)	1245 (17%)	4971
Moderate	599 (11%)	1062 (18%)	1935 (26%)	3596
Extensive	2734 (50%)	3360 (56%)	4334 (58%)	10428
Total	5507	5974	7514	18995

Barts/Royal London patients, children with retinoblastoma, and children with no CCLG registration are excluded.

Table 3 Composition of prognostic groups for survival analysis

5-year survival ≥ 90%	Hodgkin lymphoma
	Choroid plexus papilloma
	Low grade astrocytoma
	Pituitary adenoma
	Craniopharyngioma
	Meningioma
	Glioneuronal tumours (all types)
	Intracranial germinoma
	Wilms tumour
	Malignant bone tumours NEC
	Fibrohistiocytic sarcomas
	Alveolar soft part sarcoma
	Gonadal germ cell tumours
	Thyroid carcinoma (all types)
	Nasopharyngeal carcinoma
	Salivary gland carcinoma
5-year survival 80-89%	ALL, non-Down syndrome, age 1-14
	Chronic myeloid leukaemia
	Non-Hodgkin lymphoma
	Neuroblastoma, age <1
	Clear cell sarcoma of kidney
	Hepatoblastoma
	Fibrosarcoma (excluding MPNST)
	Leiomyosarcoma
	Synovial sarcoma
	Non-CNS extragonadal germ-cell tumours
5-year survival 70-79%	Mature B-cell leukaemia
	Medulloblastoma, age 3-14
	Pinealoma & pineocytoma
	Non-germinoma CNS germ-cell tumours
	Miscellaneous peripheral nervous tumours
	Pleuropulmonary blastoma
5-year survival 60-69%	ALL, Down syndrome
	AML
	Myelodysplasia
	Leukaemia NEC
	Ependymoma
	Oligodendroglioma
	Astrocytoma NEC
	Renal carcinoma
	Ewing sarcoma family tumours (bone & soft tissue)
	Rhabdomyosarcoma
	Specified soft tissue sarcoma NEC
	Adrenocortical carcinoma
	Malignant melanoma
5-year survival 50-59%	ALL, age <1
	JMML/CMML
	Neuroblastoma, age 1-14
	Osteosarcoma
	MPNST
	Non-germ-cell gonadal tumours
	Carcinoma NEC

5-year survival <50%	Choroid plexus carcinoma
	High grade astrocytoma
	Medulloblastoma, age 0-2
	PNET
	ATRT
	Glioma NEC
	Pineoblastoma
	CNS tumour NOS
	Rhabdoid renal tumour
	Hepatic carcinoma
	Chondrosarcoma
	Renal pPNET
	Extrarenal rhandoid tumour
	DSRCT
	Soft tissue sarcoma NOS
	Colorectal carcinoma
	Other specified cancers NEC
	Cancer NOS

Abbreviations:

ALL	Acute lymphoblastic leukaemia
AML	Acute myeloid leukaemia
ATRT	Atypical teratoid/rhabdoid tumour
CMML	Chronic myelomonocytic leukaemia
DSRCT	Desmoplastic small round cell tumour
JMML	Juvenile myelomonocytic leukaemia
MPNST	Malignant peripheral nerve sheath tumour
NEC	not elsewhere classified
NOS	not otherwise specified
PNET	Primitive neuroectodermal tumour
pPNET	Peripheral primitive neuroectodermal tumour

Table 4 Five-year % survival (95% CI) by period of diagnosis and level of shared care at PTC for all childhood cancers except retinoblastoma and for broad diagnostic groups

Diagnostic group	Shared care level	1997-2000	2001-2004	2005-2009
All cancers	Little or none	74 (72,76)	77 (75,79)	81 (79,83)
	Moderate	76 (72,79)	76 (73,78)	82 (80,83)
	Extensive	76 (75,78)	77 (75,78)	80 (79,82)
Leukaemia & lymphoma	Little or none	81 (78,83)	84 (81,87)	87 (84,90)
	Moderate	81 (76,85)	85 (82,88)	89 (86,91)
	Extensive	81 (79,83)	84 (82,86)	89 (87,90)
CNS tumours	Little or none	69 (65,73)	74 (69,78)	76 (71,80)
	Moderate	66 (58,73)	70 (64,75)	76 (71,79)
	Extensive	72 (69,75)	69 (66,72)	72 (69,75)
Other solid tumours	Little or none	68 (64,71)	71 (67,75)	77 (71,82)
	Moderate	77 (70,82)	65 (59,70)	75 (71,79)
	Extensive	72 (69,75)	72 (69,74)	75 (73,78)

Table 5 **Five-year % survival (95% CI) by period of diagnosis and levels of shared care at PTC for all childhood cancers except retinoblastoma, for prognostic groups as defined in Table 3**

Prognostic group	Shared care level	1997-2000	2001-2004	2005-2009
≥90%	Little or none	93 (91,95)	93 (91,95)	95 (92,97)
	Moderate	91 (85,95)	94 (91,97)	94 (91,96)
	Extensive	94 (92,96)	94 (92,96)	94 (92,95)
80-89%	Little or none	84 (82,87)	89 (86,91)	90 (87,93)
	Moderate	86 (81,90)	88 (84,90)	93 (90,94)
	Extensive	85 (82,87)	88 (86,89)	91 (90,93)
70-79%	Little or none	77 (67,85)	74 (61,83)	81 (65,90)
	Moderate	65 (42,81)	70 (55,81)	68 (52,80)
	Extensive	73 (63,81)	73 (63,80)	69 (60,76)
60-69%	Little or none	64 (59,69)	64 (58,70)	67 (59,74)
	Moderate	69 (59,77)	61 (53,67)	72 (66,78)
	Extensive	65 (60,69)	64 (60,68)	70 (66,73)
50-59%	Little or none	45 (38,52)	51 (42,59)	63 (51,73)
	Moderate	58 (42,70)	44 (34,55)	57 (48,65)
	Extensive	51 (45,57)	56 (50,61)	64 (59,69)
<50%	Little or none	28 (22,34)	36 (28,44)	42 (33,51)
	Moderate	30 (19,43)	30 (21,40)	28 (20,37)
	Extensive	37 (31,43)	28 (23,33)	36 (30,41)

Table 6 **Five-year % survival (95% CI) by period of diagnosis and level of shared care at PTC for non-Down syndrome children aged 1-14 years with acute lymphoblastic leukaemia**

Shared care level	1997-2000	2001-2004	2005-2009
Little or none	86 (83,89)	90 (86,92)	90 (86,93)
Moderate	86 (79,90)	89 (84,92)	95 (92,97)
Extensive	86 (83,88)	90 (87,91)	93 (91,95)