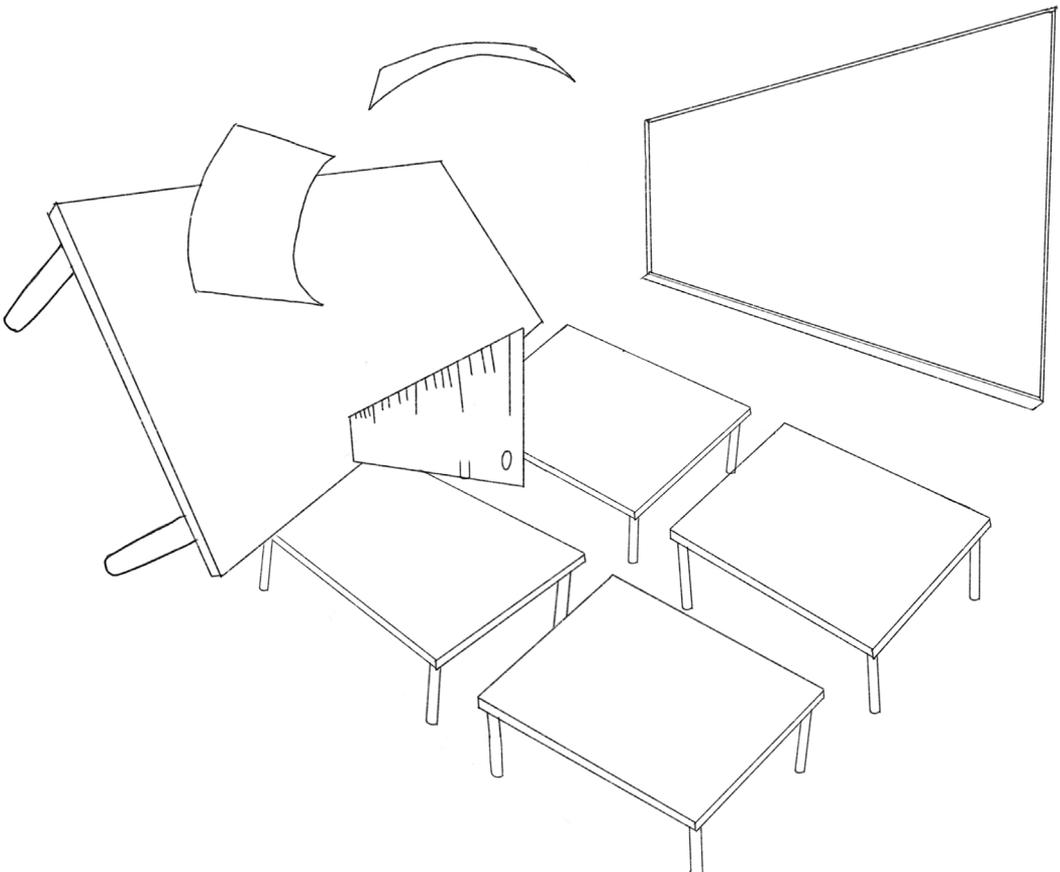


Academic Performance in Swedish Ninth Grade Students Treated for Brain Tumours

Malin Lönnerblad



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Academic dissertation for the Degree of Doctor of Philosophy in Special Education at Stockholm University to be publicly defended on Friday 26 February 2021 at 10.00. The defence will be held via Zoom. Link at <https://www.speped.su.se/>

Abstract

The overall aim of this thesis was to investigate how children in Sweden treated for brain tumours performed in their ninth year at school compared with matched controls. The studies investigated grades and results from national tests in the theoretical subjects of Swedish, English, and mathematics; grades in the practical and aesthetic subjects of art, crafts, music, home and consumer studies, physical education and health; and the frequency of delayed graduation and qualification for school years 10-12 (corresponding to upper-secondary school or high school).

The results from this thesis demonstrate significant differences in performance between the group of children treated for brain tumours (cases) and their controls, both in the theoretical subjects and in the practical and aesthetic subjects. However, there were larger differences between cases and controls in the theoretical subjects than in the practical and aesthetic subjects. The largest differences were found in the subject of English, and there were also significant differences between cases and controls with regard to delayed graduation and qualification for school years 10-12. Graduation for children treated for brain tumours was delayed more often than for controls, and qualification for school years 10-12 was significantly higher among controls than for children treated for brain tumours. The results also showed different effects based on sex. For example, the gap between the girls treated for brain tumours and their controls was, in most cases, greater than for the boys and their controls. Whether the child had been treated for a high- or low-grade tumour did not have any significant impact on the results in any of the studies. Children treated at ages 0-5 and 6-9 years old were at particular risk of lower average grades in theoretical subjects or not qualifying for school years 10-12, although the latter result was significant only for the girls. Age at diagnosis was another significant factor for national test performance. There was also a positive correlation between the parents' education levels and qualification for school years 10-12 for children treated for brain tumours.

The implication of the results are that the academic performance of all children treated for brain tumours, regardless of sex, age at diagnosis, tumour grade, or parents' education should be closely monitored when starting or returning to school after brain tumour treatment. It is also important to have a long-term perspective, as school difficulties do not disappear, but rather may increase over the years. Children treated before starting school should be monitored extra closely as well as children treated at ages 6-9, as a considerable number of basic skills are taught during these first school years. Moreover, it is of particular importance that girls and boys are equally monitored. Yet, the range of difficulties for children treated for brain tumours is wide and extremely heterogeneous. Thus, the type of support or intervention should be adapted to each child's individual needs.

Keywords: *School performance, academic performance, brain tumour, academic grades, national tests, delayed graduation, theoretical subjects, practical and aesthetic subjects.*

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STUDENTS TREATED FOR BRAIN TUMOURS

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Stockholm
University

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In memory of my mother.

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List of publications

Study 1

Lönnerblad, M., van't Hooft, I., Blomgren, K., & Berglund, E. (2020a). A nationwide, population-based study of school grades, delayed graduation, and qualification for school years 10-12, in children with brain tumors in Sweden. *Pediatric Blood & Cancer*, 67(2), 1-9.

<https://doi.org/10.1002/pbc.28014>

Study 2

Lönnerblad, M., van't Hooft, I., Blomgren, K., & Berglund, E. (2020b). A nationwide, population-based study of school grades in practical and aesthetic subjects of children treated for brain tumours. *BMJ Paediatrics Open*, 4(1), 1-9. <https://doi.org/10.1136/bmjpo-2019-000619>

Study 3

Lönnerblad, M., Berglund, E., van't Hooft, I., & Blomgren, K. (2021). Can National Tests from the Last Year of Compulsory School Be Used to Obtain More Detailed Information about Academic Performance in Children Treated for Brain Tumours? A Nationwide, Population-Based Study from Sweden. *Cancers*, 13(1), 1-17 <https://doi.org/10.3390/cancers13010135>

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Abbreviations

PBTS Paediatric Brain Tumour Survivors

PD Pass with Distinction

PRAEST Practical and Aesthetic

PSD Pass with Special Distinction

TBI Traumatic Brain Injury

Definitions

Age at diagnosis is the age when the child or youngster first got her or his brain tumour diagnosis, and this information was obtained from the Swedish Childhood Cancer Registry.

Children with intellectual disabilities refers to children with an IQ of below 70 and with the right to attend the compulsory school for children with intellectual disabilities with a curriculum other than that followed in regular compulsory school.

Delayed graduation refers to students finishing school at age 17 or later, as most children graduate and get their final grades at age 15 or 16. The reasons for the delay are due to the child starting school at an older age than expected or having to repeat one or more school years.

First foreign language (as school subject) refers to the subject of English. First foreign language is used when results in the subject are compared between different countries.

Late effects refer to the difficulties that may appear as an effect of the treatment or the tumour itself. Also called *sequelae* or *late complications*.

Mother tongue (as school subject) refers to the school subject mother tongue in the country, i.e. Swedish in Sweden, Danish in Denmark and so on. The term ‘mother tongue’ is used when results in this subject are compared between different countries.

School years 1-9 and grades 1-9 are during the assessed years (2003-2012) equivalent in Sweden, as pre-school class was not compulsory. Thus, the term ‘school years’ used in these studies does not correspond to the term school years used in the British school system.

School years 10-12 (equivalent to upper secondary school or high school) refers to the three non-compulsory school years after the compulsory school years 1-9 in Sweden. Again, the term ‘school years’ used in the studies does not correspond to the term school years in the British school system.

Introduction

Brain tumours are the second most common type of childhood cancers, and represent about 20-30% of all cases (Kaatsch, 2010; Lannering et al., 2009). In most cases, the cause of a child's brain tumour is unknown (Spector et al., 2015). During the period 1984-2005 the annual brain tumour incidence in Sweden for children under the age of 15 was 4.2/100,000 (Lannering et al., 2009). When a child is diagnosed with cancer, not only the child is affected, but also the parents, siblings, and other relatives (Long et al., 2018; Norberg & Steneby, 2009; Wakefield et al., 2017). Fifty years ago, only about 40% of Swedish children diagnosed with a brain tumour survived, whereas nowadays, the five-year survival has increased to more than 80%, although not for all brain tumour diagnoses (G. Gustafsson et al., 2013; Swedish Childhood Cancer Fund, 2019). Thus, the number of children who attend schools and have been treated for brain tumours has grown in the last decades.

However, survival comes at a cost, and difficulties that appear later as an effect of the treatment or because of the tumour itself – so-called late effects, sequelae, or late complications – are common (Bitsko et al., 2016; Mulhern et al., 2004; Nathan, 2007). As many as 95.7% of children who have survived a brain tumour seem to still be affected as adults (Han et al., 2009), although these numbers may vary depending on the type of effects and the population included (Signorelli et al., 2017; Tønning-Olsson, 2015). In regard to school subjects, difficulties with mathematics, reading and spelling are common for children treated for brain tumours, which has been shown both in international studies (Kieffer et al., 2012; Upton & Eiser, 2006) and a Swedish study (Lönnnerblad et al., 2017). Furthermore, performance in some of these skills may worsen over the years (Mabbott et al., 2005; Merchant et al., 2014). Moreover, these children often obtain lower grades in various types of school subjects compared with their peers (Ahomäki et al., 2017; Andersen et al., 2017; Lähteenmäki et al., 2007).

Interviews with children treated for brain tumours (Bruce et al., 2008; Gunn et al., 2016; Kristiansen et al., 2019; Macartney et al., 2014; Vanclooster et al., 2019b, 2020) have shown that they often experienced changes in memory performance, difficulties with concentration, and less academic capacity, as

well as psychosocial and physical difficulties after their treatment. Parents of children treated for brain tumours were also aware of their children's new academic challenges (Norberg & Steneby, 2009; Vanclooster et al., 2018), and some were especially concerned about their child's invisible deficits, as these were harder for teachers to detect and understand (Bruce et al., 2008). Therefore, many parents also requested information about their child's performance after the cancer diagnosis, for example at school re-entry and at the end of treatment, as they often felt unprepared for the child's return to school (Ruble et al., 2019).

Over recent years, review studies have shown that collaboration between school, home and hospital when children treated for cancer return to school are beneficial, although the evidence for the impact is limited (Helms et al., 2016; Thompson et al., 2015). Yet, there still seems to be a lack of knowledge and understanding among teachers and other school personnel about the special needs of children treated for brain tumours (Barrera et al., 2005; Bruce et al., 2008; Hocking et al., 2018; Paré-Blagoev et al., 2019; Upton & Eiser, 2006; Vanclooster et al., 2019a). Moreover, previous studies have shown that teachers and other school personnel in contact with children who were undergoing or had undergone treatment for brain tumours often felt unprepared when the child returned to school, and did not always find the information they were given relevant (Brown et al., 2011; Selwood et al., 2013). Many teachers specifically asked for information concerning the educational context or educational needs, and others wished for long-term follow-up (Brown et al., 2011; Tresman et al., 2016). Thus, there is a need for research to increase the knowledge in schools and among teachers regarding what academic problems children experience, and from this knowledge discuss how to design efficient support for the children with the goal to improve their school experiences and performance.

From the Nordic countries, there are some large registry studies examining school performance of children treated for brain tumours. In Finland, Lähteenmäki et al. (2007) studied the final year nine grades for 300 children treated for brain tumours born during the years 1974-1986, and Ahomäki et al. (2017) have examined grades and graduation for 2,343 children born 1960-1992 and treated for different cancers, including children treated for brain tumours. There is also a large registry study from Denmark regarding final grades and national tests from year nine with 1,320 children born during the years 1982-1988 and treated for different cancers, including brain tumours (Andersen et al., 2017). All these three studies have shown that children treated for brain

tumours have lower grades in their mother tongue, in foreign languages (English), and in mathematics. Studies by Ahomäki et al. (2017) and Lähteenmäki et al. (2007) also found that children treated for brain tumours had lower grades in physical education (sports), compared with controls. Yet until now, there have not been any large Swedish registry studies examining grades or national tests from school year nine of children treated for brain tumours. As treatment regimens and survival rates both change over the years, and among countries, and as school systems and systems for educational support differ between countries and over time as well, recurrent specific analyses for various countries are needed.

In the next section, the Swedish school context is explained, followed by specific information about brain tumours in children, and the different kinds of difficulties that may appear after treatment and tumours. Thereafter follows a description of the theoretical framework, aims of the thesis, methods, results, a discussion of the findings, and the practical implications of the results. Lastly, limitations and strengths of the study and suggestions for future research are discussed.

Background

The Swedish school context

In Sweden, the majority of children attend pre-school (Swedish National Agency for Education, 2000). For example, in 1999, when the later part of the cohort included in the studies in this thesis (born 1988-1996) were of pre-school age, 74.9% of all the children in Sweden aged one to five were enrolled in pre-school. Most children also started pre-school class the year they turned six, and even though this year was not included in the compulsory school until 2018, more than 90% of the children of this age were enrolled in a pre-school class in 1999 (Swedish National Agency for Education, 2000). The year they turned seven they started their first school year; then they continued for nine years, and typically finished the year they turned 16 (Table 1).

Table 1. Pre-school, pre-school class, compulsory school (school years 1-9) and post compulsory school (school years 10-12) in Sweden for children 0-18 years.

Swedish school system	Ages
Pre-school/kindergarten [förskola]	0-5
Pre-school class [förskoleklass]	6
Grades/school years 1-3 /Lower classes [lågstadiet]	7-9
Grades/school years 4-6 /Middle classes [mellanstadiet]	10-12
Grades/school years 7-9/ Higher classes [högstadiet]	13-15
School years 10-12/ Upper secondary school/High school [gymnasiet]	16-18

School subjects and academic grades

Since 1994, final grades have been given in 17 school subjects included in the Swedish curriculum (Swedish National Agency for Education, 2003, 2018). First, there are the three school subjects in which, until 2011/2012, all children had to obtain at least a pass as their final grade to qualify for school years 10-12. These subjects are Swedish (which also includes Swedish as a second language), a first foreign language (English), and mathematics. There are also the science studies subjects of biology, physics, technology and chemistry, and the social studies subjects of geography, history, religion and civics. Most students also studies a second foreign language (often Spanish, French or German, but there may be other options). Moreover, five compulsory practical and aesthetic (PRAEST) subjects are included in the Swedish curriculum. These subjects are home and consumer studies, physical education and health, art, crafts and music. Most of the theoretical subjects are studied from the first school years, whereas the practical and aesthetic subjects are studied more intermittently throughout the nine school years (Swedish National Agency for Education, 2013).

Until 2012, most students got their first grades in the spring term of school year eight, and during the years 1994 to 2012, Sweden had a four-step scale for academic grades with IG = fail [icke godkänt], G = pass [godkänt], VG = pass with distinction [väl godkänt], and MVG = pass with special distinction [mycket väl godkänt]. To apply to school years 10-12, an average, a merit rating [meritpoäng], of the school subjects is calculated. The way to calculate this in Sweden is to count the grade pass as 10 points, the grade pass with distinction as 15 points, and the grade pass with special distinction as 20 points. A fail does not give any points.

Qualification for school years 10-12 in Sweden

Since 1994, school years 10-12 in Sweden have consisted of a theoretical or a vocational three-year programme. Both the theoretical and vocational programmes may give the student admission to higher education. Until 2011, the student had to obtain at least a pass in only the three subjects Swedish, English, and mathematics to qualify for upper-secondary school (SFS 2010:2039). However, in 2011/2012 stricter rules were applied, and since then, students have to obtain a pass in at least eight or 12 subjects, depending on the programme they wanted to follow. Even though school years 10-12 are not compulsory in Sweden, most students chose to continue school during these years if they are qualified. For the years in question in the studies included in this

thesis, 2003-2012, the number of all students in Sweden that were qualified varied between 89.9% in 2003/2004 and 87.5% in 2011/2012 (Swedish National Agency for Education, n.d.-b).

National tests

In 1998, National tests were introduced in Sweden in the school subjects Swedish, English, and mathematics (Swedish National Agency for Education, 2016) (Table 2). Nowadays, Swedish students have national tests at school years three, six and nine. The purpose of the national tests is to assess the students' knowledge in the subject, and also to ensure that the final grades will be as fair as possible across all schools in Sweden (Swedish National Agency for Education, 2016). The national tests are not a final exam but should be counted as a part of all the exams during the school year. As the national tests assess different skills in the subjects, they can provide teachers with more detailed information in relation to students' knowledge. The science and social science subjects also have national tests. Additionally, there are optional national tests in the second foreign language (Spanish, French, or German), but not in the practical or aesthetic subjects. The instructions to teachers for the national tests inform them that they are allowed to make adaptations to the test situation for students in need, such as extended time, or the opportunity to perform the tests in multiple shorter periods (Swedish National Agency for Education, n.d.-a).

Table 2. Content of the different subtests in the national tests in Swedish, English, and mathematics.

Subject and subtest	Description of the subtest
Swedish and Swedish as a second language - Reading Subtest A - Reading and understanding	Write answers or choose between multiple-choice answers after reading texts in Swedish.
Swedish and Swedish as a second language - Oral Subtest B - Oral	On several occasions listen to different texts in Swedish and then discuss the text with a peer.
Swedish and Swedish as a second language - Writing Subtest C - Writing	Write a more extensive text in Swedish. Four topics are given to choose from.
English - Oral Subtest A - Oral production and interaction	Discussing various subjects in English with a peer.
English - Reading/listening Subtest B1 - Reading Subtest B2 - Listening	Write answers or choose between multiple-choice answers after reading or listening to texts in English.
English - Writing Subtest C - Writing	Write a coherent text in English. Two topics are given to choose from.
Mathematics Subtest A - Oral	A group discussion with three to four students about a mathematical task, to which each student should present a solution.
Mathematics Subtest B1 - Short answer questions Subtest B2 - Geometrical tasks	Individual tasks. Calculator is not allowed.
Mathematics Subtest C - Problem solving	Individual tasks, for which complete solutions and how the tasks are solved are required. Calculator is allowed.

Difference in school performance due to sex or parents' education

Official data from the Swedish National Agency for Education for the years 2003-2012 showed that girls in Sweden, on a group level, had a higher merit rating and higher grades in all subjects except physical education and health compared with boys (Swedish National Agency for Education, n.d.-b, 2011b). However, results showing that girls are performing better in school than boys are not seen only in Sweden, but in many other countries around the world (OECD, 2014; Voyer & Voyer, 2014).

Another factor that may have an impact on children's school performance is parents' education (Bronfenbrenner & Ceci, 1994; J.-E. Gustafsson & Yang Hansen, 2018). In 1982, White published a meta-analytic study that reviewed studies on the correlation between students' academic achievement and their parents' socio-economic status. The concept 'socio-economic status' is estimated in different ways; for example, by income or by parents' education (Sirin, 2005; White, 1982). Since then, according to Sirin (2005), several studies have found similar correlations while other studies have found none.

Swedish studies from recent decades have shown that an aspect of socio-economic status, 'parents' education', does have a strong impact on children's grades (Swedish National Agency for Education, 2011a). For example, in 2005/2006, only 70.2% of children whose parents had lower education (school years 1-9), qualified for school years 10-12, whereas these numbers were 87.0% for children whose parents had a medium-level of education (school years 1-9 + 10-12), and 95.5% for children whose parents had a higher education (Swedish National Agency for Education, 2011b). It has also been shown that the effect of parents' education has increased during the years 1998-2014 (J.-E. Gustafsson & Yang Hansen, 2018).

Students in need of extra support

The Swedish Education Act (SFS 2010:800) states that all students should be given support so that they can develop to their full potential. The school should also strive to compensate for students' different prerequisites to ensure they benefit from their education (SFS 2010:800; Swedish National Agency for Education, 2014). In a document from the Swedish National Agency for Education (2014) it is stated that for students in need of special support, the first thing that is expected from schools is adjustments in the classroom [Extra anpassningar]. These adjustments could be, for instance, computers with special programmes, special schedules, preferential seating in the classroom, or the opportunity to obtain different tasks explained by means

of written, recorded or visual instructions. A teacher needs no formal approval to make such adjustments. If the student remains at risk of failing one or more subjects, the next step is that the principal of the school decides whether the student is entitled to special assistance [Särskilt stöd]. In that case, an individual education plan [Åtgärdsprogram] should be written with needs and actions described in detail (Swedish National Agency for Education, 2014). Before 2011, most of these regulations were rules, but not written in the Swedish Education Act as they are nowadays (Swedish National Agency for Education, 2011b).

If a student is frequently absent, or if the goals in the different subjects are not reached for other reasons, the principal at each school can decide whether the student is allowed to repeat the school year (SFS 2010:800). This was not regulated in the 1985 Education Act (SFS 1985:1100). Moreover, there is a special regulation in the Swedish Education Act that allows students who endure a long stay at hospital to attend the hospital schools (SFS 1985:1100; SFS 2010:800). Sweden also has compulsory school for children with intellectual disabilities [Särskolan], for children diagnosed with an IQ of below 70 (SFS 1985:1100; SFS 2010:800). From 2003 to 2012, about 1.4% of all Swedish children were enrolled in compulsory schools for children with intellectual disabilities, which have a different curriculum to that of regular compulsory schools, and no national tests (Swedish National Agency for Education, n.d.-c, n.d.-b, 2010). Approximately 20% of these children were included in the regular compulsory schools, but followed the curriculum for children with intellectual disabilities (Swedish National Agency for Education, n.d.-b, 2010).

Children treated for brain tumours

In Sweden, there are not any official statistics showing to what extent children treated for brain tumours are enrolled in compulsory schools for children with intellectual disabilities. However, one study from Sweden (Ehrstedt et al., 2016) found that of 139 children treated for brain tumours, 3% were enrolled in compulsory schools for children with intellectual disabilities. This can be compared with 1.4% in the general population as mentioned above. The study by Ehrstedt et al. (2016) also found that of the children enrolled in the regular compulsory school, 32% had some kind of educational support. Studies from countries other than Sweden have shown that children treated for brain tumours need special education more often than their peers or siblings. For example, a registry study from Canada (Lorenzi et al., 2009), including 782 children treated for different kind of cancers, showed that 32.5% of the these had

received special educational support compared with 14% in the approximately 10 times larger control group. Children treated for brain tumours required the most support. A study from the USA (Mitby et al., 2003) which analysed questionnaires from 12,430 children treated for brain tumours and 3,410 siblings, found that one-quarter of the children treated for brain tumours received special educational support in school, compared with less than one-tenth of their siblings. There may be different reasons for the large number of children treated for brain tumours in need of educational support. In the following sections, the development of the brain is briefly explained, along with an account of the late effects, i.e. possible negative consequences of the brain tumour and the treatment.

Late effects after a brain tumour and treatment

The development of the brain starts the first weeks after gestation (Lagercrantz, 2016) and is not fully developed until the age of 20 or more (Johnson et al., 2009). The outer layer of the brain, the cerebral cortex, consists of grey matter, under which is the white matter consisting of nerve fibres that connect different parts of the brain (Klingberg et al., 2000; Semple et al., 2013). Different parts of the brain increase in volume at different points in time. While the white matter increases linearly, with the largest increase being the first two years of life and a continuation up to the age of about 25, the cortical grey matter increases before adolescence but decreases after adolescence (Giedd et al., 1999; Klingberg, 2011; Lenroot et al., 2007).

When the maturing brain is exposed to cancer therapy such as radiotherapy and chemotherapy, as well as to surgery alone, there is a substantial risk of brain damage (Ikonomidou, 2018; Liu et al., 2015; Makale et al., 2017), especially for the white matter, that may lead to a range of late effects. Difficulties can also appear as an effect of the tumour itself (Iuvone et al., 2011; Tonning-Olsson, 2015). The late effects can be divided into different categories: neurocognitive late effects, psychosocial late effects, and medical late effects (Turner et al., 2009); these are described in the following sections.

Neurocognitive late effects

The functional consequences in the brain of the tumour itself and the different treatments reveal that children treated for brain tumours often have difficulties with processing speed, working memory and attention (de Ruiter et al., 2013, 2017; Mulhern et al., 2004; Robinson et al., 2010), and these functions are all important for academic performance. Processing speed is the pace at which a child takes in information, makes sense of it, and begins to respond. This information can be visual, such as letters and numbers, and can also be auditory, such as spoken language. As processing speed interacts with other cognitive functions, and dictates the rate at which mental tasks are performed relatively automatically, a faster processing speed implies less strain on the working memory (Wolfe et al., 2012). Thus, a reduced processing rate affects all aspects of cognitive functions, and may negatively influence learning and the possibility of keeping the same pace as peers at school (Barkon, 2009; Mabbott et al., 2008; Palmer et al., 2014).

A reduced working memory (the memory resource that holds and manipulates information) may affect many of the academic skills, such as mathematics, reading comprehension and spelling (Gathercole et al., 2004, 2016; Wolfe et al., 2012). Attention is another important function that is needed to perform most tasks in daily life, and is particularly relevant for children in the classroom, as attention is crucial to their learning (Pierson et al., 2016; Wolfe et al., 2012). Although most children treated for brain tumours may be able to focus for short periods, a large number have difficulties in maintaining attention (Butler & Copeland, 2002; Nathan, 2007). Working memory and attention are aspects of what is called the executive functions, which also include abilities such as organizing, planning, metacognition and problem solving (Wolfe et al., 2012). In summary, children treated for brain tumours often have difficulties with one or more of the executive functions that are all important for academic performance.

Neurocognitive late effects related to sex

Studies of biological differences between the female and the male brains have demonstrated that parts of female brains tend to be maturing earlier than male brains (Bledsoe et al., 2019; Gur & Gur, 2017; Johnson et al., 2009; Lenroot et al., 2007). For example, the grey matter in the frontal lobe and parietal lobe is often fully developed in girls at the age of eleven, but one year later in boys (Giedd et al., 1999). However, clinical and experimental studies on differences in cognitive late effects related to sex are not all consistent. Many studies (i.e. Armstrong et al., 2007; Corti et al., 2018; Di Pinto et al., 2012; Mulhern et al.,

2004, 2005; Netson et al., 2013; Ris et al., 2001) have found that female sex is a risk factor for worse outcomes after being treated for brain tumours; for example, a decline in IQ. Still, a few studies have shown that there are no differences in performance between girls and boys regarding neurocognitive outcome (Mabbott et al., 2008; Ris et al., 2013) or that boys might be more affected than girls after cancer therapy (Conklin et al., 2008; Tønning Olsson et al., 2014). Furthermore, it is important to notice that the differences in performance between girls and boys may interact with various other factors, such as type of task performed, age at diagnosis, or tumour size (Etchell et al., 2018; Tønning Olsson et al., 2014).

Neurocognitive late effects related to tumour grade

There are different types of brain tumours; the most common type is astrocytoma, occurring in about 45% of cases (Lannering et al., 2009). The second most common type is embryonal tumours, like medulloblastoma and the recently-abandoned entity primitive neuro ectodermal tumour (PNET), which affect about 19% of cases, followed by ependymomas affecting about 10%. Many of these tumours are commonly found in the cerebellum, and they differ in malignancy and treatment. Astrocytomas may be high-grade (WHO grade III-V) or low-grade (WHO grade I-II), where the latter are by far the most common tumour type in children. Low-grade tumours are most often treated only with surgery, whereas high-grade gliomas and embryonal tumours are treated with a combination of surgery, chemotherapy and radiotherapy. Ependymomas may occur in the cerebellum, but also in other parts of the central nervous system, and are primarily treated with surgery, but sometimes with radiotherapy and/or chemotherapy.

Children treated for high-grade tumours are considered to be particularly at risk of late effects (Makale et al., 2017; Merchant et al., 2010). However, in recent years there has been an increased consensus that children treated for low-grade tumours are also at risk of adverse late effects (Ehrstedt et al., 2016; Ris et al., 2008; Ris & Beebe, 2008), and also that both the treatment, and to some degree the tumour itself, may lead to damage in the brain (Iuvone et al., 2011; Tønning-Olsson, 2015) and cause cognitive difficulties.

Neurocognitive late effects related to age at diagnosis

Depending on when in the child's life the tumour appears, treatment may cause different late effects. Tumours and treatments occurring at a younger age are well-known risk factors for more severe late effects, as the degree of

brain maturation seems to correlate inversely with the potential damage (Mulhern et al., 2004; Nathan, 2007; Reddick et al., 2014). It is also established now that children treated for brain tumours are at a high risk of experiencing a decline in neurocognitive functions and academic performance over time (Mabbott et al., 2005; Merchant et al., 2014; Mulhern et al., 2004; Robinson et al., 2010). In a paper by Dennis et al. from 2014, different scenarios for a non-typical development after a brain injury, for example as a consequence of a brain tumour and the treatments, are discussed. They suggested that the development of children with different kinds of brain deficits, compared with non-injured peers, might have different developmental trajectories. For example, the development can be stable, but below the typical development, or delayed with an increasing gap compared with typical development over the years, or in the worst case, degenerating, i.e. worsening (Dennis et al., 2014).

Psychosocial late effects

Various psychosocial problems have been reported within the population of children treated for brain tumours (de Ruiter et al., 2016; Eilertsen et al., 2011; Stavinoha et al., 2018). The deficits in executive functions discussed above may sometimes also affect social skills (Holland et al., 2018; Jacobson et al., 2011; Nigg et al., 1999). This may be one reason for the observations of a deterioration in social interaction in a number of individuals after brain tumour treatment, which may also cause psychological distress (Desjardins et al., 2019; Hocking et al., 2015; Schulte & Barrera, 2010; Wolfe et al., 2013). Thus, it may not be just the tumour and its treatment itself that directly contribute to increased psychological distress, but also the deterioration in social functioning (Zebrack et al., 2004). Some children treated for brain tumours have described that they feel different from peers, as their peers do not understand what they have been through, that they may feel that they are being treated differently, or that they have lost contact with former friends or feel isolated (Bruce et al., 2008; Gunn et al., 2016; Mattsson et al., 2007).

Other common complaints, such as mental fatigue (Daniel et al., 2013; de Ruiter et al., 2016; Irestorm et al., 2020; Macartney et al., 2014) and sleep problems (van Kooten et al., 2019), may also negatively affect psychosocial wellbeing and school performance. There are also a couple of studies that found that children treated for cancer may experience bullying when returning to school, which could add to their educational as well as their social problems (Collins et al., 2019; Lähteenmäki et al., 2002; Park et al., 2018). Some children treated for brain tumours may develop behavioural problems (Gerber et

al., 2008; Turner et al., 2009), even though the number of children identified with these symptoms vary (Upton & Eiser, 2006; Vance & Eiser, 2002). However, girls treated for brain tumours have an especially increased risk of suffering anxiety symptoms, depression, or hospitalization for psychiatric disorders (Barrera et al., 2007; Ross et al., 2003; Turner et al., 2009; Zebrack et al., 2004).

Moreover, a couple of studies have demonstrated that adults who in their childhood were treated for cancer, and especially those with brain tumours or other type of treatment affecting the brain, often had lower income, less education and a higher risk of unemployment compared with controls (Boman et al., 2010; de Boer et al., 2006; Kirchhoff et al., 2010). One study showed a higher risk of no education after comprehensive school but not a significantly higher risk of unemployment (Ahomäki et al., 2017). Compared with the general population, children treated for brain tumours are also at higher risk of leaving home later (Koch et al., 2006) and being unmarried as adults (Koch et al., 2011; Langeveld et al., 2003). Yet, some children treated for brain tumours also describe some positive consequences, such as better self-confidence, an expanded worldview or view of others, and an increased appreciation of everyday events (Engvall et al., 2011; Gunn et al., 2016; Mattsson et al., 2007).

Medical late effects

Children treated for brain tumours often experience medical late effects. Such effects could be more visible permanent changes of the body, for example scars, deformed skull, altered gait, impaired speech, difficulties with balance or coordination, facial palsy, alopecia (i.e. complete or partial permanent loss of hair), short stature, as well as invisible changes such as pain, fatigue, infertility, visual or hearing impairments, endocrine dysfunctions, lower tolerance for noise, reduced grip strength and reduced oxygen uptake (Macartney et al., 2014; Ness et al., 2010; Netson et al., 2013; Turner et al., 2009; Vanclooster et al., 2020; Weiss et al., 2017). There is also an increased risk of secondary malignancies, i.e. new types of cancers (Marks & Packer, 2012; Turner et al., 2009).

Factors to consider regarding school

With the increased knowledge of late effects, the question arises whether it is possible to reduce these (Askins & Moore, 2008; Butler, Copeland, et al., 2008, 2008; Mulhern et al., 2004; Nathan, 2007). In 1995, international guidelines were published for school and education of children affected by cancer (Masera et al., 1995). These guidelines stressed the importance of returning to school after diagnosis and included proposals for reintegration, for example, by multi-professional teams, development of individual study plans and cooperation between home, school and hospital in addition to a school re-entry program.

In Sweden, the goal is that all children treated for brain tumours, especially those treated with radiation, should have a neurocognitive follow-up about one or two years after diagnosis (RCC i samverkan, 2019). Depending on the extent and range of late effects, the follow-up can be repeated on a regular basis. The recommendation is that a multi-professional team, including a child neurologist, a neuropsychologist, a physiotherapist, a speech therapist, a special education teacher and a social worker, should do the follow-ups. The team should assess each child's strengths and difficulties, and parents and school personnel should be informed of the results.

Still, academic as well as social or neurocognitive difficulties may arise both from environmental factors and biological factors (e.g. Bronfenbrenner & Ceci, 1994; Cantor et al., 2019; Lenroot & Giedd, 2008; Osher et al., 2020; Robinson et al., 2010; Vanclooster et al., 2020). Thus, it is important to consider both these factors when discussing school performance of children treated for brain tumours. In the following section, a theoretical framework in line with this is presented.

Theoretical framework

Developmental systems theories

During recent decades, new knowledge about how children in general learn and develop has evolved from diverse fields such as learning sciences, psychology, neuroscience, social sciences, and developmental sciences (Cantor et al., 2019). In developmental systems theories, children's development is described as a dialectic process between the environment and the individual (Cantor et al., 2019; Darling-Hammond et al., 2019; Lerner, 2006; Osher et al., 2020; Overton, 2013; Sameroff, 2010). It is a relational metatheory in which systemic syntheses replace dichotomizations such as those between nature and nurture, between stability and instability, and between continuity and discontinuity (Cantor et al., 2019; Lerner, 2006).

Developmental systems theories are characterized by stressing the potential for plasticity, i.e. systematic change (Lerner, 2006). In other words, children's development is neither only genetically predetermined, nor can it be explained only by environmental factors (Osher et al., 2020). Thus, "development is a constructive enterprise shaped by ongoing, reciprocal interaction between children's biology, their developing brains, and their physical and social contexts, with the latter playing a defining role" (Osher et al., 2020, p. 6-7). By using developmental systems theories it is possible to understand both the variability and the stability in children's performance in different contexts, which was not possible through sole reliance on developmental stage-based theories (Cantor et al., 2019).

The model of brain reserve capacity, cognitive reserve capacity, and age-based functional plasticity

To explain individual differences in school outcome for children treated for brain tumours, a theory that stresses individual factors as well as the context may serve well. One possible option is the model, by the neuropsychologist Maureen Dennis, of brain reserve capacity, cognitive reserve capacity, and

age-based functional plasticity (Dennis et al., 2007, p. 56). This model (Figure 1) includes different aspects affecting the outcome after an acquired brain injury, due to trauma or a brain tumour and the following treatment.

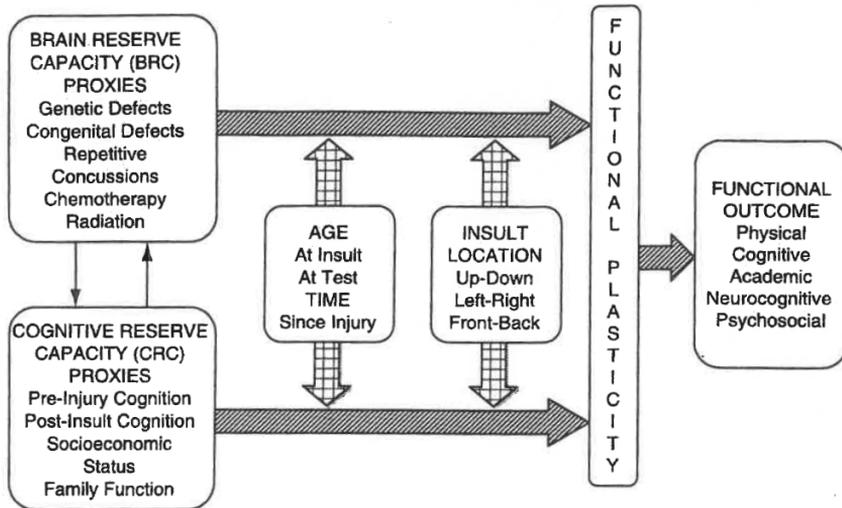


Figure 1. Developmental model of brain reserve capacity (BRC) and cognitive reserve capacity (CRC) showing mediated (striped) and moderated (crosshatched) relations (Figure and text from Dennis et al., 2007, p. 56).

In the model, the brain reserve capacity (BRC) – including genetic defects, congenital defects, repetitive concussions, or cancer treatments – interacts with the cognitive reserve capacity (CRC) which includes factors such as pre-injury cognition, post-injury cognition, and environmental factors, for example socio-economic status and family function. Neither the brain reserve capacity, nor the cognitive reserve capacity are constant during development. The brain reserve capacity and cognitive reserve capacity in children experiencing a brain injury are moderated by two sets of variables – age/time and location. Age/time considers both the age of the child at time of injury, age when tests are performed, and the time since injury. Location means the location of the injury. Subsequently, the action from the mediators, brain reserve capacity and cognitive reserve capacity, and the moderators, age/time and location, together constitutes the functional plasticity. In other words, due to the age/time factors, the same brain injury, such as consequences after a brain tumour, can affect the functional plasticity differently, and thereby also the functional outcome (Dennis et al., 2007, 2014).

As shown in the model, the functional plasticity influence the functional outcomes. These outcomes are traditionally based on measurements of direct performance in the various domains (Dennis et al., 2014). For example, to assess the cognitive functional outcome after brain tumour treatment, neuropsychological tests can be used, and to assess the academic outcome, school related tests as well as classroom observations of everyday functions and self-reports can be performed. In this thesis, only the academic outcome is assessed, and this is done by investigating academic grades, national tests, delayed graduation, and qualification for school years 10-12.

Aims of the thesis

Overall aim

The overall aim of this thesis was to investigate the academic performance in Swedish ninth grade students treated for brain tumours compared with matched controls. Grades and national tests from school year nine in the theoretical subjects of Swedish, English, and mathematics, and grades in the practical and aesthetic subjects of art, crafts, music, home and consumer studies, physical education and health, as well as delayed graduation, and qualification for school years 10-12, were investigated. The studies are performed in order to contribute with more information and understanding of these children's school situation and needs, which is one of the prerequisites for more specific and helpful resources during their school years. As stated by Dennis et al. (2014, p.19):

The job of formulating a useful developmental outcome assessment is important for children with brain insult throughout the lifespan, because accurate assessment of functional outcome is necessary to make inferences, not only about the level, rate, and trajectory of development in the face of brain insult, but also about constructs such as plasticity, recovery, and restitution of function.

Research questions in the different studies

Study 1

Study 1 examined how children treated for brain tumours performed in the theoretical subjects of Swedish, English, and mathematics and includes the following research questions:

- How do children in Sweden treated for brain tumours perform in school with regard to final grades from year nine in Swedish, English, mathematics, delayed graduation, and qualification for school years 10-12, compared with matched controls?
- Is school performance affected by sex, age at diagnosis, tumour grade (high or low), or parents' education?

Study 2

Study 2 examined how children treated for brain tumours performed in the practical and aesthetic (PRAEST) subjects, and includes the following research questions:

- How many of the children treated for brain tumours fail the different PRAEST subjects of home and consumer studies, physical education and health, art, crafts and music compared with controls?
- Are there any differences between girls and boys, age at diagnosis, or tumour grade (high or low) for the risk of failing a grade?
- How do children treated for brain tumour perform in school, as judged by their average grades in the PRAEST subjects from the final year of compulsory school, compared with controls?
- Are the average PRAEST grades different between girls and boys, and do they vary depending on age at diagnosis or tumour grade (high or low)?

Study 3

The main objective of Study 3 was to investigate if national test results in Swedish, English, and mathematics could be used to identify specific academic strengths and difficulties in children treated for brain tumours, beyond what can be detected from information of final grades alone, and includes the following research questions:

- How do children treated for brain tumours perform in national tests in Swedish, English, and mathematics compared with controls?
- Are there any differences in performance between the oral, reading and writing subtests in Swedish and English for children treated for brain tumours and controls, respectively?
- Are there any differences within the group of children treated for brain tumours due to sex, age at diagnosis and tumour grade (high or low)?

Methods

Procedure and participants

This thesis was based on registry data from the Swedish Childhood Registry and Statistics Sweden. The Swedish Childhood Cancer Registry is included in the Swedish National Quality registries and contains information from 94% of all children in Sweden treated for cancer (National Board of Health and Welfare, 2015). The data from Statistics Sweden are also of a very high quality and include data from almost all schools in Sweden (Statistics Sweden, n.d.-a, n.d.-b).

Data were requested from the Swedish Childhood Cancer Registry about all children treated for brain tumours born between 1988 and 1996. Received registry data included information about sex, age at diagnosis, tumour type (Table 3), relapses and whether they were still alive. The personal identification numbers were sent directly from the Swedish Childhood Cancer Registry to Statistics Sweden, from which data were obtained about the children's school grades from year nine, including if they studied Swedish as their first or second language, national test results in Swedish, Swedish as a second language, English, and mathematics, and parents' education. Only information from children with grades from the curriculum in the regular compulsory school was obtained as children with intellectual disabilities do not follow the same curriculum, and thus have not the same system for grades or national tests (Swedish National Agency for Education, n.d.-c, n.d.-b, 2006, 2010).

Table 3. Medical characteristics of included children treated for brain tumours (cases, n=475). Tumour classification according to the Swedish Childhood Cancer Registry. High-grade tumours, WHO III-IV and low-grade tumours, WHO I-II.

Tumour classification	Cases N (%)	High- grade N	Low- grade N
Ependymomas	33 (6.9)	12	21
Choroid plexus tumours	10 (2.1)	1	9
Astrocytomas	172 (36.2)	10	162
Optic nerve gliomas	41 (8.6)	-	41
Embryonal tumours (e.g., medulloblastoma and PNET)	57 (12.0)	57	-
Oligodendrogliomas	12 (2.5)	2	10
Mixed and unspecified gliomas	12 (2.5)	3	9
Neuroepithelial glial tumours of uncertain origins	4 (0.8)	-	4
Pituitary adenomas and carcinomas	10 (2.1)	2	8
Tumours of the cellar region (craniopharyngioma)	31 (6.5)	-	31
Pineal parenchymal tumours	8 (1.7)	3	5
Neuronal and mixed neuronal-glial tumours	38 (8.0)	1	37
Meningiomas	11 (2.3)	-	11
Specified intracranial/intraspinal tumours	1 (0.2)	-	1
Unspecified intracranial/intraspinal tumours	8 (1.7)	-	8
Other specified/unspecified tumours	2 (0.4)	-	2
Nerve sheath tumours	5 (1.1)	-	5
Germ cell tumours	8 (1.7)	1	7
Non-CNS tumours by definition	12 (2.5)	-	12

Statistics Sweden also matched the children treated for brain tumours to five controls each by birth year, sex and place of residence at diagnosis. About 97% of the children treated for brain tumours were at least one-year post diagnosis at the time when they got their grades from the years 2003-2012. Children treated for brain tumours were not eligible as controls, and each control only appeared for one child treated for brain tumours. Thus, in all three studies, 475 children treated for brain tumours and 2,197 controls were included, and the same cohort was used in all three articles (Figure 2 next page).

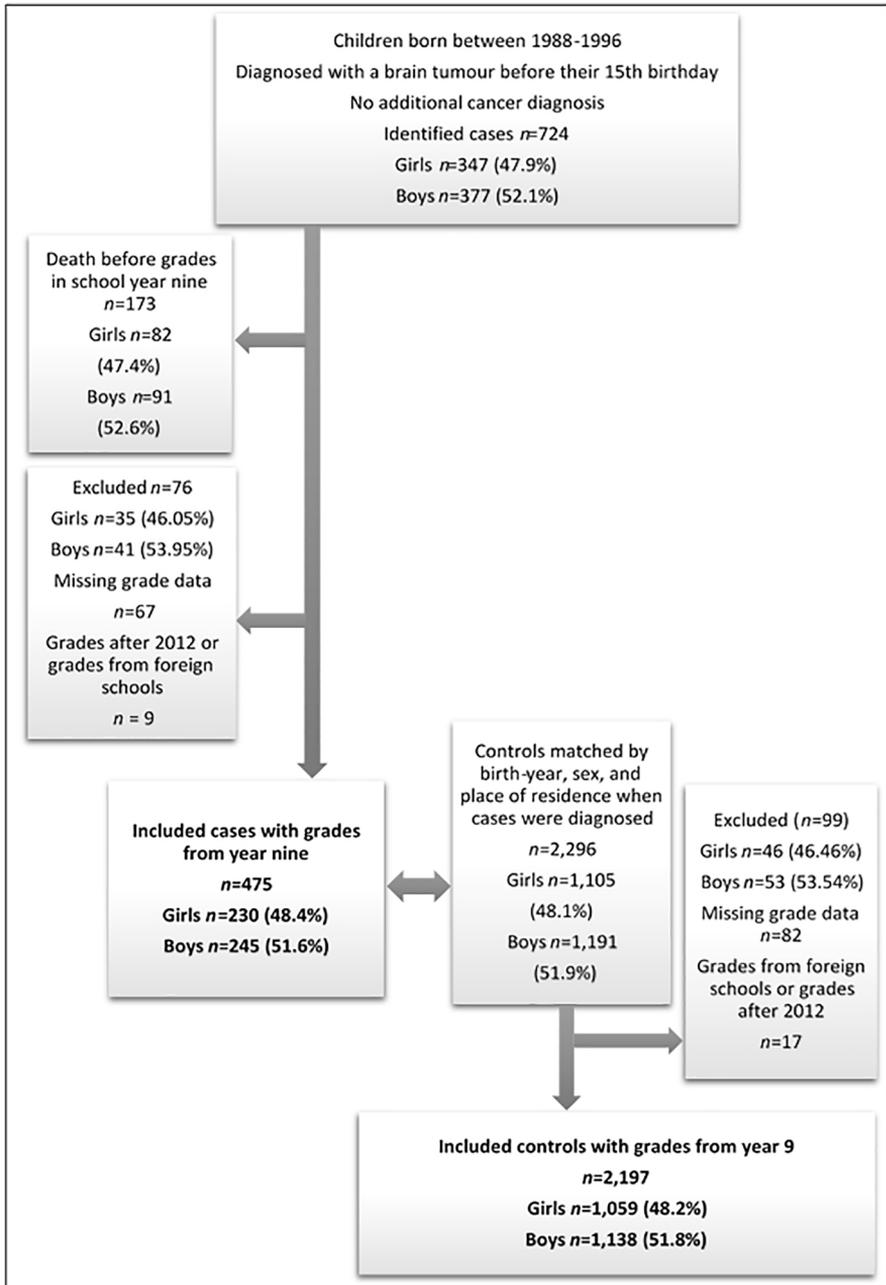


Figure 2. Inclusion and exclusion criteria for children treated for brain tumours ($n=475$) and their matched controls ($n=2,197$).

When background factors were reviewed for included children, no significant differences were found between cases and controls for sex ($p = 0.931$), mothers' education ($p = 0.245$), fathers' education ($p = 0.284$), or Swedish as the first or second language ($p = 0.396$). Pearson's chi-square test was used for comparison between cases' and controls' background variables (Table 4).

Table 4. Characteristics of included children treated for brain tumours (cases, n=475) and controls (n=2,197). High-grade tumours, WHO III-IV and low-grade tumours, WHO I-II.

	Cases N (%)	High grade N	Low grade N	Controls N (%)
All	475	92	383	2,197
Girls	230 (48.4)	43	187	1,059 (48.2)
Boys	245 (51.6)	49	196	1,138 (51.8)
Age at diagnosis				
Girls 0–5 years	82 (35.6)	20	62	
Girls 6–9 years	51 (22.2)	13	38	
Girls 10–14 years	97 (42.2)	10	87	
Age at diagnosis				
Boys 0–5 years	87 (35.5)	15	72	
Boys 6–9 years	66 (26.9)	10	56	
Boys 10–14 years	92 (37.6)	24	68	
Swedish				
As the first language	450 (94.7)			2,101 (95.6)
As the second language	25 (5.3)			96 (4.4)
Mothers' education				
Low (school years 1–9 or less)	36 (7.6)			219 (9.9)
Medium (school years 10–12) ^a	236 (49.7)			1,091 (49.7)
High (higher education)	201 (42.3)			881 (40.1)
No information about education	2 (0.4)			6 (0.3)
Fathers' education				
Low (school years 1–9 or less)	82 (17.3)			353 (16.1)
Medium (school years 10–12) ^a	229 (48.2)			1,156 (52.6)
High (higher education)	154 (32.4)			660 (30.0)
No information about education	10 (2.1)			28 (1.3)

^a Until 1994, school years 10-12 could be two (vocational educations) or three (theoretical educations) years in Sweden

In the studies, we analysed the importance of age at diagnosis. Depending on age at diagnosis, cases were split into three groups. These age groups follow the Swedish school system: ages 0-5 comprise the years before school starts;

ages 6-9 the pre-school class and the first to third school years; and ages 10-14 the fourth to eighth years. Study 1 also refers to delayed graduation. This includes those students finishing school at age 17 or later, as most children graduate and get their final grades the year they turn 16. The reasons for the delay are that the child started school at an older age than expected or repeated one or more school years.

Statistical methods

In Studies 1, 2 and 3, IBM SPSS version 25 or version 26 and R version 3.5.2 or version 3.6.0 were used for statistical analyses. *P*-values below 5% were considered significant.

In Study 1, focus was on grades from school year nine in the subjects of Swedish, English, and mathematics. The differences between children treated for brain tumours (cases) and controls with regard to grades, qualification for school years 10-12, and delayed graduation were described with odds ratios (OR) and tested using Pearson's chi-square test. For comparison between girls and boys treated at different ages and in order to adjust for high- or low-grade tumours, and mothers' and fathers' education, linear regressions were used to analyse the average grades (including fail, pass, pass with distinction, and pass with special distinction) for each subject. To analyse the factors associated with qualification for school years 10-12 for children treated for brain tumours, logistic regressions were used. Sex and age at diagnosis (0-5 years, 6-9 years or 10-14 years) were included in all regression models, and the interaction between these factors was tested in all models and added when significant. All the statistical models were also adjusted for tumour grade (high or low), and mothers' and fathers' education, respectively.

In Study 2, data about grades in the practical and aesthetic (PRAEST) subjects of home and consumer studies, physical education and health, art, crafts and music were in focus. Logistic regressions were used to calculate odds ratios with 95% confidence for failing in the different PRAEST subjects for comparing cases and controls. To investigate whether the sex difference in the proportion failing differed between cases and controls, an interaction term was added between sex and diagnosis to a logistic regression model. In this model, failing in the different subjects was used as a dependent variable, and sex and diagnosis were used as independent variables. Differences within the group of children treated for brain tumours for age at diagnosis (0-5 years, 6-9 years or

10-14 years) or tumour grade (high or low), were analysed with logistic regressions and adjusted for models for mothers' and fathers' education, respectively. Regarding average grade (including fail, pass, pass with distinction, and pass with special distinction), an independent sample t-test was used to detect differences between cases and controls. To investigate whether the sex difference in average grade differed between the cases and controls an interaction term between sex and diagnosis was added to a linear regression model, including average grade as a dependent variable and sex and diagnosis as independent variable. To analyse differences within the group of children treated for brain tumours for average grade due to age at diagnosis (0-5, 6-9 and 10-14) and tumour grade (high or low), a linear regression was used. The model was also adjusted for mothers' and fathers' education, respectively. Average grades in the different PRAEST subjects were used as dependent variables, and age at diagnosis and tumour grade (high or low) were used as independent variables.

In study 3, data about national tests were analysed. To investigate if there were overall differences between children treated for brain tumours and their controls for missing information and all the national tests grades fail, pass, pass with distinction, and pass with special distinction, chi-square tests were used. For further analyses of differences in proportions between children treated for brain tumours and controls only for missing information or failing and calculating odds ratios and 95% confidence intervals (CI), chi-square tests were again used. These analyses were also performed for girls and boys separately to compare girls treated for brain tumours with their female controls and boys treated for brain tumours with their male controls. To investigate if there were any differences regarding performance between the three subtests in Swedish and English within the group of children treated for brain tumours and the control group, respectively, we used Friedman's ANOVA test. *Post hoc* analyses were done with Wilcoxon signed-rank tests and a Bonferroni correction, resulting in a significance level of $p < 0.017$. These analyses could not be performed in the subject mathematics as only the composite grades from the national tests in this subject were available. To detect possible differences in performance within the group of children treated for brain tumours due to sex, age at diagnosis (0-5 years, 6-9 years or 10-14 years) or tumour grade (high or low), logistic regressions were performed, with age at diagnosis and tumour grade as independent variables, and missing information and failing as dependent variables. All models were adjusted for mothers' and fathers' education, respectively.

Ethics

Ethical approval

Ethical approval for this study was given by the Regional Ethical Review Board in Stockholm (no. 2017/995-31/5).

Ethical considerations

To have informed consent, to do no harm to participants, no invasion of privacy and no deception are important ethical principles for studies in social science (Bryman, 2016). Concerning informed consent, all the parents of the included children treated for brain tumours in the studies have given written permission to allow their child to be included in the Swedish Childhood Cancer Registry. The children themselves were asked again if they wanted to remain in the registry when they turned 18. In the information given to the parents and the children it is expressed that by accepting to being included in this registry, they will probably be a part of several studies without being asked again. The ethical consideration that was made to not contact each participant again, apart from the fact that the participants or their parents had already consented to be included in the registry, was that a new contact could be stressful or even traumatic for the child or the family. The child's cancer treatment was probably a difficult time in life that many families may not want to be reminded of. There may also be children included in the study who have passed away.

Another reason was the risk of bias, for example if only those that were very affected by late effects answered or only those who were not affected at all consented. The risk of invasion of privacy was very small, as it is not possible to identify a single person. All data from the Swedish Childhood Registry were sent directly to Statistics Sweden. Any personal information that would make it possible to identify individuals has not been handled. All participants were de-identified by Statistics Sweden who has the code key. This code key is automatically destroyed three years after the application was approved if no application for a prolongation is submitted. Based on this, the present study will most certainly not do any harm to the participants. Concerning deception, the purpose with the study is clear and the results will not be used for anything other than research. The purpose of the study is to gain new information that can lead to a better understanding about the needs of children treated for brain tumours so that adequate help in schools can be provided.

Reliability and validity

Reliability deals with the question of whether the results from the studies are repeatable or not (Bryman, 2016); measurements with good reliability should produce similar results in different time points and situations (Borg & West-erlund, 2012). To ascertain good reliability, data were collected from the years 2003 to 2012 (children born 1988-1996) as the grade system or the national tests construction did not change during these years.

Moreover, in quantitative studies, there are four different kinds of validity that should be considered: internal validity, external validity, statistical conclusion validity and construct validity (Taylor, 2013). Internal validity relates to the question of causality. In these studies, the causality was checked for through previous literature studies that found a strong correlation between children acquiring a brain tumour and receiving treatment, and school difficulties (Ahomäki et al., 2017; Andersen et al., 2017; Kieffer et al., 2012; Lähteenmäki et al., 2007; Lönnerblad et al., 2017; Mabbott et al., 2005; Upton & Eiser, 2006). External validity concerns whether the results are generalizable beyond the specific investigation; this is also considered by literature studies that demonstrate that children treated for brain tumours perform worse in school compared with peers. It would appear to be possible to generalize the results from the studies included in this thesis (Lönnerblad et al., 2020a, 2020b, 2021) to other countries, for example Denmark (Andersen et al., 2017) and Finland (Ahomäki et al., 2017; Lähteenmäki et al., 2007), countries with school systems quite similar to the Swedish one.

Furthermore, the results also seem to be generalizable to countries and cultures other than the Nordic, for example Korea (Park et al., 2018), Canada (Lorenzi et al., 2009) or USA (Mitby et al., 2003), although the measurement of academic outcome is performed in other ways in those studies. To strengthen the statistical conclusion validity, i.e. that the statistical conclusions drawn in the studies can be trusted, a high number of participants has been included. However, a large sample does not guarantee precision (Bryman, 2016), but with a larger sample it becomes possible to use more sophisticated statistic methods (Cohen, 2007). A control group matched by sex, birth year and place of residence was also used to ensure minimal differences between cases and controls as is possible with these background factors.

Due to the fact that children treated for brain tumours is a very heterogeneous group, regression analyses were used to minimize confounding factors as advocated by Taylor (2013). In the analyses, age at diagnosis, sex, tumour

grade (high or low), and parents' education was tested separately, and the interaction effect between age at diagnosis and sex was also tested. Construct validity has to do with the degree to which a test measures what it is supposed to measure. To assess school performance of children treated for brain tumours, school grades from year nine and national tests from the same year were chosen as measurements. School grades are based on the aims in the National Curriculums and there are clear instructions for teachers to follow. National tests in Sweden are constructed and developed at some of Sweden's Universities.

Results

In this section, the main results from the three different studies are briefly presented. However, they are not discussed until the discussion section that follows the results.

Results from Study 1

Study 1 examined final grades from school year nine in the theoretical subjects of Swedish, English, and mathematics. The main findings were:

- A significantly larger number of children treated for brain tumours failed one or more of the subjects Swedish (OR 2.38), English (OR 3.62), or mathematics (OR 2.33) compared with controls. There were larger differences between girls treated for brain tumours and their controls than between boys treated for brain tumours and their controls. Significantly fewer children treated for brain tumours obtained the two highest grades, pass with distinction or pass with special distinction, compared with controls.
- The odds for qualifying for school years 10-12 were 2.84 times higher for controls (90.6%) than for children treated for brain tumours (77.3%).
- Girls treated at ages 0-5 and 6-9 were significantly less likely to qualify for school years 10-12 (70.7% and 66.7%, respectively) compared with girls treated at ages 10-14 (85.6%). There were no significant differences between boys treated at different ages (0-5: 78.2%; 6-9: 81.8%; 10-14: 76.1%). Neither were there any significant differences between children treated for high-grade tumours and low-grade tumours.
- An effect of both mothers' and fathers' education was seen, with a positive correlation between the parents' education level and the child's qualification for school years 10-12.

- The odds for delayed graduation were 5.40 times higher for children treated for brain tumours (n=54/475) compared with controls (n=51/2,197). Boys (n=35/245) treated for brain tumours had a 2.03 times higher odds for delayed graduation compared with girls (n=18/230) treated for brain tumours. In the control group, the odds were 2.27 times higher for boys (n=36/1,138) compared with girls (n=15/1,059).
- Within the group of children treated for brain tumours there were significant differences in the average grade for Swedish between girls and boys treated for brain tumours, with girls having a higher average compared with boys. Children treated at ages 10-14 had a significantly higher average grade compared with children treated at ages 0-5.
- For English, there were no significant differences between girls and boys, but both girls and boys treated at ages 10-14 had a higher average grade compared with girls and boys treated at ages 0-5 and 6-9.
- For mathematics, there was only a significant difference between girls and boys treated at ages 6-9, with boys having a higher average grade compared with girls. Girls treated at ages 10-14 had a significantly higher average grade compared with girls treated at ages 0-5 and 6-9. In mathematics, this difference between age groups was not seen among the boys.

Results from Study 2

Study 2 examined final grades from school year nine in the practical and aesthetic (PRAEST) subjects of home and consumer studies, physical education and health, art, crafts and music. The main findings were:

- Children treated for brain tumours failed the subjects of music, art, and physical education and health to a significantly higher extent compared with controls, whereas there were no significant differences in the subjects of crafts and home and consumer studies.
- Girls treated for brain tumours had 2.23-3.20 times higher odds for failing in one of these subjects compared with their controls. For boys treated for brain tumours, there were no significant differences compared with their controls in any of the subjects.
- There were no significant differences between children treated for high- or low-grade tumours, or children treated at different ages (0-5, 6-9 or 10-14).
- There was a significant difference for average grades in all five PRAEST subjects between cases and controls. Girls treated for brain tumours had significantly lower average grades in all subjects compared with their controls, whereas boys treated for brain tumours only differed with their controls in physical education and health and music. The largest differences between cases and controls was seen in physical education and health and the smallest difference was seen in art.

Results from Study 3

Study 3 examined performance in national tests in Swedish, English, and mathematics, and whether these tests could be used to identify specific academic strengths and difficulties in children treated for brain tumours. The main findings were:

- National tests can be used to detect differences in school performance between children treated for brain tumours and controls, although it is important to also include missing information about national tests as a variable on its own in these analyses.
- There were significant differences between cases and controls for missing information and failing in all subjects and subtests, except for failing in two of the subtests in Swedish (oral and writing). The largest differences were seen in the subject of English.
- There were larger differences in results between girls treated for brain tumours and their controls, than for boys treated for brain tumours and their controls, whereas there were no significant differences for sex or tumour grade (high or low) within the group of children treated for brain tumours.
- Not doing any of the national tests in a subject was a strong predictor of failing the final grade in the subject.
- Age at diagnosis was a significant factor for all subtests in the subject of English. Children treated at ages 0-5, but also at ages 10-14, especially had more missing information compared with children treated at ages 6-9, whereas children treated at ages 6-9 failed to a larger extent compared with children treated at ages 0-5 or 10-14. In Swedish, there was a significant difference only between boys and girls treated at ages 10-14 and in mathematics, children treated at ages 0-5 and 10-14 had significantly more missing information compared with children treated at ages 6-9.
- In the subjects of both Swedish and English, children treated for brain tumours and controls performed better on the oral subtests than on the writing subtests. For children treated for brain tumours, these were the only subtests with significant differences. Controls had significant differences between all subtests in both Swedish and English except between the reading/listening and the oral subtest in English.

Discussion

The overall aim of this thesis was to investigate the academic performance in Swedish ninth grade students treated for brain tumours compared with matched controls. In the following sections, the main findings from Study 1 (Lönnerblad et al., 2020a), Study 2 (Lönnerblad et al., 2020b), and Study 3 (Lönnerblad et al., 2021) are discussed with a focus on the different measurements of academic outcome (grades, national tests, delayed graduation, and qualification for school years 10-12). Then factors included in the different analyses and previously known to have an impact on the functional plasticity – i.e. sex, tumour grade, parents' education and age at diagnosis – are discussed. However, location of the brain tumour is not discussed, as no specific information about this was included in the studies. After a section about possible interventions, there is a summation of new knowledge obtained. Finally, practical implications, strengths, and limitations of the present studies and suggestions for future research are discussed.

Functional plasticity measured by functional outcome

As stated in the theoretical framework, functional plasticity varies due to factors such as sex, high- or low-grade tumour, age at diagnosis and parents' education. Moreover, different domains of functional plasticity are usually measured by different tests and methods (Dennis et al., 2007, 2014). In the present studies, the academic outcome is assessed by analysing the final grades in theoretical, practical and aesthetic subjects, qualification for school years 10-12, delayed graduation, and through analyses of the national test in Swedish, English and mathematics.

Academic grades

Both Studies 1 and 2 assessed the academic grades from school year nine. However, while Study 1 investigated the theoretical subjects of Swedish, English and mathematics, Study 2 had the practical and aesthetic subjects in focus. As in previous international studies (Ahomäki et al., 2017; Andersen et al., 2017; Lähteenmäki et al., 2007), the results from Study 1 indicated that children treated for brain tumours performed worse than peers in all the three assessed subjects; mother tongue (Swedish), first foreign language (English), and mathematics. The largest differences between cases and controls were seen in English, and the smallest differences in Swedish. In the practical and aesthetic subjects assessed in Study 2, the children treated for brain tumours experienced most difficulties in the subjects of music and physical education and health. It seems that the results regarding the full range of practical and aesthetic subjects have not been assessed together in any previous study.

However, a handful of studies have shown that the subject of physical education could be more problematic for children treated for brain tumours compared with controls (Ahomäki et al., 2017; Lähteenmäki et al., 2007; Park et al., 2018). Furthermore, one other study demonstrated comparable results both for physical education and arts/music for children treated for a number of different cancers, including children treated for brain tumours (Yilmaz et al., 2014). One possible reason why music and physical education were the two most problematic subjects for children treated for brain tumour could be that the level of noise during lessons in these two subjects may affect them more severely as they are commonly reported to suffer from tinnitus or other auditory deficits (Weiss et al., 2017; Whelan et al., 2011). A second reason could be that the children have difficulties with muscle strain and motor skills that often appear after brain tumour treatment (Ness et al., 2010; Vanclooster et al., 2020). However, to understand these effects would require specific studies to address them in more depth.

The results also indicated that there were larger differences in grades between cases and controls for the theoretical subjects assessed in Study 1 than in the practical and aesthetic subjects assessed in Study 2, although to some extent the results are related to sex, which is discussed later. One reason could be that in the practical and aesthetic subjects, there are no national tests that have to be considered by the teachers when grading the children. Another explanation could be that there are probably more differentiated ways for the children both to learn and to show what has been learnt in the practical and aesthetic subjects.

Delayed graduation

Many children undergoing treatment for brain tumours have a high degree of school absence, both during and after treatment, due to hospital visits, problems with fatigue, headache or illness (Mitby et al., 2003; Upton & Eiser, 2006; Vance & Eiser, 2002). School absences could have a duration of only a few days or weeks, up to several years, and may often occur intermittently (French et al., 2013; Upton & Eiser, 2006). For some children, it becomes necessary to repeat a school year. The number of children treated for brain tumours who repeat a year in school has been shown to vary between countries. For example, in the study from Finland, the number was about 6.0% (n=19/300) (Lähteenmäki et al., 2007), whereas the number in a Swiss study was 16.4% (n=18/110) (Kuehni et al., 2012).

In Study 1, when repeating a school year was assessed, the results showed that of all 475 included children treated for brain tumours, 11.4% (18 girls and 36 boys) had a delayed graduation compared with 2.3% (15 girls and 36 boys) in the control group. This was a smaller number compared with Switzerland, but a larger number compared with Finland. Yet, the numbers may not be entirely comparable, as they may have been calculated in different ways. In Study 1, it is also unknown whether the delay is due to starting school year later or repeating a grade, as the official statistics of the total number of children in Sweden who repeat a school year is unknown while there are facts about the total number of children attending a pre-school class one year in advance or one year later. For example, for the years 2001/2002 and 2002/2003, when children in the studies born between 1994 and 1996 turned six, only about 1% of all children in pre-school class started one year earlier or one year later. The proportion of boys that started pre-school class one year later was twice the proportion of girls during these years (Swedish National Agency for Education, n.d.-b). This could be a part of the explanation for the results in Study 1 that also showed that twice the number of boys had a delayed graduation compared with girls. Still, it is not clear from research whether repeating a school year is beneficial or not. For students in general, some studies have shown negative effects (Jimerson, 2001; McCoy & Reynolds, 1999), while others have shown positive effects (Allen et al., 2009; Im et al., 2013; Marsh, 2016), concerning for example test scores in reading and mathematics, school grades and relations with teachers, peers and parents. It has also been shown that some of these positive effects decreased in long-term follow-ups (Wu et al., 2010). Thus, the outcome of repeating a year may vary depending on what factors are measured, as well as how and when they are measured (Wu et al., 2008).

Qualification for school years 10-12

In Study 1, one of the research questions was to what extent children treated for brain tumours were being qualified for school years 10-12 compared with controls, and whether there were any differences between girls and boys, children treated at different ages, or children with high- or low-grade tumours, and what role their parents' education played. The results showed that the odds ratio for qualifying for school years 10-12 were more than twice as high for controls compared with children treated for brain tumours. In particular, it is worrying that only 67% of the girls treated at ages 6-9 and 71% of the girls treated at age 0-5 were qualified for school years 10-12. Among the boys, those treated at age 10-14 seem to be most at risk of not qualifying, with only 76% qualifying for school years 10-12. To not qualify for years 10-12 is problematic, as youngsters without post-compulsory education are demonstrated to have higher risks of lower income and unemployment (Swedish Public Employment Service, 2016). This may also have a negative impact on their well-being (Clark & Lepinteur, 2019) and other mental health issues (Bartelink et al., 2020), although the causal relationship for the latter is not entirely clear.

National tests

National tests in Swedish, English and mathematics were assessed in Study 3, and the results showed that there were significant differences between children treated for brain tumours and their controls for missing information and failing in most subjects and subtests. The largest differences were found in the subject of English for both missing information and failing. The differences were smaller between cases and controls for failing national tests compared with failing final grade (assessed in Study 1). This could be due to the number of children treated for brain tumours for whom information on national tests was missing.

Those with missing information on all three subtests in a subject were 9.0% in Swedish, 12.8% in English, and 17.9% in mathematics. It is only possible to speculate about the reason for the missing information, but it is very likely because the child did not participate. Thus, many children treated for brain tumours miss the opportunity to show their strengths and/or academic difficulties, which is the idea of the national tests. It would probably be beneficial for these children to have closer contact with their school to create plans for how they could participate in the national tests. Nevertheless, when comparing the performance on the different subtests, the results indicated that children treated for brain tumours and controls performed better on the oral subtests

than on the writing subtests in both Swedish and English (the two subjects with available results on different subtests). This information could indicate that it might be beneficial for some children to have oral, rather than written, tasks and exams. For children treated for brain tumours this could be even more important as they may also have difficulties relating to muscle strain or motor skills (Ness et al., 2010; Rueegg et al., 2013) which, for instance, can affect their writing ability (Ewing-Cobbs, 2004).

Differences between girls and boys

Reports from both Sweden and other countries (OECD, 2014; Swedish National Agency for Education, n.d.-b, 2011a, 2011b) have shown that girls in general perform better than boys, on a group level, in almost all school subjects. This difference between girls and boys in school performance was observed in all three studies in this thesis. A meta-analysis (Voyer & Voyer, 2014) concerning sex differences in scholastic achievement showed that differences in performance between girls and boys are greater in languages than in mathematics. Yet, in Study 1, when assessing the difference in average grades between girls and boys treated for brain tumours, the results showed that there were only significant differences between girls and boys in Swedish, not in English. In mathematics, there was only a significant difference between girls and boys in the group of children treated at ages 6-9. This seems to indicate that the academic advantage of girls over boys in general appears to be less evident among girls treated for brain tumours. For the national tests assessed in Study 3, there were no significant differences between girls and boys treated for brain tumours with regard to failing, or missing information in any of the subtests or subjects.

Still, in Studies 1, 2 and 3, the gap in results between girls treated for brain tumours and their controls was larger in almost all subjects compared with boys treated for brain tumours and their controls. This fact was most evident in Study 2, assessing the practical and aesthetic subjects, where significant differences in failing between girls treated for brain tumours and their female controls in all subjects were found, whereas there were no significant differences in failing between boys and their controls in any practical or aesthetic subject. When making the same comparison with average grades, there were still significant differences between the girls in all subjects, but only in the subjects of physical education and health and music for boys.

Whether the differences depend on the variances in the brain maturation (described earlier) or are due to surrounding factors such as support or relations to peers and teachers, is not possible to determine from the data in our three studies. Other Swedish registry studies investigating children with asthma (Nilsson et al., 2018) and diabetes (Dahlquist et al., 2007) have shown other types of results concerning the differences between girls and boys, although these two studies are not completely comparable as they include the final average overall grades, with all subjects included. The registry study on the effect of asthma (Nilsson et al., 2018) on grades for children born between 1994-1996, showed that girls had significantly higher final overall grades than boys, whereas for children that had developed diabetes (Dahlquist et al., 2007) during the years 1977-2000, there were no significant sex-related differences in their different final overall grades. This might suggest that the eventual problems are related more to characteristics of various diagnoses than on the children's school and social experiences; however, this has to be examined further.

Children treated for high- or low-grade tumours

Children treated for high-grade tumours often experience severe late effects (e.g. Makale et al., 2017; Merchant et al., 2010) as they often receive more intense treatment. However, children treated for low-grade tumours also commonly experience cognitive late effects after their treatment (Aarsen et al., 2006; Ehrstedt et al., 2016; Ris et al., 2008; Ris & Beebe, 2008). This is in line with the results in Studies 1, 2, and 3, which showed no significant differences between children treated for high-grade tumours (n=92; 19.4%) or low-grade tumours (n=383; 80.6%) in any of the studies. Nevertheless, in analyses with a smaller number of included participants, such in the analyses of the different age groups for girls and boys, it is important to take into consideration the occurrence of high- or low-grade tumours. In the included sample in Studies 1, 2, and 3 the occurrence of high-grade tumours was higher for girls treated at ages 0-5 (n=20; 24.4%) and 6-9 (n=13; 25.5%) than for girls treated at ages 10-14 (n=10; 10.3%) or boys treated at ages 0-5 (n=15; 17.2%) or 6-9 (n=10; 15.2%), but lower than for boys treated at ages 10-14 (n=24; 26.1%). Thus, tumour grade could also be a part of the explanation for the differences seen between girls and boys diagnosed at different ages, discussed in the next section.

Age at diagnosis

Age at diagnosis, has been demonstrated to play a significant role for neurocognitive outcomes after brain tumour treatment (e.g. Mulhern et al., 2004; Nathan, 2007). In particular, children treated at a very young age are well known to be at high risk of late effects. The results from Studies 1 and 3 indicated that particularly the children treated at age 0-5 and 6-9 obtained lower results in the subjects of English and mathematics. A young brain is more vulnerable to the effects of the cancer treatment, which can lead to more severe late effects (Mulhern et al., 2004). There are also context factors that could be a part of the explanation of why, for example, children treated at ages 6-9 perform worse than children treated at an older age. At age 6-9, children in Sweden participate in their first years in school. During the first school years, the most basic skills in both mathematics and English are taught, and for most children these subjects are new. Having a high level of school absence, particularly during the early school years when the foundation for both English and mathematics is established, may influence the whole school experience and then become evident in school year nine when national tests are performed, and final grades are set. Regarding Swedish, most children in Sweden have acquired an understanding from an early age, and their knowledge may thus be more robust. The particular difficulties for children treated at age 0-5 may relate to the fact that the brain tumour and the treatment have made it more difficult for the child from the start to learn new skills.

Concerning time since treatment and age at test, also highlighted in the model by Dennis et al. (2007), previous studies have shown that it may take some time before the late effects of the brain damage become evident (Turner et al., 2009; Wolfe et al., 2012). As a consequence, the gap of academic performance between children treated for brain tumours and their peers may increase over the years (Lönnerblad et al., 2017; Mabbott et al., 2005). However, school re-entry may be harder for older children due to greater difficulties in keeping up with missed study material and more psychosocial problems (Vanclooster et al., 2020). Thus, it is possible that if the measurements in the three different studies had been done at an older age, when a longer time had passed, the differences between the age groups would be less evident, but the differences in relation to controls even more apparent.

The impact of parents' education

Parents' education has been studied as a factor in itself in Study 1. Yet, it has also been included as a possible confounding factor in the analyses in Studies 2 and 3. In line with previous Swedish reports and research (J.-E. Gustafsson & Yang Hansen, 2018; Swedish National Agency for Education, 2011b, 2011a) the results from Study 1 demonstrated that parents' education had an impact on the results; there was a positive correlation between parents' education and qualification for school years 10-12 for children treated for brain tumours. These results are also in line with previous literature concerning school performance or neuro cognitive outcome of children treated for brain tumours (Ach et al., 2013; Laffond et al., 2012). Parents also have an important role in the collaboration between the home, the hospital, and the school (Moore et al., 2009; Rynard et al., 1998). Nevertheless, not all teachers or school personnel may be aware of parents' education level, and it is important to support all children treated for brain tumours, regardless of their parents' education. One possible way is through the school re-entry programmes discussed in the next sections.

Interventions and support

The ideas about how schools should best support children with difficulties have varied over the years and, according to Skidmore (1996, 1999), in particular there have been three different influential paradigms in special educational research, namely the psycho-medical, the organizational, and the sociological. These three different paradigms have presented different models about how to address special educational needs. In the psycho-medical model of causation, the difficulties are seen as deficits within the individual, whereas in the organizational model of causation, the learning difficulties derive from deficiencies in organization in the schools, and in the sociological model of causation the learning difficulties derive from structural inequalities in society (Skidmore, 1999). In addition, as highlighted in the theoretical framework, the interaction between nature and nurture, the individual and the surroundings have been in focus in developmental research of recent decades (Cantor et al., 2019; Darling-Hammond et al., 2019; Lerner, 2006; Osher et al., 2020; Overton, 2013; Sameroff, 2010).

Interventions to obtain optimal conditions for development, also called nurturing environments, are important for all children to prevent psychological

and behavioural problems, and can be implemented through multiple strategies (Biglan et al., 2012; Biglan & Prinz, 2017). As the needs of children treated for brain tumours are complex and heterogeneous (Tonning-Olsson, 2015; Vanclooster et al., 2020), interventions may concern different levels depending on each child's needs. Thus, how to effectively improve the school situation for children treated for brain tumours has to include interventions encompassing different theoretical paradigms.

Cognitive, physical, and pharmacological interventions

There are several interventions within the psycho-medical paradigm. Some of the interventions aim to enhance the child's own capacity in various ways. One example is the Cognitive Remediation Program (CRP) for children with attention deficits after cancer treatment. This programme has shown statistically significant improvements after programme completion regarding attention (Butler, Sahler, et al., 2008; Butler & Copeland, 2002). Another training programme is the Swedish Memory and Attention Re Training (SMART), originally named the Amsterdam Memory and Attention Training for Children (AMAT-C), which has also shown significant improvements in attention and memory for children with acquired brain injuries compared with controls (Dvorak & van Heugten, 2018; Robinson et al., 2014; van't Hooft et al., 2007). Training with the computerized working memory programme Cogmed has also resulted in significant improvements in working memory, attention and executive functions compared with controls for children treated for brain tumours or leukaemia (Conklin et al., 2015).

In addition, physical training has shown to have a positive impact on the brain recovery after treatment with radiation (Riggs et al., 2016; Szulc-Lerch et al., 2018). For example, physically active video gaming or adventure based training have shown to reduce fatigue and improve motor coordination and daily living activities for children treated for brain tumours (Li et al., 2018; Sabel et al., 2016, 2017). Other interventions have focused on pharmacological treatments. One example is methylphenidate, which improved attention regulation, social skills, and academic abilities for children treated for brain tumours or other cancers (Conklin et al., 2010; Mulhern et al., 2004). Another example is metformin, which improved the working memory for children treated with cranial radiation (Ayoub et al., 2020).

Support and interventions to promote nurturing environments

In regards to the organizational and sociological paradigms, focus on the context is the most important (Skidmore, 1996, 1999). One example of interventions for children treated for brain tumours, focusing on optimizing the environments, is the school re-entry programmes. School re-entry programmes for children treated for cancer often focus on the transition from hospital to school, collaboration between the family, school and hospital, and increased knowledge about the diagnosis and its late effects (Annett & Erickson, 2009; Bruce et al., 2012; Prevatt et al., 2000). Different reviews have found that some of the school re-entry programmes have shown significant results on positive attitudinal change, increased specific knowledge for teachers and peers, and lowered levels of depression or enhanced academic achievements for the child with cancer, although there is still a need to evaluate many programmes (Helms et al., 2016; Thompson et al., 2015).

Some programmes have specifically targeted teachers and other school personnel working with children treated for brain tumours or other cancers through workshops, computer-based programmes, or individual programmes in order to increase awareness and knowledge of the late effects (Annett & Erickson, 2009; Bruce et al., 2012; Dubowy et al., 2006; Ellis et al., 2013; Prevatt et al., 2000). For example, in a project from USA (Brown et al., 2011) school practitioners worked collaboratively with medical practitioners to develop a training programme for teachers. First, an assessment of the teachers' training needs was performed. In the assessment, 528 teachers completed a questionnaire in which they were asked to rate, on a scale from one to five, how prepared they were to cope with various issues concerning the child with cancer in the classroom. Based on the needs expressed by the teachers, the training programme was developed, and finally its practical utility was evaluated. The results showed that perceived knowledge and preparedness increased significantly among the teachers after the training programme. The teachers also found the programme effective and easy to use. Moreover, most of the teachers were positive about using computer-based training in the future (Brown et al., 2011).

The advantage of these types of workshops or computer-based programmes is that they can be designed to be both time and cost effective (Dubowy et al., 2006; Glang, McCart, et al., 2018; Prevatt et al., 2000). Other programmes have included peers, and have also shown positive results in increased knowledge of medical or psychosocial aspects relating to the child with cancer, or enhanced the interaction between peers and the child with cancer (Helms et al., 2016; Prevatt et al., 2000).

Furthermore, there also exist a number of school re-entry programmes for children who have experienced traumatic brain injuries (TBI) (Arroyos-Jurado & Savage, 2008; Chesire et al., 2011; Glang et al., 2004; Lindsay et al., 2015). Although they have not yet been evaluated or lack evidence, they can still be beneficial (Glang, Todis, et al., 2018), and many of the programmes for children with TBI may also well suit children treated for brain tumours (Barkon, 2009; Grandinette, 2014; Lindsay et al., 2015). However, it is important to remember that there are some differences between children undergoing cancer treatment and children with TBI, although there are also many similarities. One important difference is that children with TBI are most often medically stable when entering rehabilitation and going back to school, while children treated for cancer are not (Grandinette, 2014). According to Grandinette (2014), another important difference is that children who are undergoing treatment for a brain tumour will probably have more frequent absences due to the occasions for the treatment, as well as its side effects.

In addition, there are also other interventions or programmes with the goal to provide children with different educational needs access to the general curriculum, for example, the Universal Design for Learning (UDL) (Rao et al., 2014). As this method is flexible, and can thus meet different individual needs as it provides learners with a multitude of representations, expressions and engagement, it is also well suited for teaching children treated for brain tumours (Barkon, 2009). However, although the method seem to be widespread, there is still a lack of validation of its usefulness (Rao et al., 2014). There are also other examples of environmental adaptations for children treated for brain tumours, such as increased time to fulfil school assignments, written summaries from lessons, being allowed to write on a computer instead of doing assignments with paper and pen, and the option to have shorter school days or to record lectures (Mulhern et al., 2004; Sheinfeld Gorin & McAuliffe, 2008). In summary, there are different kinds of support and interventions that may be useful for children treated for brain tumours, but many of them still lack strong evidence.

Summary of new knowledge

School performance for year nine in the mother tongue, a first foreign language, mathematics and physical education have been investigated previously in large registry studies from Finland (Ahomäki et al., 2017; Lähteenmäki et al., 2007) and Denmark (Andersen et al., 2017). However, Studies 1 and 3 in

this thesis are most likely the first larger registry studies from Sweden to assess the grades and national tests from the final year in compulsory school in the subjects of Swedish, English and mathematics, and Study 2 is most likely the first study assessing all the practical and aesthetic subjects.

The main results in this thesis showed that there were significant differences in performance between children treated for brain tumours and their controls for the theoretical subjects assessed in Studies 1 and 3, and the practical and aesthetic subjects assessed in Study 2. Study 1 also showed children treated for brain tumour qualified for school years 10-12 to a lesser extent than controls. The odds for delayed graduation were more than five times higher for children treated for brain tumours compared with controls. Nevertheless, there were larger differences between cases and controls in the theoretical subjects than in the practical and aesthetic subjects. The largest differences were found in the subject of English.

The results in all three studies also showed that sex had an impact on the results. For example, the gaps between the girls treated for brain tumours and their female controls were, in most cases, larger than for the boys and their male controls for failing the different subjects, especially the practical and aesthetic subjects. However, whether the child had been treated for a high- or low-grade tumour did not have a significant impact on the results in any of the studies. Still, in analyses with a smaller number of included participants such as the analyses of the different age groups for girls and boys, the number of high- or low-grade tumours is important to take into consideration.

Parents' education was more thoroughly analysed only in Study 1 and showed a positive correlation with parents' education and qualification for school years 10-12 for children treated for brain tumours, but there could of course be individual differences. In Studies 2 and 3 parents' education was included as a controlling factor. Age at diagnosis was also included in the analyses. Study 1 showed that children treated at age 0-5 and 6-9 were at particular risk of a lower average grade in theoretical subjects or of not qualifying for school years 10-12, although the latter was significant only for the girls.

Age at diagnosis was also a significant factor for national test performance assessed in Study 3. Children treated at age 0-5 and 10-14 had more missing information compared with age group 6-9, whereas age group 6-9 failed to a greater extent compared with the other two age groups. However, Study 2 showed that age at diagnosis was of less importance for performance in the practical and aesthetic subjects.

Implications

The implications of the results in this thesis show that all children treated for brain tumours, regardless of sex, age at diagnosis, tumour grade (high or low) or parents' education, should be closely monitored. It is also important to have a long-term perspective as school difficulties do not disappear, but rather may increase over the years. In accordance with this, an individual education plan, with evaluable concrete goals should be written as soon as the child is back in school and revised each semester. In addition, schools should document what the child has missed and make a catch-up plan. To work efficiently, it is important that the catch-up plan focuses mainly on the most important areas within each subject. Yet, in implementing the catch-up plan, it is necessary to consider that the child may have low energy, suffer from mental fatigue, and may also suffer from different neurocognitive late effects such as a slow processing speed and attention difficulties. Psychosocial medical late effects may also affect the child in different ways.

Extra tutoring regarding critical skills for their future education should be offered to all children, although especially regarding their first foreign language, English, and mathematics, as these subjects seem to be most affected. Children treated before school start should be monitored extra closely as well as children treated at ages 6-9, as much of basic skills are taught during these first years in school. Furthermore, as shown in Studies 1, 2, and 3, the gap between cases and controls is larger for girls than for boys. It is therefore of importance that girls and boys are equally monitored, and that individual education plans are designed as frequently for girls as for boys.

Moreover, support and interventions on different levels are very important for this group of children, not only for the theoretical subjects but also for the practical and aesthetic subjects. As Study 3 showed that many children performed better on oral tasks than on written tasks, some children would probably benefit from being offered the possibility of oral, rather than written, tasks or exams. However, the important thing to bear in mind is that the range of difficulties for children treated for brain tumours is extremely wide and heterogeneous. Thus, a recommendation that is useful for one child and that promotes good outcomes may have the opposite outcomes for another. Some support or interventions may focus on individual factors, while others may focus on environmental factors.

Based on the fact that many re-entry programmes have been shown to be beneficial, although evidence is still lacking for some them (Helms et al., 2016; Thompson et al., 2015), a national school re-entry programme is strongly suggested to provide equality for all children treated for brain tumours in Sweden. Another suggestion is a Swedish web-based programme to enhance teachers' and other school personnel's awareness of late effects and how to facilitate for these in school for children treated for brain tumours, as these types of programmes can be designed to be both time and cost effective (Dubowy et al., 2006; Glang, McCart, et al., 2018).

A third suggestion, based on the results in this thesis, is a nationally standardized academic test, as many children treated for brain tumours do not have results from the national tests. Apart from the fact that it is a missed opportunity to assess their abilities, it also makes it difficult to have results on a group level. Moreover, the national tests are only performed in school years three, six and nine. A nationally standardized test for children with brain tumours could provide schools with necessary information for an individual study plan at the return to school or at school start. Along with a rising survival rate, it is important to ensure a rising awareness of academic strengths and difficulties of children treated for brain tumours, and how academic performance can be improved.

Strengths and limitations of the studies

In medical research, medical registries have been used for a long time (Irgens, 2012), although there is a history of criticism of various kinds concerning official statistics in social research (Bryman, 2016). Nevertheless, registry studies in particular are suitable when simple cause-and-effect relations are being explored (Cohen et al., 2017) as in this case, when it is already well known that brain tumours and the following treatment very often lead to cognitive deficits (Bitsko et al., 2016; Mulhern et al., 2004; Nathan, 2007). By using existing register data, it was possible to collect not only a sample, but also information about most Swedish children treated for brain tumours born between 1988 and 1996 and thus get a representative overview of their school performance without intrusion. Data also included solid information about background factors such as sex, age at diagnosis, types of tumour, and parents' education, as well as a large amount of matched controls (about five controls per case), and were collected from high quality registries with a high inclusion (National Board of Health and Welfare, 2015; Statistics Sweden, n.d.-a, n.d.-

b). Moreover, the reliability, internal validity, external validity, statistical conclusion validity, and construct validity (Bryman, 2016; Taylor, 2013) were also good as discussed in the validity and reliability section. It can also be argued that the studies also have a good ecological validity, i.e. that they can be generalized outside the test setting in everyday life (Bryman, 2016) as both final grades in the different subjects and grades from the national tests summarize different performances in the children's school setting, and their everyday life.

However, there are also some limitations to using existing data. One limitation was that it was not possible to have controls over the key variables. For example, there was no information about the cognitive capacity pre and post treatment, and not enough information about the exact location of all the brain tumours. Thus, this information was not included in the analyses, although it was included in the model by Dennis et al. (2007). Other ways to collect data could have been through interviews or questionnaires to children, parents, or teachers or through analyses of school-related tests, such as mathematics or reading, spelling, writing in Swedish or English, performed for example at follow-ups at the hospital. The advantage of interviews or questionnaires, compared with using existing data is that it would have been possible to have more control over how and which data were collected (Bryman, 2016).

Another limitation was the uneven proportions between controls and cases of missing data in the inclusion and exclusion process. However, one can assume that if those children treated for brain tumours from whom there was no information at all concerning grades or national tests had been included, differences between cases and controls in the results would have been even larger. It is highly likely that these children had a very high or total school absence or followed the curriculum for the compulsory school for children with intellectual disabilities. This may have led to the results in the studies underestimating, rather than overestimating, the children's difficulties.

Future research

When working with these studies, the main question that has emerged is what kind of school support would be most beneficial to enable a better academic performance in children treated for brain tumours? Interviews, both with children treated for brain tumours and their teachers, could give valuable information about this. Furthermore, there is still a lack of evaluation of intervention studies concerning school re-entry (Helms et al., 2016; Thompson et al.,

2015). As there are no national, standardized academic tests for follow-ups of children treated for brain tumours in Sweden, future research should aim for an evaluation of such tests. In addition, since the Swedish grade system nowadays includes six steps, with grades from A to F, instead of the four-step scale in the studies included in this thesis, it would be interesting to repeat this study with grades from recent years to see if more subtle differences are detectable. It would also be interesting to further investigate if the differences between children treated at different ages were still evident in adulthood.

Further research should also focus on to what extent individual education plans are written, and if they are written to the same extent for girls and boys. Moreover, it has been shown that it is important to support children treated for brain tumours with multidisciplinary teams (Chevignard, 2016; Fountain & Burke, 2017; Ruble et al., 2019; van't Hooft et al., 2016). Thus, obtaining a deeper knowledge of needs and experiences of multidisciplinary teams in schools and at hospitals would be extremely advantageous.

Sammanfattning på svenska

Introduktion

Hjärntumörer är den näst vanligaste barncancerdiagnosen efter leukemi och står för 20-30% av alla fall (Kaatsch, 2010; Lannering et al., 2009). I de flesta fall är orsaken till tumören okänd (Spector et al., 2015). För barn i Sverige yngre än 15 år var incidensen 1984-2005 4,2/100 000 per år (Lannering et al., 2009). Under de senaste femtio åren har barns överlevnad efter en hjärntumör ökat från 40% till 80%, om än inte för alla hjärntumörsdiagnoser (G. Gustafsson et al., 2013). Det innebär att antalet barn i skolan som behandlats för en hjärntumör har ökat. Den högre överlevnaden kommer dock med ett pris och det är väldigt många barn som upplever svårigheter av olika slag efter tumör och behandling, så kallade seneffekter, vilka ibland också benämns sequelae eller sena komplikationer (Bitsko et al., 2016; Mulhern et al., 2004; Nathan, 2007). En studie har visat att så många som 95.7% hade någon form av seneffekter som vuxna (Han et al., 2009), även om dessa siffror kan variera beroende på till exempel tumör, behandling och ålder vid diagnos (Signorelli et al., 2017; Tonning-Olsson, 2015). Det är inte ovanligt att barnen får svårigheter i skolan med såväl matematik, läsning och stavning (Kieffer et al., 2012; Lönnerblad et al., 2017; Upton & Eiser, 2006). Vissa av dessa svårigheter kan öka med åren (Mabbott et al., 2005; Merchant et al., 2014) och barn som behandlats för en hjärntumör får ofta lägre skolbetyg än sina jämnåriga (Ahomäki et al., 2017; Andersen et al., 2017; Lähteenmäki et al., 2007).

De senaste åren har flera studier visat att samarbete mellan skolan, hemmet och sjukhuset varit fördelaktigt för barnen även om evidensen i dessa studier ofta varit begränsad (Helms et al., 2016; Thompson et al., 2015). Ändå verkar det finnas ett behov av ytterligare kunskap kring denna grupp av barn hos många lärare (Barrera et al., 2005; Bruce et al., 2008; Hocking et al., 2018; Paré-Blagoev et al., 2019; Upton & Eiser, 2006; Vanclooster et al., 2019a). Tidigare studier har visat att lärare ofta kände sig oförberedda och tyckte sig sakna relevant kunskap när de skulle undervisa barn som var under behandling eller hade behandlats för cancer (Brown et al., 2011; Selwood et al., 2013). Andra lärare önskade långtidsuppföljningar då barnens behov på sikt var

oklara (Tresman et al., 2016). Således behövs fler studier om hur det går i skolan för barn som behandlats för en hjärntumör. I våra grannländer Finland och Danmark har det gjorts stora registerstudier om hur skolprestationerna ser ut i årskurs nio för barn som har behandlats för en hjärntumör (Ahomäki et al., 2017; Andersen et al., 2017; Lähteenmäki et al., 2007), men fram till nu har motsvarande studier inte gjorts i Sverige. Dock är det viktigt med analyser från olika länder, eftersom behandlingsmetoder och överlevnad ändras genom åren. Skolsystem och system för stöd i skolan ser också olika ut i olika länder.

Bakgrund

Den svenska skolan

År 1999, när många av barnen som var inkluderade i studien (födda 1988-1996) var i förskoleåldern, gick ungefär tre fjärdedelar av barnen i Sverige i förskolan och runt 90% började i förskoleklass under sitt sjätte levnadsår (Swedish National Agency for Education, 2000) även om det inte blev obligatorisk med förskoleklass förrän år 2018. Vid åren för studien och även idag börjar de flesta barn årskurs ett det året de fyller sju och därefter följer nio obligatoriska skolår.

Sedan 1994 ges slutbetyg i årskurs nio i 17 skolämnen i de teoretiska ämnena svenska, engelska, matematik, geografi, historia, religion, samhällskunskap, biologi, fysik, kemi och teknik och de praktisk-estetiska ämnena hemkunskap, idrott och hälsa, bild, musik och slöjd (Swedish National Agency for Education, 2003, 2018). Under åren för de slutbetyg och nationella prov som inkluderats i den här avhandlingen (2003-2012) bestod betygsystemet av en fyrgradig skala. Betygen var icke godkänt, IG (0 poäng), godkänt, G (10 poäng), väl godkänt, VG (15 poäng) och mycket väl godkänt, MVG (20 poäng). Vid ansökan till gymnasiet räknas ett genomsnittsbetyg ut, en så kallad meritpoäng.

Det svenska gymnasiet består sedan år 1994 av treåriga högskoleförberedande eller yrkesinriktade program. Beroende på val av ämnen kan båda inriktningarna ge behörighet att söka vidare till högskolan. Fram till 2011/2012 räckte det med godkänt i kärnämnen svenska, engelska och matematik för att vara behörig till gymnasiet, men under det läsåret ändrades reglerna så att eleverna var tvungna att vara godkända i minst åtta eller tolv ämnen, beroende på val av program, för att vara behöriga (SFS 2010:2039).

År 1998 infördes obligatoriska nationella prov i Sverige i ämnena svenska, engelska och matematik (Swedish National Agency for Education, 2016). De nationella proven i svenska och engelska är uppdelade i en läsförståelsedel, en muntlig del och en skriftlig del. Nationella provet i matematik består också av både muntliga och skriftliga delprov. Det finns även obligatoriska nationella prov i de samhällsorienterade och de naturorienterade ämnena samt de icke obligatoriska nationella proven i moderna språk (franska, spanska och tyska). Inga nationella prov finns i de praktiska eller de estetiska ämnena. I instruktionerna till lärarna kring utförandet av proven finns en beskrivning av vilka anpassningar som får göras, till exempel utökad provtid eller att dela upp proven i flera kortare delar (Swedish National Agency for Education, n.d.-a). När det gäller skolprestationer har officiell statistik från Sverige för åren 2003-2012 visat att flickor över lag hade en högre meritpoäng än pojkar, och att de också i högre utsträckning nådde de högsta betygen i alla ämnena utom i idrott och hälsa (Sveriges Kommuner och Landsting, 2019; Swedish National Agency for Education, n.d.-b, 2011a). En annan faktor som påverkar hur barnen presterar i skolan är föräldrarnas grad av utbildning (Swedish National Agency for Education, 2011a). Denna faktor tycks ha ökat mellan åren 1988 och 2014 (J.-E. Gustafsson & Yang Hansen, 2018).

Barn som behandlats för en hjärntumör

Flera olika internationella studier har visat att barn som behandlats för en hjärntumör i högre grad än jämnåriga eller syskon är i behov av extra stöd i skolan (Lorenzi et al., 2009; Mitby et al., 2003). En svensk studie (Ehrstedt et al., 2016) har också visat att av 139 barn som behandlats för en hjärntumör läste 3 % enligt särskolans läroplan. Detta kan jämföras med 1.5% av alla Sveriges skolbarn som beräknas läsa enligt särskolans läroplan (Swedish National Agency for Education, 2010). Skälen till att det kan uppstå svårigheter i skolan för barn som behandlats för en hjärntumör kan vara flera. Bland annat kan det bero på de skador som åsamkats hjärnan som en konsekvens av tumören i sig (Iuvone et al., 2011; Tonning-Olsson, 2015) eller av den medicinska behandlingen som barnen har genomgått (Ikonomidou, 2018; Liu et al., 2015; Makale et al., 2017). Svårigheterna kan beskrivas i termer av neurokognitiva, psykosociala och medicinska seneffekter (Turner et al., 2009).

Svårigheter med processhastighet, arbetsminne och uppmärksamhet är exempel på vanliga neurokognitiva seneffekter som kan påverka skolarbetet (t.ex. Mabbott et al., 2005; Nathan, 2007; Robinson et al., 2014). Graden av

seneffekter kan emellertid skilja sig åt bland annat beroende på kön, tumörgrad och ålder vid diagnos (t.ex. Mulhern et al., 2004; Tonning-Olsson, 2015). Vidare förekommer också ofta psykosociala seneffekter (de Ruiter et al., 2016; Eilertsen et al., 2011). En del barn som behandlats för en hjärntumör har beskrivit att de känner sig annorlunda, har tappat kontakten med jämnåriga eller känner sig isolerade (Bruce et al., 2008; Gunn et al., 2016; Mattsson et al., 2007). Andra svårigheter som hjärntrötthet (Daniel et al., 2013; de Ruiter et al., 2016; Irestorm et al., 2020; Macartney et al., 2014) eller sömnsvårigheter (van Kooten et al., 2019) kan också påverka måendet och skolprestationerna. När det gäller medicinska seneffekter är dessa också vanliga (t.ex. Turner et al., 2009). Det kan handla om synliga seneffekter som exempelvis svårigheter med balans och koordination, kvarvarande ärr, håravfall, kortvuxenhet eller mer osynliga förändringar som infertilitet, synnedsättning, hörselnedsättning, hormonförändringar, smärta, ljudkänslighet, försvagad muskelstyrka eller minskad syreupptagning samt en ökad risk för nya typer av cancerformer (t.ex. Ness et al., 2010; Turner et al., 2009; Vanclooster et al., 2020).

I det svenska programmet för långtidsuppföljning efter barncancer (RCC i samverkan, 2019) står det att målet är att alla barn som behandlats för en hjärntumör, särskilt de som har behandlats med strålning, ska följas upp ett eller två år efter diagnos. Detta bör ske i ett multiprofessionellt team där barnneurolog, neuropsykolog, sjukgymnast, logoped, specialpedagog och kurator ingår. Resultaten bör sedan återföras till både föräldrar och skola och ligga som grund för den fortsatta planeringen för barnet. Eftersom både biologiska faktorer och omgivande faktorer kan bidra till sociala och neurokognitiva svårigheter (Lenroot & Giedd, 2008; Robinson et al., 2010; Vanclooster et al., 2020) är det viktigt att båda dessa aspekter ingår när skolprestationer hos barn som behandlats för en hjärntumör diskuteras. I det följande kommer den teoretiska ramen i linje med detta att presenteras mycket kort.

Teoretiskt ramverk

Det teoretiska ramverket för avhandlingen utgörs av systemteoretisk utvecklingsteori vilken beskriver barnens utveckling som en dialektisk process mellan individen och omgivningen (Cantor et al., 2019; Darling-Hammond et al., 2019; Lerner, 2006; Osher et al., 2020; Overton, 2013; Sameroff, 2010). För att fokusera på barn som behandlats för en hjärntumör används en modell av Maureen Dennis och kollegor (2007). Modellen inkluderar olika faktorer som alla kan ha en inverkan på hur olika funktioner kan påverkas efter en förvärvad

hjärnskada, till exempel en skada som uppstår efter en hjärntumör och de följande behandlingarna. Defekter som uppstår till följd av en skada interagerar med de intellektuella förutsättningarna som finns före och efter skadan samt omgivande faktorer såsom ekonomisk status och familjeförhållanden. De påverkas också av barnets ålder vid skadan, vid vilken ålder barnets förmåga testas, hur lång tid det gått sedan skadan samt var i hjärnan som skadan sitter. Med andra ord kan en och samma skada leda till olika konsekvenser för olika barn beroende på förutsättningar. Barnets fysiska, kognitiva, akademiska eller psykosociala funktion efter skadan kan mätas på olika sätt (Dennis et al., 2007, 2014). I denna avhandling är det den akademiska funktionen, skolprestationer, som står i fokus och de har mätts genom att titta på betyg, nationella prov, behörighet till gymnasiet och hur många som slutade årskurs 9 senare än förväntat.

Syfte

Det övergripande syftet med avhandlingen har varit att undersöka hur barn i Sverige som behandlats för en hjärntumör presterar i skolan i årskurs nio jämfört med matchade kontroller. Kontrollerna matchades efter kön, födelseår och bostadsområde. Betyg och nationella prov från årskurs nio i de teoretiska ämnena svenska, engelska och matematik har undersökts liksom betyg i de praktisk-estetiska ämnena hemkunskap, idrott och hälsa, bild, musik och slöjd. Vidare har också behörighet till gymnasiet och hur många barn som slutade årskurs 9 senare än förväntat undersökts. Studierna har genomförts för att bidra med mer kunskap och förståelse för stödbehov och hur skolsituationen ser ut för barn som behandlats för en hjärntumör, vilket är förutsättningen för mer specifikt och anpassat stöd i skolan.

Syftet med Studie 1 var att undersöka hur det går i årskurs nio i de teoretiska ämnena svenska, engelska och matematik för barn som behandlats för en hjärntumör, hur många som blir behöriga till gymnasiet och hur många som slutar årskurs nio senare än förväntat. En annan fråga var om prestationerna påverkas av ålder vid diagnos (uppdelat i åldersgrupperna 0-5, 6-9 och 10-14), kön, tumörgrad (hög eller låg) samt föräldrarnas utbildning.

Syftet med Studie 2 var att undersöka hur det går i årskurs nio i de praktisk-estetiska ämnena hemkunskap, idrott och hälsa, bild, musik och slöjd för barn som behandlats för en hjärntumör. En annan fråga var om prestationerna påverkas av ålder vid diagnos (uppdelat i åldersgrupperna 0-5, 6-9 och 10-14), kön och tumörgrad (hög eller låg).

Syftet med Studie 3 var att undersöka om de tre olika nationella proven i svenska och engelska och det sammantagna resultatet för nationella provet i matematik kan användas för att identifiera specifika styrkor och svårigheter för barn som behandlats för hjärntumör, om prestationerna skiljer sig mellan barn som behandlats för en hjärntumör och deras kontroller samt om det skiljer sig mellan de olika delproven (muntligt, skriftligt, läsförståelse). En annan fråga var om prestationerna påverkas av ålder vid diagnos (uppdelat i åldersgrupperna 0-5, 6-9 och 10-14), kön och tumörgrad (hög eller låg).

Metod

Föreliggande avhandling bygger på data som inhämtats från Svenska Barncancerregistret och Statistiska Centralbyrån (SCB). I alla tre studierna inkluderades 475 barn som diagnostiserats med en hjärntumör innan sin 15:e födelsedag och 2197 matchade kontroller. Kontrollerna matchades av SCB. Alla barn är födda mellan åren 1988 och 1996. Data från Svenska Barncancerregistret innehöll information om kön, ålder vid diagnos, typ av tumör (som också delats in i höggradiga tumörer, WHO III-IV och låggradiga tumörer, WHO I-II), återfall och dödsfall. Data från SCB innehöll information om slutbetyg från årskurs nio, resultat på nationella prov i svenska, engelska och matematik, föräldrars utbildning och om de läste svenska som första eller andraspråk i skolan. Inga data om barn som behandlats för en hjärntumör och som läste enligt särskolans läroplan ingår eftersom det inte fanns tillgängligt. Data har analyserats med IBM SPSS version 25 eller version 26 och R version 3.5.2 eller version 3.6.0. Etikansökan för de inkluderade studierna har godkänts av den regionala etiknämnden i Stockholm (no. 2017/995-31/5).

Resultat

Studie 1

Resultaten från Studie 1 visade att signifikant fler barn som behandlats för en hjärntumör fick underkänt i de teoretiska ämnena svenska, engelska och matematik. Det var större skillnad mellan fall och kontroller för flickor än för pojkar. Det var också färre fall än kontroller som uppnådde de två högsta betygen, väl godkänt (VG) och mycket väl godkänt (MVG). När det gällde gymnasiebehörighet blev 77.3% av barnen som behandlats för en hjärntumör

behöriga medan motsvarande siffror för kontrollgruppen var 90.6%. Flickor som diagnostiserats i åldern 0-5 och 6-9 var i lägre utsträckning behöriga till gymnasiet (70.7% respektive 66.7%) än flickor som diagnostiserats i åldern 10-14 (85.6%). För pojkar var det inga signifikanta skillnader mellan de olika åldersgrupperna (0-5: 78.2%; 6-9: 81.8%; 10-14: 76.1%). Det var heller ingen skillnad när det gällde gymnasiebehörigheten beroende på om barnet behandlats för en höggradig eller låggradig tumör. Däremot fanns en positiv korrelation mellan föräldrarnas utbildning och barnens behörighet till gymnasiet. Oddsens att sluta ett år senare än förväntat var 5.40 gånger högre för fallen (n=54/475) än kontrollerna (n=51/2197). För pojkar som behandlats för en hjärntumör (n=36/245) var oddsens 2.03 gånger högre än för flickorna (n=18/230) som behandlats för en hjärntumör. I kontrollgruppen var oddsens 2.27 gånger högre för pojkarna (n=36/1138) jämfört med flickorna (n=15/1059).

Av enbart barnen som behandlats för en hjärntumör hade flickor i ämnet svenska signifikant högre betyg än pojkar och barn som behandlats i åldern 10-14 hade signifikant högre betyg än de som behandlats i åldern 0-5. I engelska var det inga signifikanta skillnader mellan pojkar och flickor, men både pojkar och flickor som behandlats för en hjärntumör i åldern 10-14 hade högre genomsnitt än de som behandlats i åldern 0-5 eller 6-9. I matematik var det signifikanta skillnader mellan pojkar och flickor endast i åldersgruppen 6-9. Då hade pojkarna högre genomsnitt än flickorna. Flickor diagnostiserade i åldern 10-14 hade signifikant högre betyg än flickor diagnostiserade i åldern 0-5 eller 6-9. Hos pojkarna sågs inga skillnader mellan de olika åldersgrupperna.

Studie 2

Resultaten från Studie 2 visade att barn som behandlats för en hjärntumör fick underkänt i de praktisk-estetiska ämnena hemkunskap, idrott och hälsa, bild, musik och slöjd i signifikant högre grad än kontrollerna. Uppdelat på flickor och pojkar sågs dock denna skillnad bara för flickorna som hade 2.23-3.20 gånger högre odds än sina kontroller att få underkänt i något av ämnena. Det var ingen skillnad mellan barn som diagnostiserat i olika åldrar eller med en hög- eller låggradig tumör. Det var också signifikanta skillnader för genomsnittsbetygen i alla ämnen mellan barn som behandlats för en hjärntumör och deras kontroller. Flickor som behandlats för en hjärntumör hade ett signifikant lägre genomsnitt i alla ämnen, medan pojkar endast skiljde sig från sina kontroller i idrott och hälsa och musik. Den största skillnaden mellan fall och kontroller sågs i idrott och hälsa och den minsta skillnaden i ämnet bild.

Studie 3

Resultaten från studie 3 visade att de nationella proven i svenska, engelska och matematik också kan användas för att se mer specifika skolfärdigheter eller svårigheter hos barn som behandlats för en hjärntumör. Då det saknades information om de nationella proven för en stor andel av barnen som behandlats för en hjärntumör var det viktigt att inkludera saknad information som en egen variabel. Resultaten visade också att det var signifikanta skillnader mellan fall och kontroller för saknad information och icke godkänt (IG) i alla ämnen och på alla deltester utom två stycken i svenska (muntliga och skriftliga). Det var större skillnader mellan flickor som behandlats för en hjärntumör och deras kontroller än för pojkar som behandlats för en hjärntumör och deras kontroller. Att inte ha gjort något av de tre nationella proven i svenska eller engelska, eller inte ha någon information om det sammantagna betyget i matematik, var en stark prediktor för både fall och kontroller för att inte få ett godkänt slutbetyg i ämnet.

När bara de barn som behandlats för en hjärntumör inkluderades i analyserna var det inga signifikanta skillnader mellan flickor och pojkar eller mellan barn som diagnostiserats med en hög- eller låggradig tumör. Det saknades i högre utsträckning information om provresultat för barn som diagnostiserats i åldern 0-5 och 10-14 jämfört med barn som diagnostiserats i åldern 6-9 i engelska och matematik, medan det i ämnet engelska var signifikant högre andel av barnen som diagnostiserats i åldern 6-9 som fick icke godkänt jämfört med de två andra åldersgrupperna. Resultaten visade också att både barnen som behandlats för en hjärntumör och kontrollerna presterade bättre på de muntliga deltesterna än de skriftliga i både svenska och engelska, medan skillnaderna för färdigheterna mellan de andra testerna var mindre för barn som behandlats för en hjärntumör än kontrollerna.

Diskussion

Det övergripande syftet med den här avhandlingen har varit att undersöka skolprestationer i årskurs nio för barn i Sverige som behandlats för en hjärntumör. Slutbetyg från årskurs nio för barn som har behandlats för en hjärntumör har tidigare studerats i Finland (Ahomäki et al., 2017; Lähteenmäki et al., 2007) och Danmark (Andersen et al., 2017). Studie 1 (Lönnerblad et al., 2020a) och Studie 3 (Lönnerblad et al., 2021) är dock de första större registerstudierna som undersöker hur det går i ämnena svenska, engelska och matematik för barn i Sverige som behandlats för en hjärntumör och Studie 2 (Lönnerblad et al., 2020b) den första större registerstudien som undersöker hur det går i alla de praktisk-estetiska ämnena för barn som behandlats för en hjärntumör. Huvudresultaten från de tre studierna visar att barn som behandlats för en hjärntumör presterar signifikant sämre än kontrollerna när det gäller slutbetyg i både de teoretiska och praktisk-estetiska ämnena samt på de nationella proven. Det var större skillnader mellan fall och kontroller i de teoretiska ämnena än i de praktisk-estetiska och den generellt största skillnaden var i ämnet engelska.

Faktorer som kan påverka skolprestationer

Rapporter från både Sverige och andra länder har visat att flickor i allmänhet presterar bättre än pojkar på gruppnivå i alla skolämnen (OECD, 2014; Swedish National Agency for Education, n.d.-b, 2011a), och att skillnaderna ofta är större i språkämnena än i matematik (Voyer & Voyer, 2014). Emellertid visade Studie 1 att det för barnen som behandlats för en hjärntumör endast var signifikanta skillnader i svenska men inte i engelska, och i matematik fanns det bara könsskillnader i resultaten bland barnen som diagnostiserats i åldern 6-9 år. Detta indikerar att det akademiska övertaget som ses bland flickor i allmänhet är mindre uppenbart bland flickor som behandlats för en hjärntumör. Skillnaden i resultat mellan flickor som behandlats för en hjärntumör jämfört med deras kontroller var också större än för pojkar som behandlats för en hjärntumör jämfört med deras kontroller när det gällde att icke godkänt i ämnet, särskilt i de praktisk-estetiska ämnena, men också i de teoretiska ämnena och särskilt i engelska.

När det gäller själva tumören har det visat sig att barn som behandlats för en höggradig tumör ofta får allvarliga seneffekter (Makale et al., 2017; Merchant et al., 2010), men de senaste åren har en rad studier visat att även barn som behandlats för en låggradig tumör ofta drabbas (Aarsen et al., 2006;

Ehrstedt et al., 2016; Ris et al., 2008; Ris & Beebe, 2008). Detta ligger i linje med resultaten i alla tre studierna där inga signifikanta skillnader kunde ses på grupp-nivå mellan de som behandlats för en höggradig tumör eller en låggradig tumör. Emellertid är det viktigt att ha fördelningen mellan hög- och låggradiga tumörer i åtanke, särskilt vid analyser som inkluderar färre barn, som till exempel vid analyserna av skillnaden i prestationer mellan pojkar och flickor som behandlats vid olika ålder.

Inverkan av föräldrarnas utbildning undersöktes mer noggrant i Studie 1 men fanns med som bakgrundsvariabel även i Studie 2 och Studie 3. I studie 1 framkom att föräldrarnas utbildning hade en inverkan på resultaten då det fanns en positiv korrelation mellan föräldrarnas utbildning och graden av behörighet till gymnasiet för barnen. Dessa resultat ligger också i linje med tidigare studier (Ach et al., 2013; Laffond et al., 2012).

Ålder vid diagnos har i flera studier visat sig vara en signifikant faktor när det gäller neurokognitiv förmåga efter en hjärntumör, och särskilt barn som behandlats vid en väldigt ung ålder har visat sig ha hög risk för seneffekter (Merchant et al., 2010; Mulhern et al., 2004; Nathan, 2007). När det gällde att inte få godkända betyg i de teoretiska ämnena (Studie 1) visade det sig att både att ha diagnostiserats i åldern 0-5 och åldern 6-9 i många fall är en större riskfaktor än att ha diagnostiserats i åldern 10-14. När det gällde de nationella proven (Studie 3) framkom att barn som diagnostiserats i åldern 0-5 och 10-14 oftare saknade information om det nationella proven jämfört med barn som diagnostiserats i åldern 6-9, medan barn som diagnostiserats i åldern 6-9 hade en högre grad av icke godkänt, jämfört med de andra två åldersgrupperna. Detta skulle kunna indikera att de svårigheter som finns hos barn som behandlats i åldern 6-9 har uppmärksamats mindre eller är mindre uppenbara än de hos barn som behandlats nära inpå de nationella proven eller vid en väldigt ung ålder. För de praktiska och estetiska ämnena (Studie 2) hade ålder vid diagnos ingen signifikant inverkan.

Interventioner och anpassningar

Det finns flera interventioner för barn som behandlats för en hjärntumör eller en hjärnskada i allmänhet med fokus på träning av till exempel uppmärksamhet och/eller arbetsminne (t.ex. Butler, Copeland, et al., 2008; van't Hooft et al., 2007). Vidare har fysisk träning visat sig ha en positiv inverkan på återhämtningen av hjärnan efter strålning (Riggs et al., 2016; Szulc-Lerch et al., 2018). Fysisk aktivitet i form av t.ex. fysiskt aktiva data- eller tv-spel eller annan typ av träning har också visat sig minska bland annat hjärntrötthet och

ge en ökad förmåga till koordination (Li et al., 2018; Sabel et al., 2016, 2017). Andra interventioner har fokuserat på medicinsk behandling. Ett exempel är genom metylfenidat vilket ökat uppmärksamhet, social förmåga och akademiska färdigheter för barn som behandlats för en hjärntumör eller annan cancer (Conklin et al., 2010; Mulhern et al., 2004). Ett annat exempel är genom metformin som visat sig förbättra arbetsminnet hos barn som behandlats med strålning (Ayoub et al., 2020).

Exempel på interventioner som fokuserar på att optimera omgivningen för barn som behandlats för cancer är de skolprogram som finns för återgång till skolan under och efter cancerbehandling. Skolprogrammen fokuserar ofta på övergången från sjukhuset till skolan, samarbete mellan familjen, skolan och sjukhuset samt att ge en ökad kunskap om diagnosen och seneffekterna (Annett & Erickson, 2009; Bruce et al., 2012; Prevatt et al., 2000). Olika forskningssammanfattningar har visat att några av skolprogrammen lett till signifikanta resultat när det gällde positiv attitydförändring, ökad specifik kunskap för lärare och klasskamrater och lägre grad av nedstämdhet och ökad akademisk framgång för barnet med cancer, även om flera av dessa program behöver utvärderas ytterligare (Helms et al., 2016; Thompson et al., 2015). Vissa av programmen har vänt sig till lärare och annan skolpersonal som arbetar med barn med cancer och skett genom workshops, individuella program eller datorbaserade program med syfte att öka kunskapen om seneffekter efter barn-cancer (Annett & Erickson, 2009; Bruce et al., 2012; Dubowy et al., 2006; Ellis et al., 2013; Prevatt et al., 2000). Det har visat sig att såväl workshops som datorbaserade program kan vara både tids- och kostnadseffektiva för detta syfte (Dubowy et al., 2006; Glang, McCart, et al., 2018; Prevatt et al., 2000).

Dessutom finns andra typer av interventioner med målet att förse barn med olika behov i skolan möjlighet att delta i den ordinarie undervisningen, till exempel Universal Design for Learning (UDL) även om det fortfarande saknas evidens för metoden (Rao et al., 2014). Det finns också andra exempel på hur omgivningen kan anpassas för barn som har behandlats för en hjärntumör så som förlängd tid för att slutföra skoluppgifter, skriftliga sammanfattningar från lektioner, att skriva på dator i stället för att använda penna och papper, möjligheten att ha kortare skoldagar eller att spela in lektionerna (Mulhern et al., 2004; Sheinfeld Gorin & McAuliffe, 2008).

Implikationer

Vad resultaten från föreliggande avhandling visar är att alla barn som behandlats för en hjärntumör, oavsett kön, ålder vid diagnos, hög- eller låggradig tumör och föräldrars utbildning bör följas upp noga i skolan. Det är nödvändigt att ha ett långsiktigt perspektiv med tanke på att svårigheterna inte försvinner ju längre tid som gått sedan diagnos utan i många fall kan tillta. I enlighet med detta är det viktigt att ha ett skriftligt åtgärdsprogram med konkreta och utvärderingsbara mål (Swedish National Agency for Education, 2014) som skrivs direkt när barnet är tillbaka i skolan under eller efter behandling, och att detta åtgärdsprogram uppdateras regelbundet. Under och efter behandling är det också viktigt att dokumentera vad barnet missar, att göra en plan för hur detta ska åtgärdas samt att planen fokuserar på de centrala områdena inom varje ämne. Det måste också finnas en medvetenhet om att barnet kan sakna energi, kan lida av hjärntrötthet eller av neurokognitiva seneffekter såsom långsam processhastighet eller svårighet med uppmärksamhet. Vidare kan också psykosociala och medicinska aspekter spela in.

Extra stöd gällande nödvändiga förmågor för att fortsätta att utvecklas i skolan är viktigt och särskilt i engelska och matematik då dessa två ämnen verkar vara mest påverkade. Stöd kan också behövas i både de praktiska och de estetiska ämnena. Barn som behandlats före skolstart bör följas extra noga liksom barn som behandlas i åldern 6-9 år då många av de grundläggande och nödvändiga basfärdigheterna lärs in under dessa år, och detta också verkar vara en grupp som inte uppmärksammas lika mycket som barn som behandlats i yngre ålder. Som också visats i alla tre inkluderade studier är gapet mellan flickor som behandlats för en hjärntumör och deras kontroller större än för pojkarna. Det bör därför säkerställas att flickorna som behandlats för en hjärntumör både följs upp och har ett skriftligt åtgärdsprogram i lika stor utsträckning som pojkarna. I Studie 3 framkom att många barn presterar bättre muntligt än skriftligt, varför muntliga förhör eller prov skulle kunna vara ett sätt att underlätta för barnet. Det är dock viktigt att komma ihåg att graden av svårigheter kan variera och se väldigt olika ut. Val av stöd och intervention bör därför bygga på varje enskilt barns behov.

Många av skolprogrammen som syftar till att komma tillbaka under eller efter en cancerbehandling har visat sig ha många fördelar (Helms et al., 2016; Thompson et al., 2015). Därför rekommenderas att ett nationellt skolprogram för barn som har behandlats för en hjärntumör utarbetas för att alla barn runt om i Sverige ska få en jämlik skolgång. Ett annat förslag är att utarbeta ett webbaserat nationellt program för att öka skolpersonalens medvetenhet om de seneffekter som kan uppstå då den här typen av program har visats sig vara

både tids- och kostnadseffektiva (Prevatt et al., 2000). Ytterligare ett förslag, som baseras på resultaten i den här avhandlingen, är ett nationellt standardiserat skolrelaterat test som genomförs i samband med den neurokognitiva uppföljningen eftersom många barn som behandlats för en hjärntumör saknar resultat från de nationella proven. I takt med att överlevnaden för barncancer stiger är det viktigt att medvetenheten om svårigheter som kan uppstå efteråt ökar så att resultaten i skolan för den här gruppen barn kan förbättras.

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