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Multi-Professional Follow-Up Programmes are Needed to Address Psychosocial, Neurocognitive and Educational Issues in Children with Brain Tumours

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Abstract

Aim: The aim of this study was to coordinate the structured psychosocial, neurocognitive and educational follow up of children treated for brain tumours with the medical protocol and apply the model in two Swedish healthcare regions.

Methods: We invited all children living in the two regions, who had been diagnosed with a brain tumour from 1 October 2010 through to 30 June 2012, to participate along with their parents. The follow-up programme evaluated the emotional status of the parents and patients and assessed the children's general cognitive level, working memory, speed of performance, executive functions and academic achievement from diagnosis through to adult care.

Results: During the study period, 61 children up to the age of 17.1 years were diagnosed with a brain tumour, but 18 of these were excluded for various reasons. The majority of the mothers (70%) displayed significantly poor emotional status, as did 34% of the fathers and 21% of the children. The majority of the children (57%) also showed poor neurocognitive performance and needed special adaptations at school (66%).

Conclusion: Our findings indicate the need for coordinated, multi-professional follow-up programmes, well anchored in the healthcare organisation, for children diagnosed with brain tumours.

Keywords: Multi-professional care; Neurocognitive performance, Paediatric brain tumours, Poor emotional status, Special needs

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Key Notes

- This study focused on 43 children who had been diagnosed with a brain tumour and found that most of them (57%) showed poor neurocognitive performance and needed special adaptations at school (66%).
- The majority of the mothers (70%) displayed significantly poor emotional status, as did 34% of the fathers and 21% of the children.
- The findings indicate the need for coordinated, multi-professional follow-up programmes for children diagnosed with brain tumours.

Introduction

Brain tumours account for almost 30% of all malignant disorders in childhood and are the second most common tumour type in children [1]. These days, 70% of children with brain tumours who live in Europe survive for more than five years after diagnosis and most reach adulthood [1,2]. However,

many of the survivors experience various sequelae, which are caused by the tumour itself or by the surgery, irradiation and, or, chemotherapy they receive to treat the tumour [3-5]. Despite radically improved survival rates for most paediatric cancers, patients and families display a number of psychological reactions, including anxiety, when they are given the diagnosis [6]. The outcome is uncertain throughout the treatment period and the treatment itself entails prolonged stress, which particularly affects parents [6,7]. Moreover, parents have been known to display feeling of distress and abandonment years after their child successfully completes their treatment [8,9]. Therefore, psychosocial monitoring of the entire family, starting at the point of diagnosis, has been suggested [6]. As children who survive brain tumours face the risk of late neurocognitive deficits [10-12], as well as endocrine [4] and neurological [3] dysfunctions, the psychological burden on the children, parents and the whole family is great. The child's cognitive problems must also be recognised early and taken into consideration when planning the child's schooling [13,14]. Furthermore, children without problems must be identified in order to avoid subjecting them to lengthy neurocognitive investigations. In order to make this screening possible, the test methods that are adopted have to be reliable, valid, and easily used in routine clinical settings. This prospective project took place in the Swedish healthcare regions of Stockholm and Uppsala-Örebro. Its aim was to organise the psychosocial, educational and neurocognitive follow up in such a way that it could be used for all children diagnosed with a brain tumour, as well as their parents. We also wanted to coordinate this support with the medical follow-up programme, and adjust it to the clinical setting, so that all children and parents underwent appropriate investigations and received the help they needed.

Subjects and Methods

Sweden is divided into six healthcare regions that vary in geographical size and number of inhabitants. The Stockholm region is a typical urban region, where roughly 2,250,000 people inhabit a fairly small geographical area of 9,660 km², while the Uppsala-Örebro region is a mainly rural district, with an area of 75,800 km² and 1,740,000 inhabitants.

Subjects

We approached families living in the Stockholm and Uppsala-Örebro healthcare regions who had a child under 18 years that had been diagnosed with a brain tumour between 1 October 2010 and 30 June 2012 and invited them to take part in this prospective study. Participants were recruited by the consultant nurse for brain tumours or by the responsible paediatrician at either the Astrid Lindgren Children's Hospital or the Uppsala University Children's Hospital. The inclusion criteria were that child had been diagnosed with a brain tumour, irrespective of the location and grade of malignancy, together with their age, place of residence and the family's ability to speak Swedish. Oral and written information was given to all parents and written consent was received from all families that were included. The study was approved by the Regional Ethics Review Board of Uppsala University. During the study period, 61 children from birth to 17.1 years were diagnosed with brain tumours. Of those three were excluded because the family did not speak sufficient Swedish, 11 families refused to participate, one child died before being invited and three were not invited because of an administration error (Figure 1). Thus, the study group comprised the families of 43 children diagnosed with brain tumours, 74% of the 58 eligible to take part. The characteristics of the children who were included are presented in Table 1. They included the ten children who died during the study period.

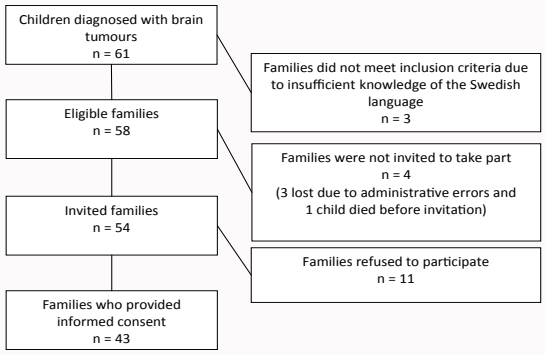

Figure 1: Attrition.

In the study group, four children were infants under one year of age at diagnosis, 20 children were 1-5.9 years old and 19 were 6-17.1 years old. In Sweden, children start preschool at six years of age and it is compulsory for them to attend school from the age of seven to the age of 19. The majority of the children we studied attended elementary or middle school. There were 38 children who lived with both biological parents and five children whose parents were no longer together. There were 34 children with siblings and the remaining nine were an only child.

Children in the Uppsala-Örebro region who had just undergone an operation stayed at the regional hospital for two to three weeks and were followed up at their local paediatric clinics, while children who received surgery in the Stockholm region were followed up at the outpatient clinic in Stockholm. If they were treated with radiotherapy for six to eight weeks following surgery they received this at the hospitals in Stockholm or Uppsala. Most of the families living in Stockholm only needed to pay day visits to the hospital during radiotherapy, but most of the children living in Uppsala-Örebro had to stay with one or both parents in a hotel or apartment close to the university hospital in Uppsala, because of the distance from their home. This meant that they were separated other family members and friends during that time. Children who needed any kind of chemotherapy or multimodal therapy received this for up to 18 months according to the treatment. Chemotherapy was administered at the university or local hospitals under the supervision of the oncologists at Stockholm or Uppsala. All children visited either the Astrid Lindgren Children's Hospital or the Uppsala University Children's Hospital for an annual medical follow up.

Medical follow up

All children underwent a thorough medical examination, including an endocrinological and neurological evaluation. Audiometry and visual examinations were performed as necessary.

Magnetic resonance imaging scanning was also conducted, in accordance with the medical follow-up protocol agreed by the Swedish brain tumour group for children.

Psychosocial follow-up

The programme specified that the psychosocial follow-up should be performed by a psychologist or a person with equal competency. In practice, psychologists were not available and the psychosocial assessments were carried out by social workers. The psychosocial follow up consisted of a two-step assessment involving screening and,

Table 1: Characteristics of patients diagnosed with brain tumours in the Stockholm (St) and Uppsala-Örebro (U-Ö) healthcare regions during the project period.

Patient characteristics	**All diagnosed brain tumours** (n=61: 38 in Stockholm and 23 in Uppsala-Örebro)	**Provided informed consent** (n=43: 26 in Stockholm and 17 in Uppsala-Örebro)	**Children who died during the project period** (n=11: 7 in Stockholm and 4 in Uppsala-Örebro)
Sex (male/female)	42/19	28/16	7/4
Median age at diagnosis (range)	6.8 (0.2–17.1)	5.3 (0.2–17.1)	8.0 (0.3–17.1)
Type of tumour	**Type of tumour**	**Type of tumour**	**Type of tumour**
Astrocytoma	23*	16	4
Medulloblastoma	8	5	
Brain stem glioma**	8	6	4
Optic glioma	5	5	1
Ependymoma	4	3	1
Plexus papilloma/carcinoma	3	3	
Craniopharyngeoma	3	2	
Other tumours***	7	3	1
Type of treatment	**Type of treatment**	**Type of treatment**	**Type of treatment**
Surgery only	25	13	1
Surgery + radiotherapy	5	6	
Surgery + chemotherapy	5	5	1
Surgery + radiotherapy + chemotherapy	14	8	5
Chemotherapy only	7	4	
Radiotherapy +chemotherapy	4	4	4
Expectant	1	1	

*Two children with tuberous sclerosis and giant-cell astrocytoma
**Not biopsied
***Dysembryoplasic epitelial tumour (DNET) 2; gangliolglioma 1; oligodendroglioma 1; neurocytoma 1;
atypical teratoid rabdoid tumour (ATRT) 1; supratentorial tumour of unknown type 1.

when needed, a more detailed assessment of the patients' and parents' emotional status, specifically their level of depression or anxiety, including traumatic reactions and chronic stress or burnout. Screening for all the study patients, mothers, and fathers followed a set schedule (Figure 2). Those who exhibited poor emotional status at screening were further assessed and, if necessary, referred for psychological intervention. In addition, all patients and parents who requested psychological intervention were given access to this, regardless of the assessment results. Participation in the project did not affect the families' access to regular psychosocial services. The psychosocial screening involved a clinical assessment of the emotional status of the patients and parents based on observation, informal conversation, and, if necessary, a short semi-structured interview. Screening was conducted face-to-face or, if more convenient, by phone. The screening was systematised using a classification tool for symptom levels, including anxiety and depression. This ranged from zero for a neutral mood with normal variations to five to nine for persistent and overwhelming feelings of anxiety and persistent experiences of severe depression. A symptom level of three or more was considered indicative of poor emotional status warranting further assessment. At each assessment, the parent was asked whether he or she agreed to be called again according to the schedule (Figure 2). If participants had symptoms in the three to nine range, further assessments took place during a personal appointment using observation, informal conversation and an established self-report instrument selected for the specific type or types of emotional problem indicated by the screening.

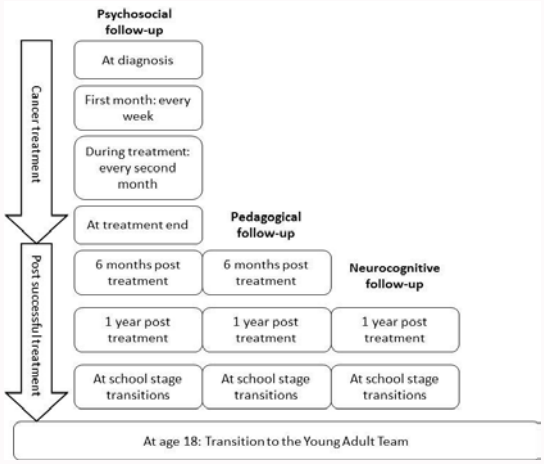

Figure 2:

Educational follow-up

Children who were between seven and 18 years of age were eligible for an educational screening on two occasions during the project period. The first was conducted six months after they finished their cancer treatment. This included a questionnaire for the children's teachers regarding the prerequisites for learning - attention, memory and information processing - as well as academic achievement and

if they needed extra support at school. The second was carried out at the hospital one year after the end of treatment by a special education teacher and this consisted of standardised tests in reading speed [15,16], reading comprehension [15-17] and basic arithmetic skills [18].

Neurocognitive follow-up

The neurocognitive screening battery that was used one year after the end of treatment consisted of the Wechsler Intelligence Scale for Children - Fourth Edition (WISC-IV) [19], which assesses general cognitive level, verbal and perceptual functions, working memory and performance speed, with a mean of 100 and standard deviation of 15 for children aged between 6-18 years. Children aged 4-5.9 years were assessed with the Wechsler Preschool and Primary Scale of Intelligence - Third Edition (WPPSI-III) [20], which does not assess working memory.

Executive functions were assessed using the Behavior Rating Inventory of Executive Function (BRIEF) questionnaire for parents and teachers [21]. This contains information about behavioural regulation, the child's ability to sustain working memory and to initiate, plan, organise and monitor their own behaviour, as well as a global executive composite. A result of more than 60 is one standard deviation above average and an indication of poor function.

Parental satisfaction with the follow-up programme

A parental satisfaction questionnaire, designed specifically for the study, was sent to mothers and fathers if their child was still alive at the end of the project period. The questionnaires were completed anonymously.

Results

Psychosocial follow-up

In 37 of the 43 families that provided informed consent, at least one family member completed an emotional status follow up on at least one occasion. Implementing the psychosocial follow-up screening schedule proved to be challenging. Several of the families who agreed to participate in the project were not followed up as scheduled or the follow up was terminated ahead of schedule. Only a few of the study families were followed up at all the scheduled points. In addition, two of the fathers and 18 of the patients were never followed up for emotional status. The reasons why scheduled follow-up assessments were not completed included referrals to a psychologist and errors in project administration. In addition, the project-specific psychosocial follow up was discontinued if the child died.

The clinical assessment tool identified poor emotional status at some point, with a symptom level of three or more, for 26 of the 37 (70%) screened mothers, 12 of the 35 (34%) screened fathers and four of the 19 (21%) screened patients.

Educational follow-up

According to the schedule, educational screening was due to take place on 13 of the school-age children six months after treatment, but only nine of the children's teachers completed the screening. Five teachers described slower processing speed, but the overall performance with regard to attention, memory and learning was equal to that of classmates. However, six of the children required extra tutoring, attended a special programme or studied an adjusted curriculum.

A special education teacher also met seven of the children at the hospital one year after treatment for the scheduled educational follow-up assessment covering reading speed, reading comprehension and basic arithmetic skills. Only one of the seven children had results that were equal to, or higher than, average for their age, with a mean score of five (standard deviation 1.97) on the standard nine-point scale in all three tests. Six of the children performed below average for their age in reading speed, one had below average results in reading comprehension and two had below average results in basic arithmetic skills.

Neurocognitive follow-up

Of the 31 children between five and 18 years old, 21 were assessed with the neurocognitive battery one year after treatment and 15 parents and nine teachers answered the BRIEF questionnaire describing the child's executive performance outside a test situation. Some of the patients did not complete the assessment because of a relapse, the length of their treatment period or because they were too young to be assessed. Two patients were regarded as too high functioning for an evaluation by the responsible physician and two families in Stockholm did not agree to the assessment taking place. In the group of 21 children who underwent neurocognitive screening, 17 had an average cognitive level for their age and four had a general cognitive level below average for their age. Working memory and processing speed were assessed for 17 of the 21 children and this showed that three had a poor working memory and five showed poor processing speed. In all, 12 of the 21 children who were assessed exhibited poor neurocognitive performance in some respect. Of the 21 patients that were assessed using the neurocognitive battery, seven had undergone multimodal treatment, that is surgery, chemotherapy and radiation. Four of these seven children showed a general cognitive level that was below average for their age and low performance in both working memory and in performance speed. The other three children who received multimodal treatment showed an average cognitive level, but significantly slower processing speed. Only one of the children who received multimodal treatment displayed an average performance for their age on all measures. Nine of the 21 children who were assessed only received surgery and all nine of those showed an average cognitive level. However, a further seven showed lower performance levels in working memory and speed than expected for their age. One child who received surgery and chemotherapy exhibited an average intellectual level, but significantly slower performance speed. Two children only received chemotherapy and one of those exhibited problems with working memory.

Parents' satisfaction with the follow-up programme

The parental satisfaction questionnaire was distributed to the 66 parents of the 33 eligible children and was completed by 34 parents. The closed-question responses revealed that 19 parents felt that the frequency of the psychosocial follow up was just right, 13 thought the follow up should have been more frequent, one would have liked less frequent follow up and one did not answer the question. When it came to psychosocial follow up itself, 27 parents were satisfied, six parents were dissatisfied and one did not answer the question. The qualitative thematic content analysis of the responses to the open ended questions revealed mixed positive and negative experiences. The negative experiences typically focused on being abandoned in one way or another. In the words of one parent: "We were satisfied with the support we received during the emergency period, but afterwards, if we had not ourselves asked for support, the support would have been almost non-existent". In relation to the follow-up programme, these accounts described a number of situations in which families

appeared to have been overlooked during different phases of the schedule. A few parents commented that asking the parents to assess the patient's emotional status as part of the follow-up process placed excessive responsibility on them. As one said: "The screening has been carried out through us as parents and it is hard for us to know how the child experienced the situation". Furthermore, the protocol was criticised for not including siblings in the follow up. The positive comments conveyed an appreciation of the recurring follow up. A number of parents stated that psychosocial follow up was essential *both* during the initial phase of crisis and chaos *and* once treatment had been completed and the family had returned to everyday life. As one parent told researchers: "You also need help after the acute phase, to be able to cope with the medical follow ups every three months and with anxiety about the future." At the same time, parents typically did not realise the necessity for psychosocial support. One parent stated that the psychosocial follow up should be "more or less compulsory, because as a parent you think that you don't need it". Another stated that "parents in crisis do not request the help they need." Moreover, a number of parents emphasised the importance of psychological competence and professionalism in the encounter with families in crisis, revealing mixed experiences. The parents were asked about their overall satisfaction with the psychosocial follow up. One replied that it was "much better than expected as we met an extremely skilled person" while another stated that "in such a vulnerable position we needed contact with a psychologist who could give more support and guidance, but the competence and reflection were lacking". Of the 34 parents who answered the parental satisfaction questionnaire, 21 had a child who had undergone a neurocognitive assessment and 20 of these were rather or very satisfied with that assessment. The open-ended questions indicated that it was important for parents to meet the assessment team and to receive both oral and written information about the results. As one parent said: "It is helpful to have the results on paper so you can understand what it means as you easily forget the oral information". They also stressed the importance of an action programme and follow up at school. One parent suggested "a mandatory meeting, perhaps two months after surgery, going through the opportunities concerning school, rehabilitation and the future".

Discussion

This small multi-professional project tried to meet the need for psychosocial, educational and neurocognitive follow up that children with brain tumours and their families have. We were also keen to coordinate this follow up in a practicable way with the medical protocol during treatment and afterwards. This was a feasible task, but it was not without problems. The aim of the psychosocial follow up was to monitor families through the different phases of the cancer trajectory. However, this proved difficult, mainly due to organisational and administrative factors in the two regions, which are geographically very different. Despite this, at least one family member in most families showed poor emotional status at some point and the parental satisfaction reports demonstrated that the psychosocial follow up was important, a finding that was consistent with other studies [6]. A feeling of abandonment was obvious in many families, especially when the treatment had finished, irrespective of the type of brain tumour and the treatment received. This must be taken into account when organising follow ups of this kind. Moreover, this programme did not include siblings and some parents expressed the view that they should have been included. The educational screening carried out six months after treatment indicated that two- thirds of the children who were screened needed some kind of extra support or adjustment at school. In addition, the educational follow up six months later showed that six of the seven children had a reading speed that was below average for their age. When it came to reading comprehension and basic arithmetic skills, most of the children had average results. Nevertheless, educational follow ups on all children are important after brain tumours, because there is a risk that reading and basic arithmetic skills will decline over time [22]. The neurocognitive tests that were carried out one year after the treatment ended revealed that more than half of the children whose cognitive levels were lower than average for their age had received multimodal treatment with surgery, radiation, and chemotherapy. The children who had just undergone surgery or chemotherapy showed an average general cognitive level, but significantly decreased information processing speed and working memory. Two-thirds of the children also needed extra support in school. Children who did not show any neurocognitive deficits one year after the end of treatment could be followed up using a brief screening battery, but the long-term follow up of all children who have been treated for brain tumours is warranted because cognitive problems often develop years after a brain tumour has been diagnosed and treated [23]. Although this study only focused on a small clinical group, the results support previous studies that have suggested a significant risk of neurocognitive sequelae in children treated for brain tumours [10]. We also identified that this risk is highest among children treated multimodally with surgery, radiation, and chemotherapy. However, there are also concerns about those children who just undergo surgery [11] or chemotherapy. When neurocognitive profiles provide evidence of specific problems with speed and working memory, these can mean that children are at risk of negative effects on learning and psychosocial development [24]. Such children are also more likely to need extra support in school than their classmates or their siblings [14,25] and to achieve lower marks than their classmates [26]. Although the aim of the study was not to examine the wellbeing or performance of the patients and their parents, the results of the neurocognitive and educational screening certainly support the need for close liaison between schools, hospitals and parents [27,28]. It is necessary for children who have had brain tumours to receive follow-up programmes that provide them with psychosocial support, cognitive development and academic achievement over a period of time. In order to accomplish and implement these programmes, the professional who participate, including physicians, psychologists, social workers and teachers, must have adequate competency as well as experience in their respective field. Furthermore, the results of our study support the need to develop a structured framework for performing prospective research on preventive and rehabilitation interventions. The strengths of this study were that it prospectively enrolled the children and it included all brain tumour types irrespective of malignancy, location and treatment. For example, tumours of a low malignancy grade that are located in the posterior fossa and are only treated with surgery can show late neurocognitive sequelae [27,30]. The study's main weaknesses were the small number of patients, the short project period and that all the families did not complete the scheduled follow up.

Conclusions

The results of this project provide further indications of the great demand for a psychosocial, educational, and neurocognitive follow-up programme for children with brain tumours. The programme needs to be coordinated with the medical follow up and well anchored in the management of the healthcare organisations treating

these children. In addition, involving competent, experienced and truly multi-professional teams may contribute to quality assurance in follow-up programmes for children with brain tumours and their families.

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