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A feasibility study of enhanced occupational therapy for children and young people with central nervous system tumours – outcomes for the families and for occupational therapy

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Abstract

A two-year feasibility study was conducted to explore harmonisation of occupation-focused practice between two UK children's cancer centres. The Short Child Occupational Profile (SCOPE) identified occupational needs of children with brain tumours to inform goal-setting, treatment-planning and intervention. A professional decision-making log was developed to focus reflection and to enhance communication of clinical decisions. The impact of a range of personal and environmental factors on participation beyond performance components was considered, enabling the occupational therapists to incorporate the child's strengths to overcome daily occupational challenges.

Twenty-four children aged 3-14 years with central nervous system tumours received enhanced occupational therapy for six months which families perceived as being helpful in rehabilitating children to participate in life and equipping them with better coping strategies for the future.

Individual occupational needs of children were highlighted using the SCOPE which helped to standardise practice. Using the SCOPE harmonised occupational therapists' unique focus on occupation in their practice with patients with brain tumours. This both evidenced intervention outcomes and strengthened professional identity. The outcome was robust preparation for a multi-centre intervention study.

Keywords

Occupational therapy, children, brain tumour, harmonised practice, SCOPE

Introduction

Following active treatment for brain or other intracranial tumours few children receive an occupational therapy service in the UK. Evidence suggests standards of provision for people with cancer are variable with limited

access to cancer specialist or general occupational therapists (College of Occupational Therapists, 2004). To enhance the quality of life of children having survived or being treated for a brain tumour, we postulated that an enhanced occupational therapy service (beyond that which is sometimes available) might promote greater ability to engage in everyday activities of self-care, play and education. We theorised that psychological wellbeing and self-esteem might be positively affected. Before a multi-centre trial could be undertaken to test the outcome of an enhanced occupational therapy service, a preliminary study was needed to explore the feasibility of harmonising practice between sites and to test the study design and selected instruments in order that differences measured in the main study would not be caused by differences in practice between centres. We report here on the outcomes for occupational therapy practice, on the impact on the patients and their families, and on the feasibility of this aspect for the main study.

Literature review

Brain, other central nervous system, and intracranial tumours (diagnostic group III in the International Classification of Childhood Cancers, Third Edition - ICC3-3) are the second most common type of childhood cancer in the UK (Steliarova-Foucher et al 2017). They account for an average of 412 new cases of cancer in children of 0-14 years being diagnosed each year in Great Britain (Cancer Research UK 2018). About 25% of all childhood tumours are of the CNS, and the 5-year survival rate is increasing: from 71% in 2003-2007 to 76% in 2008-2012 (Public Health England 2016).

Survival is often at significant cost with widespread treatment-related complications. Radiotherapy exerts particularly negative impacts on neurocognitive functioning (Grill et al 1999; Conklin et al 2008), while chemotherapy exerts less extreme yet still significant sequelae (Rutkowski et al 2005) and Patel et al (2011)

demonstrated differences in outcomes by location of the tumour. In addition, surgical intervention for CNS tumours is associated with significant morbidity in up to 65% of patients (Khan et al 2001; Neervoort et al 2010).

Sensory, cognitive and functional deficits may be experienced (Steliarova-Foucher et al 2004; Peris-Bonet et al 2006; Mulhern et al 2004; de Ruiter et al 2013), and these lead to decrease in activity, school attendance, peer-socialisation and occupation (Ness et al 2005; Wilson et al 2015). These negative sequelae are more pronounced for survivors of childhood brain tumour than for other cancers (Butler and Mulhern 2005; Duffner 2010; de Ruiter et al 2013).

In the USA, Pergolotti et al (2016) note that while adults living with cancer bear a greater risk of functional loss and associated problems, access to occupational therapy is restricted. This missed opportunity to offer a viable therapy is not limited to North America but is also seen in Europe. The study reported here was designed to explore the feasibility and potential impact of a specialist occupational therapy service for children living with and recovering from a tumour of the CNS.

One Danish study (Hansen et al 2017) suggested that the provision of occupational therapy with selected adult brain tumour patients, such as those with glioma, supported positive outcomes. However, the research paper provided limited and largely theoretical conclusions. A case study of the application of the Canadian Occupational Performance Measure (Law et al 2015) using the Assessment of Motor and Process Skills (AMPS) (Fisher and Bray Jones 2012) was persuasive, however, in presenting the case for the potential for occupational therapy in cases involving brain injuries the evidence was less extensive.

A Swedish occupational therapist (Fisher 2014) provided the Occupational Therapy Intervention Process Model as an example of how therapists may explain what their practice is and how it can be applied to the benefit of patients. Alternatively, applying the Model of Human Occupation (MOHO), a conceptual model of occupation based on dynamic systems theory, enables occupational therapists to describe their practice from a holistic perspective which values volition for occupation (Taylor 2017). The SCOPE is a MOHO-based assessment that enables children's occupational needs to be captured comprehensively and communicated (Bowyer et al 2008).

Methodology

The project aim was to test a study design for feasibility including recruitment; the use of psychometrically tested questionnaires for quality of life, psychological wellbeing, and health status; the application of SCOPE; and the potential to harmonise practice across two

centres. Patients from two to sixteen years were eligible to be recruited from two tertiary children's hospitals within two weeks of recovery from surgery. Approximately one third of patients were within three months of completing treatment in order that transition to follow-up could be included. The instruments were administered at baseline, three months and six months (completion). Approval was secured from an NHS research ethics committee (reference 13/NW/0800) and from the University of Salford research ethics committee (reference HSCR14-03).

The intervention was based on MOHO theory and the use of the SCOPE; an assessment and outcome measure developed for use with children (Bowyer et al 2008; Taylor 2017). A case formulation approach was employed that incorporated SCOPE resources for goal setting, intervention planning and review. The structured framework gathered information about patients' occupational needs from clinical observations and parent or child reports, replacing a non-standardised assessment approach. Identifying a patient's specific occupational challenges and strengths provided the therapists with an opportunity to apply their full range of therapeutic skills and interventions.

The role of the occupational therapist in acute oncology typically has a narrow remit focusing on the patient's physical needs and facilitating hospital discharge. Intervention is limited by factors such as the predominance of the medical model, complexity of cancer treatment pathways and the multidisciplinary team's perception of roles. During this study the therapists worked to their full scope of practice as defined by their professional body: "occupational therapy improves health and well-being through participation in occupation" (Royal College of Occupational Therapists, 2017).

Reflective logs with serial entries were maintained for each child which informed team discussions aimed at moving towards a harmonised approach.

Results: outcomes for children and parents

The SCOPE was designed to screen for occupational therapy services and to document progress towards intervention goals (Bowyer et al 2008). The SCOPE highlighted how personal factors could be a strength or a challenge to the occupational performance of children with a brain tumour.

Volition

Volition influences the way in which children choose, experience, and interpret their engagement in occupation (Bowyer et al 2008). Children with brain tumours often were well motivated to participate in meaningful occupations. One student chose to make adjustments

Figure 1: Decision-making reflective log

Initial Background Information / Additional Contextual Information (delete as applicable)	
Clinical Decision Making Questions	
1. What was the identified need?	
2. What were the options?	
3. Which option was selected?	
4. Why was this option or this sequence of options selected?	
5. Why were the other options not selected?	
Next Steps	

to, rather than cancel, their work-experience placement. Through reframing and positive risk-management the occupational therapist was able to reinstate their placement. When a patient’s response to challenge caused parental concern the occupational therapist empowered them to be more confident when school work proved difficult. The young person was better equipped to cope by seeking help which reduced episodes of tearfulness and feelings of frustration. The therapists supported children to reintegrate to school helping to rebuild their resilience and self-esteem.

Habituation

The occupational therapists recognised the impact on families who travelled a distance to and from cancer treatment centres. Some parents struggled to arrange alternative childcare for siblings while others had their working lives and personal commitments disrupted which was inconvenient for them, and, in some circumstances, had a negative economic impact. Offering parents a choice of therapy location convenient to

them that minimised disruption to their child’s school schedule was greatly valued by families. The therapists recognised that protected time for social participation in community activities, with siblings and friends, promoted and maintained children’s general wellbeing.

Understanding how a family managed hospital visits around everyday routines guided the therapists.

Parents created flexibility by accessing support with appointments from extended family or close friends. The occupational therapists supported scheduling of visits by being clear about the purpose of an appointment and considering whose presence was essential.

Parents reported that positive occupational therapy experiences counteracted their child’s negative recollection of hospital visits. This reduced the stress associated with appointments and for some children lessened their need for psychological intervention.

For children with multiple hospital appointments the occupational therapists considered the nature and length of appointments in relation to the child’s fatigue level before considering coordinating visits. The use of fatigue-management concepts, in particular pacing, was beneficial for many participants. This helped to engage the child in prioritising what was important to them at a point in their treatment when their energy levels were often low; yet there was a requirement to have some school attendance. Advice about sleep hygiene benefited patients who struggled to sleep well with consequent disruption of their daily functioning.

Skills

Communication and Interaction

Occupational therapists’ communication with parents and children was adjusted according to the families’

personal preferences and context. Difficulty was experienced in establishing or sustaining communication with families as parents were not always able to take personal telephone calls or respond to emails at work. Multiple hospital appointments for investigations, medical reviews or occupational therapy were competing priorities for the parent's time, so four children were lost to follow-up. For the majority, the efforts made to work around their availability were both effective and appreciated, and this was a positive factor that was reported spontaneously by parents.

The occupational therapists needed time and effort to maintain communication with families of patients with multiple long-term conditions or those with limited extended family support. Parents with reduced health and wellbeing or with complex or non-traditional lifestyles needed more support to prevent them becoming unreachable. Occupational therapists used different types of communication from seeing the family face-to-face at home, in a hospital, or at school to indirect contact with families by post, telephone and email. Using the SCOPE flexibly and incorporating the different rating scales supported effective communication between therapists and families when gathering information on changes relating to the child's occupational performance.

The therapists were in a unique position of reassessing the patient's needs at three months and six months which facilitated responsiveness, continuity of care and anticipating future issues. Parents valued a continuing relationship with the same occupational therapist rather than being referred on to a new service as this contact enabled an in-depth exploration of how personal and environmental factors continued to impact on their child's participation in family life, school and social activities. Parents described how a trusting relationship grew as an understanding developed over time of what occupation-centred therapy was through use of the SCOPE tool. This enabled the therapists to discuss sensitive issues with parents, exploring family relationships, life style choices, and the psychological challenges to young people such as responding appropriately to peers' comments about hair loss.

Occupational therapists identified psychosocial needs in families of children with CNS tumours. High stress levels were observed in parents and children as often the long-term effect of the disease and treatment were unpredictable. Most patients experienced multiple challenges at different stages which impacted negatively on their quality of life, health and psychological functioning. Common difficulties were physical and sensory impairment, cognitive deficits, reduced self-esteem and occasionally behavioural changes. Functional impairments and behavioural problems were sometimes overlooked at times in the face of more acute or serious problems. The immediate and longer-term patient's

chosen goals shifted in accordance with families' priorities over time; a responsiveness that was acknowledged as being helpful by parents.

Early on, parents sought reassurance from the occupational therapists and needed time to come to terms with what had or was happening to their child. The therapists continued to support parents intermittently during the recovery process as different stressors emerged. They exploited opportunities to review information previously provided to children and parents and to deal with emerging occupational challenges at review appointments or telephone contact. Time taken to review how advice had been applied highlighted to the occupational therapists the patient's and parent's level of understanding, engagement and motivation. Accessing therapy periodically meant that families had time to consolidate and generalise their learning which parents reported to be useful. The review process provided opportunities to reinforce patients' learning so that they were more able to incorporate the advice received into their daily habits in the context of their past, present and future life roles.

Process

A few children presented with limited decision-making or problem-solving skills which parents initially assumed to be temporary rather than permanent. The SCOPE highlighted other more subtle problems, for example with sustaining attention or specific cognitive impairments that developed later which may have been missed or might not necessarily have been associated with a need for occupational therapy. To learn that someone else understood less well-defined problems and was able to help with overcoming or adapting to them was a relief to many parents and young people.

Motor Skills

More general needs of children with cancer were addressed as well as providing targeted, intensive or longer-term rehabilitation to address specific goals, which resulted in patients increased physical ability and functional independence. Frequently patients with CNS tumours had difficulties with performance components such as specific weakness and decreased upper limb coordination which was addressed through optimising hand skills through direct therapy intervention and development programmes. Where balance and gross motor work were indicated, the occupational therapists worked in partnership with physiotherapy colleagues using the SCOPE findings to facilitate discussions. A few children experienced sensory processing difficulties that required supportive home-based strategies. On-going developmental advice and support provided through coaching, modelling and scaffolding was well-received by parents and education staff.

Environment

For hospital visits, parents’ access to private or public transport were considered by the occupational therapists alongside the accessibility of the car park in relation to the location of the clinic. Occupational therapists advised on provision of specialist equipment, for example, adapted cutlery or scissors and minor adaptations for home and school use. In particular, organising a supportive environment at school was valued by children and parents. Practical advice and strategies were offered to help families to make reasonable adjustments to their home routines and to cope better with unpredictable changes arising from the long-term sequelae of cancer that affected their lifestyles. Use of the SCOPE within the occupational therapy process to identify barriers and facilitators that impacted participation in occupation influenced the therapists to modify or adapt the child’s physical, sensory, temporal and social environments.

Occupational Dysfunction

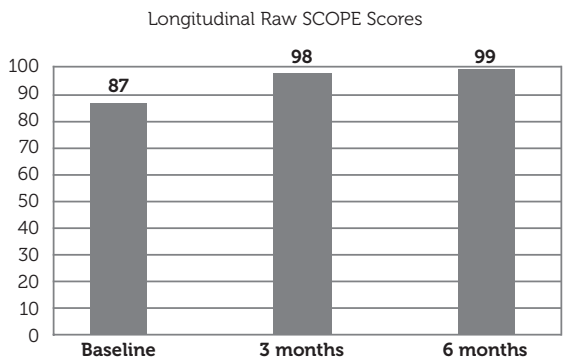
Children with brain tumours reported difficulties in occupational dysfunction which affected their daily self-care, productivity, and play or leisure routines which was the primary focus for occupational therapy intervention (Table 1). The SCOPE captured and measured positive changes and outcomes relating to occupational performance that occurred during and after intervention in a more formal and standardised way (Figure 2). The overall rating total is not a measure or standardised score but allows description of the direction of change during re-evaluation. Strengths identified were motivation, social participation and emerging resolution skills; while challenges were the impact of left-sided weakness for two-handed tasks, reduced self-confidence, and reduction in previously mastered skills.

Table 1: Occupational dysfunction identified in participants

Self-Care / Activities of Daily Living	Work / Being productive	Play / Leisure
Fatigue: general, sleep, rest, cognitive Managing stairs Walking speed and distance Getting ready to go out Eating and drinking Using the toilet Washing and drying oneself Dressing Caring for teeth Skin care, hair care, body care	Doing work experience Attending nursery, school or college Handwriting Tool usage Engaging in community activities	Playing with friends Socialising with friends Doing hobbies Doing sports Participating in religious or cultural groups

Therapists highlighted complexities around the measurement of occupational outcomes due to the high number and degree of variability in outcomes and the challenge of striking a balance between using a more measurable standardised approach and delivering purposeful, individualised therapy. This resonates with the Royal College of Occupational Therapists’ publication aligning the profession with the concept of complex interventions (Pentland et al 2018).

Figure 2: Example of longitudinal SCOPE scores from one case



Discussion

Families found occupational therapy to be both effective and empowering, helping with a range of problems but also supplementing parental skills and ability with strategies to draw on after the conclusion of the research study. There were also important outcomes for the profession and professional practice. Reflection and multi-professional deliberation about this were integral components of the study, seeking to establish the factors of occupational therapy that enhanced outcomes for families.

Technical Skills & Expertise

Parents perceived occupational therapists as a source of valuable expertise and helpful information referring them to statutory and voluntary services. From the logs it was evident that the therapists used strategies such as coaching and motivational interviewing to encourage patients’ engagement in their chosen occupations. In addition to being satisfied with the overall quality of the skills of the occupational therapist, the families highlighted positive personal attributes that they valued which facilitated a therapeutic rapport. Key attributes were being a friendly, likable person; someone who was easy to get on with and who listened actively.

The occupational therapists perceived that their understanding of cancer treatments and their side-effects was important for their role. Some of the children treated had

undergone adjuvant therapies which had implications for their ability to participate. Accordingly, the nature of input fluctuated in response to the child's stage in treatment, and this required specialist knowledge and insights into multiple treatment effects and potential patient responses.

The decision-making tool mirrored the holistic and collaborative nature of occupational therapy practice. Records did not capture explicitly all of the patient goals and outcomes that had been achieved, such as keeping the family on a pathway or maintaining school-home liaison, although these responsibilities lay within the scope of occupational therapy. Developing documentation to capture all aspects of intervention and goal achievement for children would ensure better appreciation of the breadth and depth of the role. Occupational therapists' implicit goals described in the log were driven by core values such as compassion.

The occupational therapists worked creatively with the children, supporting their recovery and development by using interesting activities that motivated the patient. Therapy was therefore perceived as "fun" rather than "work". Parents described their child as actively wanting occupational therapy, and they explained how therapy was inclusive in terms of benefitting the whole family. They reported that early access to therapy had helped their child to manage the aftermath of the initial diagnosis and treatment and had exerted a lasting impact as it taught them a new set of skills for life. Parents recognised their child's potential to continue improving after the study ended, giving families increased confidence and responsibility to continue home programmes with an improved outlook for the future.

Intermediary and Liaison Role

The occupational therapist was a point of contact and communication between home, hospital and school and held a significant intermediary and liaison role which was recognised as being important by families. The occupational therapists proactively communicated with other services often on the family's behalf.

The enhanced role of the occupational therapist included outreach to homes and regular unsolicited contact to administer questionnaires which served as a support mechanism to families. Parents described occupational therapists as a reliable and regular point of contact between the treatment centre and the family. The families used this access to ask questions, seek clarification and discuss frustrations involving the wider oncology multi-disciplinary team. These issues have been addressed increasingly in the inter-professional context. They were found to be an aspect of the problem investigated by the Francis Inquiry (2013), they have been addressed by the Academy of Medical Royal Colleges (2015) and are

factored into the ongoing "New Care Models" initiative led by NHS England (2015). A focused discussion of care coordination by Australian health professionals in relation to cancer care is provided by Haynes et al (2018), concluding that there are certainly gaps in this provision for certain diagnostic groups.

Navigating hospital and healthcare systems was confusing and prevented families approaching the medical team for help as they were not sure if their questions were valid. Regular communication between the occupational therapist and families using the SCOPE provided opportunities to check whether the family had unresolved issues. After listening to and exploring concerns the occupational therapist found out information and shared this knowledge with families.

The occupational therapists were well placed to consider the impact of the child's illness on the whole family. Even when the child was well and recovering, and prognosis was good; family members were affected emotionally by the impact of the diagnosis, surgery and treatment which influenced how they cared for their child. Parents worried about the future, and the use of SCOPE provided a record of such concerns using consistent terminology. The therapists understood the carer's role and the impact of cancer on the family as a unit.

Helping and Problem Solving

During the study the occupational therapists perceived they made a positive and significant difference to families by meeting individuals' occupational needs. They had time to exercise problem-solving skills around patients' difficulties around participation and occupational performance. The use of the SCOPE provided a child-centred assessment helping therapists to clarify specific areas to address. The use of creative thinking, practical skills and professional knowledge enabled the therapists to develop innovative solutions to the difficulties experienced by children.

Collaboration

Collaboration between the research occupational therapists and community teams was effective and timely which prevented duplication or delay in provision of assessments, equipment or therapy. The therapists bridged the gap between discharge from hospital and engagement with local therapy services. Regular communication was established, and families ultimately decided who was best placed to carry out intervention. For one family it was convenient to see the community therapist as a sibling already attended a local therapy clinic. In another case the research therapists continued input after discharge until the local team picked up the patient. Community, hospital and research occupational therapists liaised to agree a family-focused plan of

care. This model worked well as most community teams operated a priority and waiting list for children. When referrals for handwriting or perceptual problems were a low priority the research therapists provided intervention in the interim period.

Transferable Skills

The feasibility study demonstrated that experienced, paediatric occupational therapists working with children in community or hospital settings have transferable clinical skills to work effectively with patients with CNS tumours. Through using the SCOPE and a decision-making log the therapists demonstrated common core skills around assessment, activity analysis, problem solving and professional reasoning. The ability to articulate core skills was part of the required harmonisation across sites.

Continuing Professional Development

The research occupational therapists concluded that the study had enhanced their cancer-specific knowledge and extended their occupation-focused therapeutic skills. Although therapists supported and guided patients with anxiety related to invasive procedures using a range of distraction, relaxation and creative techniques, they reported this as an area for further personal development. Further post-graduate training needs in awareness and management of fatigue, visual impairment and objective management of hemiplegia were identified.

Service Outcomes

The occupational therapists reflected that resources for clinical practice were not always available. As a result some intervention choices and specific activities were based on practicality, local availability or personal preference. The therapists concluded that although their assessments were similar, various intervention strategies were considered before selecting a suitable medium through which to implement the treatment plan. The decision-making process occurred at all three stages; however the final stage demonstrated that clinical decision-making skills rely on previous experience of knowing how to use local materials effectively. This factor needs consideration when planning future multicentre studies. Otherwise, a gradual process of joint review and discussion of the outcomes of self-reflection on the decisions that were made on a case-by-case basis resulted in generally comparable responses to similar cases across sites, limited only by available resources.

Following the study new practices adopting the SCOPE for inpatient work were explored at the centres. The breadth of assessment and intervention offered was reviewed with more emphasis on psychosocial

interactions rather than physical symptoms and a business case for an outpatient service was developed.

Conclusion

Analysis of SCOPE data confirmed that the tool was suitable for use with children with brain tumours with a broad age range of abilities giving a unique perspective on their occupational performance. A decision-making reflective log developed for occupational therapists to capture their professional and informed reasoning indicated that with training and experience the SCOPE was a useful assessment systematically covering a wider range of areas of concern in addition to physical limitations. Through these means and through an iterative process of review and discussion, harmonisation was achieved in both understanding of the approach and decision-making about cases which was sufficient to allow progress to the next stage of a multi-centre study.

Key messages

The project demonstrated the feasibility of harmonising practice across sites for the next study. The process of reflection and team-wide discussion of issues was central to this.

Families especially appreciated the tailored and flexible approach to their needs and valued the coordinating role of the occupational therapist.

Much was learned for occupational therapy practice and for the profession in the application of SCOPE and the use of reflective logs.

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