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E-SURVEY OF CURRENT INTERNATIONAL PHYSIOTHERAPY PRACTICE FOR CHILDREN WITH ATAXIA FOLLOWING SURGICAL RESECTION OF POSTERIOR FOSSA TUMOUR

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- E-survey of current international physiotherapy practice for children with ataxia following
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- 24 Abstract
- 25 E-Survey of current international physiotherapy practice for children with ataxia following
- 26 surgical resection of posterior fossa tumour
- OBJECTIVE To determine current international practice regarding physiotherapy input for
 children with posterior fossa tumours (PFTs).
- 29 DESIGN An e-survey covering the following domains; participant demographics,
- 30 treatment/intervention, virtual training, intensity/timing of treatment, aims and outcomes of
- 31 physiotherapy management.
- 32 PARTICIPANTS Physiotherapists involved in the management of children with ataxia
- 33 following surgical resection of PFT. Participants contacted via 6 key groups; Paediatric
- 34 Oncology Physiotherapy Network (POPs), Association of Paediatric Chartered
- 35 Physiotherapists (APCP), European Paediatric Neurology Society (EPNS), International
- 36 Society of Paediatric Oncology (SIOP)-Europe Brain Tumour Group, Posterior Fossa Society
- 37 (PFS), Pediatric Oncology Special Interest Group (SIG) (American Physical Therapy
- 38 Association).
- 39 RESULTS 96 physiotherapists participated: UK (n=53), rest of Europe (n=23),
- 40 USA/Canada (n=10), Australia/NZ (n=10). The most common physiotherapy interventions
- 41 used were balance exercises, gait re-education and proximal control activities. The most
- 42 frequently used adjuncts to treatment were mobility aids and orthotics. Challenges raised
- 43 regarding physiotherapy treatment were; reduced availability of physiotherapy input
- 44 following discharge from the acute setting, lack of evidence, impact of adjuvant oncology
- 45 treatment and psychosocial impact.
- 46 CONCLUSIONS This e-survey provides an initial scoping review of international
- physiotherapy practice in this area. It establishes a foundation for future research onimproving rehabilitation of ataxia in this population.
- 49 Key Words; Pediatrics, brain neoplasms, ataxia, rehabilitation
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- 53 Lay Abstract
- 54 AIM To find out how physiotherapists across different countries currently treat children
- 55 with balance/coordination problems following surgery for a brain tumour.
- 56 METHOD An e-survey was used asking questions on type of physiotherapy treatment,
- 57 intensity and timing of treatment and aims and outcomes of physiotherapy management.
- 58 The e-survey was sent out to special interest groups which included physiotherapists with 59 expertise in this area.
- 60 RESULTS 96 physiotherapists participated. The most common physiotherapy treatments
- 61 used were balance exercises and gait re-education. Mobility aids and orthotics (e.g. splints)
- 62 were also commonly used. Physiotherapists raised challenges to treatment including lack of
- availability of physiotherapy following discharge from hospital, lack of evidence to guide

- treatment and impact of oncology treatment (e.g. chemotherapy/radiotherapy) on the child's
- 65 rehabilitation.
- 66 CONCLUSION There is little evidence in this area, therefore this survey provides an initial
- basis to understand the challenges of treatment and to plan future research.
- 68

69 Introduction

70

Brain tumours are the most common group of solid tumours in childhood and account for nearly a quarter of all paediatric neoplasms worldwide [1]. Approximately 50% of all childhood brain tumours are located in the posterior fossa region [2]. Management of posterior fossa tumours (PFTs) typically involves surgical resection, solely or in combination with adjuvant treatment such as radiotherapy or chemotherapy.

Children with PFT have a distinctive set of issues including potential for change pre/post 76 77 operatively, rapid onset of ataxia, hydrocephalus and increased intra-cranial pressure, in addition to potential problems from any subsequent oncological management such as 78 radiotherapy. Of these issues, ataxia is the predominant motor problem in children with PFT 79 [3,4]. Ataxia can describe a related number of impairments including upper limb control, 80 balance, gait difficulties, oculomotor dysfunction and speech problems [5]. Wilne et al [6] 81 presented a systematic review and meta-analysis with pooled data from five studies with 82 children with PFT (n=476) reporting that 60% demonstrated ataxia pre-operatively indicating 83 the prevalence of ataxia in this population group. 84

Additionally, there is an increasing understanding of the long-term impact on mobility in this population group with up to 70% of children noted to have balance problems following completion of neurosurgical/oncology treatment [3,7]. Following surgical management of their PFT, children are typically referred for rehabilitation including physiotherapy, yet there is little evidence to guide physiotherapists on how best to assess and treat this population. Balance and

90 coordination problems can be a significant challenge following initial treatment as these can affect activities of daily life, return to school and participation with peers [3.8]. 91 Despite the lack of evidence to guide best practice, it is recognised that physiotherapy is integral 92 93 to the treatment of children with neurological deficits following management of a brain tumour [9] yet to date the practices of physiotherapists in managing children with PFT is not reported. 94 Understanding current practice could help with development of clinical guidelines and assist 95 96 with the planning of clinical trials in this population. To gain increased knowledge of physiotherapy treatment for children with PFT across different countries an e-survey was 97 98 developed to scope current practice. This is the first study to investigate the current practices of physiotherapists in this population 99 group. The aim of this study was to determine current international practice regarding 100 101 physiotherapy input for children with ataxia following surgical resection of PFT. 102 Methods 103 104 105 Study design A cross sectional study design was used with data collected via an online survey (e-survey). 106 107 108 **Participants** The target population in this study was physiotherapists who were involved in the assessment 109 and treatment of children with ataxia following surgical resection of (PFT). The survey (in 110 English) was disseminated via the Paediatric Physiotherapy Network groups of Paediatric 111 Neurosciences Physiotherapists and Paediatric Oncology Physiotherapists (both UK based 112 113 groups), the Association of Paediatric Chartered Physiotherapists (APCP), International

114 Society of Paediatric Oncology European Brain Tumour group (SIOP), Children's Oncology

115 Group (COG) (international membership), Paediatric Physical Therapist Special Interest Group

(USA), Posterior Fossa Society (international multidisciplinary special interest group), and
European Paediatric Neurology Society (EPNS). Snowballing was encouraged by an automatic
request as part of the e-survey to forward the link to therapy colleagues with an interest in this
area.

120 The study was approved by Edge Hill University FOHSC Research Ethics Committee (FOHSC121 170).

122

123 Instrument

A literature search identified no previous surveys on this topic that could be used for this study. 124 Therefore an e-survey (SurveyMonkey®) was purposefully designed by the research team 125 126 (with clinical expertise in this field and with a background in survey development) to ensure the specific aim of this study was met. The e-survey had 5 domains (Table I), with a mixture 127 of open and closed questions. The e-survey began with an initial filter question checking that 128 respondents were physiotherapists working with children with posterior fossa tumours. 129 Selecting 'no' to the filter question directed potential respondents to an automatic response that 130 131 ended their participation.

The e-survey included a section on virtual training (defined as the use of computer technologies that provide an interactive environment requiring limb movement to react to on screen game play [10]), reflecting the recent trend towards the use of technology in paediatric neurorehabilitation [11,12]. This section was also planned to inform development of a future RCT examining virtual training intervention in children with ataxia following surgical resection of PFT.

Prior to disseminating the e-survey it was piloted to optimise face and content validity and
reliability [13]. Four clinicians were purposefully selected to ensure there were two contacts
from the UK (an acute hospital-based therapist and a community-based therapist), a

141 representative from Europe (speaking English as a second language) and a representative from

the USA. Minor changes were made to the questionnaire as a result of the pilot feedback.

143

144 Procedure

145 The e-survey was disseminated via gatekeepers for each of the identified network groups with permission from each group received to circulate the e-survey to its members. This enabled the 146 gatekeepers to email their members with a link to the e-survey. A short introductory page of 147 148 the e-survey provided the participants with sufficient information to enable them to reach an informed decision whether to participate. The return of the survey was deemed to be the 149 respondent's consent to participate. The respondents were given two weeks to respond then a 150 151 reminder was sent out electronically. All due care and attention was paid to the management of the data in line with guidance from local policies and the General Data Protection Regulation 152 (GDPR 2018). The respondents' responses were anonymous. 153

154

155 Data Analysis

Using Survey Monkey® the data were exported onto an Excel spreadsheet for further analysis. 156 Descriptive statistics were used to report the closed questions. The qualitative analysis was 157 informed by a deductive approach situated in an essentialist framework (reporting the 158 respondents' perceptions and experiences assuming a straight forward relationship between the 159 written responses and the perceptions) [14]. All data from selected open questions were 160 transferred from Excel into NVivo to allow the data to be read and re-read and initial codes 161 generated. Codes were sorted and organised into groups and where there was evidence of 162 recurring responses initial themes were developed and were subsequently refined. 163

164

165 Results

167 One hundred and twenty of 140 respondents who accessed the survey answered yes to the 168 initial filter question and proceeded to enter the e-survey. It is not possible to report a response 169 rate due to the method of disseminating the e-survey and subsequent snowballing as it is not 170 known how many physiotherapists the e-survey reached.

Initial questions were answered by 96 respondents with some of the later open-ended questions
answered by fewer respondents (average of 60 respondents), however, some of these questions
were only applicable to certain physiotherapist groups e.g. if they had used virtual training.
Throughout the results section percentage responses are presented calculated from the number
of respondents who answered each individual question.

176

177 Demographics

Overall 12 countries were represented with over 50 responses from physiotherapists across the
UK, 23 respondents from the rest of Europe (including Belgium, Germany, France, Italy,
Lithuania, Netherlands and Republic of Ireland), 10 respondents from the USA/Canada and 10

181 respondents from Australia/New Zealand. Further details are presented in Table II.

182 Fifty nine percent (n=56) of respondents had over 5 years' experience in working with children

with brain tumours. The median number of children treated per year with PFTs was 10. Where
respondents indicated they had completed further training, the most common type of training
was a short course in either ataxia or oncology.

The primary work setting of the respondents was an inpatient setting (72%, n=66), with 66%
(n=61) of physiotherapists reporting they worked within a specialist team for neuro-oncology
(Table III).

189

190 Therapy Intervention

191 Respondents selected from a predetermined list of therapy interventions which types they used192 in this population group. The question allowed the physiotherapists to indicate all possible

193 interventions they might use, selecting more than one possible answer. The results indicate physiotherapists use a range of interventions, with balance exercises (n=73, 97%), gait re-194 education (n=71, 95%), and proximal control exercises (n=70, 93%) utilised by the highest 195 number of respondents as illustrated in Figure 1. Additional types of treatment reported by the 196 respondents in the 'other' category included gym ball (n=3, 4%), coordination exercises (n=2, 197 3%), hippotherapy (n=2, 3%), rebound therapy (n=1, 1%), robotics (n=1, 1%), vocational (n=1, 198 1%), vojta (involves the therapeutic use of reflex locomotions www.vojta.com) (n=1, 1%), and 199 approximation exercise (n=1, 1%). 200

When asked which type of intervention they used most often three intervention types were commonly reported; balance exercises (n=21, 28%), task specific training (n=17, 23%) and proximal control activities (n=16, 21%). These three intervention types were also the most frequently ranked in the therapists 'top three' most effective types of treatment.

205 Respondents then selected from a predetermined list of 'adjuncts to therapy' which types they used in this population (multiple responses possible). The results indicate physiotherapists use 206 a range of adjuncts, with orthotics (n=61, 82%), walking/mobility aids (n=60, 81%), and taping 207 (n=32, 43%) used most frequently (Figure 2). Other adjuncts suggested by the respondents 208 209 included gym ball activities. Orthotics (n=23, 31%) and walking/mobility aids (n=23, 31%) were the two adjuncts used most often by the therapists and were also the top two adjuncts 210 rated as most effective by the physiotherapists. Treadmill training was ranked as the third most 211 212 effective adjunct to therapy.

213

214 Virtual Training

Fifty seven percent of respondents (n=44) reported they had used virtual training in their practice. The physiotherapists indicated they had used virtual training most commonly in children with posterior fossa tumours (n=32, 73%), acquired brain injury (n=28, 64%) and traumatic brain injury (n=27, 61%). 219 Respondents gave details regarding their top three benefits and challenges to using virtual training in their practice and these answers were thematically analysed. Benefits to using virtual 220 training revealed three broad categories; engagement/compliance, physical benefits and 221 222 resource/equipment benefits. Engagement/compliance was the most frequently raised benefit with therapists repeatedly reporting that virtual training was 'fun and engaging', 'games are 223 fun'. Physiotherapists thought that this method of therapy was 'patient friendly' and offered a 224 way to achieve 'good compliance' whilst being motivational. Therapists noted the potential 225 physical benefits from using virtual training which included the ability to work on specific 226 227 problems such as upper limb co-ordination and balance. Resource/equipment factors were also raised as a positive aspect with two respondents noting the potential for the technology to 'track 228 progress' and that the technology is easily available 'no additional equipment required', as 229 230 children have 'access to [it] at home'.

231 Challenges to using virtual training were also grouped into similar domains; engagement, physical and equipment/resources. Therapists were concerned that children might become 232 233 frustrated if they could not play a game they had been able to before they had become ill, another therapist highlighted that virtual training might be 'demotivating if difficult'. Physical 234 barriers/challenges were noted with therapists raising concerns that if children had visual 235 difficulties or significant mobility problems this might limit their potential to use this 236 intervention, with one respondent noting it could be 'difficult if child can't stand'. The most 237 238 frequent response with regard to challenges to virtual training focused on equipment/resource issues. The responses centred on two areas; access to the resource or technical difficulties to 239 using it in this specific population. A therapist reported that it was 'not timely to set up', and 240 241 another reported that 'it wasn't sensitive enough to use'.

242

243 Intensity and Timing of Treatment

The most common frequency of treatment in the inpatient setting was four to five times per 244 week (n=31, 42%). Treatment was typically less intense in the outpatient/community setting 245 though there was a wide range of responses for this setting, ranging from monthly to up to 4-5 246 times a week. Physiotherapists also reported that they often intensified treatment at specific 247 time points although the reasons for this varied e.g. immediately post-operatively or post 248 chemotherapy/radiotherapy. The majority of input was delivered on a 1:1 basis by a 249 physiotherapist with 89% (n=64) of physiotherapists reporting that sessions lasted between 30-250 60 minutes. Respondents were also asked how long (on average) their therapy intervention 251 252 continued for children with PFT. There was variation in responses with a relatively even spread of answers from under three months to over two years, reflecting the differing needs of this 253 population group. 254

255

256 Aims and Outcomes

Physiotherapists reported common aims for physiotherapy treatment including improving coordination, balance, muscle strength and providing education to the child/family regarding activity (Figure 3). Other aims identified by the respondents included reducing fatigue and improving participation according to the child's specific goals. Physiotherapists also indicated they considered several factors when goal setting for children typically involving functional and participation targets. These included child specific factors (e.g. age, pain levels, fatigue) and disease related factors (e.g. limitations of disease and treatment).

Seventy five percent (n=52) of physiotherapists (from 69 who responded to this question) reported they used standardised outcome measures to assess children with posterior fossa tumours. The most commonly used outcome measure was the Scale for the Assessment and Rating of Ataxia (SARA) (n=28), followed by the Berg/Paediatric Balance Scale (n=11) and the Gross Motor Function Measure (n=8). 269 Sixty-nine respondents reported frequent problems/challenges they encountered when treating children following surgical resection of posterior fossa tumour. Three main themes were 270 identified, each with two subthemes (Figure 4). Condition specific factors included direct 271 272 medical problems (e.g. impact of the tumour itself or cerebellar mutism syndrome) or treatment related issues (e.g. impact of chemotherapy and radiotherapy which may include nausea, 273 274 fatigue or chemotherapy induced peripheral neuropathy). A number of respondents (n=9) also commented that fatigue can be exacerbated by the child having to travel to another site for 275 radiotherapy; one physiotherapist commented 'during RT [radiotherapy] patients have to 276 277 travel, difficulty planning rehab' and another noted that 'children transfer to a different hospital for chemo/radio so disjointed service'. 278

Physiotherapists also repeatedly raised challenges to rehabilitation in terms of child and family 279 280 factors both from an emotional/psychosocial perspective and expectations/engagement (child 281 and parents). Emotional and psychosocial factors arising from the impact of the illness on the child were reported as challenges by the respondents such as the 'loss of friendship groups and 282 social life', another physiotherapist noted that 'psychosocial issues around functional loss had 283 huge impact on participation'. However, even if the respondents are aware of the potential 284 psychosocial factors and emotional stresses they reported it can still be difficult to manage the 285 child and family's expectations of rehabilitation. The challenge of engaging families in the 286 early stages post operatively when the child may be viewed as acutely unwell was emphasized 287 288 by therapists, as typified by this response 'initially post op barriers are gen [generally] related to family and their views on Sx [surgery] – families very over protective with the patients – 289 tend to be slow to get up and move'. Additionally, following the acute neurosurgical phase 290 291 there is then the challenge of continuing to integrate rehabilitation during the child's oncology treatment when again they might be unwell, with one respondent noting the challenge of 292 'parental coping and mental space to think about rehab versus oncology treatment'. This view 293

294 was supported by another respondent who noted the 'priority of chemotherapy/radiation vs physical therapy'. Respondents reported that parents commonly regarded rehabilitation as a 295 low priority until after oncological treatment had finished as 'sometimes the parents don't want 296 297 the therapists to work with their kids if they are hurting.' Engagement directly with the child was also seen as important to maximize therapy sessions, although this challenge was not raised 298 as frequently as the challenge of working with the families. Therapists noted that some children 299 had difficulty engaging with older staff as they were 'too much like mum, just nagging', 300 highlighting the importance rapport-building between the child and the therapist. 301

302 The challenge, most frequently highlighted by the therapists, related to service delivery of therapy input. This is presented in two areas; resource factors and lack of evidence. In terms of 303 resource deficits, the area highlighted was physiotherapy staffing levels with respondents 304 305 commenting that 'staffing [problem] as often need intensive physiotherapy post-surgery and 306 discharged home'. This seemed to be particularly influenced by a perception of pressure to discharge children home quickly, for example, 'caseload on a neurosurgical ward-time until 307 308 discharge to home', alongside problems with subsequent community/local physiotherapy input on discharge home. One respondent described the challenge as being 'DGH [District General 309 Hospital] only with limited therapy; community has variable expertise and staffing'. In addition 310 to staffing requirements, challenges related to space and equipment were also raised, including 311 312 'limited space and equipment' and 'no dedicated rehab team/ward'. In addition to resource 313 issues, the other area that respondents felt directly impacted on physiotherapy input is the lack of evidence for therapy input in this area. This was detailed repeatedly by therapists who noted 314 the 'lack of research' and 'limited evidence especially clinical guidelines'. 315

The final question of the e-survey asked therapists to document their main reasons for discharging a child from their care. The most common answers were if the child's goals had been met (n=50, 71%) or if there was a plateau in physical function (n=43, 61%). 320 Discussion

This study provides a unique contribution to the understanding of current international practice for children with ataxia following surgical resection of PFT and presents new data that have not previously been reported. The lack of evidence to guide physiotherapy practice in this area presents a challenge for therapists integrated in a culture of evidenced-based practice. This study provides an insight to current practice and a foundation from which to explore this area further.

Over 90 therapists from across 12 countries completed the e-survey, although the largest cohort
was from the UK there was good representation internationally, particularly across Europe.

The majority of respondents had been qualified for more than ten years, suggesting a broad range of experience to draw on when answering questions. However, these experienced therapists also reported looking for but failing to find post-graduate training opportunities in this field indicating that therapists may lack opportunities to develop specialist knowledge. Despite the lack of training opportunities, NICE neuro-oncology guidelines [9] recommend that clinicians involved in this specialist area should have access to training.

335

336 Team Working

337 Two thirds of the therapists reported they worked as part of a specialist Neuro Oncology Rehabilitation Team. Team working is recognized as important in rehabilitation to enable a 338 cohesive approach with children who have many professionals involved in their care [15] and 339 multidisciplinary team working is reported as best practice in the rehabilitation of adults with 340 341 brain tumours [16]. Team working may be particularly important in children with PFT who 342 have multiple transition points in their care e.g. from neurosurgery to oncology; into community management, and ultimately into late effects follow up; thus, communication 343 between professionals is essential [17]. The presence of such specialist teams does provide the 344

basis of expertise which could help in the formulation of national clinical guidelines e.g. as
seen recently in the development of the Stroke in Childhood Clinical Guidelines [18], although
clearly developing evidence based clinical guidelines would be challenging in view of the lack
of evidence in this area.

349 Therapy Interventions

Balance exercises, gait re-education and proximal control exercises were the most commonly used interventions reported by respondents. Balance exercises are regularly used in neurorehabilitation, and there is some evidence of effect for adults with ataxia [5,19], though a lack of evidence in children with PFTs is noted. The use of proximal control was also widely supported, especially in the UK, and although commonly used as a treatment for ataxia, research evidence to support its efficacy is lacking.

Adjuncts to treatment reflected consistent practice across different countries/level of experience with orthotics and mobility aids reported to be the most commonly used and deemed the most effective by therapists. This is despite there being no specific evidence published on the effectiveness of mobility aids/orthotics in children with PFTs. Further exploration of the type of orthotics used and the aim of this intervention adjunct may be useful in future research to understand the high frequency of their use.

362 Virtual Training

A number of therapists had used virtual training in some format in their practice, most commonly with children with PFTs. The results are also in keeping with recent trials which demonstrated a trend towards effectiveness when utilizing technology for therapy management of children with ataxia [11, 20, 21]. Therapists identified a number of benefits to using virtual training both in terms of engagement for the children which was repeatedly mentioned (and is reported in the literature [22]), and potential clinical gains such as working on co-ordination. 369 The potential impact on co-ordination is supported by a study in children with Down syndrome [23]. However, most studies have focused on balance [11,24,25], which did not feature 370 significantly in the therapists' views about the potential benefit of virtual training. Challenges 371 372 to using virtual training included access to equipment/training requirements, and gaming systems that are not sensitive enough to adapt to specific children's difficulties. Similar benefits 373 and challenges were reported in Levac's [26,27] exploration of clinician's experiences of 374 virtual reality working with children with acquired brain injury. Therapists were not directly 375 asked which types of virtual training they had utilised e.g. off shelf or bespoke gaming options, 376 377 further analysis of which type of virtual training therapists preferred may also be of value in the future. 378

379 Intensity of Intervention

Commonly, intense in-patient treatment was offered with intensity reducing following 380 381 discharge/transition to community settings. There is no specific evidence to support this decision, although workforce structure may be influential. However, there is evidence on the 382 benefit of intense in-patient rehabilitation in the adult brain tumour population with reports of 383 significant functional gains in the acute rehabilitation process, with the most gain found during 384 the initial inpatient stay [16,28]. Therapists reported they commonly intensified therapy 385 386 treatment at certain time points, with the immediate post-operative period being the most highly intensive treatment phase which is reflected with increased input in the inpatient setting. 387 However, they also identified a strong trend of individualizing intensity of therapy input taking 388 389 a number of factors into account such as adjuvant treatment, fatigue and availability of ongoing community services. An individualised approach is recommended in paediatric neuro-390 rehabilitation for other conditions e.g. in childhood stroke [18]. 391

392 Aims/Individualised Approach

393 An individualized approach was noted in terms of goal setting with therapists being aware of condition specific factors. Although there is no specific literature in the posterior fossa tumour 394 population to support this, the use of individualised goal setting is evident in the wider literature 395 on paediatric rehabilitation and in particular for children with cerebral palsy where there is a 396 larger evidence base [29,30]. The aims of therapy intervention covered the whole International 397 Classification of Functioning Disability and Health (ICF) from those focusing on impairment 398 399 (e.g. improving balance) to influencing activity (improve fitness) and also considering participation (e.g. assist with return to sport). Environmental and family factors were also 400 401 considered in the individualised goal setting. Three quarters of therapists reported they used standardized outcome measures again highlighting areas of good practice. The SARA [31] was 402 the most commonly used outcome measure which is encouraging as its inter-rater reliability 403 404 and construct validity has been demonstrated in this population group [32]. However, the 405 SARA is predominantly an impairment-based outcome measure and activity-based outcome measures e.g. the PEDI were less widely used. 406

407 Challenges to therapy

This is the first time that physiotherapists' views across different countries have been explored 408 identifying specific challenges to rehabilitation. Three themes emerged; condition specific 409 410 factors, child and family factors and physiotherapy delivery factors. Therapists frequently raised challenges related to engagement /expectations of parents particularly balancing 411 rehabilitation post-surgery might during 412 or when the child be unwell 413 radiotherapy/chemotherapy which is unique to this population group. Jones [33] described the emotional reactions the child and their family may experience during the initial period post 414 diagnosis, reporting shock, confusion and uncertainty about prognosis, treatment and 415 416 outcomes. Feelings of helplessness, loss of control and frustration due to lack of information 417 can also impact families' acceptance of multidisciplinary therapy input [34] and there is no 418 literature to guide practitioners regarding parental expectations of rehabilitation in children419 with posterior fossa tumours.

420

421 Limitations

The e-survey tool was piloted but not formally validated prior to use, which means that the survey results must be interpreted with some caution. Despite being aware that many people in the target networks were fluent in English, a known limitation is the survey was only available in English. Additionally, snowballing via the special interest groups means it is not possible to calculate the response rate.

Targeting special interest groups might raise a potential bias as members of an interest group 427 are potentially more likely to be following best practice which could be less representative of 428 the whole professional group. However, in order to gain views from therapists who were 429 experienced in the field this was considered the most appropriate source for the sample 430 population. IP addresses were not captured to anonymize the survey and encourage open 431 responses. However, a limitation of this is that if network connectivity is lost the responses 432 433 stop under this IP log in and if the respondent logs in again, they are counted as a new respondent. Completion rate for the survey (of surveys started) was 41%, this was influenced 434 by the fact that some questions were not applicable for all therapists to answer for example, if 435 they had not worked in a particular setting. However, it was noted there was a slight tail off in 436 responses towards the end of the survey which could reflect response fatigue due to the length 437 of the survey. A shorter survey with fewer open questions may have achieved a higher 438 completion rate. 439

440	In conclusion, this e-survey demonstrates the wide range of intervention types used by
441	therapists with common adjuncts to treatment of orthotics and walking aids. Broad consensus
442	was noted in terms of treatment intensity in the in-patient setting. Good areas of practice were
443	demonstrated including multi-disciplinary team rehabilitation and use of individualised
444	treatment planning and standardised outcome measures. This e-survey also makes an important
445	contribution to understanding the challenges to rehabilitation in this population group, whilst
446	establishing the foundation for future ataxia rehabilitation intervention research.
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588 Table I – Structure of e-survey

Section	Title	Examples of Content	Question Type
Section One	Demographics	Location of workplace, qualification, years post qualification, number of children with brain tumours treated per year	8 multiple choice tick box questions 3 short answer questions
Section Two	Treatment and Intervention	Type of therapy intervention used most frequently and adjuncts to therapy	7 multiple choice tick box questions
Section Three	Virtual Training	Benefits/challenges of using virtual training in this population group	 1 multiple choice tick box question 1 multiple choice with option for short answer 3 open questions
Section Four	Intensity and Timing	Length of physiotherapy sessions, and dosage	6 multiple choice tick box questions
Section Five	Aims and Outcomes	Common aims of therapy and outcome measures used	3 multiple choice tick box questions 5 open ended questions

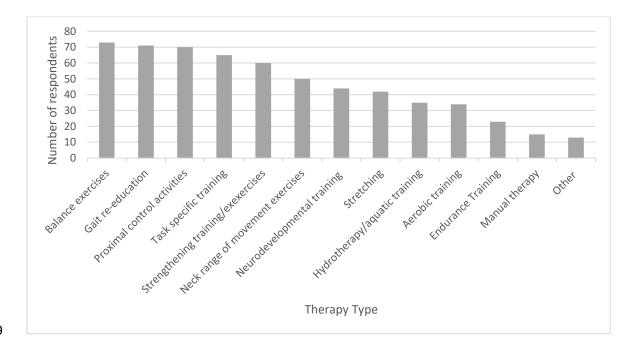
591 Table II. Respondent Demographics (N=96)

	Number of respondents (%)
Gender	
Male	6 (6)
Female	90 (94)
Qualification (*more than one option possible)	
Diploma	6 (6)
Degree	72 (75)
MSc	14 (15)
PhD	7 (7)
Location	
UK	53 (56)
Rest of Europe	23 (24)
USA/Canada	10 (10)
Australia/New Zealand	10 (10)

594 Table III. Participant experience/workplace setting (N=96)

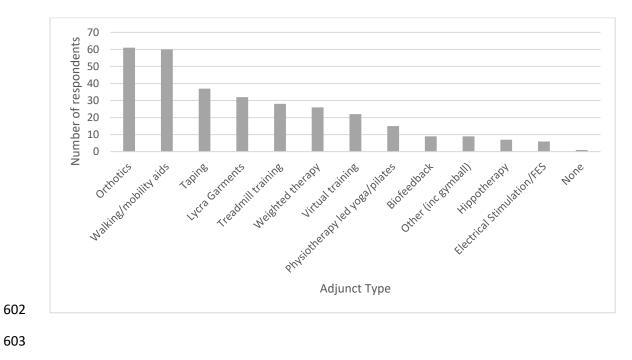
	Number of respondents
	(%)
Years of experience working with children with brain	
tumours	13 (13)
0-2	27 (28)
3-5	17 (18)
6-9	39 (41)
>10	
Post graduate training in working with children with post	
fossa tumours	22 (22)
Yes	22 (23)
No	74 (77)
Primary work setting	
Inpatient	66 (72)
Outpatient	8 (9)
Clinic	4 (4)
Community	11 (12)
School	3 (3)
Work within specialist team for neuro oncology	
Yes	61 (66)
No	
	31 (34)

597 JRM Hartley Fig 1



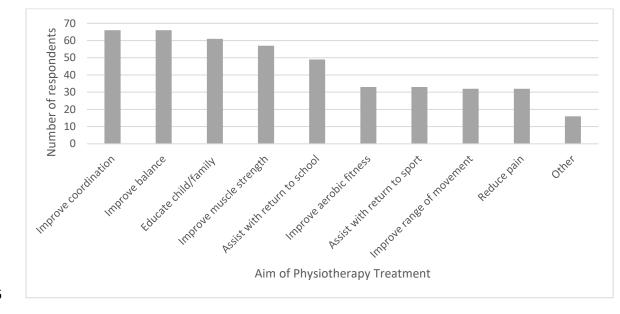
598 Figure 1. Types of therapy interventions used

600 JRM Hartley Figure 2



601 Figure 2. Types of adjunct to therapy used

604 JRM Hartley Figure 3



605 Figure 3. Aims of Physiotherapy Treatment

JRM Hartley Figure 4

Figure 4. Problems/challenges encountered when treating children following surgical management of a posterior fossa tumour

