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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 surgical resection of posterior fossa tumour

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Running title: E-survey physiotherapy for posterior fossa tumours

24 Abstract

25 E-Survey of current international physiotherapy practice for children with ataxia following
26 surgical resection of posterior fossa tumour

27 OBJECTIVE – To determine current international practice regarding physiotherapy input for
28 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
47 physiotherapy practice in this area. It establishes a foundation for future research on
48 improving 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
63 availability of physiotherapy following discharge from hospital, lack of evidence to guide

64 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
67 basis to understand the challenges of treatment and to plan future research.

68

69 Introduction

70

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

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

85 Additionally, there is an increasing understanding of the long-term impact on mobility in this
86 population group with up to 70% of children noted to have balance problems following
87 completion of neurosurgical/oncology treatment [3,7]. Following surgical management of their
88 PFT, children are typically referred for rehabilitation including physiotherapy, yet there is little
89 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
91 affect activities of daily life, return to school and participation with peers [3,8].

92 Despite the lack of evidence to guide best practice, it is recognised that physiotherapy is integral
93 to the treatment of children with neurological deficits following management of a brain tumour
94 [9] yet to date the practices of physiotherapists in managing children with PFT is not reported.
95 Understanding current practice could help with development of clinical guidelines and assist
96 with the planning of clinical trials in this population. To gain increased knowledge of
97 physiotherapy treatment for children with PFT across different countries an e-survey was
98 developed to scope current practice.

99 This is the first study to investigate the current practices of physiotherapists in this population
100 group. The aim of this study was to determine current international practice regarding
101 physiotherapy input for children with ataxia following surgical resection of PFT.

102

103 Methods

104

105 Study design

106 A cross sectional study design was used with data collected via an online survey (e-survey).

107

108 Participants

109 The target population in this study was physiotherapists who were involved in the assessment
110 and treatment of children with ataxia following surgical resection of (PFT). The survey (in
111 English) was disseminated via the Paediatric Physiotherapy Network groups of Paediatric
112 Neurosciences Physiotherapists and Paediatric Oncology Physiotherapists (both UK based
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

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

120 The study was approved by Edge Hill University FOHSC Research Ethics Committee (FOHSC
121 170).

122

123 Instrument

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

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

138 Prior to disseminating the e-survey it was piloted to optimise face and content validity and
139 reliability [13]. Four clinicians were purposefully selected to ensure there were two contacts
140 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
142 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
146 permission from each group received to circulate the e-survey to its members. This enabled the
147 gatekeepers to email their members with a link to the e-survey. A short introductory page of
148 the e-survey provided the participants with sufficient information to enable them to reach an
149 informed decision whether to participate. The return of the survey was deemed to be the
150 respondent's consent to participate. The respondents were given two weeks to respond then a
151 reminder was sent out electronically. All due care and attention was paid to the management
152 of the data in line with guidance from local policies and the General Data Protection Regulation
153 (GDPR 2018). The respondents' responses were anonymous.

154

155 Data Analysis

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

164

165 Results

166

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.

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

176

177 Demographics

178 Overall 12 countries were represented with over 50 responses from physiotherapists across the
179 UK, 23 respondents from the rest of Europe (including Belgium, Germany, France, Italy,
180 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
183 with brain tumours. The median number of children treated per year with PFTs was 10. Where
184 respondents indicated they had completed further training, the most common type of training
185 was a short course in either ataxia or oncology.

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

189

190 Therapy Intervention

191 Respondents selected from a predetermined list of therapy interventions which types they used
192 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
194 physiotherapists use a range of interventions, with balance exercises (n=73, 97%), gait re-
195 education (n=71, 95%), and proximal control exercises (n=70, 93%) utilised by the highest
196 number of respondents as illustrated in Figure 1. Additional types of treatment reported by the
197 respondents in the ‘other’ category included gym ball (n=3, 4%), coordination exercises (n=2,
198 3%), hippotherapy (n=2, 3%), rebound therapy (n=1, 1%), robotics (n=1, 1%), vocational (n=1,
199 1%), vojta (involves the therapeutic use of reflex locomotions www.vojta.com) (n=1, 1%), and
200 approximation exercise (n=1, 1%).

201 When asked which type of intervention they used most often three intervention types were
202 commonly reported; balance exercises (n=21, 28%), task specific training (n=17, 23%) and
203 proximal control activities (n=16, 21%). These three intervention types were also the most
204 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
206 used in this population (multiple responses possible). The results indicate physiotherapists use
207 a range of adjuncts, with orthotics (n=61, 82%), walking/mobility aids (n=60, 81%), and taping
208 (n=32, 43%) used most frequently (Figure 2). Other adjuncts suggested by the respondents
209 included gym ball activities. Orthotics (n=23, 31%) and walking/mobility aids (n=23, 31%)
210 were the two adjuncts used most often by the therapists and were also the top two adjuncts
211 rated as most effective by the physiotherapists. Treadmill training was ranked as the third most
212 effective adjunct to therapy.

213

214 Virtual Training

215 Fifty seven percent of respondents (n=44) reported they had used virtual training in their
216 practice. The physiotherapists indicated they had used virtual training most commonly in
217 children with posterior fossa tumours (n=32, 73%), acquired brain injury (n=28, 64%) and
218 traumatic brain injury (n=27, 61%).

219 Respondents gave details regarding their top three benefits and challenges to using virtual
220 training in their practice and these answers were thematically analysed. Benefits to using virtual
221 training revealed three broad categories; engagement/compliance, physical benefits and
222 resource/equipment benefits. Engagement/compliance was the most frequently raised benefit
223 with therapists repeatedly reporting that virtual training was ‘fun and engaging’, ‘games are
224 fun’. Physiotherapists thought that this method of therapy was ‘patient friendly’ and offered a
225 way to achieve ‘good compliance’ whilst being motivational. Therapists noted the potential
226 physical benefits from using virtual training which included the ability to work on specific
227 problems such as upper limb co-ordination and balance. Resource/equipment factors were also
228 raised as a positive aspect with two respondents noting the potential for the technology to ‘track
229 progress’ and that the technology is easily available ‘no additional equipment required’, as
230 children have ‘access to [it] at home’.

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

242

243 Intensity and Timing of Treatment

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

255

256 Aims and Outcomes

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

264 Seventy five percent (n=52) of physiotherapists (from 69 who responded to this question)
265 reported they used standardised outcome measures to assess children with posterior fossa
266 tumours. The most commonly used outcome measure was the Scale for the Assessment and
267 Rating of Ataxia (SARA) (n=28), followed by the Berg/Paediatric Balance Scale (n=11) and
268 the Gross Motor Function Measure (n=8).

269 Sixty-nine respondents reported frequent problems/challenges they encountered when treating
270 children following surgical resection of posterior fossa tumour. Three main themes were
271 identified, each with two subthemes (Figure 4). Condition specific factors included direct
272 medical problems (e.g. impact of the tumour itself or cerebellar mutism syndrome) or treatment
273 related issues (e.g. impact of chemotherapy and radiotherapy which may include nausea,
274 fatigue or chemotherapy induced peripheral neuropathy). A number of respondents (n=9) also
275 commented that fatigue can be exacerbated by the child having to travel to another site for
276 radiotherapy; one physiotherapist commented ‘during RT [radiotherapy] patients have to
277 travel, difficulty planning rehab’ and another noted that ‘children transfer to a different hospital
278 for chemo/radio so disjointed service’.

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

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

302 The challenge, most frequently highlighted by the therapists, related to service delivery of
303 therapy input. This is presented in two areas; resource factors and lack of evidence. In terms of
304 resource deficits, the area highlighted was physiotherapy staffing levels with respondents
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
307 discharge children home quickly, for example, ‘caseload on a neurosurgical ward-time until
308 discharge to home’, alongside problems with subsequent community/local physiotherapy input
309 on discharge home. One respondent described the challenge as being ‘DGH [District General
310 Hospital] only with limited therapy; community has variable expertise and staffing’. In addition
311 to staffing requirements, challenges related to space and equipment were also raised, including
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
314 of evidence for therapy input in this area. This was detailed repeatedly by therapists who noted
315 the ‘lack of research’ and ‘limited evidence especially clinical guidelines’.

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

319

320 Discussion

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

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

329 The majority of respondents had been qualified for more than ten years, suggesting a broad
330 range of experience to draw on when answering questions. However, these experienced
331 therapists also reported looking for but failing to find post-graduate training opportunities in
332 this field indicating that therapists may lack opportunities to develop specialist knowledge.
333 Despite the lack of training opportunities, NICE neuro-oncology guidelines [9] recommend
334 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
338 Rehabilitation Team. Team working is recognized as important in rehabilitation to enable a
339 cohesive approach with children who have many professionals involved in their care [15] and
340 multidisciplinary team working is reported as best practice in the rehabilitation of adults with
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
343 community management, and ultimately into late effects follow up; thus, communication
344 between professionals is essential [17]. The presence of such specialist teams does provide the

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

349 Therapy Interventions

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

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

362 Virtual Training

363 A number of therapists had used virtual training in some format in their practice, most
364 commonly with children with PFTs. The results are also in keeping with recent trials which
365 demonstrated a trend towards effectiveness when utilizing technology for therapy management
366 of children with ataxia [11, 20, 21]. Therapists identified a number of benefits to using virtual
367 training both in terms of engagement for the children which was repeatedly mentioned (and is
368 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
370 [23]. However, most studies have focused on balance [11,24,25], which did not feature
371 significantly in the therapists' views about the potential benefit of virtual training. Challenges
372 to using virtual training included access to equipment/training requirements, and gaming
373 systems that are not sensitive enough to adapt to specific children's difficulties. Similar benefits
374 and challenges were reported in Levac's [26,27] exploration of clinician's experiences of
375 virtual reality working with children with acquired brain injury. Therapists were not directly
376 asked which types of virtual training they had utilised e.g. off shelf or bespoke gaming options,
377 further analysis of which type of virtual training therapists preferred may also be of value in
378 the future.

379 Intensity of Intervention

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

392 Aims/Individualised Approach

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

407 Challenges to therapy

408 This is the first time that physiotherapists' views across different countries have been explored
409 identifying specific challenges to rehabilitation. Three themes emerged; condition specific
410 factors, child and family factors and physiotherapy delivery factors. Therapists frequently
411 raised challenges related to engagement /expectations of parents particularly balancing
412 rehabilitation post-surgery or when the child might be unwell during
413 radiotherapy/chemotherapy which is unique to this population group. Jones [33] described the
414 emotional reactions the child and their family may experience during the initial period post
415 diagnosis, reporting shock, confusion and uncertainty about prognosis, treatment and
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 children
419 with posterior fossa tumours.

420

421 Limitations

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

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

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.

447

448

449 References

450

451 1.NHS Specialised Services. Brain Tumour - Areas of Care - Principles and Best Practice
452 (Draft), London: NHS Specialised Services. 2010

453

454 2.Soria C, Callu D, Viguier D, El Sabbagh S, Bulteau C, Laroussine F, et al. Parental report of
455 difficulties, quality of life and rehabilitation in children with epilepsy or treated for brain
456 tumour. *Developmental Neurorehabilitation* 2008; 11 (4): 268-275.

457

458 3. Piscione P, Bouffet E, Mabbott O, Shams I, Kulkarni A. Physical functioning of pediatric
459 survivors of childhood posterior fossa brain tumours. *Neuro Oncology* 2014; 16 (1): 147-155.

460

461 4. Di Rocco C, Chiello D, Pettorini B, Massimi L, Calderelli M, Tamburrini, G. Preoperative
462 and postoperative neurological, neuropsychological and behavioural impairment in children
463 with posterior cranial fossa astrocytomas and medulloblastomas: the role of the tumour and the
464 impact of the surgical treatment. *Childs Nervous System* 2010; 26: 1173-1188.

465

- 466 5. Fonteyn E, Keus S, Verstappen C, Schols L, de Groot I, van de Warrenburg B. The
467 effectiveness of allied health care in patients with ataxia: a systematic review. *Journal of*
468 *Neurology* 2014; 261: 251-258.
- 469
- 470 6. Wilne S, Collier J, Kennedy C, Koller K, Grundy R, Walker D. Presentation of childhood
471 CNS tumours; a systematic review and meta-analysis. *Lancet Oncology* 2007; 8: 685-695.
- 472
- 473 7. Hartley H, Pizer B, Lane S, Sneade C, Williams R, Mallucci C, Bunn L, Kumar R. Incidence
474 and prognostic factors of ataxia in children with posterior fossa tumours. *Neuro Oncology*
475 *Practice* 2018; 33: 1-9.
- 476
- 477 8. Lannering B, Marky I, Lundberg A, Olsson E. Long-term sequelae after paediatric brain
478 tumours: their effect on disability and quality of life. *Medical and Paediatric Oncology* 1990;
479 18: 304-310.
- 480
- 481 9. National Institute for Health and Clinical Excellence. Improving outcomes in children +
482 young people with cancer – The Manual. August, Cardiff: National Collaborating Centre for
483 Cancer 2005.
- 484
- 485 10. Vernadakis, N, Derri, V, Tsitskari, E, Antoniou P. The effect of X Box Kinect interventions
486 on balance ability for previously injured young competitive male athletes: A preliminary study.
487 *Physical Therapy in Sport* 2014; 148-155.
- 488

- 489 11. Ilg W, Schatton C, Schicks J, Giese M, Schols L, Synofzik M. Video game-based
490 coordinative training improves ataxia in children with degenerative ataxia. *Neurology* 2012;
491 79: 2056-2060.
492
- 493 12. Ada L, Sherrington C, Canning C, Dean C, Scianni A. Computerised tracking to train
494 dexterity after cerebellar tumour: a single-case experimental study. *Brain Injury* 2009; 23: 702-
495 6.
496
- 497 13. Harniess P, Nikopoulou-Smyrni P. Paediatric physiotherapists' practice in
498 neurodevelopmental follow-up assessment programmes of high-risk infants. A UK web-based
499 cross-sectional survey. *APCP Journal* 2015; 6 (1): 45-58.
500
- 501 14. Braun V, Clark V. Teaching thematic analysis. Overcoming challenges and developing
502 strategies for effective learning. *The Psychologist* 2006; 26 (8): 120-123.
503
- 504 15. National Institute for Health and Clinical Excellence. Cancer Services for children and
505 young people. Quality Standard QS55 2014.
506
- 507 16. Vargo M. Brain tumour rehabilitation. *American Journal of Physical Medicine and*
508 *Rehabilitation* 2011; 90 (5): s50-s62.
509
- 510 17. Vargo M, Henriksson R, Salander P. Rehabilitation of patients with glioma. In Berger M.
511 & Weller M. eds. *Handbook of clinical neurology*. Amsterdam: Elsevier 2016; 287-304.
512

- 513 18. RCPCH. Stroke in childhood; Clinical guidelines for diagnosis, management and
514 rehabilitation 2017.
515
- 516 19. Marquer A, Barbieri G, Perennou D. The assessment and treatment of postural disorders in
517 cerebellar ataxia: A systematic review. *Annals of Physical and Rehabilitation Medicine* 2014;
518 57: 67-78.
519
- 520 20. Synofzik M, Schatton C, Giese M, Wolf J, Schöls L, Ilg W. Videogame-based coordinative
521 training can improve advanced, multisystemic early-onset ataxia. *J Neurol* 2013; 260: 26-56-
522 58.
523
- 524 21. Sabel M, Sjolund A, Broeren J, Arvidsson D, Saury JM, Blomgren K, et al. Active video
525 gaming improves body coordination in survivors of childhood brain tumours. *Disability and*
526 *Rehabilitation* 2016; 38 (21): 2073-2084.
527
- 528 22. Bonnechere B, Omelina L, Jansen B, Van Sint Jan S. Balance improvement after Physical
529 Therapy training using specially developed serious games for cerebral palsy children:
530 preliminary results. *Disability and Rehabilitation*. 2015 (early online access): 1-4.
531
- 532 23. Wang Y, Chiang C, Su C, Wang C. Effectiveness of virtual reality using Wii gaming
533 technology in children with Down syndrome. *Research in developmental studies* 2011; 32 (1):
534 312-21.
535

- 536 24. Sharan D, Ajeesh P, Rameshkumar R, Mathankumar M, Paulina R, Manjula M. Virtual
537 reality based therapy for post-operative rehabilitation of children with cerebral palsy. *Work*
538 2012; 41(1): 3612-3615.
- 539
- 540 25. Jelsma J, Pronk M, Ferguson G, Jelsma-Smit D. The effect of the Nintendo Wii Fit on
541 balance control and gross motor function of children with spastic hemiplegic cerebral palsy.
542 *Developmental Neurorehabilitation* 2012; 16 (1): 27-37.
- 543
- 544 26. Levac D, Miller P. Integrating virtual reality video games into practice: Clinicians'
545 experiences. *Physiotherapy Theory and Practice* 2013; 29 (7): 504-512.
- 546
- 547 27. Levac D, Miller P, Missiuna C. Usual and virtual reality video game-based physiotherapy
548 for children and youth with acquired brain injuries. *Physical & Occupational Therapy in*
549 *Pediatrics* 2012; 32 (2): 180-195.
- 550
- 551 28. Marciniak C, Silwa J, Heinemann A, Semik P. Functional outcomes of persons with brain
552 tumours after inpatient rehabilitation. *Archives Physical Medicine Rehabilitation* 2001; 82:
553 457-463.
- 554
- 555 29. McDougall J, Wright V. The ICF-CY and Goal Attainment Scaling; Benefits of their
556 combined use for paediatric practice. *Rehabilitation in Practice* 2009; 16: 1362-1372.
- 557
- 558 30. Cuisick A, McIntyre S, Novak I, Lannin N, Lowe K. Comparison of Goal Attainment
559 Scaling and Canadian Occupation Performance Measure for paediatric rehabilitation research.
560 *Pediatric Rehabilitation* 2006; 9(2): 149-157.

561

562 31. Schmitz-Hubsch T, Tezenas du Montcel S, Baliko L, Berciano J, Boesch S, Despondt C, et
563 al. Scale for the assessment and rating of ataxia. *Neurology* 2006; 66 (11): 1717-1720.

564

565 32. Hartley H, Pizer B, Lane S, et al. Inter-rater reliability and validity of two ataxia rating
566 scales in children with brain tumours. *Childs Nerv Syst* 2015; 31: 693–69.

567

568 33. Jones B. The challenge of quality care for family caregivers in pediatric cancer care.
569 *Seminars in Oncology Nursing* 2012; 28 (4): 213-220.

570

571 34. Walker D, Thomas S, Talbot E, Bennett E, Starzza-Smith A, Da Silva S. Cerebellar
572 Mutism: The rehabilitation challenge in pediatric neuro-oncology: Case studies. *Journal of*
573 *Pediatric Rehabilitation Medicine* 2014; 7: 333-340.

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575 Conflicts of Interest

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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

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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)

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

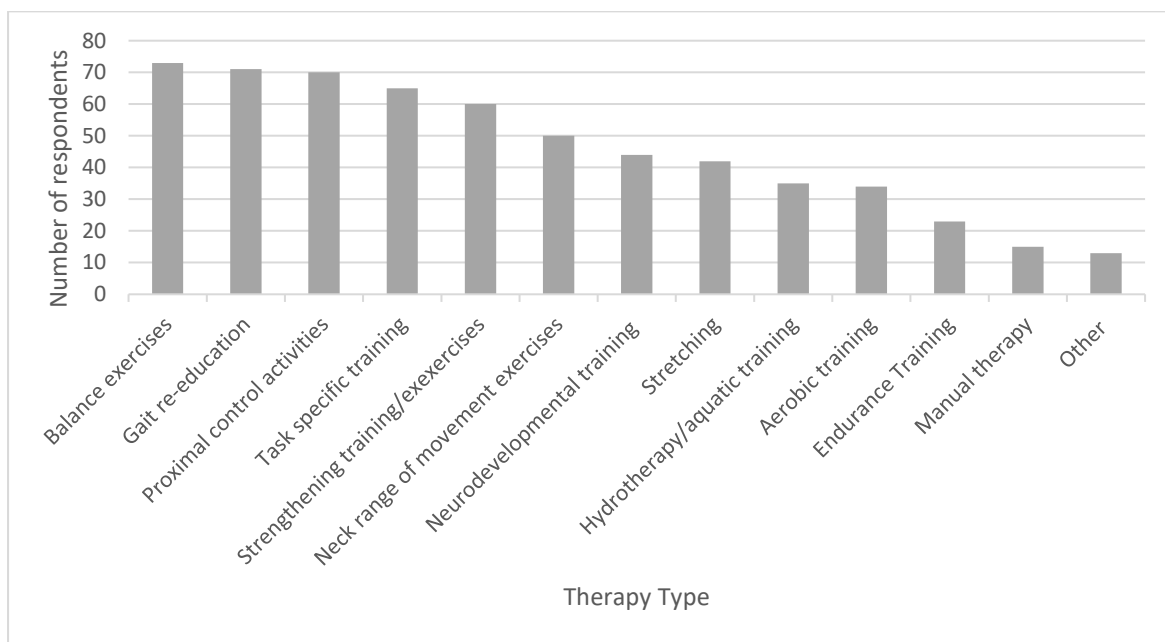
	Number of respondents (%)
Years of experience working with children with brain tumours	
0-2	13 (13)
3-5	27 (28)
6-9	17 (18)
>10	39 (41)
Post graduate training in working with children with post fossa tumours	
Yes	22 (23)
No	74 (77)
Primary work setting	
Inpatient	66 (72)
Outpatient	8 (9)
Clinic	4 (4)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

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597 JRM Hartley Fig 1

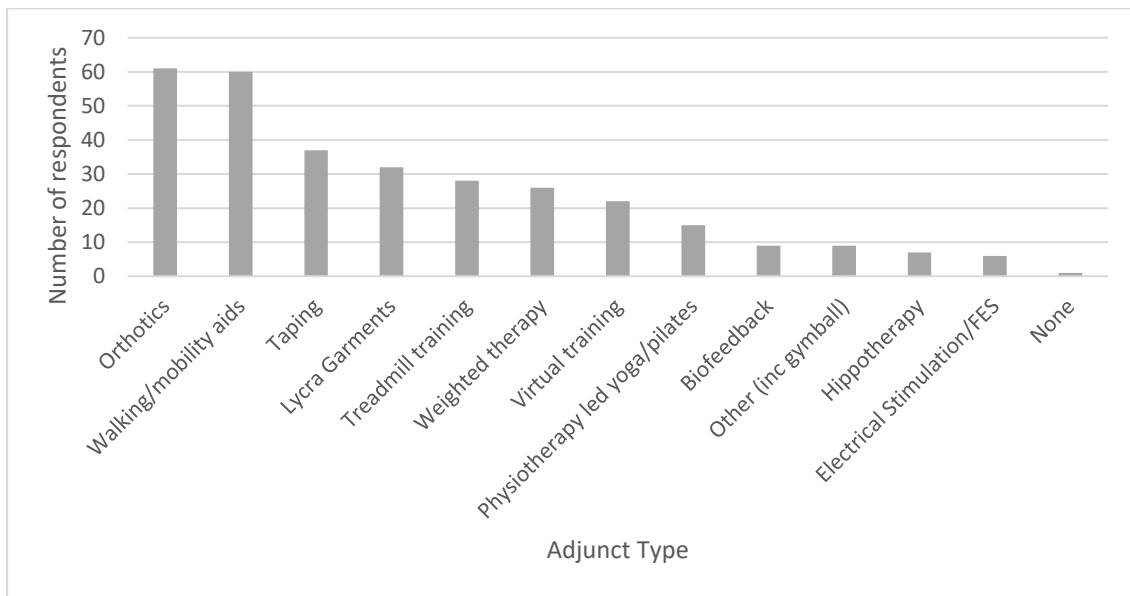
598 Figure 1. Types of therapy interventions used



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600 JRM Hartley Figure 2

601 Figure 2. Types of adjunct to therapy used

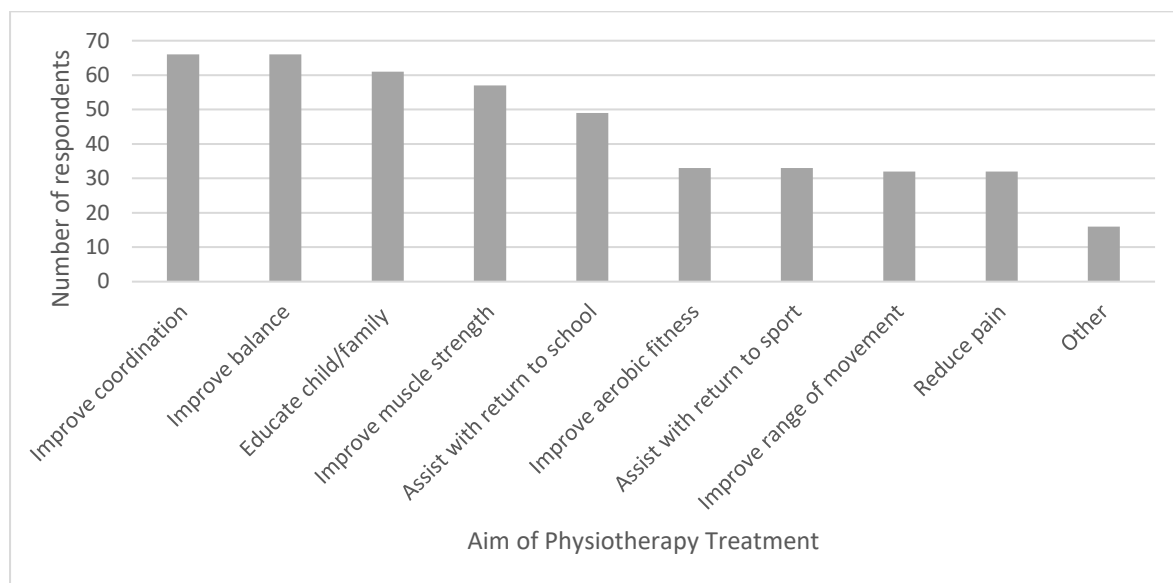


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604 JRM Hartley Figure 3

605 Figure 3. Aims of Physiotherapy Treatment



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JRM Hartley Figure 4

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

