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1 **The use of creative case studies to explore non-verbal and non-ambulant**
2 **children and young people's well-being.**

3 **Abstract**

4 **Background and purpose**

5 The aim of this paper is to describe and critically analyse creative research methods,
6 exploring how these can offer ways to enable non-verbal and non-ambulant children
7 and young people with cerebral palsy, to express their views about their well-being.

8 The context of this research explored their choices for recreational activities, seeking
9 to understand how their level of participation impacted upon their well-being.

10 **Methods**

11 A qualitative comparative case study design was chosen comprising of two
12 interviews, using photographs and diaries to elicit discussion, supported by
13 observations. These observations provided evidence of well-being indicators that
14 were interpreted by the researcher, alongside their parents. Seven participants
15 volunteered, aged nine to sixteen years. Data were analysed utilising Braun and
16 Clark's six stages. Firstly, each case's data sources were coded, themes identified,
17 then across cases comparisons, arriving at three final themes. Triangulation of data
18 sources which made up each case, enhanced the trustworthiness in this study.

19 **Results**

20 Observations were key to providing insight into their well-being. Interpretation of this
21 rich data, supported by their parents, revealed that the participants could self-
22 advocate, as shown by their intentional behaviours, to choose their level of
23 participation.

24 Discussion

25 The researcher's ability to be creative in the data collection methods is original in
26 physiotherapy. It was important to work in partnership with parents, to ensure the
27 correct interpretation of their intentional behaviours from the observations. The
28 diaries and photographs added a unique contribution to knowledge, which enabled
29 the non-verbal participants inclusion, empowering them to express their well-being.

30 250 words

31 Contribution of paper

- 32 • This creative approach to a qualitative case study design has offered a new
33 way to explore the well-being of participants who would not be able to carry
34 out a typical interview. In this case it was with non-verbal and non-ambulant
35 children and young people with complex cerebral palsy. The data has
36 illustrated how they can be empowered to indicate their well-being, as their
37 own advocates. It is important this work continues to provide deeper insight
38 into this under-reported group. Physiotherapists should consider how they can
39 include other non-verbal populations in research.
- 40 • Physiotherapists who work with non-verbal children and young people with
41 complex disabilities, need to find a way to hear their voices. A creative
42 qualitative case study design offers this flexibility and should be considered as
43 an authentic method for data collection in future studies. Children and young
44 people with complex disabilities deserve to see themselves represented in
45 research.
- 46 • Physiotherapists are unlikely to work alone to achieve advocacy on behalf of
47 non-verbal populations. Teamwork with designers, illustrators and town

48 planners can contribute to move this agenda forwards. This can then increase
49 the choices and opportunities for disabled children to enhance their well-
50 being.

51 Key words

52 Qualitative; Creative methods; Case study; Participation; Well-being; Cerebral Palsy;
53 Children

54 Introduction

55 The aim of this paper reports physiotherapy research which explored non-verbal and
56 non-ambulant children and young people with cerebral palsy's views and choices for
57 recreational activities. This study was seeking to understand how they and their
58 parents perceived their level of participation impacted upon their well-being. Well-
59 being is described by Watson & Emery as both an embodied, subjectively
60 experienced phenomena and a contextual and relational dynamic [1]. Additionally,
61 well-being has been defined as the difference between 'surviving or thriving' in a
62 person's perceived quality of life [2]. However, it is harder to express your well-being
63 if you have a communication or learning disability, such as those with complex
64 cerebral palsy, who may also have mobility limitations. There is limited
65 understanding about how well-being can be captured with this group of children and
66 young people [3]. This includes those children described as Levels IV and V on the
67 Gross Motor (GMFCS) and Communication Functional Classification Systems [4,5].
68 Both are usually excluded from physiotherapy research, due to the difficulties with
69 obtaining their consent and their physical participation in recreational activities being
70 limited.

71 The purpose of this paper is to describe and critically analyse creative research
72 methods, justifying the choice and content of a qualitative case study design [6]. Also
73 exploring how a comparative case study can offer a way to enable these children
74 and young people to be authentically included in research. Previous research has
75 often excluded this population due to challenges with gaining consent and their
76 limitations with participating. Curran and Runswick-Cole [7] have suggested now is
77 the time to rethink this exclusion, with the concept of assent being a valid way
78 forward [8]. Barley [9] has described assent during an ethnographic study, with
79 typically developing children, who controlled what she wrote in her field notes as a
80 way of empowering themselves.

81 A literature review explored the key words: participation, well-being and non-
82 ambulant children and young people with cerebral palsy. Children refers to those up
83 the age of eleven and twelve onwards to young people. Recognising the gap in
84 current research, the following research question was asked: 'How do children and
85 young people with cerebral palsy and their parent's view, experience and choose
86 their level of participation in recreational activities?' There were two exploratory
87 objectives: 1. participants' views, experiences and choices for their level of
88 participation in recreational activities, including barriers and facilitators; 2. what their
89 perceptions of the effect of their level of participation was upon their emotional well-
90 being. The data will illustrate how they were empowered to represent themselves as
91 advocates for their own well-being, supported by a familiar adult.

92 Design

93 The design of this study is explained under headings suggested by Tong et al [10],
94 starting with the philosophical position and problematising consent with this group.

95 The choice of qualitative method usually sits under a particular philosophical
96 approach, which in this study, was axiology related to ethical values [11]. These
97 values were aiming that the voices of the children and young people were at the
98 centre of the enquiry, by doing research 'with' not 'on' children and young people,
99 from an ethical position of promoting their social justice. However, it is not without
100 methodological and ethical challenges to include this group of participants in
101 research and physiotherapists have previously been limited in their intention to
102 achieve this [12-15].

103 Consent/Assent

104 Gaining consent for any research usually involves the participant's signature on a
105 consent form [16]. Alderson and Morrow [8] propose that depending upon age and
106 cognitive ability, the children themselves can give consent under the age of sixteen,
107 which is termed 'Gillick' competency. 'Gillick' competence refers to an English Law
108 from 1985 when Mrs Gillick objected to the prescription of contraceptives for her
109 daughter, then aged under 16 years. The courts in England and Wales deemed that
110 under 16, if the young person understood, they could give their own consent [17].
111 However, when considering vulnerable populations such as those with
112 communication and learning disabilities, the concept of assent was introduced.
113 Alderson and Morrow [8] suggest that assent can mean that children understand
114 some, but not all the main issues required for consent, and it can mean 'at least not
115 refusing'. For this study, the children's intentional behaviours were part of this assent
116 process and were revisited at every research contact, to ensure they were happy
117 with the researcher's intent to interview, observe or take pictures. The consent form
118 were all signed by the parents and those who could, also signed their own consent
119 forms.

120 Inclusion / Exclusion criteria

121 The criteria for inclusion is shown in Table 1 which included children and young
122 people aged 9-16 years levels III-V GMFCS and I-V of CFCS, supported by their
123 parents:

124 Table 1 Inclusion and exclusion criteria

<u>Inclusion Criteria</u>	<u>Exclusion Criteria</u>
Children and young people with cerebral palsy aged 9-16 years and their parent/carer. Level III, IV or V of the GMFCS. Level I-II of the CFCS Level III-V of the CFCS -Parent to report by proxy if child or young person unable to communicate wishes. Able to give consent or assent (able to engage in research activity).	Children and young people with cerebral palsy outside this age range 1-8;17-18 years. Levels I or II of the GMFCS. Unable to give consent or assent.

125

126 Sampling method and settings for data collection

127 This study used purposive sampling by recruiting via special schools, disability
128 sports clubs and the voluntary sector. Observational data was collected at one of the
129 child or young persons participation activities which included RaceRunning, disability
130 surfing, skiing, uniformed clubs, indoor and outdoor play schemes. Interview data
131 took place at the participant's home, with a buddy support for lone working.

132 Qualitative Case study design

133 A qualitative case study design was eventually chosen, this section will outline the
134 exploration of different approaches. There was no obvious choice of one method, to
135 authentically engage the children and young people, to capture their views,
136 experience and choices. Typical language-based interviews would be limited and an
137 ethnographic approach using lengthy participant observation would be invasive.
138 Visual methods, including photographs, showed promise, but there was the issue of
139 anonymity and confidentiality to consider. Also, the premise of why photographs are
140 taken and used has been critiqued by Pink [18] as not always being authentic to their
141 original purpose. In this study, writing was not possible due to the participants'
142 physical and cognitive limitations, as Barley had illustrated [9]. Observations of the
143 children and young people's intentional behaviours were included, however as part
144 of their ongoing assent, it was important to establish if the researcher's presence
145 was welcome or unwanted, seeking to empower the participants to indicate their
146 well-being [19]. Spradley's observational matrix, for these mainly non-participant
147 observations, was followed [20]. Usual creative methods can include drawings,
148 collages, Play-Doh and the use of a sandbox with symbolic toys, but these have
149 limitations when fine motor control is limited, as for children and young people with
150 complex cerebral palsy [21].

151 Pilot data collection

152 To explore the methods options, various pilot activities took place with a stakeholder
153 group of young adults with learning disabilities, four individuals with cerebral palsy
154 Level I, II(x2) and III of the GMFCS, aged between nine and twenty-one, who could
155 communicate verbally. Interviews in person worked well, facilitated by the
156 participant's own diary record. The opportunity to reflect after each of these events
157 enabled deeper thought about which methods could work effectively [22]. For the

158 non-verbal children and young people, it was considered that observation at one
159 their recreational activities might provide the insight into their well-being, when a
160 spoken interview was not possible. Following ethical approval in January 2017, from
161 the school of healthcare sciences at Cardiff University (REC 358), recruitment began
162 via various gatekeepers in the voluntary sector, disability sports clubs and special
163 schools in Wales.

164 Researcher's position

165 In a research context, reflexivity is described by Creswell and Poth [11] as a concept
166 that enables the researcher to position themselves in a way that takes account of
167 their own values, biases and experiences that they bring to the study. The lead
168 author acknowledged their own previous physiotherapy experiences and
169 understanding from a practice background and recorded the methodological decision
170 trail in a reflexive journal, aligned to the Gantt chart of the study's progress. This
171 position from a practice background gave insight into the struggles that families went
172 through to participate. Responses during the data collection were in an empathic
173 manner, offering open questions to minimise bias. However, the researcher's
174 position was based upon the ethical bias which sought to position the children and
175 young people's voices centrally, with a view that participation would lead to a positive
176 well-being effect. The researcher had no prior relationship with any of the
177 participants, thus minimising coercion and reducing bias.

178 Reflecting upon the pilot data, a qualitative case study design was chosen as the aim
179 was to explore the 'how' and 'why' of the topic, where the researcher had little or no
180 control over the events which were contemporary, rather than historical [6]. This
181 design offered a way to compare the different levels of participation in recreational

182 activities and how the participants perceived this effected their well-being. Thus,
183 providing an authentic and credible method, which may not be generalisable to
184 similar populations, due to the small sample size, but which provided depth.

185 Case study content

186 Although different sources can make up a case study, it does require a clear
187 boundary to explore the research question. In this case, each case study comprised
188 two interviews, using photographs and diaries to elicit discussion, supported by
189 observations of the participants over a twelve-week period. The data was collected
190 for this limited time period of twelve weeks and this period of time is known as a
191 'snapshot' [23]. This represented a school term, so was feasible in terms of
192 commitment for the families. These observations, which were a mixture of non-
193 participant and participant were based on Spradley's observational matrix, of the
194 participants provided evidence of well-being indicators that were interpreted by the
195 researcher in consultation with their parents [20]. This matrix is shown in Figure 1
196 and aspects observed included calmness, comfort, enjoyment, engagement with
197 others and creativity.

198 Figure 1: Spradley's Observational matrix

Checklist for Observations adapted from Spradley (2016)

Minutes	Time 0-10	Time 11-20	Time 21-30	Time 31-40	Time 41-50	Time 51-60
Space						
Object						
Act						
Activity						
Event						
Time						
Actor						
Goal						
Feeling						

199

200 Engagement in sandbox activities with toys to represent the children’s choice of
 201 activities, as well as the young people using eye gaze and augmentative and
 202 alternative communication (AAC), enabled a unique depth of data generation with
 203 these participants.

204 Method of recording data

205 Interview data was recorded with a Dictaphone, then transcribed, diary data was
 206 transcribed from the paper diaries written by the parents, which included
 207 photographs they had taken. Field notes were made from the observations, including
 208 a reflexive diary where researcher notes were made. Data was stored on a
 209 password protected computer and consent forms were kept separately in a locked
 210 metal cabinet. Pseudonyms were used to protect anonymity and confidentiality.

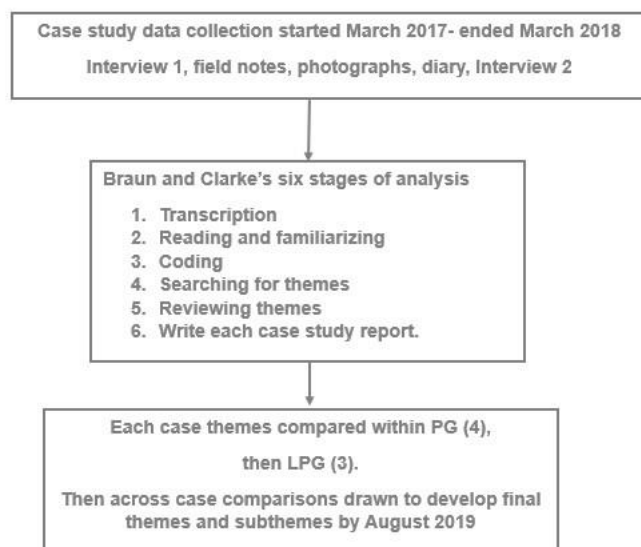
211 Analysis: Description of the derivation of themes

212 The analysis was carried out using Braun and Clark’s six stages of analysis, firstly by
213 an individual case and secondly across case analysis, using a reflexive approach
214 comparing data by intuiting ideas as the process progressed [24,25]. The six stages
215 of analysis started with transcribing the data verbatim, then offering it back to the
216 participants to check for accuracy and their right to withdraw any data. Once the raw
217 data was verified, it was anonymised, and the second stage of reading and
218 familiarisation with the data began. Thirdly, coding began on a case-by-case basis.
219 Each data source, within each case, was coded using analytic memos, recording
220 researcher observations and impressions of the data. The fourth stage was
221 searching for themes, as commonly occurring ideas prevailed. This process started
222 as soon as data collection began in March 2017, so there was overlapping of
223 ongoing data collection with analysis of each case. Once each case’s themes were
224 reviewed, the research team agreed upon these themes. Then comparisons were
225 made across cases, firstly in the Participatory group (PG) then in the Limited
226 participatory group (LPG) until three final themes were agreed upon. Data collection
227 ended in March 2018 but the analysis continued until August 2019. Figure 2
228 illustrates this in a flow diagram:

229 Figure 2: Flow diagram of analysis

230

Figure 2: Flow diagram of data collection and analysis



231

232 This process was managed logically by the lead author coding the data sources and
233 reflecting at each stage of the analysis to review ideas from the outsider 'etic'
234 perspective [11]. This was supported with NVIVO 11 and Microsoft word to identify
235 themes and added to the dependability of data management.

236 The collective analysis of the different data sources provided a more coherent whole
237 to support the confirmability across the data. The analysis process was overseen by
238 the supervision team to verify initial ideas with peer review of the coding at different
239 stages. Member checking was carried out with the parents as the stages of analysis
240 progressed. The data was then framed within positioning theory to enable the
241 participants stories to be illustrated by a kaleidoscope of well-being [26; 27].

242 Findings

243 Seven participants volunteered, aged nine to sixteen years, with their parents. Each
244 participant chose a pseudonym. The four who participated frequently in recreational
245 activities were Clare (9), Lily-May (16), Nick (14), Matthew (14). James (14), Bree (9)
246 and Poppy's (9) participation was limited partly due to their level of pain, mood, and

247 epilepsy. Lily-May and Clare used AAC and Poppy used EyeGaze Technology, this
 248 detail has been reported elsewhere [27]. Three overall themes were identified with
 249 several sub-themes as shown in Table 2:

1. Participation enhancers	i. Parental advocacy ii. Innovative designs iii. Reasonable adjustments iv. Equipped volunteers
2. Champions for disabled children and young people's emotional well-being	i. Expressing choices to indicate well-being-self advocacy ii. Professional advocacy
3. Hindrances to participation	i. Undermining attitudes ii. Parental views of being treated differently iii. Impact of pain on participation

250

251

252 Each theme is illustrated, using different data sources, to demonstrate the
 253 participant's well-being either directly or via the parents.

254 1. Participation Enhancers

255 Parental Advocacy

256 Advocacy is defined as support for an idea, plan or way of doing something [26].

257 Advocacy, in this context, refers to instances where the parents were pushing on
 258 behalf of their disabled children and young people to provide and improve access to
 259 opportunities for recreational activities [28;29]. The value and support of other
 260 parents was key to finding out about opportunities as Nick's father's interview quote
 261 highlights:

262 *“We started going to the cycle hire facility when it was a porta-cabin, a*
263 *shipping container in the car park, I think it was possibly other parents who*
264 *told us about it?”*

265 When families went on holiday, it was encouraging when they found accessible
266 activities as seen in Bree’s diary entry (written by Mum):

267 *“My Mum, Dad, sister and I went to the Forest. We hired a special bike where*
268 *Dad pedalled, and I sat on a seat in the front. We all rode the Shepherd trail*
269 *which was 5 1/2 miles and took us 1 1/2 hours. I really enjoyed it. I then went*
270 *in my walking frame and we did the Gruffalo Trail. I enjoyed the basket swing,*
271 *slide and balance beams in the playground.”*

272 This made them feel valued, as someone had considered their child’s needs without
273 their need to advocate.

274 Innovative designs

275 The importance of safe adapted equipment enabled the participants to try new
276 activities. This ranged from adapted cycling, skiing, surfing, Frame Running, Touch
277 therapy and musical events. For optimal participation, these needed to be supported
278 by the availability of a hoist and suitable changing facilities. During the study’s
279 observations only the Frame Running venue and Touch Trust had these available.
280 Lily-May’s mother suggested in her interview that due to limited storage issues a
281 community storage facility would be useful:

282 *“I think that there is a lot of equipment, like people use for when they're*
283 *travelling, beach wheelchairs, is not something you want every day, and we*
284 *haven't got room to store all these things. So almost have like a communal pot*
285 *of equipment that you could just loan, as and when you needed it, such as a*
286 *hoist...”*

287 Reasonable adjustments

288 In comparison to activities that are available for typically developing children, there
289 were less choices unless reasonable adjustments had been made. This was shown
290 by Bree’s Mum who reported in her interview that playgrounds varied in what was
291 accessible for her:

292 *“See saws, and there are some roundabouts which are suitable if it’s got a*
293 *seat on it. Some aren’t and she loves the slide but quite often the way you get*
294 *up to the slide isn’t suitable for Bree...”*

295 Bree and Nick were only able to attend Brownies and Cubs due to having a personal
296 assistant to support their participation. Lily-May went horse riding with her personal
297 assistant, as her younger sister could not participate.

298 Poppy’s Mum was pleased with how the staff attuned for his needs as shown in the
299 diary extract supported by Figure 3:

300 Figure 3 Poppy at the Halloween event in his all-terrain wheelchair (diary entry)



301

302

303 *“We went to a Halloween event. It’s a farm so we took his all-terrain*
304 *wheelchair. He joined in collecting ingredients for a magic spell, met lots of*
305 *witches, wizards and scary people dressed for Halloween. He went on a*

306 *Terror Trail where characters jumped out on him to scare him. They were all*
307 *very sensitive to his needs.”*

308 These examples highlight that when reasonable adjustments were considered,
309 attuning for their needs, this increased the well-being of the participants.

310 Equipped volunteers

311 Volunteers were essential to enable increased participatory opportunities. This was
312 observed at the Frame Running and Skiing where volunteers were seen working in
313 teams to support the children and young people to participate. This was illustrated by
314 Matthew at the monthly skiing activity supported by a volunteer who supported him in
315 the sit ski, as shown in Figure 4:

316 Figure 4 Photograph of Matthew in the sit ski, supported by a volunteer skier
317 (observation field notes)



318

319 Records from the field notes highlighted Matthew's enjoyment here- "*Matthew comes*
320 *down over the bumps and he is screeching with delight at each bump and by the*
321 *time he reaches the bottom he is smiling and lifting his arms in the air*".

322 2.Champions for disabled children and young people's emotional well-being

323 Expressing choices to indicate well-being-Self advocacy.

324 Each child had a bespoke way to express themselves regarding their choices to
325 indicate well-being which was interpreted alongside their parents. Louder excited
326 volume in the participant's vocalisations was usually an indication of well-being and
327 they often went quiet when unhappy. Appetite was also a key indicator of well-being
328 for all the children and young people, in that if they were contented, they would eat
329 well. Nick was reported to drive his powered chair to the fridge, to indicate he was
330 hungry. So, a loss of appetite was an indicator of lower well-being, which Matthew
331 had also indicated, when he did not like the respite centre, as shown in his mother's
332 quote from her interview:

333 *"Respite has gone well, if he slept well, the indicators for the respite centre*
334 *would be that he wouldn't eat his food and Matthew loves his food, so that*
335 *was a sign that he wasn't happy. Crying, screaming, attacking me, trying to*
336 *get back out and while he was there...he was very upset and took a lot of*
337 *calming. When he's happy is that he's not attacking or screaming at me, or*
338 *he's laughing."*

339 Clare's Mum felt that well-being was about confidence building and creating
340 memories for her to think about, as expressed in her interview:

341 *“Her happiness... confidence in social situations ...and in herself to try*
342 *different things and just being a more rounded person, I think, having different*
343 *experiences and things that she can relate back to”*

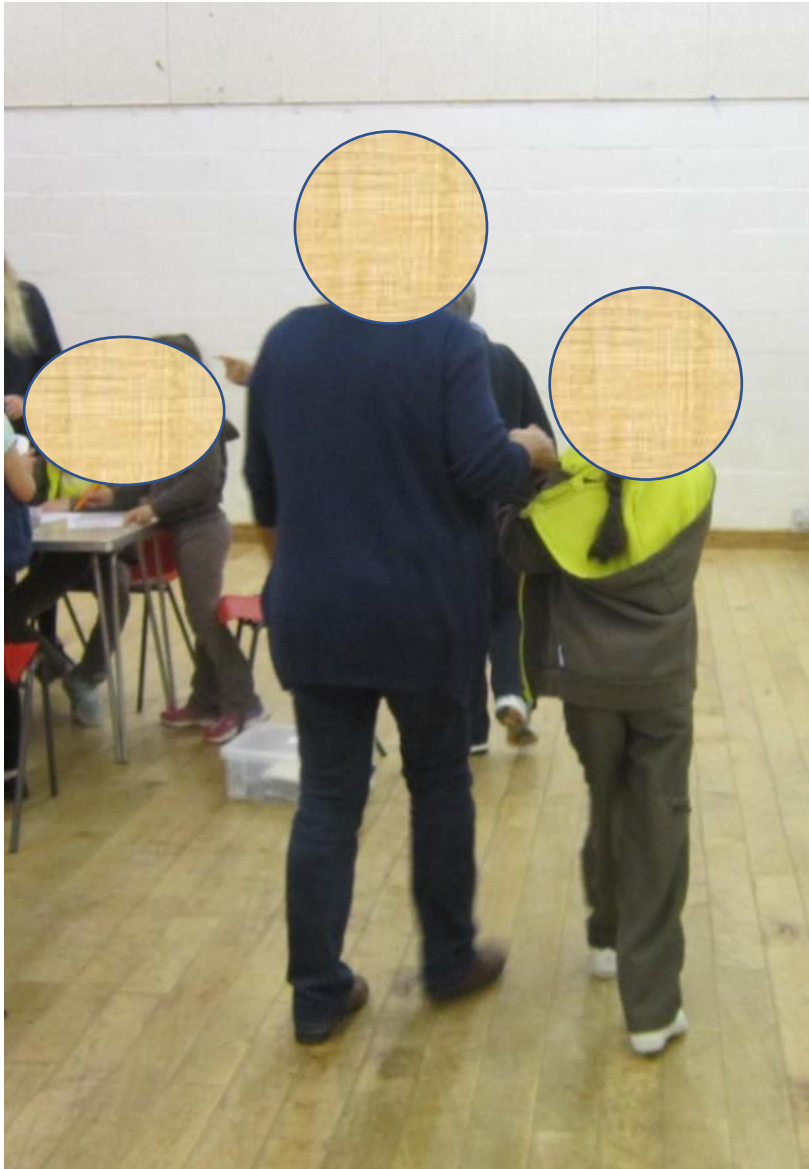
344 Although Nick loved swimming, there were times he did not want to do this, even
345 when it was available at home, as shown in this diary extract, written by his father, as
346 if from Nick’s perspective:

347 *“Had another school holiday lie-in. Me and Dad and Dougie went to the woods*
348 *for a while, then I went out with Mum in the afternoon. I was grouchy and*
349 *didn’t want to go in the pool.”*

350 Nick was also seen to choose not to engage in Frame Running but go off steering
351 his powered chair and explore the sport’s hall, to watch other children. Thus, he
352 expressed his own choices, not to participate, despite not having a physical voice.

353 Bree responded to the activities that she enjoyed by smiling and clapping and this
354 had drawn Mum to try the Touch Trust, who used a lot of clapping in their routines.
355 Bree was observed there engaging in the movement to music, she was also
356 observed at Brownies, a uniformed club as shown in Figure 5, where she was only;
357 able to attend with her personal assistant:

358 Figure 5



359

360

361 All the participants needed a high level of supervision to meet their physical care
362 needs, and when professional staff attuned into this, the parents felt they were also
363 advocates for their children and young people.

364 Professional advocacy

365 Reported in this study were staff perceived to act as advocates: physiotherapists had
366 initiated Skiing, Surfing, Frame Running and Trike riding. Bree had been signposted
367 to activities by a special need's health visitor, Matthew was supported by the social

368 worker at his respite centre to find appropriate stimulating activities for him to
369 facilitate his calmness and Lily–May was supported by the occupational therapist, to
370 have a larger cot bed which helped with her sleep patterns, to reduce her daytime
371 fatigue.

372 3. Hindrances to participation

373 Parents expressed that there were ambitions for their child’s participation that were
374 not presently possible, partly due to some people’s attitudes, which were
375 undermining.

376 Being treated differently

377 James’s mother spoke about her ambition to get onto a beach, which was limited by
378 a lack of hoist. James was observed at an accessible summer playscheme being
379 tube fed outside, which his mother described as difficult in usual outdoor spaces as
380 people would often stare. Bree’s mother experienced barriers to her joining a
381 suitable playscheme as she fell between criteria for what she could access, as her
382 interview quote illustrates:

383 *“... The council children’s play officer said they can give you funding to have a one-*
384 *to-one to send Bree to a regular play-scheme. But when I spoke to them, they didn’t*
385 *want to take her because they don’t have changing facilities and because she can’t*
386 *walk, would they be able to get her on a bus, ‘cos they go out for day trips, how*
387 *would they manage to get her up and down stairs on the bus and wherever they go*
388 *how do they know if there would be suitable changing facilities? So basically, I don’t*
389 *want to send her there to people who don’t want to look after her”*

390 These examples highlight being treated differently which did not make the parents
391 feel their child was valued, but it was difficult to evaluate the subsequent impact
392 upon the child's own well-being.

393 Undermining attitudes

394 Nick attended cubs with his Personal assistant, but he had not progressed to scouts
395 as it was considered too active. This was suggested to be related to the attitude of
396 the volunteers in the scout movement, as Dad described:

397 *“Nick just remained at cubs, when he turned 11, we were thinking oh well he’s*
398 *got to go up to scouts now and I got in touch with 4 or 5 of the local scouts*
399 *troops and they were not in the least bit interested. When I’m faced with*
400 *somebody who says ‘Well how disabled is he?’, We do climbing and*
401 *canoeing, I just walk away, I was very disappointed... they’re volunteers and*
402 *on the one hand I think it’s not great for the scout movement to, on the face of*
403 *it, in my experience, to have a “can’t do attitude to the disabled”. You know*
404 *the place he goes to cubs, like I said, he accesses the cub troop and he quite*
405 *enjoys the buzz, the peer to peer, social side, but that’s the problem with a lot*
406 *of stuff that Nick does, it’s a bit of a social activity, but his participation is*
407 *always limited”.*

408 Poppy's parents also highlighted attitudes that were unhelpful on their holiday to
409 Finland:

410 *“Mum: I made about 18 phone calls before we went, the flight was brilliant,*
411 *they were all prepared for us, but they hadn't contacted the resort to tell them*
412 *that we were there with a disabled child. They didn't help us going on any*
413 *trips, to get on the bus, or to save a seat at the front, so we didn't have to cart*

414 *him all the way to the back of the bus, wearing full on five layers they didn't*
415 *ask anyone, you know, can you just move back a couple of seats so, they*
416 *didn't help at all..."*

417 So, on this holiday experience Poppy was treated the same as everyone else, but
418 his needs were different. This lack of recognition to adjust for his needs, made this
419 stressful for Poppy's parents, but possibly he was unaware of the impact upon them.

420 Impact of Pain on participation

421 James was not able to communicate his pain, but his mother interpreted his
422 intentional behaviours as her quote highlights:

423 *"So I go on how he's behaving. He was really uncomfortable Saturday night.*
424 *He'd gone bright red and had a funny rash which is when he gets hot and*
425 *bothered. And he was doing this with his hands (shows flapping), sort of*
426 *agitated. And if he held your hand, he squeezed really hard and then had*
427 *tears."*

428 During the study period James had surgery on a dislocated ankle as shown in Figure
429 6:

430 Figure 6 James at the dinosaur exhibition after his surgery



431

432

433 This meant that he was not able to participate in hydrotherapy which he enjoyed as it
434 relaxed his body, but he was able to go to see the dinosaur exhibition at the
435 museum. Bree had developed a sacral pressure sore from bottom shuffling, but she
436 did not feel it, which led to an infection, this also limited her water-based activities for
437 a few months, whilst it healed. Poppy had regular stomach pain with frequent bowel
438 movements, which limited his participation in the community as this diary extract
439 shows in Figure 7:

440 Figure 7: Poppy's diary entry

Tuesday 14th November 2017

There hasn't been very much going on lately. Poppy has been getting a lot of tummy pain again. This is very upsetting for all of us as he doesn't want to do anything or go anywhere. He hits his head a lot with the pain and cries a lot. This has gradually been building up for about a week.

The only playing he has been interested in, has been spending a long time playing in the shower. He has been doing this a couple of times a day for the past few days for about an hour each time. He stands up and walks to the sink turns on the taps and splashes in the water around him on the floor. It has been very calming for him and also distracted him from the pain.

441 These three participants were in the LPG and thus pain was a limitation for them
442 which had not been evident in the PG.

443 Discussion

444 The creative approach used in these case studies is original in physiotherapy and
445 has developed a bricolage of data. A bricolage constructs something new from
446 materials that are usually used for other purposes, in an individual 'do it yourself' way
447 [30]. Here the bricolage was created from the mosaic of different data sources, which
448 made up each case, sometimes using the symbolic toys used to represent the child's
449 participation or real photographs to remind them of that experience. Rogers [30]
450 highlights the flexibility and plurality of such an approach, which has generated
451 meaning from participants who do not have usual means of communicating. The
452 observations and photographs provided evidence of well-being indicators that were
453 interpreted by the researcher, together with their parents, as a way of empowering
454 their voices. These attributes of well-being included being calm, comfortable,
455 creative, expressing joy and engaging with others. Shirani et al [31] suggest that a
456 diary is a record of events which can capture emotional responses. In this study, the
457 diaries provided a written record of their participation over the twelve-week period, as
458 some were written in the first person, as if the child was directly talking to the
459 researcher, this added to the authenticity of the data.

460 The triangulation of data sources which made up each case, enhanced the
461 trustworthiness and rigour in this study, ensuring the richness of data in these
462 different components [6]. Whilst these creative methods enabled representation of
463 the voices of non-verbal children and young people with cerebral palsy, this could
464 not be achieved by the researcher alone. It was important to work in partnership with

465 their parents, to ensure the correct interpretation of the children's intentional
466 behaviours from the observations, achieved through member checking the raw data
467 transcripts [32]. The interpretation of this rich data revealed that the participants
468 could self-advocate, as shown by their intentional behaviours, to choose their level of
469 participation.

470 Flyvbjerg [33] suggested that a good case study enables the researcher to get close
471 to the reality of their participants, to explore the viewpoints and behaviours that
472 characterise them as social actors. By positioning the children and young people's
473 voices at the centre of this enquiry, this axiological position, ethically included their
474 voices [11]. Daley [34] argued that if these children and young people are excluded
475 from research, their voices will remain invisible. Their voices deserve to be heard, so
476 that their agency is represented in society as autonomous individuals. Thus, in
477 contrast to Daley's [34] comment about them being invisible, this study has promoted
478 their inclusion, empowering them. Yoshida [35] has implored physiotherapists to
479 relate emotionally and show empathy and care for people to promote their social
480 justice. This is significant for this marginalised group, when it can be demonstrated
481 that sometimes people empathically attuned to their needs [36, 37].

482 Study Strengths and Limitations

483 In physiotherapy, this study which explored well-being through creative methods in
484 the data collection, is original in physiotherapy. The diaries and photographs added a
485 unique contribution to knowledge, which enabled the non-verbal participants
486 inclusion, empowering them to express their well-being. Although it was important to
487 work in partnership with parents, to ensure the correct interpretation of their
488 intentional behaviours from the observations, this limits the child's actual view and is

489 a limitation in representing their voices directly. The transferability of creative
490 methods within a qualitative case study to other non-verbal populations has yet to be
491 applied, to test the credibility [6].

492 Conclusion

493 A creative qualitative case study design offers flexibility and should be considered as
494 an authentic method for data collection in future studies. Children and young people
495 with complex disabilities deserve to see themselves represented in research. Whilst
496 this study moved in a positive direction towards enabling their voices to be heard,
497 there scope for further development to explore the construct of well-being for this
498 non-verbal population.

499

500 Ethical approval

501 Successful ethical approval was achieved in January 2017 from the School of
502 Healthcare Sciences at Cardiff University: Reference 358 REC

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506 Study + Clinical Trials Network Register (ISTCRN)Number:42717948

507 Conflict of interests

508 The authors declare no conflict of interest.

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602

603 Figures

604 Figure 1 Spradley's Observational matrix

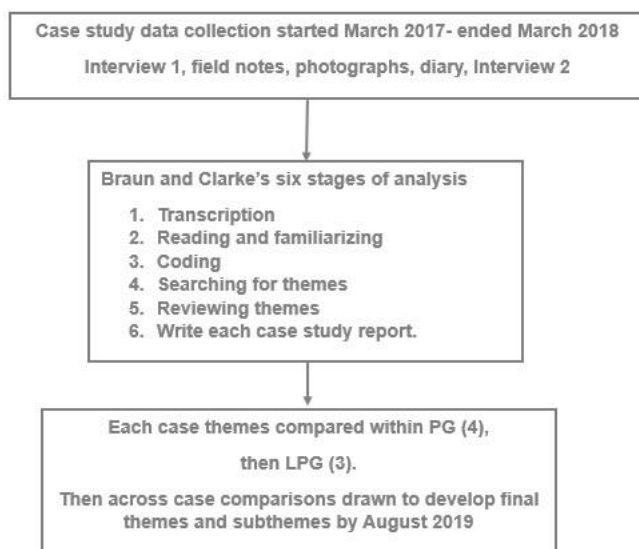
Checklist for Observations adapted from Spradley (2016)

Minutes	Time 0-10	Time 11-20	Time 21-30	Time 31-40	Time 41-50	Time 51-60
Space						
Object						
Act						
Activity						
Event						
Time						
Actor						
Goal						
Feeling						

605

606 Figure 2 Flow diagram of analysis

Figure 2: Flow diagram of data collection and analysis



607

608 *Figure 3: Poppy at the Halloween event in his all-terrain wheelchair (diary entry)*



609

610 Figure 4

611 *Figure 4 Photograph of Matthew in the sit ski, supported by a volunteer skier*

612 *(observation field notes)*



613

614 *Figure 5 Bree at Brownies with her personal assistant (observation field notes)*



615

616 Figure 6 James at the dinosaur exhibition after his surgery



617

618 Figure 7 Poppy's diary entry

Tuesday 14th November 2017

There hasn't been very much going on lately. Poppy has been getting a lot of tummy pain again. This is very upsetting for all of us as he doesn't want to do anything or go anywhere. He hits his head a lot with the pain and cries a lot. This has gradually been building up for about a week.

The only playing he has been interested in, has been spending a long time playing in the shower. He has been doing this a couple of times a day for the past few days for about an hour each time. He stands up and walks to the sink turns on the taps and splashes in the water around him on the floor. It has been very calming for him and also distracted him from the pain.

619

620 Tables

621 Table 1 Inclusion and exclusion criteria

<u>Inclusion Criteria</u>	<u>Exclusion Criteria</u>
<p>Children and young people with cerebral palsy aged 9-16 years and their parent/carer.</p> <p>Level III, IV or V of the GMFCS.</p> <p>Level I-II of the CFCS Level III-V of the CFCS -Parent to report by proxy if child or young person unable to communicate wishes.</p> <p>Able to give consent or assent (able to engage in research activity).</p>	<p>Children and young people with cerebral palsy outside this age range 1-8;17-18 years.</p> <p>Levels I or II of the GMFCS.</p> <p>Unable to give consent or assent.</p>

622

623

624 Table 2 Themes and subthemes

1. Participation enhancers	i. Parental advocacy ii. Innovative designs iii. Reasonable adjustments iv. Equipped volunteers
2. Champions for disabled children and young people's emotional well-being	i. Expressing choices to indicate well-being-self advocacy ii. Professional advocacy
3. Hindrances to participation	i. Undermining attitudes ii. Parental views of being treated differently iii. Impact of pain on participation

625