

'Knowing the noise that surrounds the athlete'

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American Journal of Physical Medicine & Rehabilitation

'Knowing the noise that surrounds the athlete': a qualitative study exploring the health seeking behaviours of athletes with limb deficiency drawing on the experiences and perceptions of the medical staff and athletes

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| Abstract: | <p>Objective To explore the health seeking behaviours (HSB) of athletes with limb deficiency, drawing on the experiences and perception of the SMT and athletes.</p> <p>Design An interpretive hermeneutic phenomenological methodology with a subtle realist paradigmatic view to investigate commonality in unique experiences within reality. Data collection was completed with two focus groups in December 2019 and March 2020. Thirteen participants took part including athletes and SMT members (Physiotherapists, Doctors, and Strength and Conditioning Coaches) working in Parasports. Focus group manuscripts were transcribed verbatim from audio recordings. An inductive, iterative process was used to identify themes and subthemes, with processes in place to establish rigour.</p> <p>Results Two themes and five sub themes emerged in relation to the 'internalisation and adjustment to social identity' and 'the importance and impact of factors which impact the athlete social identity'.</p> <p>Conclusions HSB of athletes with limb deficiency were influenced by a unique blend of personal and environmental factors that contribute towards social identity. The SMT require specific awareness of factors that may diminish HSB to deliver a personalised approach and negate consequences.</p> |

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Dear Editor,

Reference Manuscript: ***'Knowing the noise that surrounds the athlete': a qualitative study exploring the health seeking behaviours of athletes with limb deficiency drawing on the experiences and perceptions of the medical staff and athletes***

Thank you to the reviewers and editor for reviewing our manuscript, providing feedback and giving us the opportunity to re-submit this important research to the American Journal of Physical Medicine and Rehabilitation with minor revisions.

All authors have agreed to re-submission of this manuscript to the American Journal of Physical Medicine and Rehabilitation. The authors have no conflicts of interest to declare in the submission of this research for publication. We have made the changes as requested in recent emails.

There have been no previous publications from the same study.

I look forward to hearing your evaluation of the paper's suitability for the American Journal of Physical Medicine and Rehabilitation

Yours sincerely



Nicola Heneghan
PhD. MSc. FMACP.

Reviewer 1:

Thank you for the revised manuscript.

Sentence 59 still includes incorrect information, and I suggest to delete "incidence of injury during isolated Paralympic games", and just write "Research to scrutinise Para athletes' interaction with their SMT in relation to the SMT's endorsement in sporting success and quality of life does not exist"

Thank you. This has now been revised as suggested.

1 ***'Knowing the noise that surrounds the athlete': a qualitative study exploring the health seeking***
2 ***behaviours of athletes with limb deficiency drawing on the experiences and perceptions of the***
3 ***medical staff and athletes***
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49

ABSTRACT

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Objective

To explore the health seeking behaviours (HSB) of athletes with limb deficiency, drawing on the experiences and perception of the SMT and athletes.

Design

An interpretive hermeneutic phenomenological methodology with a subtle realist paradigmatic view to investigate commonality in unique experiences within reality. Data collection was completed with two focus groups in December 2019 and March 2020. Thirteen participants took part including athletes and SMT members (Physiotherapists, Doctors, and Strength and Conditioning Coaches) working in Parasports. Focus group manuscripts were transcribed verbatim from audio recordings. An inductive, iterative process was used to identify themes and subthemes, with processes in place to establish rigour.

Results

Two themes and five sub themes emerged in relation to the ‘internalisation and adjustment to social identity’ and ‘the importance and impact of factors which impact the athlete social identity’.

Conclusions

HSB of athletes with limb deficiency were influenced by a unique blend of personal and environmental factors that contribute towards social identity. The SMT require specific awareness of factors that may diminish HSB to deliver a personalised approach and negate consequences.

Key Words

Limb deficiency, Qualitative, Focus Groups, Paralympic Medicine, Elite Sport, Health Seeking Behaviour

78 **What is Known:** Health Seeking Behaviours describe an individual's decision-making as to when to
79 pursue an '*interpersonal interaction*' to aid recovery or enhance performance. Delayed HSB is known
80 to negatively impact any desirable resolution with interactions with healthcare professionals
81 influencing care expectations, patient perceptions of capacity and psychological factors contributing
82 to rehabilitation.

83

84 **What is New:** Sports medicine team and athletes perceive how social and internalised identity shape
85 health seeking behaviours in elite athletes with limb deficiency. Unique journeys and interactions
86 contribute towards positive and negative health seeking behaviours. Understanding personal and
87 environmental factors are important to personalise care.

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BACKGROUND

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Exposure of sport to the disabled population has grown exponentially since the start of the Paralympic Games. From just 17 countries participating in 1960, over 164 now compete, with the Paralympic population of over 4000 worldwide. ¹ Athletes with limb deficiency are just one of the eligible impairment groups and constitute a significant sub-population.² Within this specific impairment group, athletes may have acquired/traumatic or congenital limb deficiency.

The potential for success in Para sport has accelerated funding and performance support across the United Kingdom. Performance support includes access to a multidisciplinary sports medicine team (SMT) which might include physiotherapists, strength and conditioning coaches, physicians and psychologists, all of whom seek an inclusive, individualised understanding of athlete behaviour linked to injury prevention and athlete health management. ³ Research to scrutinise Para athletes' interaction with their SMT in relation to the SMT's endorsement in sporting success and quality of life does not exist. ^{2,4} Whole-person SMT approaches acknowledge the complexity of modern sports medicine and corroborate that context-sensitive research can imply intervention need. The different context offered by population-specific impairments challenge the SMT when delivering personalised care to achieve performance outcomes within a sports setting. Hence this research paper looks to explore the SMT and elite athlete perception of health seeking behaviours (HSB).

HSB describe an individual's decision-making process (how and when) to pursue an '*interpersonal interaction*' to aid recovery or enhance performance, when their ability for independent resolution is challenged. ⁵ Understanding HSB epitomises personalised care in athlete health. Research regarding HSB in sport is currently limited to those seeking mental health support and the barriers/facilitation that allow participation. ^{6,7} This is similarly seen amongst a Para athlete population and focus on physical health with limb loss specific research, with any approach to physical health limiting itself more generally to barriers of participation for example prosthetic adaptations, injury time loss or

117 access to sporting facilities. ⁴ There is a clear gap in literature attempting to explore the collaboration
118 of HSB and the engagement of the SMT yet, delayed HSB is known to negatively impact any desirable
119 resolution, with emotional and instrumental antecedents often absent in determining HSB. ⁵ Whilst
120 there is some analysis of antecedents and defining attributes of HSB, research investigating specific
121 population groups is now needed to inform population specific recommendations.

122

123 Literature suggests that those with congenital limb deficiency exhibit reduced cognitive strain around
124 limb deficiency as a result of 'growing up' and learning, rather than adapting following trauma. ⁸
125 Individuals with acquired limb deficiency evidence social and psychological challenges for up to two
126 years post-surgery. ⁹ Whilst recognising the variability of adjustment periods and impact of intrinsic
127 and extrinsic anxieties, there is no real acknowledgement of how this may influence HSB. A limited
128 body of research (patient narrative) does report an influence of healthcare professionals interactions
129 on expectations of care, perceptions of their body's capacity ¹⁰ and psychological factors contributing
130 to rehabilitation. ¹¹ It is evident from this that HSB go beyond conceptualisations of socio-structural
131 phenomenon and should examine reasons that reside uniquely in individuals as part of personalised
132 care. ^{12,13}

133

134 **Aim**

135 To explore the HSB of athletes with limb deficiency drawing on the experiences and perceptions of
136 the SMT and athletes.

137

138 **Objectives**

- 139 • To determine factors influencing HSB in elite athletes with limb deficiency.
- 140 • To explore the influences of an athlete's disability journey on their desired health needs from
141 the SMT.
- 142 • To explore the influence of the SMT on HSB and promotion of HSB.

- 143 • To explore the SMT's meta-perception of the athlete's social identity and how these influence
144 relationships in the context of HSB.

145

146 **METHODS**

147 **Design**

148 A qualitative exploratory study comprising two focus groups is reported in accordance with the
149 Consolidated Criteria for Reporting Qualitative Research (COREQ) (see Supplementary file 1).¹⁴

150 Focus groups involving athletes and members of the SMT enabled an exploration of the HSB in elite
151 athletes with limb deficiency through sharing dialogues and care.

152

153 **Theoretical Framework**

154 A subtle realist paradigmatic world view was assumed for the purpose of this research. Research that
155 utilises this position focuses and represents experiences that are shared. This position attempts to
156 represent reality rather than obtain the 'truth'¹⁵ and at no time can the researcher claim to have
157 absolute certainty regarding the findings.¹⁶ This position recognises the unique experiences
158 individuals have but suggests that within those experiences there is a common reality. The goal of this
159 research was to achieve 'naturalistic generalisability'¹⁷ in that we were able to access rich experiences
160 of individuals immersed in an environment and sharing common experiences that 'ring true' for the
161 reader. We identified value in using SMT members to access a great deal of lived experiences and
162 interactions with athletes but in order to focus on common realities needed to compliment this by
163 small numbers of athletes. Interpretive hermeneutic phenomenology¹⁷ was selected as the
164 methodology which would be best suited to this research question.

165

166 **Research Team**

167 Focus groups were facilitated by an experienced researcher (NH) to ensure all views were considered.

168 The lead author, (EJ) recorded field notes during the focus groups, as a first experience of qualitative

169 research. A specialist Parasport Physiotherapist (MB), with experience of qualitative theme coding
170 supported the data analysis. A Parasport Technical Lead (PM) was involved throughout the design,
171 data collection and analysis to aid trustworthiness, specifically credibility. A qualitative research lead
172 (AS) supervised the analysis.

173

174 **Participant Sampling Strategy**

175 Purposive, homogeneity, sampling ensured credibility, involving those with experience, a range of
176 expertise and professional backgrounds. Two focus groups offered flexibility for attendance. The
177 inclusion of athletes allowed a deeper, thorough analysis and challenged SMT perceptions to ensure
178 a balanced exploration. No participants, having consented to participation, declined to contribute, or
179 dropped out.

180

181 **Ethical Considerations**

182 Ethical approval was secured from the University of Birmingham. All participants were given an
183 information sheet and provided written consent. Following transcription of audio files, participants
184 were assigned a unique identifying code to assure participants anonymity from the point of analysis
185 through to dissemination.

186

187 **Data Collection**

188 A topic guide was informed by the literature and co-designed with the research team. An *a priori*
189 cognitive interview with an athlete with limb deficiency ensured data generation aligned with the
190 study's objectives.¹⁸ No changes were made to the topic guide following the cognitive interview. (See
191 Supplementary file 2)

192 Data collection occurred in December 2019 and March 2020. Focus groups allowed the facilitation of
193 interaction between participants to challenge and comment on past remarks to gain a deeper and
194 nuanced understanding.¹⁹ The focus groups were hosted in familiar settings to create a relaxed

195 environment and afford participant comfort. Due to logistical challenges and to ensure safety during
196 the Covid-19 pandemic, participants were allowed to contribute via remote means, including video
197 calls.

198 Following participant introductions, the topic guide was followed to prompt appropriate conversation.
199 Introductory discussion around the definition of HSB helped to develop relationships and initiate an
200 open forum to understanding each other's perceptions. The interviewer encouraged relaxed
201 conversation and asked explorative questions to gather an in-depth analysis, summarising answers to
202 evoke full discussion of points and stimulate true openness.²⁰

203

204 **Data analysis**

205 See Figure 1 for data analysis flow chart as guided by the framework of Palmer et al²¹. Steps to ensure
206 rigour followed the guidance¹⁵ including key verification strategies.²² We also acknowledge guidance
207 on prompts for transparency and ethical considerations²³. See Supplementary file 3 for audit trail.

208

209

210 **Patient and public involvement and engagement**

211 The study was conceived from many years of working with elite athletes with limb deficiency, in both
212 a performance and clinical context. The results of the study will be shared with key stakeholders,
213 including athletes via presentations and newsletters. Findings will be used to further inform education
214 of SMT and athletes with limb deficiency.

215

216

217

RESULTS

218

219 **Participants**

220

221 Thirteen participants were approached via email and took part in two focus groups, lasting 70 and 105
222 minutes. Focus group one comprised four physiotherapists, one sports medicine doctor and two
223 strength and conditioning coaches. Focus group two comprised of 3 physiotherapists, one sports
224 medicine doctor and two elite para-athletes with limb deficiency (See Table 1). Elite para-athletes
225 were defined within the context of performing on a World Class Programme and/or are in receipt of
226 an Athlete Performance Award. Recognition of specific sporting involvement, participant age and
227 gender is not included to protect the anonymity of what is a small population working and competing
228 in Paralympic sport.

229

230 **Themes**

231 The inductive analysis derived a thread of themes and subthemes centralised around the importance
232 of social identity and the adjustment and internalisation of social identities. Conner and Norman
233 ²⁴contemplate a framework to understanding HSB in relation to social cognition models and
234 hypothesise the impact of positive social cognition on behavioural intention. HSB are presented in the
235 construct of the following themes based on social identity.

236

237 *Theme 1: importance of social identities and factors which impact the athlete social identity*

238 This theme identifies how multiple social identities from both athletes' past, present and future selves
239 are revealed within the athlete-sports medicine professional interaction. An example of a past social
240 identity included a military social identity with all SMT participants able to relate to this from personal
241 experiences. Historical influences like a past military role, past independent work or sporting identities
242 were perceived as impacting how their present and future social identities evolved, were understood,
243 and known.

244

245 Both athletes present social identity was clearly determined by identities that they perceived as
246 'acceptable', commenting on social identities that were not acceptable. For instance, P11, as an

247 athlete, viewed the identity of an amputee positively, but that of a disabled person negatively. He
248 additionally made an observation, contrasting pre and post amputation mobility identities. The unique
249 impact of an acquired condition gave *“a sense of relief, like all of a sudden, I wasn’t disabled, I was just*
250 *an amputee”* (P11). The athlete participants also appeared to value the impact of the sport and
251 associated experiences, for instance, *“there is a real sense of freedom when you’re in a wheelchair or*
252 *if you’re on a bike”* (P11). The two focus groups shared the idea of creating ‘winners’ and ‘survivors’,
253 the former of these relating to being a minority as an elite athlete and the latter relating to overcoming
254 trauma and adversity in order to reach Paralympic status, (P04) *“they’ve got over their hang-ups, by*
255 *and large, or else they don’t get there”*. Part of an athlete’s performance identity was illustrated by
256 wanting to be seen as not having limitations and/or doing things that most can’t.

257

258 *Sub-theme 1a: The impact of peers on a shared sense of social identity*

259 This sub-theme describes shared knowledge experiences, perceived by the SMT and athletes, amongst
260 athletes which guides attitudes and behaviour. Peer support enhanced the development of a social
261 identity as an elite athlete. Athlete’s social identities evolved over time and were influenced by past
262 interactions with peers, the wider support team and the SMT; (P13) *“previous experiences whether*
263 *they’ve been positive or negative ... so if they’ve had a really negative experience, they’re unlikely to*
264 *seek that behaviour, that help again. And if it’s been more positive then they may be more likely to.”*
265 Peers were considered, by the athletes themselves and the SMT, as others who would not judge them
266 and this provided a safe space to share experiences of performance and injury management (an aspect
267 considered extremely important), evolving their identity as an athlete. *“like minded amputees, like*
268 *you do bounce of each other. You do ask each other for this kind of help and advice..... So I guess that’s*
269 *yeah health, health-seeking advice”* (P11).

270

271 *Sub-theme 1b: The impact of the SMT on perceived social identity*

272

273 In contrast to the above, Physiotherapists and Sports Medicine Doctors identified that health
274 problems could be difficult to navigate during an interaction. One athlete participant commented that
275 *“I’m just going over and over this like issue that I just want to get on with”* (P11). There was a common
276 perception that this meant underlying health issues could be played down to avoid further
277 investigation.

278

279 Part of the difficulty during any interactions was navigating what was termed as the “tricky” questions
280 that exposed perceived vulnerabilities. For instance, exploring why a limb deficient athlete may be
281 hesitant to enter the swimming pool despite rehabilitative benefits. *“We can sit there and try and pick
282 apart all of the challenges that are there and probably make people feel a bit more impaired”* (P09).
283 P08 corroborated their own challenge of exposing their residual limb however the environment of
284 elite sport has forced them to face up to it. The SMT reflected upon the need to be sensitive to such
285 issues and acknowledge the risk of identifying someone as being more disabled or more impaired.

286

287 *“And I also think I found recently, by, with one of my athletes in particular, because of her journey, how
288 she got to that point me being a little bit vulnerable to her, has, has made her be a lot more vulnerable
289 and open up and give me more insight into how she's got to making certain decisions...If you don't
290 understand their story, I think it's really difficult to understand how they make decisions surrounding
291 their healthcare”* (P13). The athlete practitioner relationship is give and take in order to develop a
292 deeper narrative.

293

294 In specific relation to work with the prosthetist, *“real skill to articulate conversation with your
295 prosthetist about how you feel what's wrong, what need changing”* (P11). Personal
296 experience/aspiration and professional opinion/ expertise may not always harmonise. The SMT
297 consider times where positive personal relationships allow for advocacy between an athlete and

298 other professionals – *“I think my role as a physio has often been like really helping to advocate for the*
299 *athlete...part of that is just understanding”* (P09). Positive and negative shared experiences between
300 the SMT and athlete guide behaviour and a deeper reflection of self/ knowledge of known past
301 traumas within all individuals. Thus, inviting vulnerability to be created around a social identity, to
302 encourage shared decision making.

303

304 *Sub-theme 1c: Influence of Past relationships*

305 This theme considers the loyalty of past relationships. Examples include a perceived sense of isolation
306 towards the coach and lack of access/seeking of the SMT, maintaining a social identity purely within
307 the sport. One participant commented; *“we’ve got a congenital athlete who...It’s almost like his trust*
308 *and loyalty in his coach is greater than, than like the multi-disciplinary team”* (P07). The risk of losing
309 trust/or having no trust in a relationship may not only lead to isolation from expertise but may
310 challenge individuals own coping mechanisms and self-care routines.

311

312 *Theme 2: Adjustment and internalisation of social identities*

313 Data illustrated the psychological impact of challenges athletes faced, including the impact of the
314 disability and the historical experiences related to the disability that could influence how they adjust
315 to what has happened and what may explain those social reactions. The SMT considered *“Where*
316 *you’re growing up in the playground, not flavour of the month”* (P04) suggesting being perceived as
317 someone different and someone in need of help, internalising their true self. The SMT recognise that
318 it is *“clear with this person is they’re looking for an identity in some way or another. And being in elite*
319 *performance fits into that criteria...very specific reasons why this athlete performs in the very sports*
320 *they do because it, it, in some ways helps manage their pain”* (P06).

321

322 The SMT considered how an athlete is viewed by others such as in a discussion evolving around a case
323 of an elective amputation, resultant of complex regional pain syndrome. The pre-morbid personality

324 surrounding this athlete was difficult to navigate for the SMT but ultimately sport provided an
325 adjustment of identity away from the action of having a leg amputated or from being an amputee and
326 towards the distractive opportunities and 'winning identity' that sport offers, "*We see the winners*"
327 (P04).

328

329 Age was not considered a factor in the embracement of self-identity. A mental process of adaptation
330 is variable amongst individuals and their adjustment may depend on their relative context of disability.
331 Acceptance of disability was illustrated as different depending on one's stability in their day-to-day
332 life and other's dependence on them and their ability to continue supporting dependents. This was
333 highlighted in the context of social factors.

334 In a psychological context, mental robustness or social stance will influence upon general ability to
335 adapt to unforeseen circumstances.

336 "*If you look at traditional – there comes an age where you perhaps are a bit more settled in your career,*
337 *you're probably more settled in the area that you live in, and it's – apart from maybe family changes,*
338 *there's less change that happens there. So could that contribute to the older, older athlete perhaps not*
339 *coping as well, or seeking more*" (P03).

340 SMT's discussed that an athlete must be adaptable within their own beliefs and accepting/willing of
341 risks, considered, for example, as the impact of increased loading leading towards pressure sores or
342 associated with remaining ambulant/being non-ambulant within certain environments.
343 Consideration must be given to the central goal of the individual both in and out of sport and question
344 the ability of the athlete to adjust identity currently to enlighten such goals. The following sub-theme
345 follows on to expand this point.

346

347 *Sub-theme 2a: Impact of their personal attitudes towards own identity*

348 All participants believed flexibility in their own views was needed to align performance goals with
349 those of the support team. SMT participants can interact with individuals who would perhaps avoid

350 the use of a wheelchair but also noted athletes that embrace the use of a wheelchair to align health
351 and performance needs. Participants commented on athletes having the ability to stand back and
352 assess the bigger picture, embracing change and flexibility, reconciling true identity. *"You know what
353 that is - the emotional intelligence to be able to stand back and assess [the emotional intelligence
354 drawn upon from reflection on past experiences, familial support and upbringing] what's going on"*
355 (P06). For a myriad of reasons some athletes can reflect on historical events to understand the support
356 that surrounds them, guiding recovery and performance despite their own perceived negative
357 identity.

358

359 Sub-theme 2b: The perceived influence of technology on identity

360 A large involvement of the SMT within limb deficient sport is their impact on equipment which may
361 include the prosthesis, the socket, mobility aids, identification, and knowledge of emerging surgical
362 techniques such as osseous implants. Identity impacts upon the acceptance of embracing technology.
363 The SMT acknowledge that the art of adapting or changing equipment is complex and multifactorial.

364

365 (In relation to an athlete opting for osseous implants). *"There were a number of challenges around the
366 initial procedure. Which meant that initial progress was slow... And it's been a, an interesting journey...
367 Um, in sometimes how, how reality is very different to the perceived benefits of a current or new
368 approach"* (P06). The SMT and athletes corroborated that a change in technology had to be warranted
369 the effort associated with the vulnerabilities of change. Identifying the need for equipment change
370 may depend on whether the athlete is required to be ambulant for their sport, however, may
371 ultimately be guided by internalised social identity.

372

373 Perception from the SMT is that there was a negative social identity associated with wheelchair use
374 and their previous experiences of how they responded to wheelchair use in the early phases of their
375 post morbid journey. *"even if there's some pressure issues they remain on the limb... the wheelchair*

376 *would be sort of a negative identity" (P12). The value of the use of the wheelchair and what it*
377 *represented was contested and this could result in frustration from the medical team that there may*
378 *be a health benefit with it's use, specifically around the situation of being in an airport and athletes*
379 *"not wanting to be in wheelchairs at the airport...because they've got a sense of authority" (P02). The*
380 *SMT thought consideration must be given to how individuals' social identity may or may not feel*
381 *influenced in a chair, "we've had people hiding pressure sores in order to maintain their*
382 *independence" (P02).*

383 **DISCUSSION**

384

385 This is the first exploration of HSB in elite para-athletes, drawing on the experiences of Para-athletes
386 and members of the SMT. Findings support existing literature¹³, which recognises HSB being unique
387 to the individual. Furthermore, findings strongly support the need to understand and work
388 collaboratively to optimise athlete health and performance; this is 'noise' that contributes to the social
389 and internalised identity of the athlete.

390

391 Social influences and identity were typically explored around their negative impact towards HSB. Risk
392 taking behaviours were widely perceived in the traumatic acquired amputee population, specifically
393 those from a military background. An element of risk-taking behaviour has previously been associated
394 with elite able-bodied athletes and Para athlete populations.^{25,26} In our study this was centred on the
395 athletes past identity and how it evolved into future identities and that of a Para-athlete identity.

396

397 A positive significance linking HSB with an athlete's identity is feeling freedom with sports
398 participation. Previous research involving para-athletes reported the pursuit of sports related health
399 benefits where the adaptive equipment affords such freedom (e.g. horse riding in equestrian).²⁷ In
400 contrast to this, research in elite sport has reported suppression of HSB where disability has been
401 emphasised with the use of assistive/mobility devices.²⁸

402

403 Wider relationships and forming trust positively or negatively influenced HSB. Messinger's¹⁰ narrative
404 helps us to understand the equivocal nature of relationships and the intricacies of patient-practitioner
405 relationships. Specifically, the importance of trust in an athlete-coach relationship and the powerful
406 support structure and caring climate is well documented.^{29,30} Such literature extends to the support
407 network, inclusive of wider agents such as parents. A positive coaching relationship should also
408 prepare athletes for high level training through physical preparation, hence appropriate HSB.³¹ Past
409 experiences and external support are known to facilitate health seeking.² In a population of para-
410 swimmers with limb deficiency, the social background and childhood experiences were found to
411 influence HSB³², adding weight to emergent themes in our study. However, our study suggests SMT
412 relationships and peer relationships are not only an influence on HSB but also on social identity.

413

414 Adjustment of identity also considered coping and HSB in relation to age and societal responsibilities.
415 Younger individuals are in a fluid, ever-changing phase of life, experiencing body changes, developing
416 their identity and understanding social norms.³³ Our findings suggest heightened HSB in those coping
417 less well and seeking control, compared to earlier findings, where reduced motivation for HSB was
418 seen in adults with societal pressures following amputation.³⁴

419

420 A distinctive theme in this study was the notion of adjustment and internalisation of identity around
421 social identity, with Para-athletes experts in their own disability.³⁵ Our SMT participants advocated
422 athletes' ability to develop independent HSB where they combine their own metacognition, peer
423 influence and align knowledge towards their own health and thus sporting performance.

424

425 A strong theme was the perceived effort of requiring new technology and current prosthetic
426 adjustments. Whilst the need for change in relation to injury risk mitigation might have been queried,
427 athletes' views and the pressures that may come with change were widely respected. Our findings

428 suggest athletes with limb deficiency avoid weight bearing sports as a solution to the prosthetic
429 creating a barrier to participation due to risk of injury.³⁶

430

431 The notion of technology advancing quicker than our understanding and implementation supported
432 HSB. Good ³¹ reports experiences where biotechnology influences clinical practice, with patients
433 desiring the newest technology, despite the unknown outcome. Earlier research found that acquired
434 amputees confided in their peers for ideas around prosthetics, corroborating our findings with
435 athletes collaboratively problem solving and exploring new experiences.³⁷

436 Equipment has a strong influence around performance. It was perceived by the SMT as the main factor
437 towards reaching performance goals, second to the athlete themselves. The understanding of
438 technology by staff and athletes is paramount to success. For instance, one discussion highlights the
439 concern around impact and the need for the athlete to understand this. The thought of a new
440 technology that would take away some of the problems with the skin prosthetic interface would be
441 enticing however there equally comes understanding of recovery time, associated risks of surgical
442 interventions and open wounds, time out of training (loss of fitness) and a lack of evidence to suggest
443 success within the elite environment. There was a sense of know from practitioners that aired caution
444 to this route and right to do so given the lengthy recovery.

445

446 With congenital limb deficiency, the SMT acknowledge that the nature of the limb deficiency may lend
447 itself to certain equipment working or not working for that individual which may influence their
448 identity choices, although the SMT note that congenital athletes generally seem more comfortable to
449 be able to propel themselves round in a wheelchair. Hence, showing a contrasting metaperception of
450 being in a wheelchair, they can see the best solution within a certain environment.

451 In an example of being in the Paralympic Village, the pinnacle of most Paralympic careers, athletes are
452 often required to increase their footfall due to the setup. ³⁸ Despite this, some continue to refuse
453 mobility aids and additionally in an environment where mobility aids are everywhere and where the

454 surrounding population mirror the same Paralympic identity. The SMT face an ongoing pursuit against
455 challenges of personal attitudes/internalisation of identity and aligning performance goals to optimise
456 health.

457 'Post traumatic growth' is a well-established concept, with similar themes seen within this study; a
458 period of growth occurring following amputation. ^{37,39,40} Where post traumatic recovery is
459 unpredictable and unique to the individual, emotional HSB must be individualised. ³⁹ The idea of an
460 adjusting identity in this sense was not explicitly transferable to those with congenital limb deficiency.

461

462 **Strengths and Limitations**

463

464 The use of SMT members and athletes within focus groups was a unique strength to inform
465 collaborative perceptions with a diverse sample. Strength is observed methodologically, in the
466 expertise of qualitative researchers and experts in the Para-athlete field, conforming relevance and
467 validity within the data collection and analysis; additionally use of Pope and Mays ²⁰ criteria for
468 assessing quality of subtle realist research, validity and relevance are considered. ¹⁵ A limitation of the
469 study was the combined use of face to face and remote data collection for the second focus group
470 (due to Covid-19); this may have impacted on participant interactions, or emotive responses. This may
471 also have contributed to fewer challenging responses which could have established a deeper true
472 meaning or emotion.

473 A clear limitation is highlighted using just two athletes, potentially limiting comprehensiveness
474 towards a reflexive analysis and ability to observe a "fair dealing" of perspectives. Secondary to this,
475 the discussion must be formulated round perceived concepts that the SMT have without opportunity
476 to consolidate feelings.

477 **Practice and Research Recommendations**

478 Findings support the need for greater awareness of prosthetics in weight bearing sports, where
479 equipment change may negate benefit. Future research into how these findings can further influence
480 the SMT in Para-athletes with limb deficiency would be welcome. Knowledge of new equipment and
481 technology is highly relevant alongside medical discussions and shared decision-making with the
482 athlete to align health and performance goals. The importance of relationships between the medical
483 staff, coaches and athlete drives willingness of athletes to seek health advice. SMT should be mindful
484 of reduced HSB in this population group and accept a need to ask “the uncomfortable question” where
485 themes have highlighted reduced HSB associated with the internalisation of certain identities.
486 Differences in the participant interactions between the groups (with and without athletes) suggests a
487 need for future research to explore individual assumptions and influenced opinions.

488

489

CONCLUSION

490

491 Findings from this exploratory study suggest a key theme around ‘identity’ in relation to athletes with
492 limb deficiency and their HSB. Findings also highlight the importance of knowledge and understanding
493 of this ‘noise’ to optimise athlete health and performance.

494 **Abbreviations**

495 HSB: Health seeking behaviour

496 SMT: Sports medicine team

497

498

499

500

501

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593 **Figure legends**

594 **Figure 1:** Figure 1 A Flow Chart to Demonstrate the Iterative Data Analysis Process and Processes to

595 Establish Rigour

596 **Figure 2:** Emerging themes and subthemes

597

598

1 ***'Knowing the noise that surrounds the athlete': a qualitative study exploring the health seeking***
2 ***behaviours of athletes with limb deficiency drawing on the experiences and perceptions of the***
3 ***medical staff and athletes***
4
5
6

7 **ABSTRACT**

8 **Objective**

9 To explore the health seeking behaviours (HSB) of athletes with limb deficiency, drawing on the
10 experiences and perception of the SMT and athletes.
11

12 **Design**

13 An interpretive hermeneutic phenomenological methodology with a subtle realist paradigmatic view
14 to investigate commonality in unique experiences within reality. Data collection was completed with
15 two focus groups in December 2019 and March 2020. Thirteen participants took part including
16 athletes and SMT members (Physiotherapists, Doctors, and Strength and Conditioning Coaches)
17 working in Parasports. Focus group manuscripts were transcribed verbatim from audio recordings.
18 An inductive, iterative process was used to identify themes and subthemes, with processes in place
19 to establish rigour.
20

21 **Results**

22 Two themes and five sub themes emerged in relation to the 'internalisation and adjustment to social
23 identity' and 'the importance and impact of factors which impact the athlete social identity'.
24

25 **Conclusions**

26 HSB of athletes with limb deficiency were influenced by a unique blend of personal and
27 environmental factors that contribute towards social identity. The SMT require specific awareness of
28 factors that may diminish HSB to deliver a personalised approach and negate consequences.
29
30

31 **Key Words**

32 Limb deficiency, Qualitative, Focus Groups, Paralympic Medicine, Elite Sport, Health Seeking
33 Behaviour
34

35 **What is Known:** Health Seeking Behaviours describe an individual's decision-making as to when to
36 pursue an '*interpersonal interaction*' to aid recovery or enhance performance. Delayed HSB is known
37 to negatively impact any desirable resolution with interactions with healthcare professionals
38 influencing care expectations, patient perceptions of capacity and psychological factors contributing
39 to rehabilitation.

40

41 **What is New:** Sports medicine team and athletes perceive how social and internalised identity shape
42 health seeking behaviours in elite athletes with limb deficiency. Unique journeys and interactions
43 contribute towards positive and negative health seeking behaviours. Understanding personal and
44 environmental factors are important to personalise care.

45

46

BACKGROUND

47
48
49 Exposure of sport to the disabled population has grown exponentially since the start of the Paralympic
50 Games. From just 17 countries participating in 1960, over 164 now compete, with a Paralympic
51 population of over 4000 worldwide. ¹ Athletes with limb deficiency are just one of the eligible
52 impairment groups and constitute a significant sub-population.² Within this specific impairment
53 group, athletes may have acquired/traumatic or congenital limb deficiency.

54
55 The potential for success in Para sport has accelerated funding and performance support across the
56 United Kingdom. Performance support includes access to a multidisciplinary sports medicine team
57 (SMT) which might include physiotherapists, strength and conditioning coaches, physicians and
58 psychologists, all of whom seek an inclusive, individualised understanding of athlete behaviour linked
59 to injury prevention and athlete health management. ³ Research to scrutinise Para athletes'
60 interaction with their SMT in relation to the SMT's endorsement in sporting success and quality of life
61 does not exist.^{2,4} Whole-person SMT approaches acknowledge the complexity of modern sports
62 medicine and corroborate that context-sensitive research can imply intervention need. The different
63 context offered by population-specific impairments challenge the SMT when delivering personalised
64 care to achieve performance outcomes within a sports setting. Hence this research paper looks to
65 explore the SMT and elite athlete perception of health seeking behaviours (HSB).

66
67 HSB describe an individual's decision-making process (how and when) to pursue an '*interpersonal*
68 *interaction*' to aid recovery or enhance performance, when their ability for independent resolution is
69 challenged. ⁵ Understanding HSB epitomises personalised care in athlete health. Research regarding
70 HSB in sport is currently limited to those seeking mental health support and the barriers/facilitation
71 that allow participation. ^{6,7} This is similarly seen amongst a Para athlete population and focus on
72 physical health with limb loss specific research, with any approach to physical health limiting itself
73 more generally to barriers of participation for example prosthetic adaptations, injury time loss or

74 access to sporting facilities. ⁴ There is a clear gap in literature attempting to explore the collaboration
75 of HSB and the engagement of the SMT yet, delayed HSB is known to negatively impact any desirable
76 resolution, with emotional and instrumental antecedents often absent in determining HSB. ⁵ Whilst
77 there is some analysis of antecedents and defining attributes of HSB, research investigating specific
78 population groups is now needed to inform population specific recommendations.

79

80 Literature suggests that those with congenital limb deficiency exhibit reduced cognitive strain around
81 limb deficiency as a result of 'growing up' and learning, rather than adapting following trauma. ⁸
82 Individuals with acquired limb deficiency evidence social and psychological challenges for up to two
83 years post-surgery. ⁹ Whilst recognising the variability of adjustment periods and impact of intrinsic
84 and extrinsic anxieties, there is no real acknowledgement of how this may influence HSB. A limited
85 body of research (patient narrative) does report an influence of healthcare professionals interactions
86 on expectations of care, perceptions of their body's capacity ¹⁰ and psychological factors contributing
87 to rehabilitation. ¹¹ It is evident from this that HSB go beyond conceptualisations of socio-structural
88 phenomenon and should examine reasons that reside uniquely in individuals as part of personalised
89 care. ^{12,13}

90

91 **Aim**

92 To explore the HSB of athletes with limb deficiency drawing on the experiences and perceptions of
93 the SMT and athletes.

94

95 **Objectives**

- 96 • To determine factors influencing HSB in elite athletes with limb deficiency.
- 97 • To explore the influences of an athlete's disability journey on their desired health needs from
98 the SMT.
- 99 • To explore the influence of the SMT on HSB and promotion of HSB.

- 100 • To explore the SMT's meta-perception of the athlete's social identity and how these influence
101 relationships in the context of HSB.

102

103 **METHODS**

104 **Design**

105 A qualitative exploratory study comprising two focus groups is reported in accordance with the
106 Consolidated Criteria for Reporting Qualitative Research (COREQ) (see Supplementary file 1).¹⁴

107 Focus groups involving athletes and members of the SMT enabled an exploration of the HSB in elite
108 athletes with limb deficiency through sharing dialogues and care.

109

110 **Theoretical Framework**

111 A subtle realist paradigmatic world view was assumed for the purpose of this research. Research that
112 utilises this position focuses and represents experiences that are shared. This position attempts to
113 represent reality rather than obtain the 'truth'¹⁵ and at no time can the researcher claim to have
114 absolute certainty regarding the findings.¹⁶ This position recognises the unique experiences
115 individuals have but suggests that within those experiences there is a common reality. The goal of this
116 research was to achieve 'naturalistic generalisability'¹⁷ in that we were able to access rich experiences
117 of individuals immersed in an environment and sharing common experiences that 'ring true' for the
118 reader. We identified value in using SMT members to access a great deal of lived experiences and
119 interactions with athletes but in order to focus on common realities needed to compliment this by
120 small numbers of athletes. Interpretive hermeneutic phenomenology¹⁷ was selected as the
121 methodology which would be best suited to this research question.

122

123 **Research Team**

124 Focus groups were facilitated by an experienced researcher (XX) to ensure all views were considered.

125 The lead author, (XX) recorded field notes during the focus groups, as a first experience of qualitative

126 research. A specialist Parasport Physiotherapist (XX), with experience of qualitative theme coding
127 supported the data analysis. A Parasport Technical Lead (XX) was involved throughout the design, data
128 collection and analysis to aid trustworthiness, specifically credibility. A qualitative research lead (XX)
129 supervised the analysis.

130

131 **Participant Sampling Strategy**

132 Purposive, homogeneity, sampling ensured credibility, involving those with experience, a range of
133 expertise and professional backgrounds. Two focus groups offered flexibility for attendance. The
134 inclusion of athletes allowed a deeper, thorough analysis and challenged SMT perceptions to ensure
135 a balanced exploration. No participants, having consented to participation, declined to contribute, or
136 dropped out.

137

138 **Ethical Considerations**

139 Ethical approval was secured from the XXXXXXXXXXXXXXXXXXXX. All participants were given an information
140 sheet and provided written consent. Following transcription of audio files, participants were assigned
141 a unique identifying code to assure participants anonymity from the point of analysis through to
142 dissemination.

143

144 **Data Collection**

145 A topic guide was informed by the literature and co-designed with the research team. An *a priori*
146 cognitive interview with an athlete with limb deficiency ensured data generation aligned with the
147 study's objectives.¹⁸ No changes were made to the topic guide following the cognitive interview. (See
148 Supplementary file 2)

149 Data collection occurred in December 2019 and March 2020. Focus groups allowed the facilitation of
150 interaction between participants to challenge and comment on past remarks to gain a deeper and
151 nuanced understanding.¹⁹ The focus groups were hosted in familiar settings to create a relaxed

152 environment and afford participant comfort. Due to logistical challenges and to ensure safety during
153 the Covid-19 pandemic, participants were allowed to contribute via remote means, including video
154 calls.

155 Following participant introductions, the topic guide was followed to prompt appropriate conversation.
156 Introductory discussion around the definition of HSB helped to develop relationships and initiate an
157 open forum to understanding each other's perceptions. The interviewer encouraged relaxed
158 conversation and asked explorative questions to gather an in-depth analysis, summarising answers to
159 evoke full discussion of points and stimulate true openness.²⁰

160

161 **Data analysis**

162 See Figure 1 for data analysis flow chart as guided by the framework of Palmer et al²¹. Steps to ensure
163 rigour followed the guidance¹⁵ including key verification strategies.²² We also acknowledge guidance
164 on prompts for transparency and ethical considerations²³. See Supplementary file 3 for audit trail.

165

166

167 **Patient and public involvement and engagement**

168 The study was conceived from many years of working with elite athletes with limb deficiency, in both
169 a performance and clinical context. The results of the study will be shared with key stakeholders,
170 including athletes via presentations and newsletters. Findings will be used to further inform education
171 of SMT and athletes with limb deficiency.

172

173

174

RESULTS

175

176 **Participants**

177

178 Thirteen participants were approached via email and took part in two focus groups, lasting 70 and 105
179 minutes. Focus group one comprised four physiotherapists, one sports medicine doctor and two
180 strength and conditioning coaches. Focus group two comprised of 3 physiotherapists, one sports
181 medicine doctor and two elite para-athletes with limb deficiency (See Table 1). Elite para-athletes
182 were defined within the context of performing on a World Class Programme and/or are in receipt of
183 an Athlete Performance Award. Recognition of specific sporting involvement, participant age and
184 gender is not included to protect the anonymity of what is a small population working and competing
185 in Paralympic sport.

186

187 **Themes**

188 The inductive analysis derived a thread of themes and subthemes centralised around the importance
189 of social identity and the adjustment and internalisation of social identities. Conner and Norman
190 ²⁴contemplate a framework to understanding HSB in relation to social cognition models and
191 hypothesise the impact of positive social cognition on behavioural intention. HSB are presented in the
192 construct of the following themes based on social identity.

193

194 *Theme 1: importance of social identities and factors which impact the athlete social identity*

195 This theme identifies how multiple social identities from both athletes' past, present and future selves
196 are revealed within the athlete-sports medicine professional interaction. An example of a past social
197 identity included a military social identity with all SMT participants able to relate to this from personal
198 experiences. Historical influences like a past military role, past independent work or sporting identities
199 were perceived as impacting how their present and future social identities evolved, were understood,
200 and known.

201

202 Both athletes present social identity was clearly determined by identities that they perceived as
203 'acceptable', commenting on social identities that were not acceptable. For instance, P11, as an

204 athlete, viewed the identity of an amputee positively, but that of a disabled person negatively. He
205 additionally made an observation, contrasting pre and post amputation mobility identities. The unique
206 impact of an acquired condition gave *“a sense of relief, like all of a sudden, I wasn’t disabled, I was just*
207 *an amputee”* (P11). The athlete participants also appeared to value the impact of the sport and
208 associated experiences, for instance, *“there is a real sense of freedom when you’re in a wheelchair or*
209 *if you’re on a bike”* (P11). The two focus groups shared the idea of creating ‘winners’ and ‘survivors’,
210 the former of these relating to being a minority as an elite athlete and the latter relating to overcoming
211 trauma and adversity in order to reach Paralympic status, (P04) *“they’ve got over their hang-ups, by*
212 *and large, or else they don’t get there”*. Part of an athlete’s performance identity was illustrated by
213 wanting to be seen as not having limitations and/or doing things that most can’t.

214

215 *Sub-theme 1a: The impact of peers on a shared sense of social identity*

216 This sub-theme describes shared knowledge experiences, perceived by the SMT and athletes, amongst
217 athletes which guides attitudes and behaviour. Peer support enhanced the development of a social
218 identity as an elite athlete. Athlete’s social identities evolved over time and were influenced by past
219 interactions with peers, the wider support team and the SMT; (P13) *“previous experiences whether*
220 *they’ve been positive or negative ... so if they’ve had a really negative experience, they’re unlikely to*
221 *seek that behaviour, that help again. And if it’s been more positive then they may be more likely to.”*
222 Peers were considered, by the athletes themselves and the SMT, as others who would not judge them
223 and this provided a safe space to share experiences of performance and injury management (an aspect
224 considered extremely important), evolving their identity as an athlete. *“like minded amputees, like*
225 *you do bounce of each other. You do ask each other for this kind of help and advice..... So I guess that’s*
226 *yeah health, health-seeking advice”* (P11).

227

228 *Sub-theme 1b: The impact of the SMT on perceived social identity*

229

230 In contrast to the above, Physiotherapists and Sports Medicine Doctors identified that health
231 problems could be difficult to navigate during an interaction. One athlete participant commented that
232 *“I’m just going over and over this like issue that I just want to get on with”* (P11). There was a common
233 perception that this meant underlying health issues could be played down to avoid further
234 investigation.

235

236 Part of the difficulty during any interactions was navigating what was termed as the “tricky” questions
237 that exposed perceived vulnerabilities. For instance, exploring why a limb deficient athlete may be
238 hesitant to enter the swimming pool despite rehabilitative benefits. *“We can sit there and try and pick
239 apart all of the challenges that are there and probably make people feel a bit more impaired”* (P09).
240 P08 corroborated their own challenge of exposing their residual limb however the environment of
241 elite sport has forced them to face up to it. The SMT reflected upon the need to be sensitive to such
242 issues and acknowledge the risk of identifying someone as being more disabled or more impaired.

243

244 *“And I also think I found recently, by, with one of my athletes in particular, because of her journey, how
245 she got to that point me being a little bit vulnerable to her, has, has made her be a lot more vulnerable
246 and open up and give me more insight into how she's got to making certain decisions...If you don't
247 understand their story, I think it's really difficult to understand how they make decisions surrounding
248 their healthcare”* (P13). The athlete practitioner relationship is give and take in order to develop a
249 deeper narrative.

250

251 In specific relation to work with the prosthetist, *“real skill to articulate conversation with your
252 prosthetist about how you feel what's wrong, what need changing”* (P11). Personal
253 experience/aspiration and professional opinion/ expertise may not always harmonise. The SMT
254 consider times where positive personal relationships allow for advocacy between an athlete and

255 other professionals – *“I think my role as a physio has often been like really helping to advocate for the*
256 *athlete...part of that is just understanding”* (P09). Positive and negative shared experiences between
257 the SMT and athlete guide behaviour and a deeper reflection of self/ knowledge of known past
258 traumas within all individuals. Thus, inviting vulnerability to be created around a social identity, to
259 encourage shared decision making.

260

261 *Sub-theme 1c: Influence of Past relationships*

262 This theme considers the loyalty of past relationships. Examples include a perceived sense of isolation
263 towards the coach and lack of access/seeking of the SMT, maintaining a social identity purely within
264 the sport. One participant commented; *“we’ve got a congenital athlete who...It’s almost like his trust*
265 *and loyalty in his coach is greater than, than like the multi-disciplinary team”* (P07). The risk of losing
266 trust/or having no trust in a relationship may not only lead to isolation from expertise but may
267 challenge individuals own coping mechanisms and self-care routines.

268

269 *Theme 2: Adjustment and internalisation of social identities*

270 Data illustrated the psychological impact of challenges athletes faced, including the impact of the
271 disability and the historical experiences related to the disability that could influence how they adjust
272 to what has happened and what may explain those social reactions. The SMT considered *“Where*
273 *you’re growing up in the playground, not flavour of the month”* (P04) suggesting being perceived as
274 someone different and someone in need of help, internalising their true self. The SMT recognise that
275 it is *“clear with this person is they’re looking for an identity in some way or another. And being in elite*
276 *performance fits into that criteria...very specific reasons why this athlete performs in the very sports*
277 *they do because it, it, in some ways helps manage their pain”* (P06).

278

279 The SMT considered how an athlete is viewed by others such as in a discussion evolving around a case
280 of an elective amputation, resultant of complex regional pain syndrome. The pre-morbid personality

281 surrounding this athlete was difficult to navigate for the SMT but ultimately sport provided an
282 adjustment of identity away from the action of having a leg amputated or from being an amputee and
283 towards the distractive opportunities and 'winning identity' that sport offers, "*We see the winners*"
284 (P04).

285

286 Age was not considered a factor in the embracement of self-identity. A mental process of adaptation
287 is variable amongst individuals and their adjustment may depend on their relative context of disability.
288 Acceptance of disability was illustrated as different depending on one's stability in their day-to-day
289 life and other's dependence on them and their ability to continue supporting dependents. This was
290 highlighted in the context of social factors.

291 In a psychological context, mental robustness or social stance will influence upon general ability to
292 adapt to unforeseen circumstances.

293 "*If you look at traditional – there comes an age where you perhaps are a bit more settled in your career,*
294 *you're probably more settled in the area that you live in, and it's – apart from maybe family changes,*
295 *there's less change that happens there. So could that contribute to the older, older athlete perhaps not*
296 *coping as well, or seeking more*" (P03).

297 SMT's discussed that an athlete must be adaptable within their own beliefs and accepting/willing of
298 risks, considered, for example, as the impact of increased loading leading towards pressure sores or
299 associated with remaining ambulant/being non-ambulant within certain environments.
300 Consideration must be given to the central goal of the individual both in and out of sport and question
301 the ability of the athlete to adjust identity currently to enlighten such goals. The following sub-theme
302 follows on to expand this point.

303

304 *Sub-theme 2a: Impact of their personal attitudes towards own identity*

305 All participants believed flexibility in their own views was needed to align performance goals with
306 those of the support team. SMT participants can interact with individuals who would perhaps avoid

307 the use of a wheelchair but also noted athletes that embrace the use of a wheelchair to align health
308 and performance needs. Participants commented on athletes having the ability to stand back and
309 assess the bigger picture, embracing change and flexibility, reconciling true identity. *"You know what
310 that is - the emotional intelligence to be able to stand back and assess [the emotional intelligence
311 drawn upon from reflection on past experiences, familial support and upbringing] what's going on"*
312 (P06). For a myriad of reasons some athletes can reflect on historical events to understand the support
313 that surrounds them, guiding recovery and performance despite their own perceived negative
314 identity.

315

316 Sub-theme 2b: The perceived influence of technology on identity

317 A large involvement of the SMT within limb deficient sport is their impact on equipment which may
318 include the prosthesis, the socket, mobility aids, identification, and knowledge of emerging surgical
319 techniques such as osseous implants. Identity impacts upon the acceptance of embracing technology.
320 The SMT acknowledge that the art of adapting or changing equipment is complex and multifactorial.

321

322 (In relation to an athlete opting for osseous implants). *"There were a number of challenges around the
323 initial procedure. Which meant that initial progress was slow... And it's been a, an interesting journey...
324 Um, in sometimes how, how reality is very different to the perceived benefits of a current or new
325 approach"* (P06). The SMT and athletes corroborated that a change in technology had to be warranted
326 the effort associated with the vulnerabilities of change. Identifying the need for equipment change
327 may depend on whether the athlete is required to be ambulant for their sport, however, may
328 ultimately be guided by internalised social identity.

329

330 Perception from the SMT is that there was a negative social identity associated with wheelchair use
331 and their previous experiences of how they responded to wheelchair use in the early phases of their
332 post morbid journey. *"even if there's some pressure issues they remain on the limb... the wheelchair*

333 *would be sort of a negative identity"* (P12). The value of the use of the wheelchair and what it
334 represented was contested and this could result in frustration from the medical team that there may
335 be a health benefit with it's use, specifically around the situation of being in an airport and athletes
336 *"not wanting to be in wheelchairs at the airport...because they've got a sense of authority"* (P02). The
337 SMT thought consideration must be given to how individuals' social identity may or may not feel
338 influenced in a chair, "we've had people hiding pressure sores in order to maintain their
339 independence" (P02).

340 **DISCUSSION**

341
342 This is the first exploration of HSB in elite para-athletes, drawing on the experiences of Para-athletes
343 and members of the SMT. Findings support existing literature ¹³, which recognises HSB being unique
344 to the individual. Furthermore, findings strongly support the need to understand and work
345 collaboratively to optimise athlete health and performance; this is 'noise' that contributes to the social
346 and internalised identity of the athlete.

347
348 Social influences and identity were typically explored around their negative impact towards HSB. Risk
349 taking behaviours were widely perceived in the traumatic acquired amputee population, specifically
350 those from a military background. An element of risk-taking behaviour has previously been associated
351 with elite able-bodied athletes and Para athlete populations. ^{25,26} In our study this was centred on the
352 athletes past identity and how it evolved into future identities and that of a Para-athlete identity.

353
354 A positive significance linking HSB with an athlete's identity is feeling freedom with sports
355 participation. Previous research involving para-athletes reported the pursuit of sports related health
356 benefits where the adaptive equipment affords such freedom (e.g. horse riding in equestrian). ²⁷ In
357 contrast to this, research in elite sport has reported suppression of HSB where disability has been
358 emphasised with the use of assistive/mobility devices. ²⁸

359

360 Wider relationships and forming trust positively or negatively influenced HSB. Messinger's¹⁰ narrative
361 helps us to understand the equivocal nature of relationships and the intricacies of patient-practitioner
362 relationships. Specifically, the importance of trust in an athlete-coach relationship and the powerful
363 support structure and caring climate is well documented.^{29,30} Such literature extends to the support
364 network, inclusive of wider agents such as parents. A positive coaching relationship should also
365 prepare athletes for high level training through physical preparation, hence appropriate HSB.³¹ Past
366 experiences and external support are known to facilitate health seeking.² In a population of para-
367 swimmers with limb deficiency, the social background and childhood experiences were found to
368 influence HSB³², adding weight to emergent themes in our study. However, our study suggests SMT
369 relationships and peer relationships are not only an influence on HSB but also on social identity.

370

371 Adjustment of identity also considered coping and HSB in relation to age and societal responsibilities.
372 Younger individuals are in a fluid, ever-changing phase of life, experiencing body changes, developing
373 their identity and understanding social norms.³³ Our findings suggest heightened HSB in those coping
374 less well and seeking control, compared to earlier findings, where reduced motivation for HSB was
375 seen in adults with societal pressures following amputation.³⁴

376

377 A distinctive theme in this study was the notion of adjustment and internalisation of identity around
378 social identity, with Para-athletes experts in their own disability.³⁵ Our SMT participants advocated
379 athletes' ability to develop independent HSB where they combine their own metacognition, peer
380 influence and align knowledge towards their own health and thus sporting performance.

381

382 A strong theme was the perceived effort of requiring new technology and current prosthetic
383 adjustments. Whilst the need for change in relation to injury risk mitigation might have been queried,
384 athletes' views and the pressures that may come with change were widely respected. Our findings

385 suggest athletes with limb deficiency avoid weight bearing sports as a solution to the prosthetic
386 creating a barrier to participation due to risk of injury.³⁶

387

388 The notion of technology advancing quicker than our understanding and implementation supported
389 HSB. Good ³¹ reports experiences where biotechnology influences clinical practice, with patients
390 desiring the newest technology, despite the unknown outcome. Earlier research found that acquired
391 amputees confided in their peers for ideas around prosthetics, corroborating our findings with
392 athletes collaboratively problem solving and exploring new experiences.³⁷

393 Equipment has a strong influence around performance. It was perceived by the SMT as the main factor
394 towards reaching performance goals, second to the athlete themselves. The understanding of
395 technology by staff and athletes is paramount to success. For instance, one discussion highlights the
396 concern around impact and the need for the athlete to understand this. The thought of a new
397 technology that would take away some of the problems with the skin prosthetic interface would be
398 enticing however there equally comes understanding of recovery time, associated risks of surgical
399 interventions and open wounds, time out of training (loss of fitness) and a lack of evidence to suggest
400 success within the elite environment. There was a sense of know from practitioners that aired caution
401 to this route and right to do so given the lengthy recovery.

402

403 With congenital limb deficiency, the SMT acknowledge that the nature of the limb deficiency may lend
404 itself to certain equipment working or not working for that individual which may influence their
405 identity choices, although the SMT note that congenital athletes generally seem more comfortable to
406 be able to propel themselves round in a wheelchair. Hence, showing a contrasting metaperception of
407 being in a wheelchair, they can see the best solution within a certain environment.

408 In an example of being in the Paralympic Village, the pinnacle of most Paralympic careers, athletes are
409 often required to increase their footfall due to the setup. ³⁸ Despite this, some continue to refuse
410 mobility aids and additionally in an environment where mobility aids are everywhere and where the

411 surrounding population mirror the same Paralympic identity. The SMT face an ongoing pursuit against
412 challenges of personal attitudes/internalisation of identity and aligning performance goals to optimise
413 health.

414 'Post traumatic growth' is a well-established concept, with similar themes seen within this study; a
415 period of growth occurring following amputation. ^{37,39,40} Where post traumatic recovery is
416 unpredictable and unique to the individual, emotional HSB must be individualised. ³⁹ The idea of an
417 adjusting identity in this sense was not explicitly transferable to those with congenital limb deficiency.

418

419 **Strengths and Limitations**

420

421 The use of SMT members and athletes within focus groups was a unique strength to inform
422 collaborative perceptions with a diverse sample. Strength is observed methodologically, in the
423 expertise of qualitative researchers and experts in the Para-athlete field, conforming relevance and
424 validity within the data collection and analysis; additionally use of Pope and Mays ²⁰ criteria for
425 assessing quality of subtle realist research, validity and relevance are considered. ¹⁵ A limitation of the
426 study was the combined use of face to face and remote data collection for the second focus group
427 (due to Covid-19); this may have impacted on participant interactions, or emotive responses. This may
428 also have contributed to fewer challenging responses which could have established a deeper true
429 meaning or emotion.

430 A clear limitation is highlighted using just two athletes, potentially limiting comprehensiveness
431 towards a reflexive analysis and ability to observe a "fair dealing" of perspectives. Secondary to this,
432 the discussion must be formulated round perceived concepts that the SMT have without opportunity
433 to consolidate feelings.

434 **Practice and Research Recommendations**

435 Findings support the need for greater awareness of prosthetics in weight bearing sports, where
436 equipment change may negate benefit. Future research into how these findings can further influence
437 the SMT in Para-athletes with limb deficiency would be welcome. Knowledge of new equipment and
438 technology is highly relevant alongside medical discussions and shared decision-making with the
439 athlete to align health and performance goals. The importance of relationships between the medical
440 staff, coaches and athlete drives willingness of athletes to seek health advice. SMT should be mindful
441 of reduced HSB in this population group and accept a need to ask “the uncomfortable question” where
442 themes have highlighted reduced HSB associated with the internalisation of certain identities.
443 Differences in the participant interactions between the groups (with and without athletes) suggests a
444 need for future research to explore individual assumptions and influenced opinions.

445

446

CONCLUSION

447

448 Findings from this exploratory study suggest a key theme around ‘identity’ in relation to athletes with
449 limb deficiency and their HSB. Findings also highlight the importance of knowledge and understanding
450 of this ‘noise’ to optimise athlete health and performance.

451 **Abbreviations**

452 HSB: Health seeking behaviour

453 SMT: Sports medicine team

454

455

456

457

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- 555
556

557 **Figure legends**

558 **Figure 1:** Figure 1 A Flow Chart to Demonstrate the Iterative Data Analysis Process and Processes to
559 Establish Rigour

560 **Figure 2:** Emerging themes and subthemes

561

Table 1: Participant characteristics

| Focus Group | Participant | Gender | Role in Parasport |
|-------------|-------------|--------|---|
| 1 | P01 | F | Member of the SMT - Physiotherapist |
| | P02 | M | Member of the SMT – Strength and conditioning coach |
| | P03 | M | Member of the SMT – Physiotherapist |
| | P04 | M | Member of the SMT – Physician |
| | P05 | F | Member of the SMT – Physiotherapist |
| | P06 | M | Member of the SMT – Physiotherapist |
| | P07 | M | Member of the SMT – Strength and Conditioning Coach |
| 2 | P08 | M | Para athlete with a classified impairment of acquired limb deficiency |
| | P09 | F | Member of the SMT - Physiotherapist |
| | P10 | F | Member of the SMT - Physician |
| | P11 | M | Para athlete with a classified impairment of acquired limb deficiency |
| | P12 | F | Member of the SMT - Physiotherapist |
| | P13 | F | Member of the SMT - Physiotherapist |

Figure 1

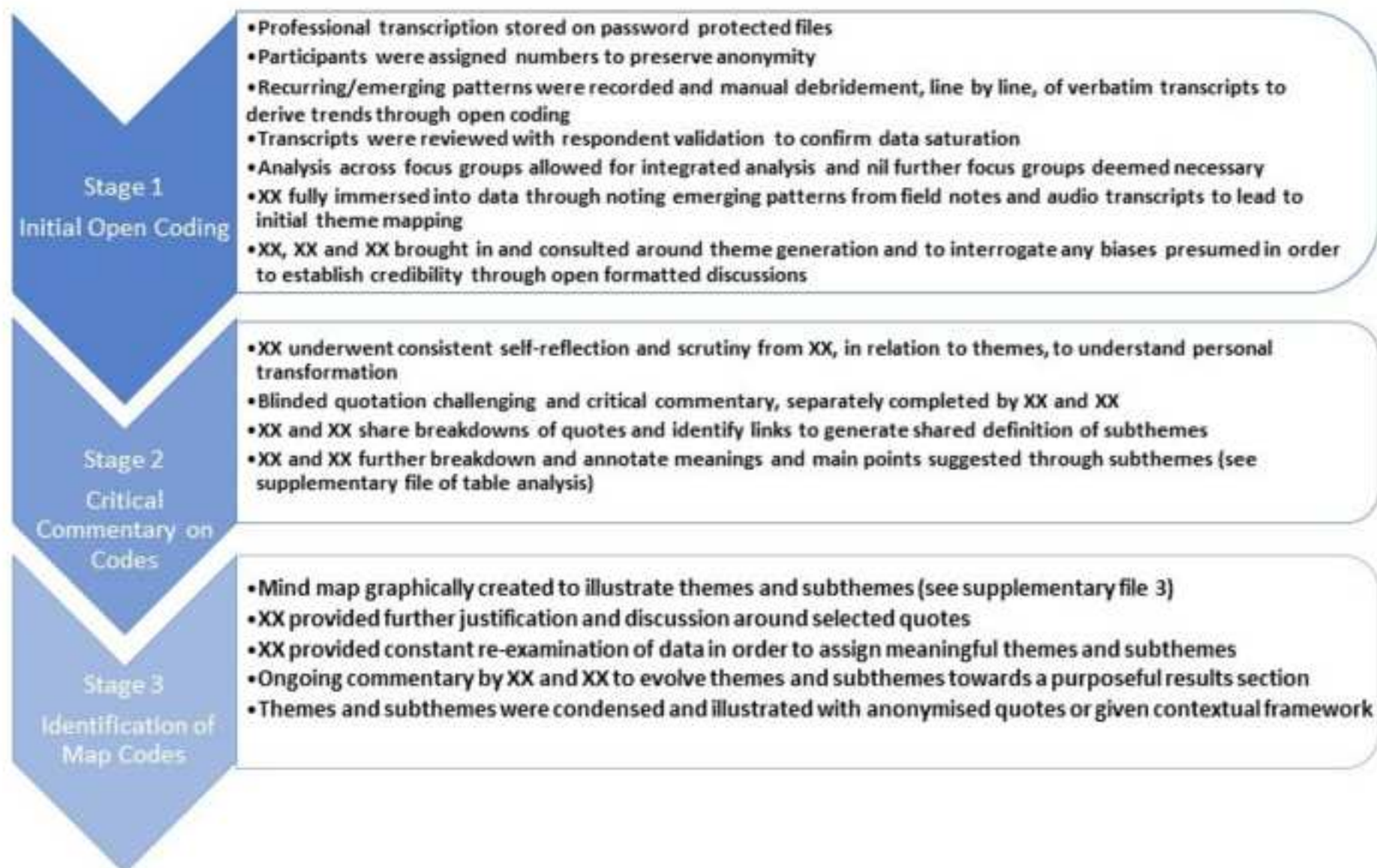
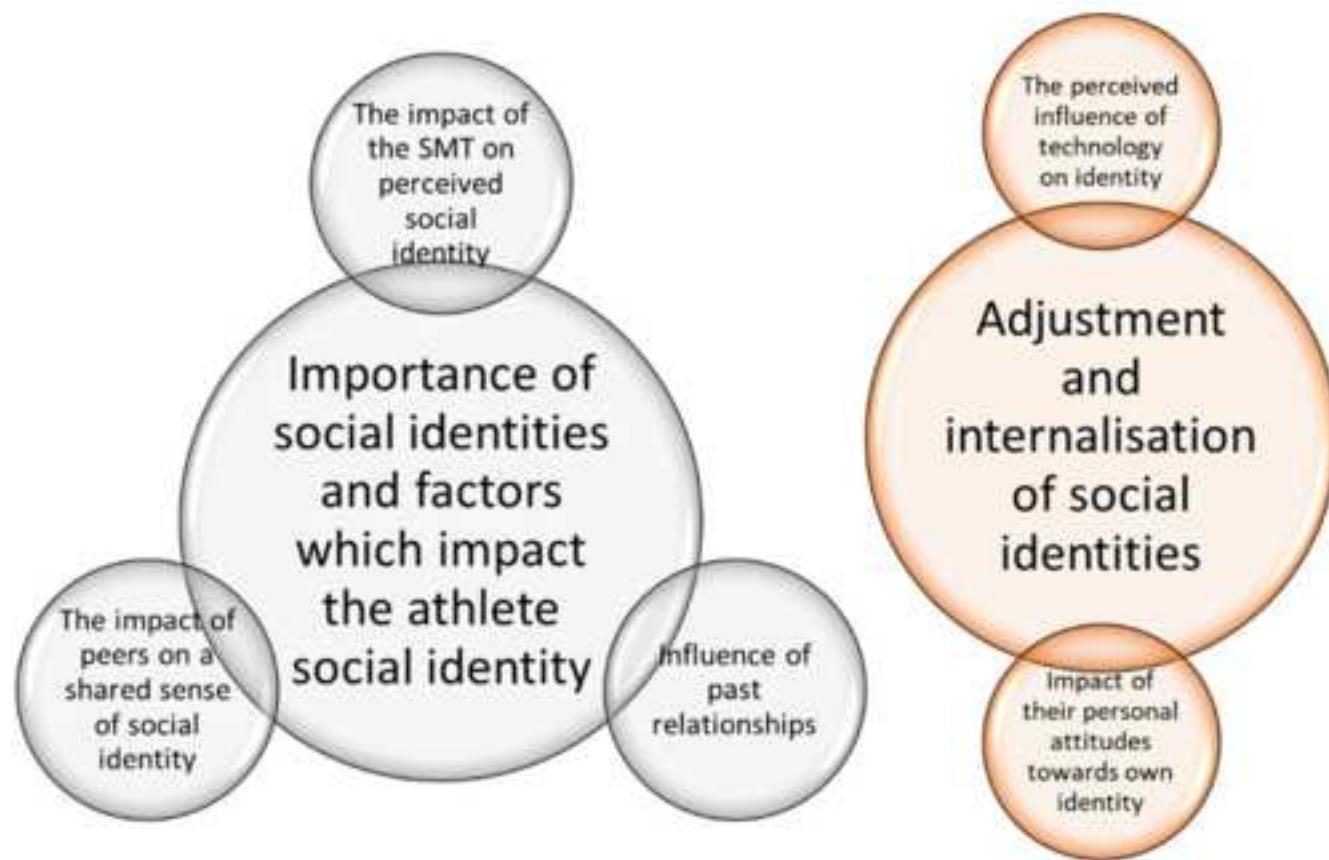
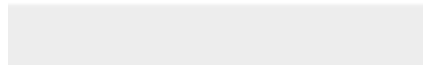


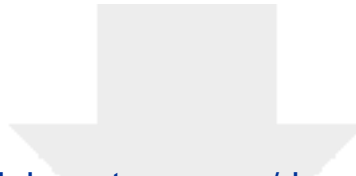
Figure 2





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