

## 1 **Abstract**

2

### 3 **Purpose**

4 The aim of this work was to qualitatively explore the personal perspectives of prosthetic and orthotic users, in  
5 the context of their past and present experiences and understand their insights for the future.

### 6 **Materials and Methods**

7 A narrative exploration study design employing a phenomenological approach was used.

8 Semi-structured interviews were conducted with three female and two male prosthetic and orthotic users from  
9 Australia and the United Kingdom. Interviews were analysed, coded and key themes and sub-themes identified.

### 10 **Results**

11 Three themes were identified. The Maximising Opportunity theme linked sub-themes of recreation and pushing  
12 boundaries. The Health Care Network theme included sub-themes of communication, peer support and building  
13 a team. The final theme, Changes over time, included sub-themes of disability perception, advice and  
14 advancements over time.

### 15 **Conclusion**

16 Prosthetic and orthotic users identified there had been vast changes in disability perception, disability rights,  
17 and their role in the health care system, along with the variety of technology and materials available. Key  
18 findings were that prosthetic and orthotic users want to be listened to, considered central to the health care team,  
19 and had a deep understanding of their own health care needs.

20

- 21 • **Keywords:** *Prosthetic orthotic users, experience, disability, perspective Qualitative*

22

## 23 **Background**

24 The way in which healthcare has been delivered has developed significantly over the last 50 years [1,2].

25 Up to and including the 1970s, the medical model of healthcare predominated [3,4]. This model

26 considered the medical expertise, namely ‘the doctor’ at the centre of the health care process, with the

27 other care providers, including the prosthetic and orthotic users, their families and/or carers at the

28 periphery [2]. The focus of health care delivery has evolved in recent decades to consider the patient, in

29 this case, the prosthetic or orthotic user or client, at the centre of their health care system [2,5]. This has

30 further progressed in recent years to an approach where the patient serves as the principal manager of

31 their care, informed through information provided by an integrated team of qualified and skilled

32 professionals [5-8]. In order to address this fundamental shift in focus of health care delivery, change  
33 in professional development and education has been necessary.

34 To address this requirement for change in the delivery of health care, health professions, such as  
35 prosthetics and orthotics, have been forced to evolve. As recently as the 1970s, the variability in  
36 prosthetic and orthotic clinician competency had been highlighted as problematic, and suggestions of a  
37 more formal and systematic approach to education, centred around key topics, was proposed as a  
38 solution [9-11]. As health care systems have modernised, so too has the prosthetic and orthotic  
39 profession, in some ways perhaps more rapidly [10,12,13]. As a result, the changes in the profession are  
40 likely to have influenced the experience of those using these Prosthetic and Orthotic services.  
41 Historically, most prosthetists and orthotists were apprentice-style trained technicians, who learned how  
42 to produce or replicate particular prostheses and/or orthoses [2,12,14]. Over the past 50 years, clinical  
43 training in most high-income countries has shifted towards a tertiary qualification where prosthetists  
44 and orthotists are educated to be competent members of the Allied Health team, demonstrating both  
45 clinical skill and problem-solving abilities [13]. In these countries, these changes to the training and  
46 education of prosthetists and orthotists are mirrored by advances in, device, manufacturing and services,  
47 technology resulting in a wider possible range of service experience that a prosthetic or orthotic user  
48 receives in 2020 [9,11,14,15]. It must be noted however, that these advancements in training and  
49 education, as well as access to technology are not consistently mirrored in middle- and low-income  
50 countries. Consequently, changes in prosthetics and orthotics health care, education, and access to  
51 technological advancements have not seen universal access [16].

52 The role that the prosthetic or orthotic user plays in their health care has also changed, mirroring the  
53 changes and advances in the healthcare systems, that the users find themselves in [17]. For example,  
54 assistive device technology has advanced greatly and these advances in technology and increases in  
55 choice impact on the ability to control and influence their own health care. While technology and  
56 advanced functionality is often seen as one of the biggest changes in prosthetic and orthotic care, more

57 recently the ability for prosthetic and orthotic devices users to customise their devices has also impacted  
58 how people view their devices, how users view themselves and users are viewed by the community.  
59 People's autonomy over their healthcare is now something that is assumed and encouraged in cases  
60 where individuals do not independently assert this autonomy [18] [19].

61 The way in which health care system processes have changed are to a large extent relatively easy to  
62 describe. Though, how these process changes impact the way people move within health care systems  
63 and their experiences of their own health care are harder to quantify, and arguably, the most important  
64 to explore. The impact of changes in healthcare organisations, device functionality, and the opportunity  
65 for customisation, the education and training of prosthetists and orthotists, along with the education of  
66 the prosthetic and orthotic users and increase in sources of information available to them, are all likely  
67 to interact and impact on a user's experiences [20]. Prosthetic and orthotic users who have had lifelong  
68 relationships with service providers, and rich experiences, are able to provide insights into the impacts,  
69 both positive and negative, on the changing nature of healthcare, assistive technology and rights of a  
70 person with a disability.

71 Therefore, a key question that remains is how the changes in the design and delivery of healthcare in  
72 prosthetics and orthotics have been perceived by the users themselves, over an extended period of time.  
73 As people at the centre of these developments, their views provide insight into the relevant success of  
74 changes, current challenges, and direction for future development. As such, the aim of this work to  
75 qualitatively explore the personal perspectives of prosthetic and orthotic users, in the context of their  
76 past and present experiences and understand their insights for the future.

77

## 78 **Methods**

### 79 *Researchers and Reflexivity*

80 Semi-structured interviews were undertaken by two researchers (xx and xx) using a standardised  
81 interview guide. Both researchers were academics working in higher education, educated to doctoral  
82 level, focussing on research related to prosthetics and orthotics. xx is a female prosthetist and orthotist  
83 whilst xx is a male biomechanist. The interviewers both worked in rehabilitation research and brought  
84 bias around their understanding of prosthetic and orthotic usage and healthcare. These biases were  
85 addressed through the semi-structured interview questions and noted in the analysis.

86  
87 Both interviewers did not have healthcare or personal relationships with the participants before  
88 conducting these interviews. Participants understood the purpose of the research was to explore their  
89 experiences as being a prosthetic or orthotic user over their lifetime. The reasons for the interviewers  
90 undertaking the research were conveyed to participants before the interview. Participants were informed  
91 that the purpose of the research was to explore their lifetime experiences as a prosthetic or orthotic user.  
92 This purpose was conveyed through the informed consent process and the initial discussions before  
93 conducting the interview. The study was approved by an institutional research ethics committee (xxxxx)  
94 and all interviewees provided informed consent prior to conducting the interviews.

### 95 *Study Design*

96 This research was a narrative exploration of a person's experience of being a user of a prosthesis or  
97 orthosis. This research approach used a phenomenological approach to explore the multiple realities of  
98 the experience of prosthesis and orthosis users and present these as different perspectives. The rationale  
99 for this approach was that this method would allow a rich exploration of the user experience and the  
100 meaning and value that these users assign to the experience. Participants were purposively sampled  
101 through known contacts and advertisements on social media requesting participants. The goal for the  
102 purposive sampling was to ensure that that the sample included in the study were prosthetics and orthotic  
103 users of varied age and gender who were geographically dispersed. Participants were contacted via

104 return email after first independently expressing an interest in participating in the research. All  
105 participants who indicated interest participated in the interviews.

106

### 107 *Data collection*

108 All interviews were conducted via online videoconference. Interviews were conducted at a time and  
109 place convenient to the participants. All interviews were conducted with the interviewer and participant  
110 only. Interviews were undertaken in the United Kingdom and Australia.

111 Inclusion criteria were that the participants were prosthetic and orthotic users, they had begun their  
112 prosthetic and orthotic use before the age of 18 and were fluent in English.

113 The questions were developed based on strategies outlined by Liamputtong [21] and Thorne [22] and  
114 were pilot tested with two prosthesis and orthosis users by xx prior to the use in the research. Summaries  
115 of each interview with key themes highlighted were provided to all participants and confirmation was  
116 sought that the insights gleaned were an accurate representation of the interview and their experiences.  
117 The interviews were audio-recorded. Interview times were on average 54 minutes (range 18 minutes –  
118 107 minutes). Interviews were coded as they were undertaken and interviews were conducted with all  
119 participants who agreed to participate in the research.

120

### 121 *Analysis and findings*

122 All three authors coded the data. Thematic coding was undertaken. First, line by line coding was  
123 conducted using NVivo QSR™, this thematic coding led to the development of nodes and a coding tree.  
124 Nodes were then examined by all three researchers using the coding tree and grouped through which  
125 key themes emerged. From these key themes, sub themes that were related became apparent and were  
126 structured into a framework. The three researchers reviewed these and aligned this with the coding tree.

127 Where there was disagreement in the analysis, a discussion was undertaken and the interviews reviewed  
 128 until consensus was achieved.

129

130 **Results**

131 Five interviews were conducted with participants from the UK and Australia. There were three female  
 132 and two male participants, two of whom were lower limb orthosis users (AFO and KAFO) and three  
 133 of whom were lower limb prosthesis users (one person with unilateral transtibial limb loss and one  
 134 with transfemoral limb loss and one participant who had bilateral transfemoral limb loss). The age  
 135 range of the participants was 33 - 67. All participants were or had been in paid work. Participants had  
 136 become prosthetic and orthotic users from birth through to the age of 17.

137

Gender	Age range	Type of Prosthesis or Orthosis user	Location
Female	33-67	KAFO user unilateral transtibial prosthesis user bilateral transtibial prosthesis user	2 Australia 1 UK
Male	42-67	AFO user unilateral transtibial prosthesis user	1 Australia 1 UK

138

139

140 Three key themes were derived from the data; *Maximising opportunity*, *Health network*, and *Changes*  
141 *over time*.

142 **Figure 1 here**

143

#### 144 *Maximising opportunity*

145 Participants spoke of maximising their opportunities, not letting others' perceptions of their disability or  
146 their disability itself, impact what they wanted to do or be. They often displayed an overt 'can do'  
147 attitude. The importance of recreation, sport, perseverance, pushing boundaries and not accepting the  
148 status quo were all highlighted as factors that positively impacted people's lives and the outcomes they  
149 experienced as prosthetic and orthotic users.

150

#### 151 *Recreation*

152 Participating in recreation and seeing others participate in recreation were all factors that impacted the  
153 participants 'living their best life' and maximising the opportunities they have to participate in their own  
154 lives.

155 Seeing other people with disabilities participate in sports and activities, people who looked like they did  
156 strongly influenced their positive outlook on recreation.

157

158 *It's the same thing as you see kids now whether they're disabled or whatever it is. It's*  
159 *so powerful to see somebody who is like you doing something great. Whatever it is,*  
160 *whether it's a sport or it's business or it's whatever. It's powerful to see that. I think*

161 *that was the turning point for me, just getting to know other people that had achieved*  
162 *things and also had one leg or didn't have any legs. Participant 1*

163

164 *...my friends would be going [skiing] and it was only that I worked with somebody*  
165 *who was probably quite tenacious like myself and said, "Well, you can do it. I've seen*  
166 *people do it. We'll find somebody". Then after that, I became involved in the disabled*  
167 *skiers and we used to take groups down and things like that....Participant 5*

168 *Perseverance and pushing boundaries*

169 Perseverance and the need to keep pushing and keep 'trying' were identified by all participants as  
170 something that was a prerequisite to achieving what they wanted. Those who became prosthetic and  
171 orthotic users as children spoke of their parents being strong advocates, encouraging their inclusion in  
172 mainstream schooling, querying healthcare decisions, and not accepting that they should be treated or  
173 forced to do things differently. Those who became users in their late teenage-years spoke of having to  
174 advocate for themselves and not accepting the views of others without question. Participants spoke of  
175 the need to challenge and push boundaries, to not accept society's or others' views of what they could  
176 or should do, and to forge their own path.

177

178 *She [mum] and dad worked really hard to make sure I probably overdid it a bit to*  
179 *make sure that I got the same opportunities as everybody Participant 2*

180

181 *I had said to my mother that I was going to lead a normal life and I just persevered*  
182 *with it. ...Well, I left home when I was 19. I moved a long way from home. It was*



183 *really hard at times ... I was able to look after myself and ... I knew that I wanted to*  
184 *live a normal life and I wanted to do what everybody else was doing and I wanted to*  
185 *explore the world. I knew there was a world out there. Participant 3*

186

187 *Anybody can get on with life without five toes and an ankle. It just means you can only*  
188 *count up to 15 and you have to learn to drive an automatic car and that's all easy.*

189 Participant 5

190

191 Not accepting that there was a difference between what they, the prosthetic and orthotic user, could do  
192 and what their peers or others were doing led to the participants pushing what they could or what was  
193 socially acceptable for them to do.

194 *Then I think it was once I started becoming active and I think it was to just broaden my*  
195 *horizons of being exposed to people with a disability and the amputees and seeing what*  
196 *they could achieve and just being exposed to those people was a huge turning point...*

197 Participant 1

198

### 199 ***Health network***

200 The personal relationships that participants had developed with their prosthetist or orthotist all impacted  
201 on their experience of being a prosthetic and orthotic user. Participants talked about developing close  
202 relationships with select clinicians and how this greatly benefitted their care, including managing people  
203 involved with their care. Communicating their needs and desires clearly to achieve the outcomes they  
204 wanted.

205

206 *Communication*

207 The importance of communication was highlighted by all participants. Participants indicated that the  
208 quality of communication provided by health care staff affected their care. For example, they noted  
209 positive experiences when communication was clear, open and honest. Conversely, they negatively  
210 described instances where communication was absent, limited, or confusing.

211 *I guess the big issue is nobody listens. I just feel that listening is a bit of a problem.*

212 Participant 3

213

214 Participants spoke extensively about the importance of being listened too. The need for prosthetists and  
215 orthotists and other members of the health care team to listen and hear what the user wanted, what their  
216 goals were, and plans for meeting these.

217

218 *I know what's right for me and what feels good and what I need to compliment my*  
219 *lifestyle. Sometimes it's not easy to get that and sometimes it's a bit of a fight and*  
220 *trying to explain why I feel this is the right thing and not what you're suggesting. I*  
221 *think that's the constant battle between patient and prosthetist is that you have to*  
222 *try and articulate how you feel. Sometimes it doesn't fit with what it says on the*  
223 *paper and that's the difficulty, I think. Participant 1*

224

225 *...there was a person who you could always talk to about issues. I guess in my early 40s my*  
226 *body started deteriorating. Nobody would listen to me or whatever. I went to see him [Dr] and*  
227 *so I used him as that linchpin...he would always find somebody to treat me. Participant 3*

228  
229 Participants identified a desire for health care providers to understand that patients have a unique insight  
230 into their bodies and a greater understanding of what works for them. Treating the user as the expert of  
231 their body, listening to their feedback, and responding to their desires resulted in a positive experience.

232

233 *I do know my body very well. I just think that they also need to give the client the*  
234 *opportunity to voice their concerns and have their concerns taken seriously. They*  
235 *should be looking at what that person's goals are, whether it's this year, just being*  
236 *able to walk or whatever and want to go back to work.... Participant 3*

237

238 *You might have some ideas and they might know straight away, there's probably not*  
239 *going to be effective or it's not going to work for you. You have to trust their*  
240 *knowledge in their area of expertise, but similarly, they've got to be willing to listen*  
241 *to where you're coming from and know that, yes, that might be what it says on*  
242 *paper. Participant 1*

243

244 *I'm the expert on my body, I will tell you if something's not working... encourage*  
245 *your clients to speak up to say what they really need, what they really want... I'm*  
246 *really lucky because knowing so many orthotists and prosthetist, the really good*

247 *ones do work as partners... I think that that's the biggest innovation in our pay in*  
248 *the last say, 18, 12 years that I've seen, this is recognition that people with*  
249 *disabilities are experts in their own right. Participant 2*

250

251 *Building a team*

252 Participants talked about the changes that have occurred in health care, how the success they have  
253 achieved is due to the teams of people they have worked with, having educated and developed cohesive  
254 and mutually respectful relationships. It was important for the participants to be central to that team and  
255 for the health care professionals in that team, to work with each other.

256

257 *The joy of going into something and having conversations with the orthotists,*  
258 *and the rehab doctor, and the OT, and whoever, and the physiotherapist about*  
259 *this is what you need and including me in the conversation. Participant 2*

260

261 *Interviewer: Was [the physio] pushing for that [orthotic treatment] for you or*  
262 *did you have to push for that [orthotic treatment] yourself?.....*

263 *Participant 4: She, my physio pushed.*

264

265 *Peer support*

266 Peer support and learning from others was a prominent thread through many conversations. The  
267 feeling of commonality and learning from the experiences of others, the sense of community, and

268 recognition of challenges were all highlighted as participants as key factors to their experiences of  
269 being a prosthetic and orthotic user.

270  
271 *Like some are like "Oh my god, yes it's so sore." I get it. I understand, "Have you tried this?"*  
272 *It's so nice to have those conversations. Participant 1*

273  
274 Learning from others was commonly identified as a positive experience from prosthetics and orthotics  
275 users. Changes to the ways in which treatment is delivered were highlighted. Some respondents  
276 indicated that common fitting and gait training spaces that they had previously used were such positive  
277 learning experiences and modern layouts, such as separate fitting rooms and private gait corridors, left  
278 them with feelings of loneliness and isolation. Other respondents, however, cited the lack of privacy in  
279 these large communal spaces as feeling like an invasion of privacy.

280  
281 *I keep telling my [prosthetist] that I got more from being in a room with other amputees and*  
282 *talking about stump care, and how to wear your underwear, and how to put your leg on, and*  
283 *what to do with this sock. Participant 3*

284  
285 *The way that the rooms are set up there is that you sit in with the other women. It's very*  
286 *exposing, ... on the walkway in front of everyone. Whereas in [previous clinic] ...we had our*  
287 *own cubicle and, yes, the rails were out in the middle of the room, but there was curtains that*  
288 *you could pull... you didn't want to walk in front of everyone. Participant 1*

289

290 *I used to see my friends wearing AFOs, and I used to beg [my Physio] for the pair, .... I*  
291 *thought I'd like to wear some of those so I could walk. Participant 4*

292

### 293 *Changes over time*

294 Participants talked about their personal perceptions and the perceptions of others changed over time.

295 For example, they noted changes in how others viewed their roles as patients, how they viewed

296 themselves as users, and how others viewed them in society at large. Participants also spoke of the

297 technological advancements that have occurred over time, bringing with it both positive development

298 and potential difficulties in the form of inequities in access. Through the experiences that participants

299 have had often over many generations, there were words of advice that the prosthetics and orthotics

300 participants had to offer to their peers explored in the sub themes below.

301

### 302 *Disability perception*

303 Marked changes in the perception of people with a disability have occurred over the past 50 years.

304 This combined with changes around gender and diversity has changed how people with disabilities are

305 perceived and participants highlighted how these attitudes and perceptions impacted them.

306

307 *at that time [50 years ago], you were considered to be a cripple. That's the way people viewed*

308 *and I guess I was born with determination or I got it anyway., I do recall a limb maker who I*

309 *thought was quite sexist. If I wanted to wear a bit higher shoes, I had to change the feet and all*

310 *that sort of thing. He made it very difficult for me to actually do it myself. Participant 3*

311

312 *Advice*

313 Having gained an immense amount of knowledge, experience, and expertise as prosthetic and orthotic  
314 users, participants were keen to offer advice to others, both prosthetic and orthotic users but also the  
315 prosthetists and orthotists who work with them.

316 To prosthetic and orthotic users, the message of not letting what other people think, might think, or  
317 might say hold you back was deemed to be important. Not allowing others' expectations of what is  
318 normal or what they think you can do define what you do. Spending time with a community of people  
319 who are "like you", especially for children, the importance of seeing other people who had similar  
320 disabilities gave a sense of belonging and a place in their community. This advice was combined with  
321 the practical advice for self-care or care of a device, such as, prosthetic sock use, prosthetic height and  
322 looking after yourself in a physical sense.

323

324 *I always wear a dress when I'm working to show people my orthotic. I always say,*  
325 *"That it will cost me \$6,500, why would I hide it under trousers?" It's not a fashion*  
326 *accessory but it's not something I'm ashamed of. Participant 2*

327

328 *it won't be easy, but it can be done. It depends on your mindset as to what sort of*  
329 *life you want to live. ... I'm a very positive person, that I'm an eternal optimist. I*  
330 *guess you do have negative thoughts, but it doesn't last long. Participant 3*

331

332 *even now. I have days where I'm like, "Well, I don't want to go and do that because*  
333 *there are a lot of people there and I don't want to go and do that." It's not very*

334 *often, but it's still there, I still get self-conscious about things. I think a lot of that*  
335 *turning point for me of being comfortable with who I am, came from being around*  
336 *other people like me and I only did that through..., being at the limb center and*  
337 *being in the kids' room. There were other children that were missing legs or*  
338 *whatever. That was brilliant because I was like, "Well, we can just play together*  
339 *and it was fine."*

340 *... once I started becoming active and I think it was to just broaden my horizons of*  
341 *being exposed to people with a disability and seeing the amputees and seeing what*  
342 *they could achieve and just being exposed to those people was a huge turning point.*  
343 *I don't think it was any particular person. It was just the more I became involved in*  
344 *sport and that community that it brings. Participant 1*

345

346 *Always wear good shoes and be careful in your [prosthetic] height. Just look after*  
347 *your socks and basically, that's all. Participant 5*

348

349 Advice to prosthetists and orthotists has been touched on within these results as participants talked about  
350 the need for healthcare professionals to listen and understand the degree to which prosthetic and orthotic  
351 users understand their own bodies and needs.

352

353 *Include me in the conversation....., encourage your clients to speak up to say*  
354 *what they really need, what they really want. Participant 2*

355



356 ...get to know what they do and get to know what they want from their limbs.

357 Participant 5

358

359 *I think it's just to be just aware and conscious of the fact that everybody is*  
360 *completely different ...because what works for one person won't work for*  
361 *another. okay, so maybe they can walk further with a better gait, but actually it*  
362 *takes twice as long.*

363 *What's the point? Because they can't live the way that they want to, so they might*  
364 *be willing to put up with a slightly altered gait for the fact that they can do what*  
365 *they want when they want and how fast they want to do it. I think that's the crux*  
366 *of it. It must be really hard for clinicians to get to that point, but I think it's just*  
367 *keeping those communication channels open. Participant 1*

368

369 *Advancements*

370 The participants spoke of the technological, societal and health care developments that have occurred  
371 during their time as users. Often, naming the rapid pace at which these developments have occurred.

372 *Every time I turn around there's something new. I went from that fixed knee to a*  
373 *free knee. The first time in my life I walked with a free knee. I walked like everybody*  
374 *else. Participant 1*

375

376 Others spoke of how these rapid developments often placed treatments or devices out of reach  
377 economically.

378

379 *[it]would be huge. Is making that [technology] more accessible to people that*  
380 *don't have millions ...in the bank Participant 2*

381

382 Finally, participants spoke of the ability to customise and design devices for specific activities and the  
383 gains things like this have made in their lives.

384

385 *we now have swimming braces. ...[mines] been spray-painted pink and black to*  
386 *match my bathers. Participant 2*

387

388

## 389 **Discussion**

390

391 When exploring the experiences of prosthetic and orthotic users over their lifetimes and asking how they  
392 saw their futures, three key themes were identified from the interviews. These themes were Maximising  
393 opportunity, Health network, and Changes over time. These themes illustrate how prosthetic and orthotic  
394 users feel that their role in the healthcare system, the perceptions of others, and the impacts of prosthetic  
395 and orthotic technology and methods of care have changed during the past 50 years.

396 The changes in the health care model over time, which places importance on the team approach with the  
397 user central and in control, has been shown through a range of studies to impact on satisfaction and  
398 feelings of self-efficacy [19,23,24]. These impacts were corroborated in the current study, with the views  
399 that the participants expressed around the changes that have occurred, in being listened to, heard, and  
400 considered as a key component of their own health.

401 *I guess the big issue is nobody listens. I just feel that listening is a bit of a problem.*

402 Participant 3

403 This is consistent with literature showing that within healthcare, people's goals and desires are now  
404 being considered to a much greater extent and much more often in recent times [18]. This is particularly  
405 relevant in consideration of the concept of self-determination in disability [24,25]. However, the  
406 common thread found in this study was, that while the concepts of self-determination are readily  
407 accepted, prosthetic and orthotic users want health care providers to listen and to hear what they are  
408 saying. Prosthetic and orthotic users spoke of recognising how well they understood their bodies and  
409 their own needs. Whilst many aspects of health care have advanced considerably, this very basic idea of  
410 listening and being heard is still a vital factor in ensuring a positive health care experience, including  
411 for prosthetic and orthotic users [26]. This concept of listening and being heard is consistent with  
412 contemporary healthcare practice that supports the notion of the health care user being central and in  
413 control of their health care journey [23,27-30].

414 Respondents talked about how the changing profile of disability has for the most part been advantageous.  
415 It was interesting that the users described changes that have occurred more recently with recreation and  
416 paralympic sport. Evidence shows that, increasingly, people with disabilities are participating in  
417 physical activity and recreation with positive effects on community integration, quality of life, and  
418 participation [27-30]. Positive steps forward in terms of the perceptions of people with disabilities were  
419 tempered in the current study, by concerns regarding expectations about what people with disabilities  
420 should be able to achieve. There was a sense of problematic societal expectations that prosthetic or  
421 orthotic users should aspire to excel and 'overcome' physical limitations and in a sense, look to  
422 normalize themselves as much as possible. These societal representations of prosthetic and orthotic users  
423 present a narrow image that may not be attainable, nor desirable for everyone and demonstrate a concept  
424 of ableism or needing to be the same rather than adapting for the individual [25].

425

426 *I think a lot of people have said to me, they were like, "I love the Paralympics."*

427 *Maybe the perceptions are slightly changing towards people with disability and*

428 *disability in general, but then you don't go up to just any able body person and go,*

429 *"Why aren't you an Olympian?" Participant 1*

430 Arguably, one of the biggest changes over the past 50 years is the materials and technologies that  
431 prosthetists and orthotists can utilise to provide positive outcomes for the people they work with. With  
432 changes in materials from metal and leather, to plastic, carbon fibre and now alternative forms of  
433 manufacture, such as additive manufacturing, how devices can be made, their weight and designs now  
434 vary greatly [31]. Interestingly, the respondents talked about the fact that whilst the technological  
435 changes are positive and that new materials, new designs, and new components all positively add to  
436 their experiences, often the most expensive, newest, or technologically advanced and assistive device is  
437 not always the ideal solution for every user.

438 *We stuck with the very old school thing which I wanted to get away from but soon*

439 *realized it's the best option for me. Participant 2*

440 Simplicity, weight, and having something that they are confident and comfortable using was important.  
441 This was often for very specific personal reasons often related to familiarity. This concept is supported  
442 through a range of other studies where comfort or absence of pain, and satisfaction in a device are shown  
443 to impact on quality of life [32-34].

444

## 445 **Limitations**

446 With the purpose of the study being to understand the experiences of prosthesis and orthosis users over  
447 time, the diversity in gender, devices used, and reasons for use give a broad range of experiences and  
448 meet the needs of the current study. In addition, the utilization of small sample sizes to gain an

449 understanding of the experience of a diverse group have been supported by several studies.[35-37]  
450 However, a more comprehensive range of perspectives may have been gleaned from a larger and  
451 particularly more geographically diverse pool of users. Related to this, the study attempted to gain a  
452 cross-section of both prosthetic and orthotic users, who ranged in age, gender, and diversity. Recruitment  
453 limitations did limit this to only lower limb. Additionally, the focus on users from high-income countries  
454 (Australia and UK) means the results may not represent the experience of users from low- and middle-  
455 income countries.

456

## 457 **Conclusion**

458  
459 In conclusion, when exploring the long-term experiences of prosthetic and orthotic users, three key  
460 themes of Maximising opportunities, Health network and Changes over time emerged. These three key  
461 themes and additional subthemes were developed using semi-structured? interviews. Changes identified  
462 by participants in this study that occurred over the preceding 50 years included changes in the perception  
463 of disability, the healthcare system, and the prosthetic and orthotic user's ability to maintain control over  
464 their own health care, along with changes to technology and materials. Further research exploring if  
465 these differences are consistent in other countries, and understanding the differences in low- and  
466 middle-income countries, would add to the evidence base and the understanding of the changes in health  
467 care systems, technology and the impacts these have on prosthetic and orthotic users' lives.

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469 WORD count 4935

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