

Prosthetic services: an opportunity for patient directed healthcare

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As a healthcare system, prosthetic services should be viewed positively if they provide effective and efficient treatment that delivers evidence-based interventions resulting in improved health outcomes for individuals and communities. The service should also maximise resources, minimises waste, be equitable and accessible, patient centred, and safe [4]. Ultimately, patient satisfaction represents a key indicator of a successful healthcare service [5], and prosthesis service satisfaction is significantly associated with frequency of prosthesis use, functional ability and levels of physical activity [1]. Prosthesis wearers' often have a reduced satisfaction in prosthesis services when there is poor communication from the service provider during prescription, when wearers do not feel included in the prescription process, and when there are increased prescription waiting times [2,3,6,8,9]. Prosthesis wearers' also demonstrate concern about access to new prosthetic devices and rehabilitation that fails to treat each patient as an individual [7:09]. We propose that more work is required to focus on the role prosthesis wearers within the healthcare system - the efforts they make to get access to the equipment, the ways in which they search and share information and ultimately the work they do in ensuring the service is fit for their needs.

Over the course of a PhD researching prosthetics, interviews exploring the prosthesis wearing experience of twenty amputees uncovered the lived experience of navigating healthcare services as an amputee. The recollected accounts of the majority of prosthesis wearers reflected many of the indicators touched upon by the literature, and other notable insights. For example, one prosthesis wearer demonstrated communication deficits where after months of trying to get a new leg from the NHS, she had secured funding, but no one knew what was happening ("I think NHS England said that they can give the funding, but they don't really know what's happening there so we're not sure how long it's going to take"). Additionally, the needs of individual amputees in some cases were clearly not addressed by the needs as defined by the healthcare system (e.g. *"he [the prosthetist] is also restricted by like... NHS protocol. So, for me, I'm an above the knee amputee, and for me, I think an important part of my rehabilitation is how, my prosthesis looks, as well as how it functions. Where as obviously the NHS has very restrained funds, so their primary concern is function- not how it looks"*).

One interviewee communicated intense frustration and disillusionment with prosthetics services and the system in general as opposed to individual prosthetists or clinicians: *"I don't have a problem with my prosthetists as such as an individual. I have a problem with is the bullshit when you want to walk. All I want to do is walk"*. Given the perception of walking as being something fundamental to this individual, it is unsurprising that being limited by service protocols and restrictions would lead to an intense reaction. Frustration in services did also lead to a situation which is best described as an 'us, vs. them' dynamic (e.g. *"We're*

sick of being ripped off- I'm sick of being told what I can and can't have by people with two legs. And I don't ask for the expensive stuff").

In order to better tailor service provision to their needs, amputees used passive experiences such as viewing other amputees at clinics to inspire their treatment options- *"you see someone at the clinic and they have something different and you- like I'll maybe say oh is there a reason that they've got that? Or, you know... do I need that... kind of, it just... makes you think about it"*. However, many amputees also reported being proactive and pushing their providers for a better standard of prosthetic provisions: *"I dunno, you just have to keep pushing and be aware... you can't accept the treatment that's given to you because it's... it's not good enough... if we don't push them to pay out, then their budgets won't be increased, because they won't be spending the money and stuff so... it's all... a nightmare."* Some interviewees went even further by actively seeking out knowledge, to be able to direct their prescription: *"basically what I've done is look stuff up and be really proactive online and research that things could be better and just really carefully have like, so not manipulative conversations, but you know what you're thinking of in your head and you just keep saying all the key words, because you can't just say "I saw this and I want it and it's on the internet" you have to let them [prosthetists] think it's their idea... but just eventually, it works. Like with this leg I've specifically said, I've looked it up... and she was like "oh you know more than me!"... yeah... funny that."*

The problem which emerges from our research is that access to information about suitable prosthetics is often moderated by the prosthetist, access to this knowledge is in effect hidden from the prosthesis users. The prosthesis users therefore spend a lot of time and energy seeking information and matching it to their experiences. This knowledge can act as a way for amputees to be empowered to get more from their healthcare service. We therefore foresee an opportunity to make prosthetic related knowledge (either components, general health, and issues) accessible so that users are empowered to suggest suitable components to their prosthetists. A tool which is capable of doing so would rebalance power-dynamics between prosthesis wearers and prosthetists. However, a strategy to provide amputees with accessible learning opportunities using classic approaches to learning (i.e. classrooms), would be impractical. Therefore, technology provides the capability to act as an accessible and scalable mode of communicating knowledge to amputees. To do so, interactive web or mobile based learning could be employed as a strategy to help amputees learn about topics such as prosthetic components, how to get the most out of clinical appointments, and likely problems at different points in the amputee journey. A technical solution would act to improve core competence amongst prosthesis wearers to access knowledge early on in their amputee journey that may either be mediated by prosthetists or accrued after many years of lived experience. However, one challenge with education is to make the learning process accessible but sufficiently challenging and not tedious. Furthermore, it is clear that it must ensure peer-to-peer exchange of lived experiences and knowledge. Rather than acting to replace clinicians, a technical solution must be thought of as a communication enhancement tool by improving a prosthesis wearers knowledge. With this increased knowledge, prosthesis wearers would be able to direct clinical appointments and have a better understanding of why they receive the prescription they do.

In conclusion we have found that prosthesis users are active in seeking out knowledge to better aid their understanding of what products and support services are available to enable freedom of walking. This information is gathered over often a long time and from multiple sources. The work that goes into this seeking and organisation of information is in effect invisible from current healthcare practice; it only comes together during appointment times. Therefore, a system which acknowledged the necessity for users to be active in the prescription process and which lessened the workload on individual users would have a benefit not only for the individual but the healthcare system as a whole.

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