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Understanding the Lived Experience of Five Individuals with Mobility Aids

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Abstract. The aim of our research is to understand the lived experience of people with mobility aids: How do people use their mobility aids and what is their lived experience with them? What problems do mobility aid users have outside the clinic? Our goal is to further study the needs of mobility aid users, mainly wheelchair, walker and prosthesis users, and furthermore, develop a technology platform and an application that supports more independent life for mobility aid users. In our study we interviewed five individuals about their experiences of using mobility aids. The aim was to recognize the main stages of the lived experience with mobility aids in order to understand how technology could help mobility aid users outside the clinic. The stages found in the lived experience with mobility aids are 1) Expectations 2) Getting the mobility aid 3) Using and living with the aid and 4) Change/Abandonment of the aid. In each of these stages we found important issues concerning the lived experience with mobility aids such as the importance of training to use mobility aids, the meaning of peer support, finding information online, what makes a mobility aid good, what kind of issues other people's perceptions may cause and how the built environment poses challenges for people with mobility aids.

Keywords. assistive technology, user requirements, mobility aids, lived experience

1. Introduction

A large number of people now use different mobility-related assistive technologies (ATs), and the number of new AT users is rising due to the aging population. People with different disabilities and elderly people are encouraged to keep mobile with ATs to achieve optimal function and independence [1] improving the quality of life. However, a many AT users abandon their assistive devices such as mobility aids. For example Phillips and Zhao [2] found that 29.3% of all AT devices used by participants were completely abandoned. The AT device abandonment undoubtedly results in the needs of the disabled individual being unmet [1]. According to Phillips and Zhao, the non-use of a device may lead to decreases in functional abilities, freedom, and independence, and increases in monetary expenses. The cost of device abandonment on a service delivery level represents ineffective use of limited funds. Phillips and Zhao argue that a better understanding of how and why AT users decide to accept or reject a specific device is critically needed to improve the effectiveness of AT interventions and

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enhance consumers' satisfaction with devices. We argue that in order to satisfy users' needs for ATs, it is vital to understand how do people live their everyday life with assistive devices. There is however very little known about people's everyday life experiences with ATs outside the clinic.

The aim of our study is to understand the lived experience with mobility aids: How do people use their mobility aids and what is their lived experience with them? What problems do mobility aid users have beyond the clinic? Our goal is to further study the needs of mobility aid users, mainly wheelchair, walker and prosthesis users, and furthermore, develop a technology platform and an application that supports more independent life for mobility aid users. Our study is part of the Adaptive Assistive Rehabilitative Technologies - Beyond the Clinic Project (AART-BC) [3].

2. Background

According to the US Technology-Related Assistance for Individuals with Disabilities Act [4] ATs include any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities. According to Scherer and Lane [5] assistive devices can be electronic, mechanical or computerized, and aim to compensate for sensory and functional loss in a way that allows the individual to obtain maximum independence and life satisfaction. Crutches, walkers, canes, wheelchairs and prostheses are some examples of assistive devices commonly used by people with mobility impairments. According to Verza et al. [1] the aims of assistive technologies are to improve functioning, to successfully manoeuvre the person's environment and to enhance independence. However, improved functioning alone is no guarantee that an AT will be used and not abandoned. As Verza et al. discuss, the term 'abandonment' refers to the disuse of a previously obtained device, for any reason, and although the term is widely accepted in the field of AT [2, 6, 7] it may be misleading, particularly when applying it to the non-use of a device due to worsening in physical condition. Phillips and Zhao [2] found four factors related to assistive device abandonment - lack of consideration of user opinion in selection, easy device procurement, poor device performance and changes in user needs of priorities.

According to Phillips and Zhao, device abandonment research falls into three important areas of study: 1) users' personal characteristics and technology acceptance; 2) the device attributes that users prefer; and 3) device utilization. According to Vash [8] a variety of personal issues affect device use and acceptance such as disability acceptance, motivation, perceived life tasks, and effort-reward balance. Vash concludes that disability acceptance and goal-directness are related to positive attitudes about devices and devices that enable the user to complete important tasks are more likely to be used. Vash also concludes that the most important device attributes users prefer were purchase cost, durability, reliability, ease of use, safety features, aesthetics, ease of repairs, manoeuvrability/portability, and good instructions. In the study by Brooks and Hoyer [9], 12 people were interviewed about their device preferences for two different settings: employment- and independent living-related devices. Their results showed that user requirements for devices may vary according to the environment.

In addition to the areas mentioned above relevant to device abandonment, social aspects and other people's perceptions can affect the experience of use of an AT. Zola [10] argues that consumers prefer devices that facilitate independence associated with social and psychological freedom, not just physical functioning. Shinohara and Wobbrock [11] studied how AT use is affected by social and professional contexts and interactions. They found that there are misperceptions that assistive devices could functionally eliminate a disability and that people with disabilities would be helpless without their devices. They argue that there should be a new design approach taken into use where accessibility should be built into mainstream technologies, and, if not possible, assistive devices should incorporate cutting edge technologies and strive to be designed for social acceptability. Louise-Bender Pape et al. [7] suggest that successful integration of assistive technology into daily lives requires potential device users to explore: 1) the meanings they assign to devices; 2) their expectations of assistive technology; 3) the anticipated social costs; and 4) ways to understand that disability is one, but not the defining, feature of one's identity. Verza et al. [1] mention that although AT is promoted as means for increasing functional autonomy, it may be seen as a symbol of disability and the individual of being ill, losing independence and diminished self-image. In the study by Scherer and Galvin, non-acceptance of the device was frequently reported as a reason for subjects never actually using the devices [12].

In order to understand the lived experience of mobility aids and how would an application help mobility aid users, we designed our interview study around the themes related to abandonment of assistive devices mentioned earlier.

3. Method

In our study, we interviewed five individuals with different disabilities who use mobility aids. Participant 1 (P1) is woman (age 50) with progressive multiple sclerosis (MS) diagnosed 12 years ago. She uses a walker with small wheels or crutches to walk. She occasionally uses a wheelchair. Participant 2 (P2) is a woman (age 52) also with progressive MS diagnosed 6 years ago. She uses a walker with wheels and a seat or crutches to walk. She occasionally uses a wheelchair. Participant 3 (P3) is a man (age 25) with muscular illness diagnosed 2 years ago. He can walk, but mostly uses a wheelchair and crutches. Participant 4 (P4) is a man (age 46) who has had legs amputated below the knee two years ago due to a pneumococcal septicaemia. He uses prostheses to walk and also occasionally a wheelchair. Participant 5 (P5) is a man (age 39) who has been paralysed from below the waist for 22 years. He uses a wheelchair.

The method we used was a semi-structured interview with the following questions about different areas related to the person, their mobility aids, and the contexts of use of the aids:

- **Getting the Device:** How long have you had the device? How did you get the device? How much input did you have into choosing the device? Was there any training? Have your needs changed since you got the device?
- **Functionality:** Does it do what you need to do? Are there things you want it to do that it doesn't? Have you ever had problems with it? What do you do when you have a problem with it?
- **Contexts:** Are there situations/places where you can't use it/ where it is less physically comfortable? Are there situations/places where you don't want to use it? Are there situations/places where you would feel uncomfortable using it?

- **Usability:** How easy is it to use? Does it support you in all the tasks you want to do? Can you do things as quickly as you want to? Was it easy to learn to use the device?
- **User Experience**: What would make you happier with the device? How do you feel when you use the device? Does it feel part of you?
- **Stigma/People's Perceptions:** What do you feel people think about your device? Do you feel that people treat you differently because you are using this device?
- **Expectations:** Can you remember what your expectations were before you got the device? Did it meet the expectations you had? Have you ever thought about abandoning it? If so, why? Could you live without this device?
- **Improvements/Changes:** How would you improve the device? How would you improve the training? How would you improve maintenance/support? How would you improve the environment to support your use of the device better?

The interviews were recorded, transcribed and the data was analysed by qualitative data analysis, in which the recurring themes and ideas were identified. Based on the interview results, we defined the main stages in the lived experience for a framework in which to organize the results. The framework of lived experience consists of 1) Expectations 2) Getting the device 3) Using and living with mobility aid 4) Change/ Abandonment

4. Results

4.1. Expectations

The walker user P1 expected the walker to be easy to use (easy to fold up, not seen as a hassle), to take little space (not to have to find somewhere to keep it in the house, keeping it in the car). P2 expected to go for longer walks (having a seat to rest on a walker), going out independently (easy to pack in the car), sturdy enough to be safe, going to park: *"...to hold myself up. That's what I was hoping from it, so that I could take [it] to the park, sit on the ground like a normal person and be able to get up, but instead I'd have to sit on a bench and try to get up from there. So I look like a mad person. I thought it would be lot more useful than it has been, but it really isn't good, its not solid or stable at all (P2)".*

P5 is an experienced wheelchair user and knew very well what he wanted. His wheelchair is now part of him as he has had it longer than he had walked. Prosthetic legs user P4 expected to continue his active lifestyle and he had very high expectations to be able to walk without a limp and to do things he used to do.

4.2. Getting Mobility Aid

4.2.1. Input into Choosing Mobility Aid

Initially walkers (for P1 and P2) and a Zimmer frame (for P1) were provided by the National Health Service (NHS) physiotherapists. P2 gave input into choosing her aid: *"I think they probably asked what type of thing I wanted and I said one with the seat, but then I realized it was dangerous (P2)".* Both wheelchair users knew exactly what they wanted. P3 even designed and built the chair by himself because otherwise it would have cost him too much: *"The only way I could afford a chair like this was to build it myself (P3)".* Prostheses user P4 had a lot of input on the fitting and aesthetics of his legs because he wanted to stay mobile asking e.g. less support for legs so muscles would stay more responsive. P4 did a lot of research on his own on the web and asked other amputees for information. There are online forums, charities, hospital limb user groups: *"My doctor or even physio if is really down to them. I can go to them and say I want these legs, but they can easily say they don't fit or are not suitable. But I don't know that, I can only take their words to certain extent. Other than that, one of the best ways to find out outside googling and internet is to go to another amputee who is using those components (P4)".*

4.2.2. Taking Mobility Aids into Use

Neither a NHS Zimmer frame or walker was suitable for P1: *"They gave [me] this horrible old ladies Zimmer frame which is big, hefty and ugly and it doesn't fold up, you can't fit it in a car. And they bought me a wheeled walker, which I couldn't use because I have a weak left hand and I couldn't use the brake (P1)."* An NHS walker was not safe to use for P2, but she is still using it:*"I think people who design these things don't have to use them properly. It is quite frightening to use it, it rolls away. And the brakes are not that great either. Even if the brakes are on, it will move (P2)".* When NHS devices were found to be unsuitable/not safe there was no alternative for P1 and no help for P2: *"They didn't have anything else. They knew I couldn't use the wheeled walker and all there was, was the Zimmer (P1)".* After having used the walkers for a while, there was no feedback asked from P1 or P2 by NHS physiotherapist: *"Oh no, they haven't. They just think, she is managing ok, she has got the frame (P1)".*

4.2.3. Training

There was very little training or follow-up for walker users. P2 was struggling in the beginning: *"When I got a walker physio came and walked me up and down the street a couple of times. She noticed I was holding the brakes and said "don't do that", but I really can't use it without holding the brakes (P2)."*

As the standard NHS aids were not suitable for P1, she ordered a walker online and looked at videos of people using them: "*You can look them up online and they have videos of people using them. There are lots of pictures of people folding them up, putting them into the car. I am amazed not seeing these more (P1)*".

For wheelchair users P3 and P5 there was very little training provided, and they had to learn mostly by themselves: "*No training, just learning by doing – 'Trial and Error' (P3)".* P5 mentioned that an able bodied person does not really understand from a paralyzed person's point of view: "*My physio showed me, taught me how to get up the curb, but she is an able bodied person so she doesn't really understand from paralysed point of view. So, I just learned by myself falling out, spending a lot of time bed rest because bumps and scrapes, tweaking a mistake, learning how to do it better (P5)*". P5 suggested that peer support is the best way to learn. P5 also pointed out the importance of training: *"Anybody that gets a wheelchair should have a session of how to use a wheelchair. Effectively and in safety they could run two sets of training programmes: a basic wheelchair skills... and a training session for active wheelchair users (P5)".*

For the prostheses user P4 there was a lot of training and support in adjusting for the prostheses and learning to walk. There was also regular follow-up in the beginning and continuous support. P4 mentioned the importance of a peer support from the very beginning: *"I saw highly motivated people and for me it was like WOW. It meant more to me than getting advice, getting praise, getting anything really from a fellow amputee than from getting from able bodied, cause fundamentally it is "what you know (P4)".*

4.3. Using and Living with the Device

4.3.1. Needs

Since having the current walker P1's and P2's needs for mobility aids have not changed. P1 abandoned her NHS Zimmer frame and walker and bought a walker by herself online and is using it all the time. *"NHS had nothing for me, I can walk around with this on my own and feel safe (P1)".* P2 has the NHS walker, which she does not feel safe to use, but she has not looked at other options or given any feedback to her physiotherapist: *"I suppose I am getting used to it (P2)."* P2 is not using the walker as much as she hoped for. *"I do use the walker every now and then, cause its got the seat and I think if I am very careful, I should keep hold of it for the times when I do dare go out with it. It hasn't been anything as useful as I thought it would be. I thought it would take me out (P2)".* Wheelchair user P5 needs have changed a lot during the 22 years of use, because of life changes (e.g. having a child) and also because he can now use the wheelchair in any situation independently. The needs for the prostheses for P4 have changed since the amputation as he keeps improving with walking and needs better legs to keep his active lifestyle.

4.3.2. Functionality, Usability, User Experience

P1 is happy with the functionality of her current walker, which she bought online. She only changed the original handles, putting handle bar tape to make handles less slippery. It is easy to adjust and fold, easy to get in and out of the car or taxi and light. P1 feels attached to her walker: *"I am attached to it. When the last one was getting old and tatty, I bought another one straightaway and got it in three days. I was happy (P1)".* P1 feels the look of her light and lovely frame is less conspicuous than NHS ones: *"I think the other walkers, big wheeled ones, the black ones, are so cumbersome and horrid looking that it makes you more conspicuous. But at least this one, is not a great big heavy one. Maybe people are looking at the lovely frame and not looking at me (P1)".* P1 feels like the walking frame is part of her*: "I don't know what I would do, if I hadn't found it in the Internet (P1)."* A walking frame has made P1's life easier and the looks of it is important: *"That frame has made my life a lot easier and it doesn't look too hideous and hospital-y. It just looks a bit fun… If I had the horrible NHS one, I would feel very depressed all the time (P1)."*

P2 does not feel her walker with a seat is safe: *"It looks as if you could sit on it, but you just can't without putting your life in danger (P2)." Interviewer: "Are there things you want to do that it doesn't?" P2: "Sit down. Use of brakes. Brakes don't really work properly. They seriously don't (P2)".* P2 finds her walker with seat difficult to use: she can't lean on it. P2's walker does not support the tasks she would want to do because of the poor brakes: *"If it had decent brakes it would make a big difference. Actually, it would make a huge difference (P2)".* P2 feels conspicuous, aged and not safe when using her walker. If P2's experience with the walker had been better, she would use it more: *"I think if t he walker was solid and fit for purpose and safe, if the brakes were safe. I would use it a lot more if I didn't feel scared of using it. If the brakes worked properly and if I could sit on it without falling backwards, otherwise I would have to sit against the wall and pray that it's not gonna roll away with me (P2)".*

P1 said the cost of good and good-looking wheelchairs is too high: *"There are some really snazzy wheelchairs, but they are expensive… and you can't get them unless you have a lot of money or you are a paralympian. Lot of self-propelled ones are quite groovy, but they are really expensive. People should think about it when dishing out these aids for disabled people. And old people like to have nice things too… I just think generally they (the NHS) don't care what they give you. They just want to get you round safe, but people care about their clothes and how they look. Horrible old wheelchairs! I think most of the people don't want get into wheelchairs cause they are such a horrible ugly things (P1)".*

P2's wheelchair is hard to get out of the car and assemble and she needs someone to help her: *"And the wheelchair, I leave it to my husband to lift out of the car because to be honest it is just too heavy for me to lift. I don't use it on my own (P2)."* P2's wheelchair is not easy to use: it is difficult to get in and out of it as she needs her crutches, but there is nowhere to put them on the wheelchair. Her legs get swollen because of a bad position of her legs and she finds it difficult to heave herself up ramps. P2 feels pathetic, like not a real person anymore, nobody, ignored, not fun when she is using her wheelchair. P2 also mentioned her walking sticks: *"I hate to rely on them, but I can't walk anywhere without them. If I am outside and if you plonk me on that car park, I would have to crawl back here cause I can't even take a step without them unless I am holding on to something. And even they don't feel particularly safe and I do fall over with them (P2)".* P5 is happy and confident with his wheelchair to go down stairs, jump off trains, go through woods.

P4 mentioned some aspects of functionality, usability and user experience of his prostheses. For him it is important that the prostheses are easy to put on and their use causes as little pain as possible. The sockets can cause pain, blisters, and abrasions. In those cases P4 said you need to rest, but it is not really always an option. *"Just because you have a blister on your foot, doesn't mean you gonna stop walking (P4)".* Prostheses are also very personal: *"They are part of my body. Even when they are giving me pain (P4)".* P4 also mentioned the importance of security and ease of use. He uses a pin lock and sleeve to keep his prostheses securely on. *"Interviewer: Do you worry about your legs coming off? No, I don't think about it. Because if I start thinking about it, it will stop me from doing the things I need to do with my life (P4)".* P4 uses multiple mobility aids: *"It's a toss between the chair and the stick. Stick, if I am going to take my stick. In terms of the chair, if I am having limb issues … I use the wheelchair as a walker… because sometimes if I wanna walk, but I am not sure and I can't take the stick and if I don't know if I am able to last for the whole duration then the chair is an option and I am using it as a walker (P4)".* His prosthetic legs do what they need to, but he could do with even better ones: *"I think if I had better set of legs, there were more things I would be able do…I have gone to that point where, I have gone as far as I can possibly go with these legs. If I had different legs I could learn, accelerate my learning (P4)".*

4.4. Contexts

We asked the users about using their mobility devices in different contexts. The walker users found that steps were difficult with their walkers. Also that ramps are often too steep or too long to get to places. P1 and P2 would use their walker when going to places like the swimming pool, local cafes, shops. They often need help from friends or family members (P1). P1 would use both walker and wheelchair for example when going for a walk or a museum. P1 takes her walker as well as her wheelchair: *"Because this is so light, whist sitting on chair, I can fold it up and hold it on my lap. So I can have both (P1)."* Family can push the wheelchair or bring it locally if needed if P1 gets tired with walker.

Some situations and places where it is hard to use mobility aids or it is less physically comfortable the walker users mentioned included: *"Bumpy ground (P1)", "Black taxis are too high (P1)" "Just about everything: rough ground, its difficult to take it to the park, gravel is impossible, it gets stuck, I get stuck... Sand, I can't take it to the beach. Steps, are quite hard. I did one in here without too much trouble, but in reality when you are out and been going down some curbs and things its quite difficult to manoeuvre it (P2)."* P1 mentioned situations and places where she doesn't want to use mobility aids: *"Crowded places, rude people who stare and do not let you pass (P1)."*

Concerning wheelchairs and context of use, P1 said that it is great to have motorised chairs available in shopping centres, but there is nowhere to put shopping: *"I said to the shopping centre manager that I would come here more often shopping if I could whizz around and buy stuff and have somebody to take back to the car (P1)".* P2 uses motorised wheelchairs when going to Kew Gardens or the National Gallery. She mentioned that you have to book them in advance, but it is not reliable and they run out of battery fast (not been fully charged/ not know how long they should last). P2 also mentioned that ramps are difficult to use alone with a wheelchair: *"I find it very hard to push myself up the ramps. If you are on your own, its impossible a lot of the time. And even my husband finds it hard (P2)".* P2 said that the ramps can be too long or too steep. P5 finds his wheelchair hard to use sometimes at places like the theatre because it is hard to stay still in the wheelchair. He also mentioned heavy, cumbersome doors being difficult for wheelchair users. P5 thinks there is more awareness of disabilities now, more dropped curbs, buses and trains that are more accessible, parking spaces. P2 mentioned that a wheelchair is hard to use on the Underground in London alone because the lifts are so far away from the platforms.

P4 did not do many changes to his home after the amputation: *"I have not done major changes, because I, myself have to learn to overcome these obstacles while I am on my feet (P4)".* As no two terrains are the same, it is always about learning: *"There are different kind of stairs, different heights, different fits, different surfaces, all those things are taking a lot into account walking on the steps what's on a level, to walking on a step what's on a slope, changes whole dynamics of everything (P4)".* Sometimes he has had to leave, but he tries his best to overcome these things (P4).

Planning ahead is needed, especially in using public transport or going to unfamiliar environments: users do drive around to find out about disabled parking facilities and use parkopedia or Google maps. Google maps is thought to be very user friendly and provide real time information.

4.5. Motivations and Attitudes

One of the main motivation for the two MS patients, who can still walk with a walker or crutches, is a desire to stay as mobile and independent as long as possible and therefore to avoid using a wheelchair: *"I am so desperate to keep my mobility that I use this (walker instead of a wheelchair). It is very easy to give up and sit in a chair (P1)*". "*But I know if I was in a wheelchair all the time, my legs would just get into such a mess that you would go straight into wheelchair and I can't stand up (P1)*". "*I use wheelchair as little as possible, because I need to keep mobile: once you use it, you lose it* (P2)". *"God, why do I have to do this, being pushed by my husband in a wheelchair, so inhumane. It's not fun for him and it's not fun for me. It's not doing my legs any good but at least it is a relief to feel safe. But then again, it too beguiling cause I don't want to spend the rest of my life in a wheelchair if I can help it (P2)".*

P5 who is paralyzed from the waist down, has accepted his disability and that he is not able to walk: *"It's just so natural to me. If you had magic touch now and you said you could make me walk now, I would say I am all right. I am fine. I can go anywhere I want to go. I get two for one tickets everywhere. I get a seat, I get a reduction on my road tax (P5)".*

For P4 using prostheses to stay mobile is vital, but he needs to plan his day ahead: *"Well, not two days are the same. Now I just have to get on with them, even the days when they feel uncomfortable or sometimes reschedule or rethink my day, what can I do less or what should I not do that's going to hinder my days (P4)".* P4 said that a positive attitude towards life, new interests and social involvement is important*:" My life is very different. My life is more full, interesting. Certainly a lot more fulfilling. Things that I didn't enjoy before, I do enjoy now. I participate in sports, I am a volunteer for [a] few charities now, and mentor some youngsters. I have become a personal trainer for disability exercise and I have been invited to limb user group… a lot more meaningful than before (P4)". "Through this journey that I have had, I have realised how important it is how I conduct my life especially when I am working with these people within charities having a more positive attitude to overcome my disability (P4)".* P4 talked about disabled people's responsibility of sharing experiences: *"We have a duty. If we want to change how people perceive disabilities then it is our duty to do that, its not necessarily able bodied people. You can't expect change if you are going to hide behind closed doors. So we are as much responsible for that change as able bodied people…. Disabled people being able to share their stories and experiences and that's across whole spectrum cause there are no two people the same and disability can affect all them differently (P4)".*

P4 also mentioned the need to push yourself: *"We, disabled people, we have a tendency to sit with what we feel comfortable with. And sometimes they won't go outside that zone. Sometimes you have to push yourself out that comfort zone (P4)".* On the need to be motivated to learn and have come terms with disability, he noted: *"I feel person has to be motivated enough to want to do that. You can have the best physio, the best GP or the best prosthesis, but if you have a patient who is not motivated or willing or you can't find the way to engage with that person, doesn't matter what you give them. So there is emphasis on that person, but if the disablement is new or they haven't come to terms with it, doesn't matter what you give that person. They will have to come to terms with that (P4)".*

4.6. Other People's Perceptions

When we asked about other people's perceptions of using mobility aids, the walker users said people would stare at them because of a conspicuous aid: *"I think the other walkers, big wheeled ones, the black ones, are so cumbersome and horrid looking that it makes you more conspicuous (P1)". "I think they just look at me with astonishment and stare, because it is so conspicuous (P2)".* Also, people would stare because they were just rude and not helping: *"There are people who when they see people with disabilities they look away rather than help them when they cross the road (P1)." "Oh, aren't people rude – people won't get up, they don't open doors. People just stare at you and don't offer you a seat (P1)."* Also, people would be look because of a lovely walker: *"But at least with this one, is not a great big heavy one. Maybe people are looking at the lovely frame and not looking at me (P1)".* Some people are also supportive, giving comments: *"I have had people, men, stopping at my street saying, one man said: you are so wonderful. I will never complain about my bad ankle again when I see you walking along. You are so brave (P1)."* P1 mentioned that some people think an easily foldable walker is cool (P1). P1 found people fall into three categories: helpful, staring or ignoring.

P1 and P5 find people ignore her in her wheelchair. *"I find it hard when people walk past me that I know, don't notice me (P5)".* P4 who uses prostheses said that people comment if they can see the prostheses, but most of the time they are covered by trousers: *"My legs have covers over them. So its not so obvious when I am sitting like this and I don't wear shorts (P4)".*

4.7. Abandonment of Mobility Aids, Changing Needs

P1 had an ugly, heavy, hard to self-propel chair for holidays. She soon abandoned it and bought a secondhand, lighter one which fitted her well. P2 has thought about abandoning the walker, because it is not safe and she finds it hard to use. However, she has not abandoned it, but rather adjusted herself to it.

4.8. Improvements

When we asked about how to improve mobility aids, the walker user P2 commented: *"Everything should be more carefully designed and tested with people using them. I can't see how this walker got into production when it really is not safe (P2)".* Wheelchair user P5 mentioned that during the 22 years he has had a wheelchair, there has been significant improvements in components, shape, size (more compact, materials are better), there is more room for bags underneath and wheels are stronger. P5 thought his wheelchair could not be improved in any way, because it was made the way he wanted it. P2 and P3 need somewhere to attach crutches to a wheelchair: *"I still use a crutches when I walk. I always have a collapsible stick with me, which fits into a box under my wheelchair. It's more convenient to carry than traditional crutch. If I were to use the square box standard frame (not one like he has now) I would wrap the crutches at the back of the wheelchair with the Velcro. Can't do it with this frame. When I get my new frame, I intend to 3D print a bracket which I clip onto the frame and I can hang the crutches (P3)".*

We asked about how to improve the training for mobility aids and P2 said that *"any training would be good". "Just a chance to try them out for a couple of weeks.*

When I was trying to tell the physio who brought me this, she just said no, no its fine, you will be fine (P2)". All interviewees also mentioned the importance of peer support and a buddy system.

5. Discussion and Conclusions

In our study we were able to find the main stages of the lived experience with mobility aids. These stages are 1) Expectations 2) Getting Mobility Aid 3) Using and Living with Mobility Aid 4) Change/Abandonment. In each of these stages we found important issues concerning the lived experience with mobility aids.

For Expectations, the users expected mobility aids to help them to do their everyday tasks easily and safely. Some users knew exactly what they wanted from their mobility aid and had high expectations for their devices. The walker users had very little input into choosing the device and consequently they were not happy with the standard, free walker option provided by the NHS.

The Getting Mobility Aid stage was quite a different experience for all users, but they all wished there had been more training and also peer support or a buddy system in training to use the device. Online instructions, communities and the web seem to be good ways of finding information, for example about different kinds of mobility aids or how to use the mobility aid. The walker users had a very little input into choosing their device, poor training and there was no follow-up on how they were getting on with the walker. Mobility aid users need to be proactive and self-motivated to learn to adapt to living with a mobility aid.

When living and using the mobility aid in daily life people have very different disabilities and their mobility aid needs to meet the personal needs of different users. Walkers and wheelchairs need to be safe, easy to use, light, inconspicuous, "good looking". The participants explained what were positive qualities of a walker/Zimmer frame: It feels safe (good brakes, stable). It is easy to fold. It has a carrying bag or pockets. It has colour options and looks nice (jolly, fun, colourful). They also explained what were negative qualities of a walker/Zimmer frame: It is hefty, big and ugly, does not fold up. It cannot fit in the car or house. It is not safe (bad brakes, too light, smooth and slippery handles). The participants explained the positive qualities of a wheelchair: It is light, easy to get in the car, space for a bag and water bottle, space for walking sticks and can be used in any situation safely. They then explained the negative qualities of a wheelchair: it is not safe because if the road is too bumpy or it tips over and you fall out. Also, too long a frame causes a large turning circle, legs sticks out, it is hard to get into cars, clumsy and heavy frame. Prostheses need to fit well, be safe and help the user to achieve as high a level of mobility as possible.

We found that people who can walk with a mobility aid want to stay as mobile as possible and do not want to use a wheelchair as it is seen as the "last hope" and means deteriorating mobility. We also found that there are many obstacles still in the built environment, for example ramps that are too steep or too long or that finding disabled parking spaces can be difficult. We found that the role of the web as a source of information is important, for example about the accessibility of museums, trains, buses, tube, swimming pools or any other places people with mobility aids may want to go. Finally, we found that peer support is very important for learning and motivation.

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