This Is Your New Normal: A Qualitative Study Of Barriers And Facilitators To Physical Activity In Veterans With Lower Extremity Loss

By: Alyson J. Littman, Ph.D., M.P.H., Erin D. Bouldin, Ph.D., M.P.H., and Jodie K. Haselkorn, M.D., M.P.H.

Abstract
Background: Regular physical activity (PA) is essential for aging well with a disability, preventing the onset or worsening of chronic conditions, functional loss, and maintaining or improving quality of life, yet PA levels are low in those with disabilities, including those with a lower extremity amputation (LEA). Objective: To determine methods for promoting PA in this population, our objective was to better understand the barriers and facilitators to PA that persons with LEA face. Methods: Semi-structured interviews were conducted with male Veterans with a LEA. Two raters analyzed interview transcripts using a qualitative descriptive approach, involving both a priori and emergent themes. Results: Among the 27 male Veterans (mean age = 54 years) interviewed, facilitators to PA included acceptance of their limb loss, confidence (to try new activities or adapt activities), creating a daily routine involving PA, resources, supportive others, perceived benefit, and having a history of being physically active. Barriers to PA were illnesses/injuries, poorly-fitting prostheses, low self-efficacy, insufficient resources, unsupportive others, and hassle. Conclusions: Our study builds upon the literature indicating that individual, interpersonal, and environmental factors should be addressed to increase adoption and maintenance of PA, including making PA a regular, low-hassle activity, increasing access to resources that facilitate PA, and training health care providers, family and friends on how to best to support those with LEA to be more physically active. Addressing prosthetic socket issues that affect fit and stability and promoting acceptance and self-efficacy will also be instrumental.

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Our study builds upon the literature indicating that individual, interpersonal, and environmental factors should be addressed to increase adoption and maintenance of PA, including making PA a
regular, low-hassle activity, increasing access to resources that facilitate PA, and training health care providers, family and friends on how to best to support those with LEA to be more physically active. Addressing prosthetic socket issues that affect fit and stability and promoting acceptance and self-efficacy will also be instrumental.

**Keywords**

Lower limb amputation  
Physical activity  
Qualitative research

Approximately 1 million people in the U.S. are living with a lower extremity amputation (LEA); that number is expected to more than double by 2050.\(^1\) Directly, and indirectly through weight gain, low levels of physical activity (PA) can exacerbate chronic illness, joint pain, and depression.\(^2\)–\(^8\) Conversely, PA offers numerous benefits, including improved cardiopulmonary functioning,\(^2\) quality of life,\(^9\)\(^,\)\(^10\) self-esteem,\(^9\) and body image.\(^11\) Unfortunately, inadequate PA is common among people with a LEA.\(^12\)

Several studies have identified factors that influence PA in persons with LEA.\(^10\)\(^,\)\(^13\)–\(^19\) Previously-identified PA barriers include problems with prosthetic devices, pain, lack of access to resources such as adaptive/specialized equipment or organizations/activities, lack of knowledge about safe exercises, and self-consciousness.\(^13\)\(^,\)\(^14\)\(^,\)\(^19\) A history of PA or sports participation prior to one's amputation has also been identified as an important facilitator of being active after amputation.\(^12\)\(^,\)\(^19\)\(^,\)\(^20\) Most,\(^10\)\(^,\)\(^13\)–\(^16\) but not all,\(^17\)–\(^19\) of these findings come from surveys using close-ended response options. Of the three qualitative studies on PA in people with an LEA that have been conducted,\(^17\)–\(^19\) all\(^17\)–\(^19\) were conducted in Europe and included those with amputations more proximal than the ankle (not including individuals with more distal LEAs, which are performed nearly twice as frequently as transtibial and more proximal amputations\(^21\)). Additional qualitative studies are needed, in diverse populations and including those with distal as well as proximal amputations, to better understand “how” and “why” factors may serve as barriers or facilitators of PA. Veterans bear a disproportionate burden of LEA, partially due to their frequent history of smoking\(^22\) and elevated diabetes prevalence.\(^23\) More than 68,000 Veterans with LEA\(^24\) receive care in the Department of Veterans Affairs (VA), the largest integrated health care system in the US. The VA could serve as a “laboratory” in which to develop and test programs to promote PA for people with LEA because of the large number of VA patients with LEA and its' unique and long track record of national programs in physical medicine and rehabilitation, prosthetics, recreation therapy, integrated mental health care, and weight management.\(^25\)

The purpose of this study was to use qualitative methods to examine barriers and facilitators to PA, and why and how these factors manifest themselves, to inform the development of an effective PA promotion program for individuals with LEA.

**Methods**

**Participants**
We sought to recruit ~25–30 participants, as this number was expected to provide sufficient depth and coverage of topics under study. Eligibility criteria included having a LEA (unilateral or bilateral, toe or more proximal) at least 6 months prior to the interview, being a US military Veteran, receiving care at the VA, and being willing to provide written, informed consent. We used a purposive sampling strategy to gain a rich understanding of the variety of factors associated with PA for people with LEA. To better understand barriers and facilitators of PA among those who were active, we recruited from among attendees at VA-sponsored sports events and clinics and individuals who completed a survey on PA and weight management who reported >60 min per week of aerobic PA (e.g., walking, stationary bicycling, swimming). To understand the barriers and facilitators to PA faced by typical Veterans with LEA, we: i) recruited via flyers and brochures distributed in VA clinics (e.g., prosthetics, amputation, podiatry) and national organizations and ii) invited individuals who completed the same survey mentioned above who reported performing no aerobic PA and having no major health conditions to participate in an interview.

**Data collection**

We (AL and EB) collected data via semi-structured interviews (n = 27) between June and November 2012. Interviews lasted between 23 and 98 min (mean = 54 min); nine were conducted in person, the remainder (n = 18) were conducted over the telephone. We attended the sporting events from which some participants were selected. Notably, for one of these events, AL attended for 4 days, permitting her to observe, establish rapport and engage with the participants during activities, meals, and social activities. We defined PA as any bodily movement produced by skeletal muscles that results in energy expenditure. Using this definition, PA includes exercise, but also encompasses activities such as household chores, physical therapy exercises, using the stairs and walking or wheeling for transportation. Table 1 includes key domains and sample questions from the interview guide. All interviews were audio-recorded and transcribed. This study was approved by the VA Puget Sound Institutional Review Board (#00343).

Table 1. Key domains in the interview guide.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sample questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Military service history</td>
<td>Tell me about your military service.</td>
</tr>
<tr>
<td></td>
<td>When did you serve? In what branch did you serve?</td>
</tr>
<tr>
<td></td>
<td>Tell me about how you lost your foot/leg.</td>
</tr>
<tr>
<td>Amputation details</td>
<td>When did you lose your leg? (how long ago? What year?) Describe your amputation</td>
</tr>
<tr>
<td></td>
<td>on your left leg and on your right leg.</td>
</tr>
<tr>
<td></td>
<td>How do you typically get around (use prosthesis? Manuel or motorized wheelchair?)</td>
</tr>
<tr>
<td></td>
<td>Describe a usual day, including physical activity.</td>
</tr>
<tr>
<td>Daily routine and PA</td>
<td>Do you perform any physical activity to maintain or improve your strength or fitness?</td>
</tr>
</tbody>
</table>
Theme | Sample questions
--- | ---
What has helped you to be active? What has gotten in the way of you being active? | Has there been a time when you were not physically active? How did you resume activity? If inactive: have you thought about being more active than you are now? Have you taken any steps toward being more active? Are there any activities you would like to do that you are not doing now? Tell me about your activity before your amputation? Were PA and/or sport important in your life before your amputation?
Information gaps related to PA | Based on your experience, is there anything you wish you had known, relating to PA early after your amputation?

Analysis

Data were analyzed using qualitative descriptive analysis. Sandelowski explains that “basic qualitative description … entails the presentation of the facts of the case in everyday language”. We began analysis while recruitment and interviews were ongoing and added probes to the interview guide to reflect our questions as they emerged. We (AL and EB) listened to each interview at least once, reviewed transcripts multiple times, and iteratively coded each transcript in Microsoft Word independently. We (AL and EB) met regularly to discuss our individual work. New codes were added as the need arose. Codes were condensed and refined as our thinking about the themes evolved. In the theme generation and discussion phase, we included a total of 15 PA barriers and 18 PA enablers. We reviewed the themes and wrote a short description of their meaning and selected exemplary quotes. Though we initially thought about barriers and enablers separately, during analysis, we consolidated codes that were discussed in terms of being both a barrier and enabler (e.g., social support, resources, cost/benefit, health, acceptance, prosthesis issues, physical environment, knowledge, interest, money), leaving a total of 21 themes. As the characterization of the experience of PA in individuals with LEA unfolded, we expanded upon the most salient themes, and continually checked for trustworthiness against the interview data. We further assessed our thoroughness, comprehensiveness, and rigor and by sharing preliminary findings with the Qualitative Resources Workgroup at the VA Puget Sound, other colleagues at scientific meetings through presentation of results as a poster, and discussion of our results with other stakeholders (e.g., a leader in the Amputee Coalition of America), and refining our analyses based on feedback received.

Results

Participants

Participants ($N = 27$) were male Veterans with an average age of 54 years (SD = 13, range: 24–69 years; Table 2). Six ($n = 6$) individuals had a bilateral amputation and/or an upper extremity amputation in addition to a LEA. Participants had been living with an LEA for an average of 12 years (SD = 15, range 6 months–44 years). Seventy-four percent of participants reported
regularly using a prosthesis. One individual with a transfemoral amputation used crutches with no prosthesis, one person with a transmetarsal amputation used an orthotic only, and five individuals (19%) used either a manual or motorized wheelchair. Thirty percent of participants were employed part or full-time; the remainder were retired, unemployed, or unable to work because of disability.

Table 2. Characteristics and source of recruitment of participants.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, n (%)</td>
<td>Male</td>
<td>27</td>
<td>100%</td>
</tr>
<tr>
<td></td>
<td>Combat-related</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td>Cause of amputation, n (%)</td>
<td>Motorcycle, car, other trauma</td>
<td>8</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>Chronic illness</td>
<td>14</td>
<td>52%</td>
</tr>
<tr>
<td></td>
<td>Unilateral, at or below the knee</td>
<td>16</td>
<td>59%</td>
</tr>
<tr>
<td></td>
<td>Unilateral, above the knee</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>Bilateral and/or upper &amp; lower extremity amputation</td>
<td>6</td>
<td>22%</td>
</tr>
<tr>
<td></td>
<td>0.5–&lt;1</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>1–4</td>
<td>9</td>
<td>33%</td>
</tr>
<tr>
<td></td>
<td>5–9</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td>Amputation level, n (%)</td>
<td>10–19</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>20–29</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>30–39</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td>40–44</td>
<td>3</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>No activity (sedentary, unemployed, little or no housework)</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>Years since amputation</td>
<td>Household, work activity only (gardening, home repairs, working/volunteering outside the home regularly)</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>Light exercise (sporadic sports or weightlifting, walking, wheeling, or cycling regularly for exercise);</td>
<td>9</td>
<td>33%</td>
</tr>
<tr>
<td></td>
<td>High exercise (regular weightlifting, sports, running, etc.)</td>
<td>11</td>
<td>41%</td>
</tr>
<tr>
<td>Activity level at time of interview</td>
<td>Sporting event/clinic for Veterans</td>
<td>13</td>
<td>48%</td>
</tr>
<tr>
<td></td>
<td>Prior study participant from Pacific NW</td>
<td>10</td>
<td>37%</td>
</tr>
<tr>
<td></td>
<td>Other mailings/postings</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>Employed, part or fulltime</td>
<td>8</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>Retired, unemployed, unable to work (on disability)</td>
<td>19</td>
<td>70%</td>
</tr>
<tr>
<td></td>
<td>Uses a prosthesis to ambulate</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7</td>
<td>26%</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>20</td>
<td>74%</td>
</tr>
</tbody>
</table>

**Physical activities**
Strength training was the most commonly identified type of PA reported, mentioned by about half of participants. Nearly as many participants mentioned aerobic activities such as bicycling (stationary and outdoors), swimming, and water aerobics. There was considerable overlap in those reporting strength training and aerobic activities. Other participants reported PA as household chores, shopping, and getting from place to place (“walking with the prosthesis, a lot of times, is more than enough”).

Themes

We report the nine most salient themes relating to barriers and facilitators to PA. In cases where a factor was identified as a facilitator for some and a barrier for others, we discuss both together. Exemplary quotes for themes are presented in the text; additional examples are included in Table 3.

Table 3. Additional exemplary quotes.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine/purpose</td>
<td>It [exercise] gives you a reason to get out of bed. -8</td>
</tr>
<tr>
<td></td>
<td>Keeping busy doesn't solve problems, but kind of keeps problems at bay – idleness can cause its own problems. -13</td>
</tr>
<tr>
<td></td>
<td>When I had the amputation they told me no, they said [a motorized wheelchair is] going to enable you. ‘We're going to get you to walking, so you don't need a scooter.’ And you know, it took me a while, and now I agree with that. Some things I can't see for myself, you know. And they've been through that, so they kind of talk to you and encourage you. And you'd be saying to yourself, that I do need these things, I want to go further. But I want to ride further or something like that, but what would I rather do, ride or walk? I'd rather walk. -24</td>
</tr>
<tr>
<td>Social support</td>
<td>It [being physically active/exercising] makes me feel great. I'm in the best shape I've been since I was in the military ... if I quit, I'm going to feel the way I used to feel, and I don't like feeling that way. I like feeling the way I feel right now. -8</td>
</tr>
<tr>
<td></td>
<td>Um, I wanted to lose some weight, and I wanted to get better. I mean, not that I was sick or anything. I mean, I do have type-2 diabetes, but I wanted to lose weight and I wanted to be able to get my diabetes under control, and the best way to do that was by doing exercise and reducing intake of food. -13</td>
</tr>
<tr>
<td>Perceived benefits and costs</td>
<td>I don't want to die right now, and I don't want to be sick. And by being a patient in the VA, you see a lot, and you see a lot of people who tell you if they had taken care of themselves a little better before, these things wouldn't have happened. So I'm trying to start early. So I eliminated those things and hope that I didn't do too much harm to my body. So I just keep at it. -24</td>
</tr>
<tr>
<td>Themes</td>
<td>Quotes</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Confidence/acceptance</strong></td>
<td>This is your new normal, that's what you have to learn. It doesn't mean it's going to be worse, it's just new. It's like going – it's like joining the military, like, you're no longer a civilian. This is the way your life is going to be, and that's the train of thought you have to move in to. It's like, your life is not ever gonna be the way it was. -11</td>
</tr>
<tr>
<td></td>
<td>If I had privacy ... I have the swimming pool down street from me that I used to attend when I had both legs, and it's at a school ... Since I lost the leg I have not been inside of a pool ... I didn't wanna crutch myself on the wet surface through all that and then have something happen and then fall and then, you know. So I just never tried it. I had always said if I found a private pool, you know, like in somebody's back yard or something like that, then I would try to do it. But I wouldn't put myself out there in front of people. Which I'm not really shy ... I, I guess I'm just a little nervous. -3</td>
</tr>
<tr>
<td><strong>Lack of acceptance</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Active history</strong></td>
<td>I've always since, you know, young age, I've always done sporting. Just you know, besides when my dad put me in little league I've always on my own – cycled, triathlons, road races, you know. You name it, I've always tried it and I've always done stuff. And so being athletic or doing sports or whatever you want to call it, I've always been not driven by it, per se, but always incorporated it into my daily life. -10</td>
</tr>
<tr>
<td></td>
<td>I had a prosthesis that really didn't fit me well and it moved a lot and there was a lot of piston action, you know, up and down. And she [a lady who worked at the amputee clinic] asked me if I was a veteran and I said, ‘Yes, I am.’ And she says, ‘Well we cannot have our Veterans walking around like that.’ And from that day on, it got better ... it was just like I was born again, and that's the truth. -6</td>
</tr>
<tr>
<td><strong>Resources</strong></td>
<td>Well I was fortunate enough in a way to be at that [hospital name]. They have great recreational therapists ... They give you information, and you can go anywhere you want to with it ... Oh my god, I didn't know that in a wheelchair you can play basketball or tennis, or something that they used to do ... a hand cycle, I never ever thought about that before ... I think just if I have the information, how to do stuff, or – not even a step by step, just, [if someone were to tell me] ‘You can ride a bike again. These are the places you can go and get information on it.’ -10</td>
</tr>
<tr>
<td></td>
<td>And I had problems with getting the perfect fit, you know, so if you run around on your prosthesis it just cause some more wear and tear on different areas around your stump and you're gonna cause more pain and you're gonna be sore and tired. And you're gonna have lower back problems after that. -1</td>
</tr>
<tr>
<td><strong>Health</strong></td>
<td>I often kid that the foot's doing great if I don't have to stand on it or walk on it. -5</td>
</tr>
</tbody>
</table>
Themes

Quotes

Now that I've had 3 shoulder surgeries I'm – I don't really lift so much anymore, so I have to do other things. I: Because it hurts your shoulders? R: My shoulders, they ache all the time, and I can't walk that far [he uses standard crutches to walk], and they start getting painful. -11

Over the years I'd lost a lot of confidence in myself because I wasn't able to do the things the things I had always done. I was always in to some kind of sports, be it hunting, fishing, baseball, basketball. All the sports, I pretty much like, and I was just hesitant. -6

But I mean, I can do it [play catch], it's just pretty unstable. And I'm at that point now I don't want to crash or fall anymore ... I don't like it. Because it's so easy to fall and I'm just too protective right now. -10

I remember sweating really profusely, you know, trying to keep my leg straight when I, um ... oh yeah, hot temperatures my leg sweats because it's encased ... the encasement there makes it sweat, and because of sweat it's easy to turn, and try that on a hot day, you know, it's, it's crazy. Go back to your prosthetist and tell him about it and he tells you he can't do anything about it, other than put baby powder down there, you know, keep it dry. -3

My goal was to go be active and do everything. But I've never been able to get a socket to fit me, so, since 17 years, I've never been able to get a socket to fit to allow me to do these things. So it's very frustrating in that regard.” -11

Self-efficacy

Prosthesis issues

Routine/purpose

For many participants, PA was viewed positively both immediately following their amputation (e.g., during their initial rehabilitation) and currently because it gave them “something to do, somewhere to go” as many had an excess of unstructured time. During the rehabilitation period post-amputation, PA provided structure to their day, a sense of accomplishment and prevented boredom and depression.

I: What got you interested in exercising? R: I was really bored, I didn't have a whole lot to do. -15

PA was also viewed as an important component of a larger goal or purpose, such as being able to work or care for others (“I gotta learn how to walk, because I've got grandbabies, and I have to walk to the park.”).

Social support

Participants cited ways that doctors, therapists, friends, and family members helped them become or stay active. For example, emotional support was important, because as one participant stated, “they [rehabilitation professionals and his wife] ... always knew that I could do it.”
Doctors and therapists were helpful in supporting PA for some participants by having high expectations and providing accountability:

_The physical therapist ... was a lieutenant commander, and she was heartless. She didn't take any excuse from any of us as to why we couldn't push ourselves that day to perform what she expected to be done in our rehabilitation. I think that attitude ... belief in ... how we wanted to get back to a normal life as much as I could, were important._ -2

Family members sometimes provided instrumental support for PA by serving as exercise partners (“_We do it [exercise] together._”). For other participants, family members hindered PA by lacking confidence in them (“_She [wife] was always saying, 'Don't do this, don't do that.'_”). Some participants' lack of family members or friends to exercise with was identified as a PA barrier. Participants also discussed changes in a spouse's PA or divorce as causing them to reduce their own activity (“_Before I used to do things because I had somebody to do them with._”).

Some participants described gaining perspective from interacting with others with a disability that were physically active and had a positive attitude. Meeting others with a disability prompted participants to reflect on their own abilities and disabilities (e.g., that they had it better than others). Other individuals with a LEA or other disability sometimes served as role models and provided unintentional support by doing their own activities, thereby helping participants change their expectations around PA:

_I could see him [an amputee] ambulating ... and I didn't notice a limp with him. And I said to myself, 'That's where I want to be doing. That's where I'm going to be.'_-7

**Perceived benefits and costs**

Perceiving an immediate and/or long-term benefit of PA facilitated making or sustaining behavior changes. Perceived PA-related benefits included improvements in physical functioning (“You've got more energy”); mental health (“My temper's not as bad”); and stress relief (“I'm out there getting away from the stress of everything else”).

Another perceived benefit was feeling “normal.” There were a few participants who talked about how performing an activity (e.g., skiing) post-amputation that they had done before their LEA made them feel like they used to. One participant explained that he was so immersed in the activity that he “had forgotten that [he] was missing a leg.”

Conversely, for some, the logistics (“hassles”) necessary to perform the PA (e.g., carrying crutches on a bicycle to walk when not bicycling or putting a bicycle on a car to access flatter terrain) were not worth the potential benefit (“_Just the ... increased amount of difficulty to do things that used to be easy._”).

_I can't even get a walking leg, never mind a socket that fits that allows me to sit on a bike to pedal ... So I just ... pedal with one leg. And yeah, I can do it, but – and I have to strap on my crutches to my bike because ... you're gonna need your crutches._-11
Acceptance

Accepting one's limb loss (“This is gonna be for the rest of my life.”) and the concomitant limitations was essential to becoming active. As one individual noted, the alternative to acceptance was to “sit on my butt and bemoan my fate.” Instead, participants acknowledged “I'm not dead yet” and had something to live for. Being physically active meant that they were not just “sit[ting] around”; they were “do[ing] something.”

Just because you lose something or something happened, if you don't have a good mindset, well, I'm still alive. Just because I've got one left leg and no toes, that's not going to stop me from keep living my life, you know. And I'm not going to check out because this little thing happened. – 27

The self-consciousness expressed by others, though in some ways distinct from acceptance, demonstrated a lack of acceptance of their current body. Some participants avoided certain PAs because they felt self-conscious about other people seeing their prosthetic leg or residual limb.

Active history

Performing PA before their amputation made the transition to doing activities after their amputation easier (“And I would ski like a normal, you know, 2-legged skier, and it was no problem for me because I grew up skiing.”). Few individuals referred to activity they did while in the military, though attitudes inculcated during their military service (“I was a Marine and I still think like one. And they took two words out of my vocabulary: I can't.”) were mentioned as helpful in overcoming barriers to PA.

Resources

Resources that promoted PA included gyms, adaptive sports equipment (e.g., handcycle), specialized prostheses, information about adaptive sports, and opportunities to participate in events like the VA Sports Clinics and Wheelchair Games (“something to look forward to.”). Some of these resources facilitated performing sports that participants enjoyed before their amputation, whereas other resources provided opportunities for new activities. For example, one participant got a battery assist for his handcycle, which allowed him to keep up with two-legged cyclists and generally made riding more enjoyable because he went further, faster.

So the battery [on the bicycle] has actually gotten me out a lot more ... it was kind of boring with an arm cycle because you can't go as fast as the leg people and so you're always in the rear ... It's like, man it's taken me forever to get to the top of this hill and everybody with two legs is already over the hill, they're on the next hill.-17

Another participant described how obtaining a lighter weight wheelchair made navigating his physical environment easier because he could move the lighter wheelchair in and out of his car by himself, unlike the standard wheelchair (“And so now I'll just go and do it [shopping].”).

Health
Chronic health conditions as well as fatigue, pain, injuries, and difficulty sleeping were identified as barriers to PA. These health issues acted as barriers to PA both immediately following their amputation surgery (“And I was really tired for quite a while ... it took me a few years to get any real amount of energy back [after getting out of the hospital]”) and years later (“There's times there that I won't get out of bed for 2 days ... my body's too sore”).

Self-efficacy

Participants' confidence in their ability to perform PA was instrumental to being active and manifested itself as a willingness to try new activities and persistence in seeking opportunities, equipment, or other resources. Some participants demonstrated a tenacity that bordered on defiance (“I don't need you telling me I can do it. I know I can do it.”). Conversely, some individuals whose efforts at walking or performing PA resulted in a fall or crash lost confidence in themselves and their ability and no longer wished to try to perform activities that might result in injury (“I don't want to crash or fall anymore.”).

Prosthesis issues

When participants had prostheses that fit poorly and caused or exacerbated injury or pain, they reduced or moderated their PA. Even if their prosthesis fit well in certain environments, heat caused problems with prosthesis fit and increased the risk of skin injuries because the socket did not breathe well (“summertime, perspiration building up, the fungal infections, breakdown of the skin, …and then I need to get off of it [prosthesis] and allow myself to heal up before I can get back into it”). Participants with poorly fitting prostheses were concerned about their balance and feared falling in any environment. Consequently, uneven surfaces, stairs, and hills were barriers to being active for transportation, walking in their community, or walking elsewhere for many of these individuals, resulting in fewer opportunities for PA.

Discussion

Our evaluation of PA facilitators identified several novel PA facilitators that are modifiable. Our goal was to add to the evidence base of factors that could improve PA adoption and maintenance in this population. We envisioned that this research would lead to programs that could be applied to individuals with a LEA, regardless of etiology, prosthetic use, or amputation level. Consequently, our inclusion criteria were liberal. First, among those who were regularly physically active, a central theme was that PA provided their day with structure and gave them a sense of accomplishment. A common barrier in the general population is lack of time. However, since most individuals in our study were unemployed or underemployed, their problem was too much unstructured time. PA provided them with a way to fill their day, which in and of itself was beneficial.

Second, social support, particularly from spouses, peers, and health care professionals, was an important facilitator by helping persons with LEA set and meet goals for PA. While social support from family and friends has long been identified as an important facilitator to PA in the general population and those with other disabilities, our findings are novel due to the kinds of support that were identified. For example, when talking about rehabilitation professionals,
participants most appreciated that rehabilitation professionals had high expectations for them and believed in their capacity to achieve important functioning targets and be physically active. An important characteristic of the support participants perceived as helpful was that it promoted their independence, rather than a reliance on the support of others.

Third, people who were regularly active perceived tangible benefits of PA, including weight loss, better sleep, lower stress, or simply the satisfaction of knowing that they had done something that day other than eat, sleep, and watch TV.

Fourth, participants' acceptance of their amputation represented becoming a ready and active participant in their life, which was a necessary step to being physically active. This finding is noteworthy because acceptance is thought to be important for quality of life facilitating adjustment to life following amputation.32,33

We confirmed previously reported findings12,13,16,19,20 regarding having an active history being a facilitator and insufficient resources, (poor) health, issues related to prosthesis, low self-efficacy, self-consciousness, unsupportive social environment, unsupportive/challenging physical environment, and hassle, serving as barriers.

Strengths and limitations

Strengths of our study are that we were able to assess themes that cut across various LEA characteristics, and we were able to investigate factors that prevent or lead to PA initiation and maintenance. Furthermore, we attended events for people with LEA to interact with, recruit, and observe potential participants increasing the trustworthiness of our findings.34 Nevertheless, several limitations should be considered when interpreting our data. Because our interviews did not involve a comprehensive assessment of PA, our inventory of activities may not be complete. Nonetheless, it gives a sense of the kinds of activities people with LEAs were performing currently or had done in the past (but since their amputation). Furthermore, the study included only men; further research is needed to better understand barriers and facilitators in women with LEA.

Implications for practice

Our study and the broader scientific literature12,13,16,19,20,35,36 suggest that PA interventions in this population should attempt to address not only individual-level factors, but interpersonal and social/physical environmental factors as well. Key components of PA interventions might involve encouraging individuals to create a routine involving PA, helping individuals identify how PA may directly help them (increasing perceptions of benefit), assisting individuals with access to resources that will make PA easier or more enjoyable, increasing their self-efficacy for performing PA, and promoting acceptance of their limb loss and a positive self-image. Additionally, interventions to increase PA may promote greater acceptance of individuals' amputation and improve quality of life. At the interpersonal level, interventions should foster independence through positive, non-judgmental support and modeling from health care providers, family, and friends. Facilitating contact between individuals with LEA and other persons with a LEA or other disability could lead to productive social comparisons (e.g., ‘that
person's disability is more severe than mine and see how active s/he is') and improving the individual's understanding of the PAs that are possible and if needed, how to access resources to perform them. While physical therapists and other health professionals are already key members of the support system cited by people with LEA, there may be untapped potential in engaging prosthetists, who have the unique ability to assist with mobility or prosthetic fit issues that arise as individuals become more active, as well as psychologists, who can assist with facing the challenges that may arise. Lastly, at the societal level, shifting the cultural norms related to the PA expectations of people with LEA may be important both for individuals with LEA and those who interact with them. Media campaigns (e.g., “how I walk” nchpad.org/howiwalk) that challenge the way we think of the word “walk” may be important first steps. Continuing to improving features of the physical environment and expanding accommodations for individuals with mobility limitations is also important. Future studies are needed to determine the efficacy of interventions including the components described and potential benefits in terms of function, quality of life, and secondary conditions.

Conclusions

Several facilitators and barriers to PA among men with LEA identified in this study are novel, including the importance of PA as a part of routine that provides purpose to one's day, acceptance, and the influential role of health care providers and peers, and the impacts – both positive and negative – of family members. We also gained more insight into previously identified barriers like problems with prosthetic fit, health issues, and self-consciousness. These factors provide an important evidence base from which to create interventions to assist with sustainable behavior change in this population.

Prior presentations

Parts of this work were presented at the Society for Behavioral Medicine Annual Meeting in San Francisco (March 2013) and the VA Health Services Research and Development Annual Meeting in Philadelphia (July 2015). At both meetings, a poster presentation was made.

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Conflicts of interest

The authors report no conflicts of interest.

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