



Sports and amputation

Mihai Brăgaru

Stellingen

behorende bij het proefschrift

Sports and amputation

1. Sports should be included in rehabilitation programs, and individuals with limb amputations should be encouraged to pursue a physically active life following hospital discharge. *(dit proefschrift)*
2. Data concerning the energy efficiency, technical characteristics and special mechanical properties of prostheses or prosthetic adaptations for sports, other than running, are scarce. *(dit proefschrift)*
3. In the Netherlands, more individuals with upper limb deficiency participate in sports compared to individuals with lower limb deficiency. *(dit proefschrift)*
4. The characteristics of the sports participation of individuals with upper limb deficiency are more similar to the ones of able bodied than with the ones of individuals with lower limb deficiency. *(dit proefschrift)*
5. Family and friends play an important role in sports participation of individuals with upper limb deficiency. *(dit proefschrift)*
6. Clinicians should emphasize that sports does not have only physical but also important psycho-social benefits. *(dit proefschrift)*
7. Work related physical activity should not be considered equivalent to sport. *(dit proefschrift)*
8. "The only disability in life is a bad attitude." *(Scott Hamilton)*
9. "To understand is far more important than to know." *(Alexandru Ioan Cuza)*
10. "Respect and authority should be rightfully obtained rather than requested or imposed." *(my mother)*

Mihai Brăgaru
12 June 2013

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Mihai Brăgaru

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For Alexandru Mihai, ma joie de vivre

Groningen, June 2013

Chapter 1

General Introduction

Regular participation in sports is generally perceived as beneficial for the body as well as the mind. This notion is not new, and even before concrete scientific arguments were offered to support it, individuals that regularly participated in sports (athletes) were valued and revered by others mainly due to their healthy near to “perfect” bodies and their athletic achievements. To celebrate athletic performance, but also to honour their gods, the Greeks organized once every four years the Olympic Games. These were considered a major event in the ancient world and for the duration of these games any hostilities ceased while sports and athletic competition captured all resources and attention.^[1] Modern Olympic Games take place also once in four years and are considered one of the most important events an athlete can have in his/her record.

One of the first written evidence that acknowledge the beneficial influence of sports is the one from the 5th century BC historian Hippocrates who wrote in his book “Regimen of Acute Diseases” that “the sick will of course profit to a great extent from gymnastics with regard to the restoration of their health and the healthy will profit with regard to its maintenance, and those who exercise will profit with regard to the maintenance of their well-being and a lot more”.^[2] Nevertheless, Juvenalis (1st century AD) is the author of perhaps the most well-known quote usually associated with sports “Mens sana in corpore sano”.^[3] Originally written “every man should pray for a sound mind in a sound body”, in more recent times it became widely associated with the benefits of regular participation in sports and physical activities. Today the peer reviewed literature contains sufficient evidence available supporting the beneficial influence regular participation in sports has for both body and mind.^[4-6]

Athletic performance has been positively associated with a good physical condition, thus there it should be obvious why all ancient and pre 20th century athletes are represented as having near to “perfect” bodies and physical health.^[7] Apparently, until the beginning of the 20th century, there are no records of individuals with physical disabilities to ever participate in an organized sporting event. The first record of an individual with physical disabilities participating in an organized sports dates back at the beginning of 20th century and concerns George Eyser.^[8] He was an athlete with an amputation of the lower limb who participated at the 1904 Olympics. Despite his handicap he competed successfully against able bodied athletes and won 6 Olympic medals in one day (3 gold, 2 silver and 1

bronze).^[8] Considering that there are major functional differences between able bodied individuals and the ones with lower limb amputation, his performance was quite remarkable.^[9;10] These functional differences made it almost impossible for athletes with physical disabilities to participate in organized sporting events and competing against able bodied athletes.

The first sporting event especially organized for individuals with physical disabilities took place in 1948 at the Stoke Mandeville Hospital, under the initiative of Sir Ludwig Guttmann, a British neurologist of German descent.^[11] The Stoke Mandeville Games are considered to be the precursor of the first Paralympic games which took place for the first time in Rome (1960) and became a regular event once every 4 years.^[12] The number of participants and sports performed increased with every edition of the Paralympic games and in London Summer Paralympics of 2012, 4237 athletes competed in 20 sports.^[13;14] Not only the number of sports and athletes increased but also the variety of accepted disabilities. While in Rome only athletes with spinal cord injury competed, in London athletes competed in 6 separate disability groups: Amputees, Cerebral Palsy, Intellectual Disability, Visually Impaired, Wheelchair and "Les Autres". These separate categories were needed in order "to ensure competition is fair and equal, and that winning is determined by skill, fitness, power, endurance, tactical ability and mental focus, the same factors that account for success in sports for able bodied athletes".^[15]

Each disability is associated with a specific burden, mostly a limitation in physical or sensorial functioning, intellectual abilities or even a combination of physical, sensorial and intellectual abilities. Regular participation in sports and physical activities has a beneficial effect on various domains, thus decreasing to some extent the disability burden.^[16;17] Similar to able bodied individuals, disabled individuals who participate in sports and or physical activities acknowledge that apart from an obvious improvement in physical domain they also experience benefits in the psychological and social domain.^[18-21] Individuals missing their upper or lower limb, completely or partially, have in general better physical condition compared to individuals with other physical disabilities (e.g. cerebral palsy or spinal cord injury).^[22;23] Still, they may experience significant limitations in physical functioning as compared to able bodied individuals.^[24] Besides the functional limitation, most of lower limb amputees (LLA) are more likely to suffer from depression in the first 2 years following their amputation.^[25;26] Based on

available evidence, presented by peer reviewed literature, it appears that regular participation in sports has a beneficial influence on physical and psychosocial characteristics of LLA, thus decreasing to some degree the burden of amputation.^[24;27-33] Nevertheless, due to the amputation self and the accompanying medical condition LLA tend to be less physically active than able bodied individuals.^[34-36]

Studies focusing on amputees' sports participation are generally characterized by small sample sizes, diverse outcome variables and anecdotal reports. For example around 30% of Dutch LLA^[37] and 60% of American LLA^[38] participate in sports. Also most of the studies addressing this topic do not define sports participation. Mentioning this definition may reduce the bias of reporting. One such definition is the one used by World Health Organization which defines sport as an activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour and where skills and physical endurance are either required or to be improved.^[39] Physical activity was defined as any bodily movement produced by skeletal muscles that require energy expenditure.^[40] Consequently, in this thesis, an athlete is considered the individual that participates in sports and physical activities according to the above mentioned definition.

In the near future the number of amputees, especially LLA, will increase due to increasing life expectancy as well as increasing incidence rate of diabetes mellitus and cardio-vascular diseases.^[41] Consequently, the need of assistive devices, rehabilitation programs and rehabilitation centers are also more likely to increase. For the able bodied, regular participation in sports may help to reduce the economic burden of disease by increasing physical capacity, mobility and reducing the risk of cardio vascular disease.^[42] By increasing the number of LLA that participate in sports it may be that a similar effect as compared to able bodied will be observed. Nevertheless in order to be able to increase the activity level in a population, one has to identify the initial state of the population and later the factors, including barriers and facilitators, which influence participation in sports of this population. Based on this information professionals working with individuals with limb amputations may develop rehabilitation programs aimed to increase or just support the activity level of these individuals. Eventually, increasing the number of amputees that participate in sports will have a beneficial

effect not only on their personal characteristics and wellbeing but also on their social environment.^[6;16;17]

Thesis aim and research questions

The general aim of this thesis is to gather scientific data related to the participation in sports of individuals with limb amputations, to identify the participation rate in sports, the factors influencing participation in sports and the barriers and facilitators for sports participation. More specifically, this thesis aims to answer the following research questions:

- What is the level of evidence as presented by peer-reviewed literature concerning individuals with upper and lower limb amputations and their participation in sports and/or physical activities? (Chapter 2)
- What are the biomechanical characteristics of their physical activity, cardio-pulmonary function, psychological wellbeing, rehabilitation and functional outcome and injuries characteristics? (Chapter 2)
- What is the level of evidence and the knowledge gaps as presented by peer-reviewed literature for both upper and lower limb sport prostheses? (Chapter 3)
- What are the characteristics of the sports participation of Dutch individuals with upper limb deficiency (ULD) and the factors associated with this participation? (Chapter 4)
- What are the reasons individuals with ULD participate or not in sports? (Chapter 4)
- What is the percentage of Dutch lower limb amputees (LLA) that regularly participate in sports and the factors influencing this participation? (Chapter 5)
- What are the barriers and facilitators that influence participation in sports of LLA? (Chapter 6)

Chapter 2

Amputees and Sports: a Systematic Review

Sports Medicine 2011, 41(9): 721-740

M. Bragaru, R. Dekker, J.H.B. Geertzen & P.U. Dijkstra

ABSTRACT

Amputation of a limb may have a negative impact on the psychological and physical well-being, mobility and social life of individuals with limb amputations. Participation in sports and/or regular physical activity has a positive effect on the above mentioned areas in able-bodied individuals. Data concerning participation in sports or regular physical activity together with its benefits and risks for individuals with limb amputations are scarce. No systematic review exists that addresses a wide range of outcomes such as biomechanics, cardiopulmonary function, psychology, sport participation and sport injuries. Therefore, the aim of this article is to systematically review the literature about individuals with limb amputations and sport participation. MEDLINE (PubMed), EMBASE, CINAHL® and SportDiscus® were searched without time or language restrictions using free text words and MeSH terms. The last search date was 31 March 2010. Books, internet sites and references of included papers were checked for papers relevant to the topic under review. Papers were included if the research topic concerned sports and a minimum of ten individuals with limb amputations were part of the study population. Papers were excluded if they included individuals with amputations of body parts other than upper or lower limbs or more distal than the wrist or ankle, or if they consisted of case reports, narrative reviews, books, notes or letters to the editor. Title, abstract and full-text assessments were performed by two independent observers following a list of preset criteria. Of the 3689 papers originally identified, 47 were included in the review. Most of the included studies were older than 10 years and had cross-sectional designs. Study participants were generally younger and often had more traumatic amputations than the general population of individuals with limb amputations. Heterogeneity in population characteristics, intervention types and main outcomes made data pooling impossible. In general, sports were associated with a beneficial effect on the cardiopulmonary system, psychological well-being, social reintegration and physical functioning. Younger individuals with unilateral trans-tibial amputations achieve better athletic performance and encounter fewer problems when participating in sports compared with older individuals with bilateral transfemoral amputations. Regardless of their amputation level, individuals with limb amputations participate in a wide range of recreational activities. The majority of them were not aware of the sport facilities in their area and were not informed about available recreational activities. Sport prosthetic devices were used mostly

by competitive athletes. For football, the injury rate and pattern of the players with an amputation were similar to those of able-bodied players. Individuals with limb amputations appear to benefit both physically and psychologically from participation in sports and/or regular physical activity. Therefore, sports should be included in rehabilitation programs, and individuals with limb amputations should be encouraged to pursue a physically active life following hospital discharge.

INTRODUCTION

Amputation of a limb may cause permanent disability and decreases mobility temporarily or permanently.^[24] Individuals with limb amputations often see themselves as part of a special group that, according to able-bodied people, has special needs and requires additional attention.^[25] These perceptions contribute to the relatively high depression and anxiety rates recorded amongst individuals with limb amputations, especially in the first two years after amputation.^[26;43;44] Consequently, they will experience difficulties with social participation and in returning to everyday life.

Individuals with limb amputations in general are in poor physical condition not only due to the amputation itself but also because of the illness preceding and leading to the amputation. In the United States, about 82% of all lower and upper limb amputations are due to vascular conditions, whereas 16% of amputations are due to trauma.^[45] The remaining 2% of amputations are necessary due to cancer or inflammation or represent congenital birth defects. It has been predicted that the number of individuals with limb amputations will increase as a consequence of the population's increasing age and increasing incidence of diabetes mellitus and cardiovascular diseases.^[41]

In general, participation in sports or physical activities is important in maintaining physical fitness.^[5;17] Lack of physical exercise is the most important determinant of a deteriorating physical state, often leading to coronary heart disease.^[46] Health organisations recommend 30 minutes or more of moderately vigorous daily physical activity.^[47] Because of the amputation and the underlying diseases persisting after amputation, individuals with limb amputations tend to be less active than the able-bodied.^[34] Participation in sports and an active lifestyle are assumed to be important for individuals with limb amputations as they enhance psychological well-being, self-confidence and coping behaviour.^[48]

Publications focusing on sports participation among individuals with limb amputations are generally characterised by a limited number of participants, anecdotal reports and diverse outcome variables.^[49-53] Even though there are a number of reviews^[48;54;55] concerning some aspects of the sport participation of individuals with limb amputations, none of them address both upper and lower limb amputations, nor do they offer a full picture of all important variables

associated with sport participation, like participation rate, psychosocial modifications or injury rate. A complete overview may help professionals working in the sector of rehabilitation of individuals with limb amputations to evaluate sports or a physical training program as part of a treatment program for their patients and to better understand the benefits and risks of sports participation for this group. Therefore, the aim of this study was to systematically review the literature on participation in sports and/or physical activity among individuals with upper and/or lower limb amputations and to identify their biomechanical characteristics, cardiopulmonary function, psychological well-being, sport participation and physical functioning and injury characteristics.

REVIEW METHODS

For this systematic review, sports were defined as *an activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour and where skills and physical endurance are either required or to be improved.*^[39] Physical activity was defined as *any bodily movement produced by skeletal muscles that require energy expenditure.*^[40]

Four databases were searched: MEDLINE (PubMed), EMBASE, CINAHL® and SportDiscus®. The search strategy used consisted of a combination of database-specific Mesh terms, free text, “wild cards” (words truncated by using “*”) and Boolean operators (“AND”, “OR”, “NOT”). No time or language restrictions were applied. The search was structured in two parts. One part concerned papers related to amputations, while the second part concerned papers related to sports and physical activity. The two parts of the search were combined using the Boolean operator “AND”. The search details are presented in Appendix 1, Table A1. Sports were only searched as Mesh headings and as a general free text word, not by means of specific types of sports, like running, cycling or basketball. All retrieved papers were combined in a single database and duplicates were removed. The most recent search date was March 31, 2010.1

1 Authors’ note: the literature search was updated on 21 February 2011. Following the same inclusion/exclusion criteria as described in section 1; The newly identified studies [31;35;90;91] were added to table 1 under the relevant characteristics analyses. The results of these studies did not influence the conclusion of this review and therefore they were not brought up for discussion.

Papers were selected for this review in three stages after evaluation of the title, abstract and full text. Papers were included if the research topic was sports or physical activity and a minimum of ten individuals with limb amputations were part of the study population. Papers were excluded if they concerned minor amputation (distal to the wrist or ankle), amputation of body parts other than upper and lower limbs (e.g. ear, breast) or endoprostheses. In addition, case reports, narrative reviews, editorials, notes and letters to the editor were excluded. If, after title and abstract assessment, the paper's inclusion or exclusion remained questionable, the paper was included in the next selection stage. References of papers selected for inclusion in the final assessment stage of the review were checked for relevant citations, which were later retrieved and assessed in the same way. Each assessment was performed by two independent observers. If the observers were not fluent in the language of the paper, a native speaker translated the paper into English with the two observers present. In case of assessor disagreement, a consensus meeting was held. If disagreement persisted, a third observer gave a binding verdict. The full text of a paper was assessed if the paper fulfilled the following inclusion criteria: a minimum of ten (1) individuals with limb amputations (2) were part of the study population and sport or physical activity was considered (3). Methodological quality was based on the assessment of the following criteria: reporting of inclusion (1) and exclusion (2) criteria; the numbers or percentages of males and females (3); age (4) [as mean and standard deviation or median and inter-quartile range]; cause of amputation (general description of cause [5] and exact number [6] per cause) and level (7); and side (8) of amputation.

RESULTS

A total of 3689 papers were identified, of which 895 were duplicates. After title and abstract assessment, 85 full-text papers were selected for further assessment. As a result of reference checking, 29 additional potentially relevant papers were identified. In total, 17 papers could not be retrieved for bibliographic reasons or because there was no complete paper available. After full text assessment, 50 papers were excluded because they did not fulfil the inclusion criteria, leaving 47 for final inclusion in this systematic review (figure 1). Inter-observer agreement, expressed as Cohen's Kappa, for the full-text assessment of

the 47 included papers was 0.83 (95% CI 0.78, 0.89). The quality of the included papers was moderate, with only four papers fulfilling all eight criteria. The frequency distribution of the methodological quality of all studies is presented in figure 2.

In general, there was substantial heterogeneity in interventions, population characteristics and main outcomes between the studies. In order to provide structure to the findings, main outcomes were organized into five categories:

- Biomechanical aspects and athletic performance: papers in this category had to present data regarding forces or any other biomechanical variables of the subjects or activity.
- Cardiopulmonary function: papers in this category had to present biometric data recorded during or after physical activity or sports
- Psychological aspects and quality of life: papers in this category had to present data regarding psychological aspects and quality of life.
- Sports participation and physical functioning: papers in this category had to present data about sports participation and modifications in physical functioning following participation in sports or physical activities.
- Sports injuries: papers in this category had to present data about sports injuries.

Biomechanical Aspects and Athletic Performance

Ten studies analysed the biomechanical aspects of swimming,^[56] running^[57-59] and long jump^[60-65] and athletic performance of individuals with upper and lower limb amputations. Video cameras, force plates or Doppler devices were used to measure step length and rate, joint angles, ground reaction force and speed, among other variables. An overview of these papers is presented in Table 1. Young individuals with unilateral trans-tibial amputations who were provided with prostheses and were adequately trained were able to run.^[57;58] Runners with lower limb amputations demonstrated a difference between the prosthetic and non-prosthetic limbs regarding step length and vertical, mediolateral and horizontal displacement of the centre of mass. The prosthetic and non-prosthetic limbs also differed in these variables from those of able-bodied individuals.^[59;65]

Long jumpers with trans-tibial amputations jumped further than those with trans-femoral amputations did.^[60;64] Long jumpers with trans-tibial amputations who used their prosthetic limb for take-off had a shorter last step and a lower vertical velocity at touch-down than did those jumpers using their sound limb for take-off.^[61] Runners with lower limb amputations^[58;59] and swimmers with upper limb amputations^[56] increase their speed by increasing their pace rather than their step or stroke length.

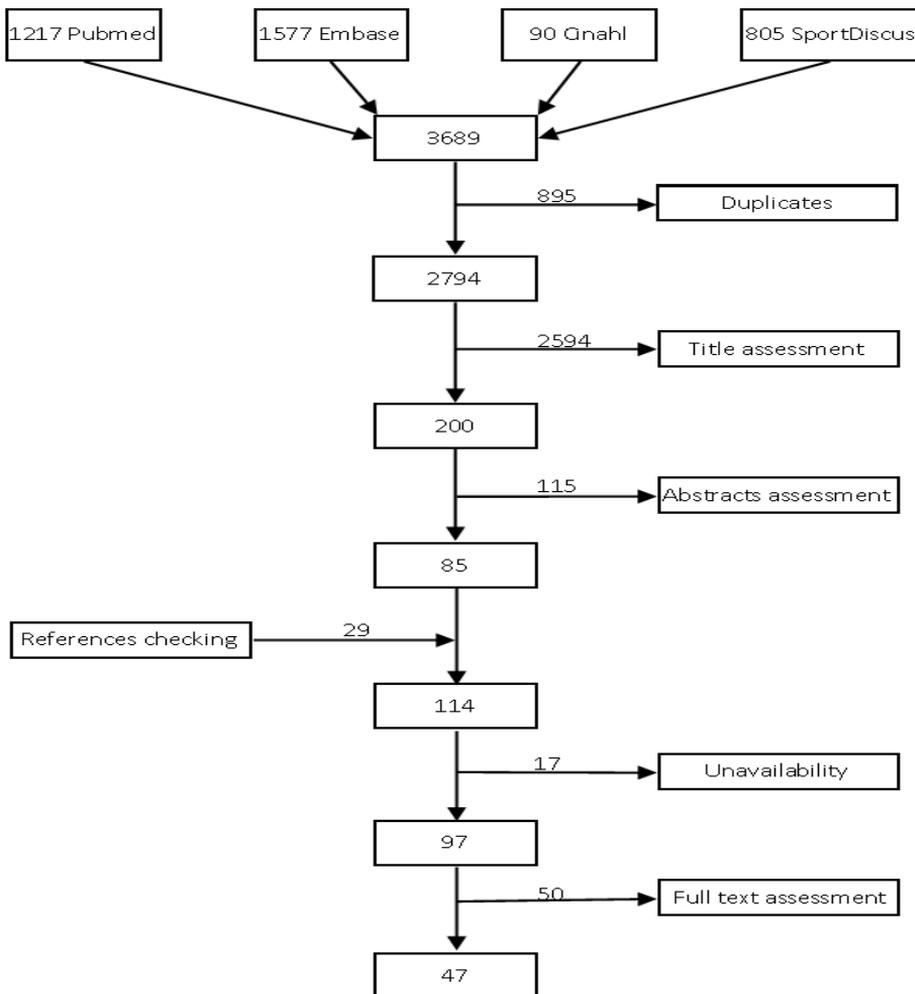


Figure 1 Flow chart of the systematic review

Cardiopulmonary Function

Twelve studies analysed cardiopulmonary function in relation to sports or physical activity among individuals with limb amputations.^[22;24;27;28;52;66-72] Training equipment such as an exercise cycle or rowing ergometer was used. An ECG, spirometer, sphygmomanometer, and Doppler device were used to measure maximal oxygen intake (VO_{2max}), heart rate (HR), blood pressure (BP), anaerobic threshold (AT), and maximum power output (W_{max}). An overview of these papers is presented in Table 1. The general physical condition of individuals with limb amputations is worse than the reference values for able-bodied people of similar age.^[24;66] Nevertheless, individuals with limb amputations have better aerobic and anaerobic power outputs than do individuals with other locomotor disabilities.^[70] Participation in sports or physical activity has beneficial influences on the cardiopulmonary system, muscle force and body mass of individuals with limb amputations.^[27;28;52;69] The rehabilitation time of individuals with limb amputations was shorter when physical training was part of their rehabilitation program.^[71]

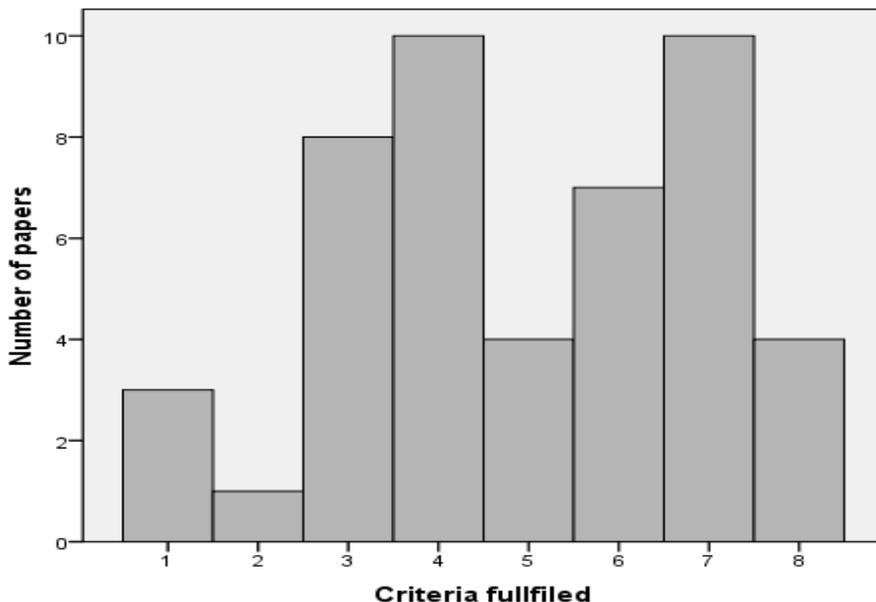


Figure 2 Methodological quality of identified papers

Psychological Aspects and Quality of Life

Six studies analysed the relationship between sport participation and the psychological aspects and quality of life of individuals with limb amputations.^[23;29;30;32;73;74] Questionnaires or interviews were used to measure motivation to participate in sports, self-esteem and perceived benefits and barriers in physically active individuals with limb amputations. An overview of these papers is presented in Table 1. Quality of life and self-esteem of individuals with limb amputations who participated in sports and physical activities were higher than those of people with limb amputations who did not participate in these activities.^[29;73] Sports and physical activity helped these individuals to increase their number of social contacts and their knowledge about sporting equipment that could facilitate their participation in sports. It also helped them to accept their disability and to improve their motor skills.^[32;74] Participation in sports and/or physical activity decreased following the amputation as a direct result of physical constraints and accessibility issues.^[74]

Sport Participation and Physical Functioning

Fifteen studies analysed associations between sport participation and/or physical activity and physical functioning of individuals with limb amputations.^[33;36-38;75-85] A combination of self-developed and published questionnaires as well as specific tests addressing mobility outcomes were used as measurement tools. The main outcome variables were sport participation rate, the type of preferred physical activity, type and use of prosthesis and modifications of physical functioning following a physical training program. An overview of these papers is presented in Table 1. From the included papers, it appears that between 11% and 61% of individuals with lower limb amputations participate in sports and/or physical activities.^[37;75] The choice of which sports to take part in was influenced by gender, the sport's specific energy requirements and the load on the prosthetic limb.^[80;85] Fishing, swimming, golfing, walking and cycling were favoured sports. Younger individuals with unilateral trans-tibial amputations due to non-vascular causes were more active than older individuals with bilateral trans-femoral amputations due to vascular causes.^[38;79] A short but intensive physical training program improved walking distance and speed of individuals with traumatic lower limb amputations.

Sports Injuries

Four studies analysed the sports injuries suffered by individuals with limb amputations.^[86-89] Questionnaires were used to assess the injury rate and injury-related phenomena such as pain or activity restriction. An overview of these papers is presented in Table 1. The injury pattern and rate among individuals with limb amputations who play football (soccer) appear to be the same as for able-bodied individuals. Sport-related muscle pain occurs more frequently in those with limb amputations than in individuals with other types of locomotor disabilities.^[88] The emotional benefits of participating in sports outweighed the possible risk of injury.^[86] The presence of pain did not influence perceived activity restrictions.^[87]

Table 1. Studies analyzing characteristics of individuals with limb amputations

Authors (year)	QS	S(n); Ic/Ec	Gender M/W; Age ^a	Amputation characteristics		Study design	Analysis aim	Results	
				Level	Side				
Biomechanical Aspects and Athletic Performance									
				Level	Cause (G/S)	Side			
Enoka et al. (1982) ^[58]	4	10; N/N	9/1; 39	10 TT	N/N	10 Uni; LL	CS	Running gait characteristics	60% of young individuals with Uni TT amputations who used a prosthesis were able to run at speeds ranging from 2.7 to 8.2 m/s; Speed increase is related to an increase in stride rate; Step length of the ProSL is directly related to speed increase.
Engsborg et al. (1993) ^[57]	4	21 (221); N/N	17/4; 11	21 TT	N/N	21 Uni; LL	CS	Running characteristics of AB and children with TT amputations	NonProSL generated greater vertical, anteroposterior and mediolateral forces as compared to ProSL of AB; With increasing speed, the NonProSL generated greater forward propulsion than the ProSL.
Gavron et al. (1995) ^[59]	4	12; N/N	12/0; N	12 TT	N/N	12 Uni; LL	CS	Sprinting characteristics of individuals with TT amputations	ProSL and NonProSL were asymmetric with respect to stride length and time and vertical displacement of centre of mass; NonProSL stride contributed more to horizontal displacement than ProSL stride.
Nolan et al. (2000) ^[60]	4	16; N/N	16/0; N	8 TT / 8 TF	N/N	16 Uni; LL	CS	Take-off characteristics during long jumping	Athletes with TT amputations jumped further, had a faster approach speed and a lower centre of mass compared to athletes with TF amputations.
Simpson et al. (2001) ^[65]	4	23; N/N	17/6; (18-36)	20 TT / 3 TF	N/N	22 Uni / 1Bii; LL	CS	Locomotor characteristics of long jump	ProSL of individuals with TT amputations had a greater step length compared to their NonProSL; More proximal amputations generated larger interlimb kinematic asymmetry/individuals with TF amputations increased speed by increasing step length of their NonProSL; Individuals with TT amputations increased speed by increasing step length of their ProSL.
Patritti et al. (2005) ^[64]	3	34; N/N	11/9; N	20 TT / 14 TF	N/N	N/LL	CS	Approach velocity of long jumpers	Individuals with TT amputations ran faster and jumped further than individuals with TF amputations

Nolan et al. (2005) ^[61]	3	14; N/N	14/0; N	7 TT / 7 TF	N/N	N/LL	CS	Influence of take-off leg during the long jump	Athletes with TT amputations who took off from their ProSL were able to better control their downward velocity at touch-down and had a shorter last stride.
Nolan et al. (2006) ^[62]	4	17; N/N	0/17; N	9 TT / 8 TF	N/N	17 Uni / LL	CS	Kinematic characteristics of women with TT and TF amputations during long jump	Approach velocity more strongly influenced the jumped distance of women with TT amputations than that of the women with TF amputations; Women with TF amputations had a lower centre of mass than the ones with TT amputations; Women with TF amputations had greater joint angles (hip, knee and leg) on all jump phases compared to the athletes with TT amputations.
Nolan et al. (2007) ^[63]	4	13; N/N	13/0; N	6 TT / 7 TF	N/N	13 Uni / LL	CS	Kinematic and temporal characteristics of long jump	Athletes with TF amputations had slower horizontal velocity and shorter stride length on the second to last and last strides compared to athletes with TT amputations; Athletes with TF amputations lowered their centre of mass in the last stride more than athletes with TT amputations; Athletes with TF amputations had greater joint angles (hip, knee and leg) on all jump phases compared to athletes with TT amputations.
Osborough et al. (2009) ^[56]	4	13; N/N	3/10; 16.9 (±3.1)	13 ED	N / N	13 Uni / UL	CS	Swimming characteristics of individuals with UL amputations related to their anthropometric characteristics	SF was related to maximum swimming speed ($r=-.72$); SF was related to biacromial breadth ($r=-.86$), shoulder girth ($r=-.64$) and upper-arm length ($r=-.58$).
Osborough et al. (2010) ^[90]	6	13; N/N	3/10; 16.9 (±3.1)	13 ED	NonPVD / Y	13 Uni / UL	CS	Swimming characteristics of individuals with UL amputations related to their inter-arm coordination	Swimming speed ($r=-.59$) and SF ($r=-.66$) were related to the coordination of the amputated arm.
Cardiopulmonary Function									
Tomaszewska et al. (1965) ^{b [52]}	3	19; N/N	16/3; N	6 TT / 11 TF	N / N	17 Uni / 2 Bli; LL	Long	Changes of cardiopulmonary and muscle force characteristics after training	HR and BP decreased in the majority of individuals with limb amputations after 2 weeks of indoor training. Inspiration frequency and muscle force of hand, shoulder and back increased in the majority of individuals with limb amputations in the second day of skiing.

van Alste et al. (1985) ^[66]	7	39; Y/N	28/11; 67	10 TT / 13 TF / 11 KD	PVD/Y	35 Uni / 4 Bil; LL	CS	HR during PA and the threshold of prosthetic ambulation	Individuals with limb amputations achieved 80% of the predicted HR _{max} value for AB of same age; Work capacity of 60 watts was the threshold of prosthetic ambulation.
Pitetti et al. (1987) ^[27]	6	10; Y/N	N; 39	4 TT / 3 TF	NonPVD /Y	8 Uni / 2 Bil; LL	Long	Changes of cardio-pulmonary and work capacity characteristics after aerobic training	HR during rest and exercise decreased; HR during volitional exhaustion increased; VO _{2max} and Wmax increased.
Alaranta et al. (1988) ^[67]	5	10; N/N	9/1; 35 (23-57)	3 TT / 3 TF, 4 UL	NonPVD /Y	N; 6 LL / 4 UL	CS	Suitability of tests evaluating skiers' physical capacity	Most tests were not suitable for skiers with limb amputations; Recommended tests: rowing ergometer for individuals with TF amputations; "walking with sticks" ^{nc} for individuals with TT amputations and/or individuals with Uni UL amputations, treadmill running for individuals with Bil UL amputations.
Chin et al. (1997) ^[68]	5	53; Y/N	40/13; 42	11 TT / 37 TF / 5 HD	N/N	53 Uni; LL	CS	Validity of the one-leg cycling ergometer test in determining AT	AT correlated (r=0.66) with predicted VO _{2max} ; One-leg cycle ergometer is valid in AT determination.
Kurdy-ballo et al. (1997) ^[69]	5	78 (90); N/N	78/0; N	34 TT / 37 TF	NonPVD /Y	61 Uni / 17 Bil; LL	Long	Changes of cardiovascular characteristics and body mass after swimming pool exercises	BP decreased as a result of suppressing the influence of the sympathetic nervous system; Body mass decreased
Hutzler et al. (1998) ^[70]	4	10 (50); Y/N	10/0; 39 (±9.2) ^d	N	N / N	N / LL	CS	Difference in power outputs between individuals with limb amputations and individuals with other types of physical disabilities	Individuals with limb amputations had better aerobic and anaerobic power outputs and fatigue indices than individuals with other types of physical disabilities.
Chin et al. (2001) ^[28]	6	24; Y/N	N; 41 (±18.4)	24 TF	NonPVD /Y	24 Uni / LL	Long	Changes in cardio-pulmonary characteristics after endurance training based on AT	VO _{2max} increased for the endurance group compared to pre-training and to a control group; AT increased for the endurance group compared to pre-training and to a control group.

Chin et al. (2002) [24]	7	31 (49); Y/N	18/13; 26 (±5.7)	10 TT / 20 TF / 1 KD	NonPVD / Y	31 Uni / LL	Long	Changes of cardio-pulmonary and physical fitness after physical training compared to AB	VO _{2max} increased to the level of AB; AT increased to the level of AB. Higher PA level was associated with lower BP and HR; Higher PA level was associated with a shorter rehabilitation time.
Kobzev et al. (2002) [21]	4	18; N/N	18/0; (19-44)	N	NonPVD / Y	N / LL	CS	Influence of PA level on BP, HR and rehabilitation time	Higher PA level was associated with lower BP and HR; Higher PA level was associated with a shorter rehabilitation time.
Huonker et al. (2003) [22]	3	17 (125); Y/N	N; 34 (±11.5)	17 TT	N / N	17 Uni / LL	CS	Vascular characteristics of physically active individuals with limb amputations and AB	Blood flow and diameter of the common femoral artery of the ProSL were smaller compared to NonProSL and to untrained AB.
Chin et al. (2006) [72]	7	49; Y/N	34/15; 67 (±5.6)		19 PVD, 30 Non-PVD / Y	49 Uni / LL	CS	To identify the threshold of prosthetic ambulation	Exercise intensity of ≥50% VO _{2max} was the threshold of prosthetic ambulation.
Psychological Aspects and Quality of Life									
Valliant et al. (1985) [29]	1	33 (161); N/N	19 / 14; N	N	N / N	N	CS	Relationship between self-esteem, locus of control and PA of individuals with limb amputations	Physically active individuals with limb amputations had higher self-esteem than inactive individuals; Active men with limb amputations had a lower locus of control than inactive men; Active women with limb amputations had a higher locus of control than inactive women.
Mastro et al. (1996) [23]	3	22 (138); Y/N	17 / 5; 29	N	N / N	N	CS	Athletes' attitudes towards each other and their ranking of disability preferences	Individuals with limb amputations were ranked highest in the hierarchy of preferences due to the lowest perceived disability.
Wetterhahn et al. (2002) [30]	6	56; Y/N	36 / 20; N	34 TT / 22 TF	8 PVD 48 NonPVD / Y	48 Uni / 8 BI / LL	CS	Relationship between PA and body image	MBSRQ and ABIS scores were significantly higher (p=0.0001 respectively p=0.01) for active individuals with limb amputations compared to an inactive group; A relationship exists between PA level and body image of individuals with limb amputations; No data presented to substantiate the nature of the relationship between PA level and body image; A chronic illness did not influence body image in the active group.

Lowther et al. (2002) ^[73]	2	15; Y/N	15/0; (19-28)	N	N/N	N	CS	Relationship between athletic performance, self-efficacy and psychological skills	High self-efficacy was associated with successful athletic performance; The usage of activation and relaxation skills was associated with high self-efficacy and successful athletic performance.
Spornier et al. (2009) ^[32]	1	57 Y/N	115/17g; 47.4 ^B (±13.4)	N	N/N	N	CS	Relationship between participation in organised sport events and psychosocial characteristics	Participation in organised sporting events increased the knowledge of sporting equipment (92%), mobility skills (84%) and disability acceptance (84%); 98% felt that participation in organised sporting events improved their lives; Increased numbers of friends, interaction with other disabled people and ability to be competitive were seen as benefits of participation in organised sporting events; Participants in organised sporting events had decreased cognitive and physical limitations (CHART) compared to non-participants; For 63% of the participants, taking part in organised sport events represents their only sporting activity.
Couture et al. (2010) ^[74]	7	15; Y/N	8/7; 65.1 (±13.9)	11 TT / 4 TF	PVD/Y	15 Uni / LL	Long	Characteristics of leisure activities of individuals with LL amputations	Participation in leisure activities decreased following amputation; Leisure satisfaction of individuals with LL amputations was higher than ILP reference value; Individuals with LL amputations encounter more constraints than AB in terms of functional abilities and accessibility when engaging in leisure activities.
Tatar Y. (2010) ^[31]	6	37; Y/N	25/12; N	18 TT / 19 TF	4 PVD / Y	37 Uni	CS	Relationship between participation in sports and body image of amputees	Participation in sports increases perceived body image of amputees.
Sport Participation and Physical Functioning									
Kegel et al. (1977) ^[15]	6	134; Y/N	103/31; 47	87 TT / 27 TF	65 PVD, 69 Non-PVD / Y	114 Uni / 20BII / LL	CS	Level of sport participation, preferred sports and prosthetic use	61% were active in sports Fishing and swimming were most frequently performed 6% used sport prostheses

Kegel et al (1978) ⁽¹⁾⁽⁷⁶⁾	6	134; Y/N	103/31; 47	81 TT / 3 KD / 19 TF / 5 HD	65 PVD, 69 Non- PVD / Y	114 Uni / 20Bil / LL	CS	Functional capabilities and population characteristics of active individuals with limb amputations	Younger individuals with TT amputations were more active than older individuals with TF amputations
Kegel et al. (1980) ⁽¹⁾⁽³⁸⁾	6	100; Y/N	85/15; 45	58 TT / 25 TF	29 PVD, 71 Non- PVD / Y	83 Uni / 17 Bil / LL	CS	Characteristics of sport participation: level, barriers, prosthesis use and complaints	Younger individuals with traumatic limb amputations were more active than older individuals with vascular limb amputations Barriers to sports participation: pain, embarrassment, lack of special organised programs for individuals with limb amputations, lack of awareness of the existing sport facilities (93%) Prosthetists did not want to modify the prosthesis according to the suggestions of individuals with limb amputations in 45% of cases
Medhat et al. (1990) ⁽⁷⁷⁾	4	131; Y/N	122/9; 58 (24- 90)	82 TT/61 TF	47 PVD, 84 Non- PVD / Y	N/LL	CS	Factors influencing ADL and sport participation	Individuals with TF amputations reported more problems in ADL than did individuals with TT amputations Sport participation was problematic for individuals with both TT and TF amputations; Least problematic sports: canoeing and swimming
Pohjolainen et al. (1990) ⁽⁷⁸⁾	7	175; Y/N	127/48; 62 (±15.8)	93 TT/62 TF	142 PVD, 33 Non- PVD / Y	155 Uni / 20Bil / LL	CS	Characteristics of prosthetic use, walking ability and factors influencing walking	60% used their prosthesis >12 hours/day 15% could walk 2-3 hrs and 23% could walk more than 1 km Ischemic pain restricted walking
Gailey R. (1992) ⁽⁸²⁾	5	1214; Y/N	Nj; Nj	Nj	242 PVD, 972 Non- PVD / Y	Nj	CS	Characteristics of recreational activities: type, return to, amount and barriers	Nj
Burger et al. (1997) ⁽⁷⁹⁾	7	228; Y/N	191/37; 53.3 (±15.4)	114 TT / 2 KD / 108 TF / 4 HD	NonPVD / Y	228 Uni / LL	CS	Changes in sports participation and preferred recreational activities following amputation	Sport participation decreased Preferred recreational activities changed towards "more energy efficient" ones

Burger et al. (1997) ^[86]	7	223; Y/N	187/36; 54 (±15.4)	115 TT / 102 TF / 2 KD / 4 HD	NonPVD /Y	203 Uni / 20 Bil / LL	CS	Influences of age, amputation level and time since amputation on walking, cycling and independence level	Younger individuals with TT amputations walked longer and were more likely to cycle than older individuals with TF amputations A shorter time since amputation lead to a higher independence level
Legro et al. (2001) ^[80]	3	92; Y/N	79/13; 54.95 (±13.7)	58 TT	N/N	N/LL	CS	Preferred recreational activities and factors influencing the choice of activities.	Fishing was the most frequently preferred recreational activity (n=15) Gender, required energy level, ProSL impact load and age influenced choice of recreational activity
Rau et al. (2007) ^[83]	8	58; Y/Y	58/0; 37 (±10.9)	43 TT/15 TF	NonPVD /Y	58 Uni / LL	RCT	Changes of walking characteristics after short intensive physiotherapy for individuals with limb amputations compared to controls	Training program was effective in increasing walking distance and speed, ProSL maximal load and PCI
Yazicioglu et al. (2007) ^[81]	8	24; Y/Y	24/0; 28 (±4.6)	24 TT	NonPVD /Y	24 Uni / LL	CS	Differences in physiological and QoL characteristics of soccer players compared to controls	A difference in physiological characteristics was recorded, favouring players QoL improved for players with regards to pain, emotional role and fear of falling
Yari et al. (2008) ^[83]	8	46; Y/Y	21/25; 55.8 (±12.1)	31 HD/15 HP	6 PVD, 40 NonPVD /Y	46 Uni / LL	CS	Activity level and mobility limitations of individuals with HD and HP amputations	39% participated in sports Swimming, fitness, sailing and golf were the most practiced sports
Walker et al. (2009) ^[84]	7	36(62); Y/Y	21/15; 32.5 ^a	36 TTK	NonPVD /Y	36 Uni / LL	CS	Difference in outcome following fibular lengthening or amputation	No difference in sport participation between fibular lengthening patients and patients with amputation No difference in sports activity between fibular lengthening patients, patients with amputation and control group. Patients with amputations scored significantly better than fibular lengthening patients on the job satisfiers content scale

Karmarkar et al. (2009) ^[85]	7	42; Y/Y	N; 42.11 (±16)	1 AD/ 20 TT / 3 KD / 14 TF / 4 HD	13 PVD, 27 Non- PVD / Y	28 Uni / 10 Bil / 8 UL / 34 LL	CS	Personal characteristics and functional performance related to mobility device in physical active veterans	Amputation level and degree of difficulty of the intended activity were related to participation in sports Prosthetic users with a more proximal amputation had more problems participating in sports compared to wheelchair users of same amputation level.	
Kars et al. (2009) ^[37]	8	105; Y/Y	71/31; 58.7	1 AD / 58 TT / 13 KD / 27 TF / 5 HD / 1 HP	42 PVD, 63 Non- PVD / Y	101 Uni / 4 Bil / LL	CS	Participation in sports of individuals with LL amputations	32% participated in sports Participation in sports before the amputation was related to participation in sports following the amputation Swimming, fitness and cycling were the most practiced sports 42% complained about their prosthesis or sport organisation, and 80% of them found this problem hindering their participation in sports	
van den Berg-Emons et al. (2010) ^[35]	8	18 (461); Y/Y	17/1; 56 (±13.13)	18 TT	9 PVD, 9 NonPVD / Y	18Uni / LL	CS	Activity level of individuals LL amputations	Individuals with TT amputations are 40% less active than AB Rehabilitation physicians significantly overestimate the activity levels of individuals with limb amputations	
Bekkering et al. (2011) ^[91]	7	43 (82); Y/N	22/21; 16.1 (±4.4)	4 TT / 11 KD / 12 TF / 16 RP	43 Non- PVD / Y	43Uni / LL	CS	Difference in physical activity between young adults undergoing limb-salvage or ablative surgery	No difference in physical activity level between young adults who underwent limb-salvage interventions and the ones who underwent ablative surgery.	
Sports Injuries										
Kegel et al (1994) ^[86]	3	75; Y/N	72/3; 29 (18-44)	N	17PVD, 58 Non- PVD / N	N; 61LL / 14UL	CS	Injury characteristics of amputee soccer players	Physical injuries appeared minor compared with emotional benefits induced by sport 52% of individuals with limb amputations never sustained an injury while playing soccer The injury pattern of individuals with limb amputations was similar to AB	
Meizer et al. (2001) ^[89]	7	32 (56); Y/N	32/0; 42.4	N	NonPVD / Y	32 Uni; LL	CS	Contralateral knee osteoarthritis prevalence in individuals with limb amputations who play or do not play volleyball	Contralateral knee osteoarthritis was significantly more common among individuals with limb amputations compared to controls (p<0.05) No difference in the prevalence of contralateral knee osteoarthritis was observed between individuals with limb amputations who played volleyball and the ones who did not play	

Author (Year)	1	28	N; N	N	N/N	N	CS	Prevalence of SRMP	75% of individuals with limb amputations exhibited SRMP. Individuals with limb amputations are more likely to present SRMP than any other disabled group (OR=15.4) Presence of SRMP was associated with a BMI between 24.6 and 30.9 (OR=3.4) and more than 7 hrs/week of training (OR=3.8)
Bernardi et al. (2003) [98]	1	(227); Y/N							
Desmond et al. [97] (2008)	6	89; Y/N	62/27; >60m	55 TT / 30 TF / 4 KD	16 PVD, 73 Non-PVD / Y	89 Uni; LL	CS	Association between pain, prosthesis satisfaction and activity restriction	Pain was associated with prosthesis dissatisfaction. Pain presence was not associated with activity restriction

a Mean or (range) or [mean – SD].

b Training programme was not standardized and the measurements were not distributed according to a standard schedule throughout the study duration.

c Similar to 'Nordic walking'.

d Value for the total sample, including individuals with limb amputations.

e A higher locus of control represents a more externalized person. f The ability to increase energy.

g Characteristics for the whole population (n = 132).

h Possibly the same study population.

i Similar results reported by the three studies for sport participation and use of special sport prostheses.

j Inconsistent data presented by the author.

k Characteristics for the whole study population.

l Authors state that the population sample was too small to sustain a 'statistically reliable conclusion'.

m 65.2% were over 60 years of age.

AB= able-bodied; ABIS = Amputee Body-Image Scale; AD= ankle disarticulation; ADL = activities of daily living; AT = anaerobic threshold; BMI = body mass index; BP = blood pressure; CHART = Craig Handicap Assessment Reporting Technique; CS= cross-sectional; ED= elbow disarticulation; G/S = general cause for amputation/specific numbers per cause; HD= hip disarticulation; HP = hemipelvectomy; HR= heart rate; HR_{max} = maximum HR; ILP = individual leisure profile; in/ex = inclusion/exclusion criteria reported; KD= knee disarticulation; LL = lower limb; M= men; MBSRQ= Multidimensional Body-Self Relations Questionnaire; N= no, data missing or criterion not fulfilled; non-Prost = non-prosthetic limb; non-PVD = any cause of amputation other than peripheral vascular disease, including trauma, infection or cancer; OR= odds ratio; PA= physical activity; PCI = physiological cost index calculated using the values obtained from the 2 min test as follows: [HR_{finish} - HR_{rest}]/speed; ProSL = prosthetic limb; PVD= peripheral vascular disease; QoL = quality of life; QS= quality score of the study; RCT= randomised controlled trial; RP= rotationplasty; S (n) = number of subjects with limb amputations (total number of participants); SF = stroke frequency; SRMP= sport related muscle pain; TF = trans-femoral; TT = trans-tibial; UL = upper limb; VO_{2max} = maximal oxygen uptake volume; W= women; W_{max} = maximal power output; Y = yes, data present or criterion fulfilled.

DISCUSSION

The aim of this study was to systematically review the literature on biomechanical characteristics, cardiopulmonary function, psychological wellbeing, sport participation and physical functioning and injury characteristics related to sports and/or physical activity among individuals with upper and/or lower limb amputations. Only 47 (1.3%) out of 3689 papers initially identified were selected for inclusion in this systematic review. Most of the included studies were older than 10 years, were observational, had cross-sectional designs and used convenience sampling from a single rehabilitation centre. In most studies, the mean age of the study participants was below 65 years, and the study samples consisted of a high percentage of individuals with non-vascular amputations. The general population of individuals with limb amputations has an average age above 65 years, and most of these individuals have vascular amputations.^[92] Due to this difference, the results of the current review do not necessarily apply to the general populations of individuals with limb amputations.

Age, gender and amputation level were found to influence running and long jumping performance in athletes with limb amputations.^[62-64;76] Participation in sports and physical activity positively influences their physical fitness, psychosocial well-being and physical functioning.^[27-29;32;33;71;80] A more proximal amputation, older age and a vascular cause of amputation may lead to more problems in completing the activities of daily living among individuals with limb amputations.^[77;79;85] Various studies have identified different factors influencing participation in sports among individuals with limb amputations without reaching overall agreement on a single one. In clinical practice, the type of sport or physical activity should be chosen according to each patient's characteristics, needs and physical capabilities.

When young individuals with a trans-tibial amputation are able to run,^[58] they can participate in a wide range of sports in which running is a basic component. Athletic performance was determined by the amputation level, with more proximal amputations leading to poorer performance as a result of more pronounced limb asymmetry.^[60;64;65] For long jumpers with trans-tibial amputations, better results were recorded among individuals who used their prosthetic limb for take-off compared to those using their intact limb for take-

off.^[61] The findings of two studies, one^[93;94] with a small sample size ($n=5$) and a literature review^[70] suggest that prosthesis characteristics influence running performance, therefore influencing also athletic performance. To clarify the influence of prosthesis characteristics on athletic performance, further research is needed in which athletes with limb amputations are repeatedly tested with different types of prostheses. Every athlete with a limb amputation should be assessed individually because each has a unique running style. Individual prosthesis modifications, special components or advice may be required.

One study investigated swimming technique among individuals with upper-limb amputations.^[56] The authors concluded that when swimming at higher speeds (at least 75% of the individual's maximum swimming speed), stroke frequency was more important than stroke length in gaining and maintaining speed. The similar results found for running^[58] may indicate that for increasing speed in running or swimming, athletes with limb amputations rely more on increasing their pace than on the length of their stride or stroke. Because data regarding swimming characteristics are available only from a single study, further research on this topic is needed before drawing conclusions.

Cardiopulmonary function of individuals with limb amputations was better when a simple physical exercise program was included in their rehabilitation program. The intensity of the program should be based on each individual's heart rate during AT and should not exceed 80% of the maximum peak value.^[68] Individuals with limb amputations must be subjected to a maximal test to obtain a peak value. This is not always possible because vigorous physical activity may be contraindicated by underlying cardiac problems. Therefore, only individuals with limb amputations who are healthy enough to undergo a peak test should do so. If an individual cannot be subjected to a peak test, clinicians can adjust the value for able-bodied persons of the same age according to the individual's physical condition. The rehabilitation programs may vary in duration, intensity, desired results and available rehabilitation time. An ergometer test can be used along with questionnaires (Medical Outcome Study 36-item short-form, SF-36,^[95] and Prosthesis Evaluation Questionnaire, PEQ^[96]) to assess the ability to walk. Individuals with lower limb amputations who are able to achieve an exercise intensity of 50% VO_{2max} ^[72] or 60 watts can be expected to become successful prosthetic walkers.^[66;72] When an individual's walking prognosis is known, the

rehabilitation process can be adapted according to the expected outcome, therefore optimising the results.

The psychological impact of the disability on athletes with limb amputations was found to be smaller as compared to athletes with other disabilities, such as audio-visual impairment or spinal cord injury.^[23] This is an interesting finding considering that an amputation is often perceived by the able-bodied as one of the worst physical disabilities.^[97] Unfortunately, no similar comparison between different disabilities has been performed in non-sporting or inactive individuals. Therefore, we cannot say if this difference is due to selection bias. Participation in sports and physical activities has a positive influence on self-esteem, perceived body image and locus of control.^[29;30;98] In general, the benefits of participation in sports outweigh the inconvenience of the disability. When individuals with limb amputations participate in sports and physical activities, they can set aside the concerns related to their disability. Because the majority of them have an underlying chronic disease, encouraging them to participate in sports may help them to overcome their disability by increasing their self-esteem. By taking part in organised sporting events, they can increase their knowledge of relevant sporting equipment and techniques to improve their performance. In addition, they improve their mobility skills, personal relationships and the acceptance of their own disability.^[32] When surrounded by other individuals with physical disabilities, persons with limb amputations gain a sense of normality, and they may feel more comfortable with their disability.^[99]

Participation in sports decreases following amputation.^[74] In Europe, 11 to 39% of individuals with limb amputations participate in sports or regular physical activity, while in the United States this percentage is 61%.^[37;38;75;76;79;83] This high percentage may be biased by sample characteristics in the United States studies, including an average age of 52 years and predominantly traumatic limb amputation in the study samples.^[49-51] In general, individuals with limb amputations are older than 65, and more than 80% have a vascular cause for amputation.^[92] The difference between European and North American studies may also be related to general differences in sports and physical activity habits between European and North American people.^[100] The sports that individuals with limb amputations prefer to take part in are similar regardless of the continent: swimming, cycling, golf, fishing, fitness.^[37;38;80;83] Most individuals with limb amputations do not use special sport prostheses because of high costs, lack

of knowledge about such prostheses or the feeling that they are unnecessary.^[37;38;80;83] A high percentage (42%) of all individuals with limb amputations reported at least one complaint about their prosthesis or about the sport organisation in which they participated.^[37] Sport participation appears to be hindered to some extent by unavailability of a suitable prosthesis, poor performance or high cost of the prosthesis, inadequate facilities or insufficient information.^[37;38] To increase sport participation, these factors have to be addressed. Individuals with limb amputations could be introduced to sports that do not require prosthesis use, like wheelchair or sitting sports. Professionals should encourage individuals with limb amputations to participate more in sports or physical activities and advise them in choosing appropriate sport prosthesis.

Several factors were associated with the physical functioning, mobility and activity level following amputation, including age,^[38;76;79] aetiology,^[38] amputation level and previous sport participation.^[77;80;85] However, discrepancies were found concerning the importance of aetiology^[37;78;79] and amputation level.^[38;76] For example, two studies^[78;79] using samples with different proportions of vascular and nonvascular amputations had similar main outcomes. This finding might lead to the conclusion that aetiology has no influence on sport participation and mobility outcomes. This statement contradicts other results on this topic^[38;76;101] showing that individuals with non-vascular limb amputations are more active than individuals with vascular amputations. In some studies,^[38;76;85] a more proximal amputation was found to lead to a decrease in sport participation. Other studies^[37;83] have found similar rates of sport participation regardless of the amputation level. Less discrepancy exists concerning the influence of age on physical functioning, mobility and activity level following amputation.^[38;76;79] Rehabilitation practitioners need to consider that a more proximal amputation, older age and the presence of comorbidity usually lead to a longer and more difficult rehabilitation.^[102]

Sport-related muscle pain was more frequent amongst individuals with limb amputations than amongst individuals with other physical disabilities.^[88] This difference is probably caused by the relatively limited amount of muscular tissue still available, which is subjected to more intense use as compared to individuals with other physical disabilities. Only one study of sport injuries was found that focused completely on individuals with limb amputations.^[86] Other papers

assessed sport injuries in a mixed group of athletes with different locomotor disabilities.^[103-106] Unfortunately, they did not address each disability as a separate category, making it impossible to identify disability-specific injury rates or patterns. Additionally, the sports in which individuals with limb amputations prefer to partake, such as fishing, swimming and golf,^[23;38;77] were not investigated concerning injury rates or patterns.

LIMITATIONS OF THE CURRENT SYSTEMATIC REVIEW

The literature search used only the generic term “sports”, and no separate searches were conducted for studies involving individual sports. We assumed that studies relevant to the topic of this review would most likely have the word “sport” or “athlete” somewhere in their content or be registered under the Mesh terms “Sports” or “Physical Activity”. During the title assessment phase, papers were excluded if the title had no connection to the topic of the review. It is possible that some papers that did not include the word “sport” or were not included in the “Sports” Mesh category may have been incorrectly excluded. Therefore, a reference check of the included papers was performed, resulting in the identification of 29 additional studies. The minimum number of 10 participants was arbitrarily chosen to reduce the influence of outliers on outcome and to increase the possibility to generalise the results. Seventeen papers could not be retrieved due to unavailability or indexing errors. These papers included book chapters, dissertations and oral presentations. If, as in the main sample, only 1% of these missing papers could be included in this review, the effects on the main outcome would be negligible.

The findings of this review should be interpreted cautiously because only few studies had a high methodological value. Only one randomised controlled trial was identified. Conducting a randomised controlled trial on individuals with limb amputations may prove difficult because of the limited number of subjects available. Additionally, physical activity tests can only be performed on a healthier subgroup of individuals with limb amputations. Finally, only four studies included individuals with upper limb amputations in their study populations.

CONCLUSIONS

Participating in sports or physical activity is beneficial for individuals with lower limb amputations. The psychosocial benefits for these individuals are at least equal to those experienced by able-bodied persons.

Future research should focus on the inclusion of a larger variety of sports and individuals with upper limb amputations in the study population. The influence of prosthetic technical characteristics on athletic performance needs further clarification because only running, long jumping and swimming have been analysed so far. The influence of sports on quality of life needs to be more thoroughly investigated. The determinants of sport participation are controversial. Therefore, more studies investigating these determinants are needed. A physical training program to improve cardiopulmonary function as part of the rehabilitation of individuals with limb amputations should be developed and tested for its efficacy.

Appendix 1

Table A1

Details of the literature search

SN	MEDLINE (Pubmed)	EMBASE	CINAHL/SportDiscus ^a
1	("Amputees"[Mesh] OR "Amputation"[Mesh] OR "Amputation, Traumatic"[Mesh]) OR (amput*) OR ("Artificial Limbs"[Mesh]) OR (prosthe* OR "artificial limb")	amputation'/exp OR 'disabled person'/exp OR amput*:ab,ti OR 'above knee prosthesis'/exp OR 'arm prosthesis'/exp OR 'hand prosthesis'/exp OR 'leg prosthesis'/exp OR 'limb prosthesis'/exp OR 'prosthesis'/exp OR prosthe*:ab,ti OR 'artificial limb'/syn	(MH "Amputees") OR (MH "Amputation") OR (MH "Amputation, Traumatic") OR amput* OR (MH "Limb Prosthesis") OR (MH "Myoelectric Prosthesis") OR prosthe* OR "artificial limb"
2	(Locomotion[Mesh] OR "Motor Activity"[Mesh] OR "physical activity") OR ("Sports"[Mesh] OR "Sports Equipment"[Mesh]) OR (sport OR sports OR athlet*)	'sports and sport related phenomena'/exp OR 'physical activity, capacity and performance'/exp OR 'athlete'/exp OR 'athletic rehabilitation'/exp OR 'sport'/syn OR 'sports'/syn OR 'athlete'/syn OR 'athletics'/syn	(MH "Sports") OR (MH "Physical Activity") OR (MH "Physical Fitness") OR sport* OR athlet*
3	1 AND 3	1 AND 3	1 AND 3
4	("lower extremity" OR leg OR ankle OR foot OR tibia OR fibula OR knee OR femur OR hip OR "upper extremity" OR arm OR wrist OR forearm OR radius OR cubitus OR ulna OR elbow OR humerus OR shoulder)	('lower extremity'/syn OR 'leg'/syn OR 'ankle'/syn OR 'foot'/syn OR 'tibia'/syn OR 'fibula'/syn OR 'knee'/syn OR 'femur'/syn OR 'hip'/syn OR 'upper extremity'/syn OR 'arm'/syn OR 'wrist'/syn OR 'forearm'/syn OR 'radius'/syn OR 'cubitus OR 'ulna'/syn OR 'elbow'/syn OR 'humerus'/syn OR 'shoulder'/syn)	lower extremity OR leg OR ankle OR foot OR tibia OR fibula OR knee OR femur OR hip OR "upper extremity" OR arm OR wrist OR forearm OR radius OR cubitus OR ulna OR elbow OR humerus OR shoulder
5	3 AND 4	3 AND 4	3 AND 4
6	("Arthroplasty"[Mesh] OR "Ligaments"[Mesh] OR "Prosthesis Implantation"[Mesh] OR "Hip Prosthesis" [Mesh]) AND "humans"[MeSH Terms]	('prothesiology'/exp OR 'ligament'/exp) AND [humans]/lim	(MH "Arthroplasty+") OR (MH "Ligaments+")
7	5 NOT 6	(5 NOT 6) AND Embase/lim	5 NOT 6
8	7 NOT (Editorial[ptyp] OR Letter[ptyp])	7 NOT ([editorial]/lim OR [letter]/lim OR [note]/lim OR [review]/lim)	7 NOT Publication Type: Book Review, Commentary, Editorial, Interview, Letter, Review, Systematic Review

a: databases CINAHL and SportDiscus are managed by the same search engine (e.g. EBSCOhost) therefore, the same strategy was used. SN: search number; Mesh/MH: medical subject heading; lim: limit; *: word truncation; exp: exploded term; syn: synonym; ab: abstract; ti: title.

Appendix 2

Amputees and Sports: A Systematic Review

Search update

Using the same search strategy and selection process as the one described by Bragaru et al 2011^[107], an update search was performed on August 28th 2012. Data contained by 2 major electronic databases MEDLINE (Pubmed) and Embase was assessed. Of the 464 titles initially identified 35 were selected for full text analysis and finally 10 papers matched the inclusion criteria. An additional 4 papers were identified by screening the references and additional sources. A complete list of these 14 papers is presented in Table 1.

Some of these papers come either to support previous findings or to fill in the gaps identified by the systematic review published in 2011.^[107] For example, based on the available evidence we can state that a physical training improves the cardio-pulmonary function and functional outcome of individuals with limb amputations.^[27;69;108;109] An interesting finding with immediate clinical applications is that a 10 week training program aimed to increase performance of hip muscles lead to a significant increase in efficiency of energy consumption during walking for individuals with lower limb amputations.^[108] Considering that ambulation is one of the major concerns of the rehabilitation team, training of the hip muscles should become of foremost importance. Beside the functional benefits, psychological benefits of sports were also mentioned by several authors.^[110-112] A recent epidemiologic study identified that 64.6% of adults, survivors of childhood lower limb sarcoma are physically non-athletes.^[113] Although this means that more than 30% of this population is physically active according the norm of CDC Physical activity guidelines,^[47] the sample characteristics are not representative for the general population with lower limb amputations. More to the point, the studied population is on average 37 years old and has an amputation caused by sarcoma, while in general individuals with lower limb amputations are older than 65 years and have an amputation due to vascular causes.^[92;114] In addition an age older than 65 and a vascular cause of amputation are factors which have a negative influence on the sports participation of individuals with lower limb amputation.^[36;38;76]

Taking into consideration that in within a year more 12 new scientific papers were published on the topic of sports participation of individuals with lower limb amputees is encouraging. Nevertheless it seems that data acquired from a study population that mirrors the general population as well as data regarding sports participation of individuals with upper limb amputations are still missing.

Table 1. Studies analyzing characteristics of individuals with limb amputations (update 2013)

Authors (y)	S (n)	Gender M/W; age	Amputation characteristics		Study design	Analysis aim	Results	
			Level	Side				
Biomechanical aspects and Athletic performance								
Nolan et al (2012) ⁽¹¹⁵⁾	16	16 / 0; N	16 TT	N	16 Uni; LL	CS	Influence of shank length on the performance of amputee long jumpers	Performance of amputee long jumpers is not influenced by the length of their residual shank. A stronger relationship, between athletic performance and residual shank length, was observed for amputees who jumped from their prosthetic feet
Pernot et al (2011) ⁽¹¹⁶⁾	10 (33)	8 / 2; 48.9 (± 11.9) ^b	5 TT / 4 TF / 1 HD	N	7 Uni / 4 Bi; LL	CS	Validity of test-table-test (TTT) for Nordic skiing	Center of pressure displacement classification significantly associated with the TTT classification with the exception of LW10 & LW10.5 disability classes The TTT is a valid and reliable test for assessing paralympic classification for Nordic skiing for the disability classes LW11, LW11.5, LW12
Molik et al (2012) ⁽¹¹⁷⁾	27 (54)	N / N; 30.85 (± 7.99) ^b	N	N	18 Uni / 9 Bi; LL	CS	Association between disability grade, anthropometric parameters and efficiency in Ice Sledge Hockey	Training frequency, body height and sledge length are disability specific and the values differ significantly between double amputees, single amputees, individuals with SCI and Les Autres. Game efficiency is not different between the 4 groups. Training frequency and sledge length are significant variables influencing game efficiency
Cardiopulmonary function								
Ulger et al (2011) ⁽¹⁰⁹⁾	41	23 / 18; 12.97 (± 3.23)	17 TT / 20 TF / 4 HD	Non-PVD; 21 Cong / 20 Acq	41 Uni; LL	Long	The influence of a physical training on the functional outcome of children with congenital or acquired LL amputation	Children with Con LL amputations scored significantly better at the initial and 3 weeks measurements compared to children with Acq LL amputations. At 6 months measurements children with Acq LL amputations matched the step width, velocity, cadence and weight bearing on the amputated side of children with Con LL amputations. Children with Con LL amputations had a longer stride length and step length with the amputated sides as well as with the intact side compared to children with Acq LL amputations. Prosthetic use helped improve functional outcome of children with Acq LL amputations

Nolan et al (2012) ^[108]	16	11 / 5; 45.06 (±9.36)	8 TT / 9 TF	Non-PVD	15 Uni / 1 Bil; LL	Long	Effect of a 10 week physical training on hip strength of lower limb amputees	Following training, flexor and extensor strength increased for intact limb. The strength of the hip extensor for the intact limb was significantly greater for the training group as compared to the control group. The strength of the hip flexor and extensor of the residual limb was significantly greater for the training group as compared to the control group. The training group consumed significantly less energy during walking following the 10 week training program. A training program aiming to increase hip strength may positively influence running ability in lower limb amputees
Wezenberg et al (2012) ^[118]	36	26 / 10; 61.7 (±6.1)	23 TT / 13 TF	26 Non-PVD / 10 PVD	36Uni; LL	CS	Influence of amputation aetiology on the cardiopulmonary characteristics of individuals with LL amputations	Individuals with vascular LL amputations have significantly lower peak power output, peak heart rate and peak aerobic capacity when compared to individuals with traumatic LL amputations. Psychological aspects and Quality of life
Berg Pasek et al (1996)* ^[110]	14	7 / 7; 15.07 (±1.32)	8TT / 3TF / 3N	Non-PVD; 9 Con / 5 Acq	12Uni / 2 Bil; 13LL / 1UL	Long	Influence of skiing on occupational adaptation and relative mastery	Skiing efficiency and effectiveness increased with increased practice time. Skiing had a positive influence on self-satisfaction and self-esteem. Family members and friends of skiers rated the skiing trip as beneficial.
Pensgaard et al (1999)** ^[111]	11 (30)	N	N	N	N	CS	Comparison of motivational factors and coping strategies of Olympic and Paralympic athletes	Paralympic athletes perceive a significantly more mastery-oriented climate and they are more satisfied with their effort and results as compared to Olympic athletes. Olympic athletes employ more redefinition and growth strategies as compared to Paralympic athletes.
Banack et al (2011) ^[112]	19 (113)	N	N	N	N	CS	The relationship between Intrinsic motivation, basic psychological needs and coach autonomy support of Paralympic athletes	For Paralympic athletes, perceived coach autonomy is a significant predictor of autonomy and relatedness. Perceptions of competence and autonomy are significant predictors of intrinsic motivation to accomplish. Perceived competence is a significant predictor of intrinsic motivation to know.

Gallagher et al (2011) ^{(1),(5)}	148	110/38; N	N	N	N; 66LL / 18UL / 65N	CS	Environmental barriers, activity limitations and participation restrictions of individuals with limb amputations	Restriction to participation in sports or physical recreation were experienced by 73.4% of participants. Individuals with LL amputations were more likely to experience some restrictions in community life and sports recreation than individuals with UL amputations. Individuals with UL were more likely to experience restriction in employment and job seeking than individuals with LL amputations. 69.2% of individuals with LL amputations experienced difficulties with the emotional effect of disability. 43% of individuals with LL amputations and 41% of individuals with UL amputations experience difficulties that severely interfere with their lives.	
Da Silva et al (2012) ⁽¹²⁰⁾	22	15 / 7; N	13TT / 1KD / 7TF / 1HD	6PVD / 17Non-PVD	2Uni / 1Bi; LL	CS	Physical activity and quality of life of individuals with LL	Men are more physically active and spend more time in sedentary behavior than women. 63.6% are physically very active, while 13.6% are physically active. Physical activity level significantly correlates with the psychological domain	
Sport participation and Physical functioning									
Ozunlu et al (2010) ⁽¹²¹⁾	174	174 / 0; 30.54 (±7.78)	N	N	N; 140LL / 34UL	CS	Physical and socio-demographic profile of Turkish amputee soccer players	Trauma is the most frequent cause of amputation. The majority of individuals with LL amputations have an amputation above knee while the majority of individuals with UL amputations have an amputation at shoulder level. Wheelchair basketball is the most played sport by individuals with LL amputations. Individuals with LL amputations usually experience problems with their prosthesis. Individuals with UL amputations do not commonly use prosthesis.	
Wampler et al (2012) ⁽¹¹³⁾	315 (610)	307 / 303 ^b ; 37 (19-53) ^{ab}	36TT / 264TF / 15HP	Non-PVD	N; LL	CS	Physical activity levels among survivors of childhood sarcoma	64% of the survivors treated with amputation are physically inactive. Being a woman, having a HP, and a treatment with platinum or vinca alkaloids increases the chances for a person to be physically inactive	
<p>a: (range); b: data for the entire sample (610); c: 65.2% were over 60 years old; *- due the use of limits in our previous search, the paper of Pasek [110] was not present in the final selection of papers; **-the paper of Pensgaard [111] did not match our search terms and selection criteria; ***- the paper of Ozunlu [121] was entered in Embase database at a date following our update search.</p> <p>N (n): number of amputees (total participants); M/W: men/women; N – no data; TT: trans-tibial; TF: trans-femoral; KD: knee disarticulation; LL: lower limb; UL: upper limb; Uni: unilateral; AB: able bodied; CS: cross-sectional; SRMP: sport related muscle pain; ORa: adjusted odds ratio; BMI: Body Mass Index.</p>									

Chapter 3

Sport Prostheses and Prosthetic Adaptations for the Upper and Lower Limb Amputee: An Overview of Peer Reviewed Literature

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ABSTRACT

Sport prostheses are used by both upper- and lower-limb amputees while participating in sports and other physical activities. Although the number of these devices has increased over the past decade, no overview of the peer-reviewed literature describing them has been published previously. Such an overview will allow specialists to choose appropriate prostheses based on available scientific evidence rather than on personal experience or preference. To provide an overview of the sport prostheses as they are described by the papers published in peer-reviewed literature. Four electronic databases were searched using free text and MESH terms. Papers were included if they concerned a prosthesis or a prosthetic adaptation used in sports. Papers were excluded if they did not originate from peer-reviewed sources, if they concerned prostheses for body parts other than the upper or lower limbs, if they concerned amputations distal to the wrist or ankle, or if they were written in a language other than English. Twenty-four papers were included in this study. The vast majority of these papers contained descriptive data and consisted of expert opinions and technical notes. Data concerning the energy efficiency, technical characteristics and special mechanical properties of prostheses or prosthetic adaptations for sports, other than running, are scarce.

INTRODUCTION

Participation in sports has been shown to help amputees improve their physical condition and overall well-being.^[17;107] To engage in sports, amputees typically utilise technical aids, such as prostheses, wheelchairs, or crutches. Lower limb prostheses are required for running and other sports that require a dynamic upright position. Upper limb prostheses are required for sports such as rowing or cycling so that upper limb amputees can propel or steer a boat or a bicycle. Nevertheless, there are sports in which amputees can engage freely without prostheses. For example, a lower limb amputee may have minimal or even no disadvantages when kayaking or swimming without prosthesis.^[122] Additionally, during world championship competitions in sports such as swimming^[123] or soccer^[124] the use of prostheses is not allowed.

Some sports can be performed with a regular prosthesis that is not specifically adapted for a particular sport. However, other sports require special prostheses or sport-specific prosthetic adaptations. During recent years, the development of specialised prostheses, prosthetic components and prosthetic adaptations that are used for sports has increased, leading to an increased number of sport prostheses and prosthetic adaptations that are available for amputees to use while participating in sports.^[54]

To date, an overview of the sport prostheses and prosthetic adaptations for sports described in the peer-reviewed literature has not been presented. Such an overview will enable rehabilitation specialists (i.e., physicians, prosthetists, physiotherapists and occupational therapists) who are working with amputees to choose the prosthesis that is most appropriate for each patient based on the patient's goals and the available scientific evidence. Identifying the information gaps present in the peer-reviewed scientific literature concerning these devices will stimulate new research and eventually broaden the base of scientific knowledge. The peer-review process is important because it increases the level of scientific quality by identifying, without bias, potential flaws and errors in research prior to its being published, thus helping to ensure reliable data. Consequently, the aim of this study is to provide an overview of the peer-reviewed sport prosthesis literature for both upper and lower limbs and to identify the knowledge gaps present regarding these devices.

REVIEW METHODS

A literature search was performed in Embase, PubMed, Cinahl and SportDiscus. The search was performed using a combination of Medical Subject Headings (MESH), specifically “artificial limb”, “limb prosthesis” (Embase, Cinahl and SportDiscus) and “artificial limbs” (PubMed), along with the name of the sport investigated “OR” the MESH term associated with the sport, using the Boolean operator “AND”. Considering that amputees often prefer to engage in sports such as swimming, skiing, golf, baseball, running, jogging, biking, cycling, bowling, kayaking, tennis and rowing, these sports were entered as free text terms in the search.^[80;38] All papers published before April 2011 were retrieved.

Papers that provided detailed information on sport prostheses or prosthetic adaptations used in sports were included. Papers that did not originate from a peer-reviewed source, papers concerning amputations distal to the wrist or ankle and papers written in a language other than English were not included. Reviews of any type and expert opinions were also not included. The references cited in each paper included in this study were checked for relevant publications. Sources that publish information without submitting it to a scientific peer-review process prior to publishing were not considered peer reviewed.

RESULTS

A total of 24 papers describing sport prostheses or prosthetic adaptations for sports were included. All of the identified information concerning sport prostheses and prosthetic adaptations was organised first by the body region that it addressed (lower or upper limb) and then alphabetically by the type of sport.

Lower limb prostheses and prosthetic adaptations for sports

Cycling

Following the assessment process, only one article concerning the use of prostheses by lower limb amputees for the purpose of bicycling fulfilled our inclusion criteria, and this article addressed only trans-tibial amputees.^[125] Regardless of their amputation level, it is recommended that lower limb amputees who desire to cycle consult their prosthetist or rehabilitation physician before starting.^[125] Although one-leg cycling is possible, using a prosthesis can

help to reduce inter-limb asymmetry. If the prospective cyclist wishes to use a regular prosthesis for cycling, it may be helpful to attach the prosthetic foot to the pedal using a cleat.^[125] Attaching a cleat to the prosthetic foot increases the effective length of the cycling prosthesis. Therefore, the effective length of the prosthesis to be used for cycling (racing) should be measured from the centre of the knee to the centreline of the cleat, and not to the heel, which is the case with a regular walking prosthesis. Additionally, the pedal should be laterally offset to allow for easier mounting and dismounting from the bicycle.^[125] If a leg prosthesis used for cycling is fitted with an energy-storing foot, the cyclist may experience a loss of propulsive power, especially while pushing the pedal with the amputated limb.^[125] This problem becomes more noticeable with an increasing cycling frequency. Consequently, a racing cyclist may feel the need to remove the foot altogether and connect the pedal directly to the prosthetic pylon using a toe cleat.^[125]

Golf

The internal rotation of the residual limb within the socket during repetitive golf swings can result in discomfort.^[126] Using a torsion adaptor, trans-tibial amputees can attain greater hip rotation and, consequently, greater shoulder rotation. This will lead to improved performance while minimising the internal rotation of the residual limb.^[122;126] In general, lower limb amputees may benefit more from the addition of a torsion adaptor if the amputation is located at the forefoot (the foot which is positioned slightly forward in relation to the other foot) rather than the swing foot (generally on the right side). Regardless of the amputation side, trans-tibial amputees report that the stress on their residual limb decreases with the use of a torsion adaptor.^[126] In contrast to trans-tibial amputees, the general range of motion during the golf swing of trans-femoral amputees is even more limited. Using two torsion adaptors, one below and one above the knee joint, may represent a solution for this issue.^[127] By adding the second adaptor, the general range of motion can increase from approximately 45 degrees to almost 90 degrees.^[127]

Running/Jogging

One of the first prosthetic feet designed to be used during more strenuous physical activity or sports was the Seattle Foot®. This foot included a series of fibreglass leaf springs and a rubber deflection bumper in its construction. These

components provided a higher energy return than conventional prosthetic feet at that time, allowing amputees to walk and run in a pattern that is more similar to the able-bodied gait.^[128;129] With the introduction of carbon fibre prosthetic feet, such as the Flex-Foot[®] or the Re-Flex VSP[®], lower limb amputees were able to achieve a more energy-efficient running style than those using feet such as the SACH[®] foot, which had a lower energy return.^[130;93] While using Flex-Foot Modular III[®] prosthetic feet, lower limb amputee runners have been able to achieve an “up on the toes” sprinting position, a position that is characteristic of able-bodied sprinters.^[131] With the introduction of prosthetic feet specialised for running and sprinting, amputees can achieve higher running speeds with lower energy consumption than would be possible using regular prosthetic feet.^[132;133] Furthermore, using running-specific prostheses may allow amputee runners to achieve higher speeds and similar metabolic costs compared to non-amputee runners.^[134;135] Nevertheless, data regarding the influence of running-specific prostheses on metabolic costs and running speeds are still controversial, and more research is needed to clarify this point.^[136;137]

While running, trans-femoral amputees may encounter more problems than trans-tibial amputees due to the increased interlimb asymmetry.^[107] One characteristic that is specific for the running style of trans-femoral amputees is the presence of a swing delay that can be up to 36% greater for the amputated side than for the non-amputated side.^[138;139] The swing delay is caused by the inertia of the prosthetic leg, which keeps the lower prosthetic shank from accelerating forward as quickly as the non-amputated limb.^[140] An attempt to remedy this problem was the Oklahoma cable running system.^[139] This system allowed the prosthetic lower shank to be propelled forward to achieve maximal knee extension at the moment of maximal hip flexion. With the development of more technically advanced prosthetic knees, the Oklahoma cable became obsolete and therefore this system is no longer in use. Another way to reduce the extension delay caused by the inertia of the prosthesis is to lower the prosthetic knee's horizontal axis.^[140] This modification has to be performed according to each subject's physical and running characteristics and preferences. An additional method to improve the running style of trans-femoral amputees consists of a spring or telescopic component mounted in the lower prosthetic shank (Terry Fox Jogging Prosthesis).^[141] In addition to improving energy return, the spring provides a cushioning effect, decreasing the stress that is exerted on the residual limb upon

initial contact.^[141] Unfortunately, the design of this apparatus was based on data obtained from an unimpaired jogger. Due to the differences between able-bodied and amputee running styles, the tested prosthetic prototype did not satisfy all the biomechanical requirements of a jogging prosthesis.^[141]

Skiing/Snowboarding

A regular prosthetic foot can also be stripped to its basic components to use only the parts that are needed to attach the foot to the skis.^[142] In this way, an ankle adaptor can be directly connected to the sole of a ski boot, allowing a direct connection between the prosthesis and skis and eliminating the need for the rest of the shoe.

Snowboarding, due to the particular position of the snowboarder's legs, requires a greater degree of movement in the ankle than skiing.^[143] Because of this, a specially designed ankle unit that allows plantar flexion and dorsiflexion as well as inversion and eversion has been shown to be more useful than regular prosthetic ankles for snowboarding.^[143]

Swimming

Both unilateral lower and upper limb amputees can swim quite easily without prostheses. The use of prostheses while swimming may help strengthen the residual limb muscles and lead to a more effective and symmetric swimming style.^[144;145] In addition, lower limb amputees who use prostheses may have less difficulty getting to, into and out of the pool.

Lower limb amputees who choose to use their prosthesis while swimming have to make sure that their prosthesis is waterproof.^[146] To increase propulsion while swimming, a flipper can be directly attached to the trans-tibial prosthetic socket.^[145] The total length of the flipper prosthesis should be equal to the length of the sound limb. Additionally, the vertical axis of the prosthesis needs to be laterally offset to avoid contact with the sound limb.^[145] Regardless of the type of prosthetic device that is used for swimming, there must be a secure connection between the residual limb and the socket. The use of a neoprene sleeve or a harness for trans-tibial prostheses is one means to provide a more secure fit.
^[145;146]

Socket adaptation

The residual limb volume may vary up to 17% between the minimum and maximum volumes during competition or training.^[147] Therefore, an adjustable socket may be useful for trans-femoral amputees, whose residual limbs typically have greater muscular mass than those of trans-tibial amputees. One solution to this problem is to cut (slit) the socket on the lateral side and then fit it with an adjustable flap.^[147] This way, athletes can adjust the socket volume themselves. When athletes use this type of socket modification, they have to be careful not to tighten the socket too much to avoid residual limb problems due to the increased pressure and reduced blood flow.^[147]

Upper limb prostheses and prosthetic adaptations for sports**Baseball**

Due to the different upper limb movements that are specific to each action, upper limb amputees may require two different prosthetic adaptations to play baseball, one for batting and one for catching. Conventional below-elbow prostheses do not have wrist units that allow flexion-extension or lateral motions, such as abduction and adduction, movements that are required for batting. These drawbacks can be eliminated by mounting a ball-and-socket joint between the prosthetic socket and the prosthetic hand.^[148]

Cycling

Upper limb amputees use their prosthesis to grip the handle bar to steer and to operate the gears and brakes. For this purpose, any prosthetic hand that is fitted with a voluntary opening/closing mechanism should be sufficient.^[149] A prosthesis used during cycling competitions should be able to be used in different positions during a race, should be light and should be specific to each competitive cycling discipline. Therefore, competitive cyclists require specialised cycling prostheses.^[150] A prototype prosthetic device that meets the demands of a below-elbow amputee has been designed, manufactured and tested.^[150] For above-elbow amputees, an elbow unit can be attached to the prosthetic device. This elbow joint can be locked at different angles or can be left unlocked, allowing the cyclist to assume various elbow positions during a race.^[150]

Fishing

When fishing, upper limb amputees use their prosthesis to manoeuvre the casting rod and the spinning reel.^[151] In both cases, prosthetic adaptations consisting of an aluminium tube mounted at the distal end of the socket can be useful. The diameter of this tube should match the diameter of the fishing rod or the spinning reel.^[151]

Golf

Unilateral upper limb amputees can play golf without a prosthetic aid; however, a loss in control and speed will occur.^[152] When using prosthetics in golf, the golf club can be attached directly to the prosthesis at the distal end of the socket with the use of a special adaptor. This type of modification has been described in detail in a paper by Bhala et al.^[152]

Kayaking

Upper limb amputees typically require an adaptation that allows them to hold and manoeuvre the paddle. The USF Kayak Hand[®] and the TRS Hammerhead Kayak Hand[®] allow the amputee to manoeuvre the paddle in a way that is similar to an able-bodied kayaker.^[153;154]

Skiing

Upper limb amputees can choose to have their ski poles directly attached to their prosthetic sockets.^[142] This option may be useful to bilateral upper limb amputees because it is often difficult for them to connect and disconnect the ski poles without the use of a functioning hand.^[142]

DISCUSSION

Twenty-four papers published between 1964 and 2011 were identified in the present study. The identified data consisted mostly of manufacturing indications and clinical commentaries. Scientific data concerning the efficiency, reliability and functionality for the large majority of the sport prostheses or prosthetic adaptations were absent. A number of expert opinions published in peer-reviewed and non-peer-reviewed sources were identified by the search.^[149;155-161] Even though the authors of these papers are respected and experienced professionals in their field, the papers themselves present little scientific data providing evidence for their claims.^[162] Expert opinions were not considered for

this study because they represent, as their name suggests, a personal opinion based on an individual's experience rather than on epidemiological and biostatistical calculations. As a result, it is nearly impossible for others to address the validity, quality and unbiased nature of these reports.

A large variety of sport prostheses and prosthetic adaptations can be found on manufacturers' websites. Almost all of the major manufacturers of prosthetic components have at least one product that is specifically designed for use during participation in sports. In addition, patients' or prosthetists' association websites may represent valuable information sources for individuals searching for sport prostheses or prosthetic adaptations for sports. The number of young traumatic amputees is expected to rise in the coming years, mainly due to armed conflicts or dangerous hobbies. Consequently one can expect that the request for specialized sport prostheses will also increase. Therefore besides thoroughly testing their devices, prosthetic manufacturers should also use their available resources to develop new specialized prosthetic devices for sports and physical activities.

The relative lack of scientific data available on sport prostheses and prosthetic adaptations for sports may be partially explained by the fact that there are a limited number of amputees who engage in sports and/or physical activities^[37;38;107] and even fewer who engage in sports at elite levels. Another explanation may be either that the vast majority of sport prostheses or prosthetic adaptations for sports are not thoroughly tested or that the results of these tests have not been published in peer-reviewed journals. Thorough testing would require a series of biomechanical tests performed in laboratory settings that are later followed by a thorough analysis of the data gathered. Most of the papers we identified consisted of observations or manufacturing indications that clearly lacked the phases we described above. Considering the increasing importance of evidence-based medicine, prosthetic manufacturers and developers of new prosthetic technologies should aim to provide information about their products through studies published in unbiased peer-reviewed journals. The peer-review process helps to increase the level of scientific quality by identifying potential flaws and errors in research prior to publishing.

A discrepancy in the amount of available data was also noticed between various types of sports. For example, the majority of the data concerning kinematic analyses and efficiency tests that were performed on prosthetic devices

were specifically focused on running or jogging prostheses. This finding can be explained by the fact that running is a principal component of many other sports, thus the data provided by these studies can be quite easily extrapolated to other sports. Another explanation may be the larger number of athletes who are practising this sport (running) and the increasing presence of mass media at these events. Therefore, we can understand the fact that some authors choose to address this topic in various reviews, including systematic reviews, expert opinions or clinical commentaries.^[94;163] The presence of these data is most welcome, considering the scarcity of scientific information that is available in this field. Nevertheless, one must consider that running or jogging can represent difficult skills for the average lower limb amputee to master. An array of factors amongst which fitness level, adequate training, associated co-morbidities and prosthesis may influence the ability to run or jog of lower limb amputees. Additionally with a more proximal level of amputation the interlimb asymmetry increases^[107] and therefore makes it even more difficult to acquire and maintain a dynamic alternating period of support and non-support on both intact and amputated limb.^[58]

Professional athletes or amputees who participate in competitive sports should consider that specialised sport prostheses could potentially improve their athletic performance. The best way to acquire a prosthesis that is optimally fitted to one's needs and capabilities is to collaborate closely with a sport coach and prosthetic technician. In this way, a prosthesis can be modified and adapted to each specific individual based on his or her specific athletic and physiological attributes.

In the future, researchers, clinicians and manufacturers in the field of sport prostheses should focus on conducting clinical studies in which the technical characteristics and performance of sport prostheses and prosthetic adaptations for sports are thoroughly tested and later published in peer-reviewed journals. This will hopefully minimise the gaps identified in the scientific knowledge of this field, as shown by this review. Ultimately, the data generated by the close collaboration of researchers, clinicians, prosthetists and manufacturers will lead to an increase participation in sports and physical activities of upper- or lower limb amputees.

Due to the fact that the current study design, review of literature, does not imply the use of either human or animal test subjects, the approval of the local medical ethical committee was unnecessary.

CONCLUSION

The data identified in the peer-reviewed literature concerning sport prostheses and prosthetic adaptations for sports were scarce and mostly descriptive in nature. However, the utility of running prostheses and prosthetic components has been substantially documented by peer-reviewed literature. More efforts should be made by researchers, clinicians and prosthetists alike to publish data concerning the energy efficiency, technical characteristics and special mechanical properties of sport prostheses in peer-reviewed publications.

Chapter 4

Sports Participation of Individuals with Major Upper Limb Deficiency

(submitted)

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ABSTRACT

The aim of this study was to analyse sports participation of individuals with upper limb deficiency (ULD) and associated factors. Individuals with ULD originating from the Netherlands were invited, via their attending physiatrist or prosthetist, to answer a digital or paper questionnaire. The questionnaire consisted of 34 items related to personal characteristics, type of deficiency and participation in sports. Of the 175 respondents, 57% participated in sports for at least 60 minutes per week (athletes). Results of logistic regression analysis indicated that presence of an additional health problem hindering sports participation ($\beta = -1.31$, $p < .001$) and a more proximal onset of the limb deficiency ($\beta = 0.76$, $p = .022$) had a negative influence on sports participation. For individuals with an acquired ULD a medium education level ($\beta = .77$, $p = .11$) and participation in sports before their amputation ($\beta = 1.11$, $p = .007$) had a positive influence on sports participation. The desire to stay healthy and the pleasure derived from sports participation represented the main reasons for participation in sports according to athletes. The presence of an additional medical problem and a lack of motivation were reasons for non-athletes to not participate in sports. The majority of individuals with ULD participate in sports regularly. The presence of an additional medical problem, the level of the ULD, educational level and participation in sports before amputation were related to participation in sports.

INTRODUCTION

Able-bodied and individuals with physical disabilities may benefit from regular participation in sports or physical activities.^[17;47;164] In general, able-bodied individuals who regularly participate in sports are healthier, have a lower chance of developing cardiovascular diseases or diabetes and have an overall better quality of life compared to those who do not participate in sports.^[5;46] For individuals with physical disabilities, participation in sports helps them put aside the trauma of their disability, improves their social life, and makes them feel competitive and less disabled.^[32;165;166] However, fewer individuals with physical disabilities (19%) participate in sports compared to able-bodied individuals (33%).^[16;167] Amputation of a limb or a congenital limb deficiency is considered to have a significant functional and psycho-social impact.^[9;25;97] A limb deficiency may also influence participation in sports. Individuals with lower limb deficiencies (LLDs) may choose to participate in sports that place less stress on their residual limb or may even completely stop participating in sports.^[107] To date, no data are available regarding the sports participation of individuals with upper limb deficiency (ULD) and the reasons why they do or do not participate in sports. These data are important due to the differences in age, etiology and functional impact of the disability between individuals with LLD and those with ULD.^[41] Additionally, these data can be used to evaluate effectiveness of future interventions studies.

The aim of this study was to analyze the sports participation of individuals with ULD and factors associated with this participation.

METHODS AND PROCEDURES

Population

Individuals with at least one major ULD with an onset at least 12 months before the date of survey were eligible for the study. A major ULD was defined as an amputation or a transverse congenital deficiency through the wrist or at a more proximal level. All individuals 18 years and older with major ULD listed in the databases of four major prosthetic manufacturers and eight rehabilitation centers in the Netherlands were recruited. The (Dutch) National Society of Amputees

(Landelijke Vereniging van Geamputeerden - LVvG) and an internet forum for individuals with an amputation of an upper or lower limb (Korter maar Krachtig - KmK) agreed to post a link to the online version of the questionnaire on their websites. An incentive (10 euros) was offered to those who returned the complete questionnaire. A total of 392 envelopes were sent to either the rehabilitation specialists or prosthetic manufacturers over a period of 3 months (March-May 2011). Data acquisition ended on the 1st of August, 2011. Because an electronic survey was used informed consent was impossible to request. The first page of the questionnaire presented the aim of the study and the possible burden associate with participation. Participants were given the option to proceed with the questionnaire or quit the study. This study was presented to the local Medical Ethics Committee who approved the research protocol (file number M 10.091129).

Instrument

The questionnaire was largely based on a questionnaire used in a previous study investigating the sports participation of individuals with LLD.^[37] Additionally, findings of a systematic review^[107] and data from an unpublished study addressing barriers and facilitators for the sports participation of individuals with LLD were used to formulate new items for the questionnaire. The questionnaire containing 34 items (see Appendix 1, Questionnaire, which contains a version of the paper based questionnaire) was available both on paper and online. The online version was constructed using EFS[®] software, and it was hosted by the online portal for surveys offered by UNIPARK[®]. Duplicate entries were searched for by comparing postal address, date of birth, gender and amputation type. If found, the most complete entry was kept for analysis.

Sports were defined in the questionnaire *“as physical exercise 2 times per week for a minimum of 30 minutes per session, thus a minimum of 60 minutes per week, of moderately intensive physical activity, with or without game or competition elements, where skills and physical endurance are either required or to be improved.”*^[39] *Mind sports like chess or checkers do not represent sports according to this definition.”*

Individuals who were active in sports ≥ 60 minutes per week were considered athletes. Individuals who were active in sports < 60 minutes per week or were participating in mind sports were considered non-athletes.

Statistical analysis

Crosstabs and Pearson's Chi-square tests were used to analyse associations between participation in sports and gender, civil status, children living at home, education, work status, the presence of additional health problems, cause of ULD, side and the onset level of the ULD. A t-test for independent samples was used to analyse the age of athletes and non-athletes. A Mann-Whitney test was used to analyse the influence of the time elapsed since the amputation on sports participation. For the group of individuals with an acquired ULD, the influence of sports participation before amputation on the current status of sports participation was analysed using the McNemar test. The significance level for all tests was preset at 0.05. The variables associated ($p \leq 0.2$) with participation in sports were entered in a logistic regression analysis (backward LR) for the total group and for individuals with an acquired ULD.

To facilitate logistic regression, several variables were categorized. Civil status was categorized into living together/married vs. living alone/widowed/separated; education was classified as high (higher professional training and academic), medium (vocational training) and low (elementary school); the level of deficiency was classified as below elbow versus through or above the elbow; and the cause of ULD was classified as congenital versus acquired. All statistical analyses were performed with the Statistical Package for the Social Sciences for Windows (Version 18.0.3, SPSS Inc., Chicago, IL).

RESULTS

Characteristics of the sports participation of individuals with ULD

A total of 209 responses were received, of which 34 were excluded from analysis due to duplication (5), incomplete entries (15), unusable data (7), minor amputation (5) or respondents being younger than 18 years of age (2). Subsequently, the data of 175 respondents (mean age 48.5 ± 14.4 years) were eligible for analysis. The acquired amputations ($n=118$) were caused by trauma

(n=88), cancer (n=14), vascular disease (n=5), infections (n=5) or other reasons (n=9). In total, 99 (57%) of the respondents were athletes (Table 1). No significant differences were found between athletes and non-athletes regarding age, gender, civil status or educational level. Although not-significant, less individuals with an acquired ULD were athletes compared to those with a congenital ULD ($p = .061$). Athletes had less health problems ($p = .034$) and additional health problem hindering their participation in sports ($p < .001$) than non-athletes. Athletes were less likely to have a deficiency through the elbow or more proximal than non-athletes ($p = .026$).

Table 1. Characteristics of the investigated population (n=175)

Characteristics		Athletes (n=99)		Non-athletes (n=76)		p	
Age, mean (\pm SD)		48.3 (\pm 13.7)		48.7 (\pm 15.3)		.864	
		n	(%)	n	(%)		
Gender	Men	59	(60)	49	(64)	.511	
Civil status	Living together or married*	67	(68)	52	(68)	.917	
Children living under the same roof	No	60	(61)	51	(67)	.376	
Education	Low	4	(4)	9	(12)	.137	
	Medium	64	(65)	43	(57)		
	High	31	(31)	24	(32)		
Work status	Paid work	51	(52)	40	(53)	.669	
	Retired	13	(13)	13	(17)		
	Unpaid work	35	(35)	23	(30)		
Lower limb deficiency (3missing)	No	94	(95)	73	(97)	.291	
Additional health problems	Yes	35	(35)	39	(51)	.034	
	-Hindering sports participation	Yes	16	(46)	30	(77)	<.001
	-Problem type**	Joint / Rheumatic disease	23	(23)	22	(29)	
		CVD / Diabetes	11	(11)	13	(17)	

	Other [#]	6	(6)	20	(27)	
Unilateral upper limb deficiency		98	(99)	74	(97)	.448
Level of upper limb deficiency	Hand or wrist ex-articulation & trans-radial	66	(67)	38	(50)	.026
Cause of upper limb deficiency	Amputation	61	(62)	57	(75)	.061
	-Months since amputation, median (25 th ; 75 th)	149(81.5;360.5)		90.5(32.2;316.2)		.103
	-Participated in sports before amputation	44	(72)	28	(49)	.135
Sufficient information about participation in sports received (4 missing)	Yes	53	(53)	36	(50)	.648

*– versus living alone/ divorced / single; ** – Respondents were allowed to provide more than one answer; CVD – Cardiovascular diseases; # – chronic pain, digestive diseases and pulmonary diseases.

The sports in which athletes participated were cycling (44%), fitness or similar indoor training (35%), walking (33%), running or jogging (21%), swimming (21%) and racquet sports (19%). Sports participation characteristics of the 99 athletes are presented in Table 2.

Table 2. The characteristics of sports participation of the 99 athletes

<i>Characteristics</i>		<i>N</i>	
Sport frequency per week	1	27	
	2	39	
	3	18	
	≥5	15	
Sport level	Recreational	83	
	Local/regional competition	15	
	National/international competition	1	
Type of assistive device used during sports	Daily prosthesis without sport adaptations	27	
	Daily prosthesis with sport adaptations	4	
	Special sport prosthesis	13	
Type sport with (SP)/(NP)*		SP	NP
	Fitness	4	13
	Cycling	8	13
	Walking	4	5
	Running	3	5
	Swimming	4	2
	Racquet sports	3	5
Reason for not using an assistive device during	Unnecessary		50
	Insufficient information		2

sports	It's not easy (uncomfortable)	3
Member of a sport club (1missing)	For able bodied	42
	For disabled	4
Contact with sport	Friends / Family	40
	Previous experience	33
	At own initiative	19
	Professionals within the rehabilitation center	14
	Professionals outside the rehabilitation center	13
	Internet	4
	Other	10

SP – sport prosthesis; NP – normal prosthesis; * – some respondents participated in more than one sport.

<i>Predictors</i>	β	<i>S.E.</i>	<i>Sig.</i>	<i>Exp(β)</i>	<i>95% C.I. EXP(β)</i>
Presence of additional health problems hindering participation in sports	-1.31	0.37	< .001	0.27	0.13; 0.56
Distal upper limb deficiency*:	0.76	0.33	.022	2.14	1.12; 4.08
Constant	0.18	0.26	.491	1.19	0.71; 1.98

β – regression coefficient; S.E. – standard error; Sig. – significance; Exp(β) – odds ratio; * –hand or wrist ex-articulation & trans-radial

Factors that influence the sports participation of individuals with ULD

The results of the backward LR regression showed that individuals with an additional medical problem hindering participation in sports and with a more proximal level of ULD have reduced odds to be athletes (Table 3). For individuals with an acquired ULD, an additional medical problem hindering participation in sports reduced the odds of being an athlete, while participation in sports prior to amputation and a medium level of education increased the odds of being an athlete (Table 4). For individuals with a congenital ULD, the results of the logistic regression showed that an additional medical problem hindering participation in sports reduced the odds of being an athlete ($\beta = -1.537$, $p = .016$).

Table 3. Results of logistic regression analysis on the total population (n=175) to predict their participation in sports

<i>Predictors</i>	<i>β</i>	<i>S.E.</i>	<i>Sig.</i>	<i>Exp(β)</i>	<i>95% C.I. EXP(β)</i>
Education*			.05		
Low education	-1.56	1.17	.18	.21	.021; 2.09
Medium education	.77	.48	.11	2.16	.84; 5.54
Presence of additional health problems hindering participation in sports	-1.31	.48	.01	.27	.11; .70
Participation in sport before amputation	1.19	.45	.01	3.28	1.37; 7.86
Constant	-.74	.54	.17	.48	.17; 1.37

β – regression coefficient; S.E. – standard error; Sig. – significance; Exp(β) – odds ratio; *Education was entered in the Backward LR regression as a categorical variable with three levels (high, medium & low).

Table 4. Regression analysis on the individuals with an acquired upper limb deficiency (n=118) to predict their participation in sports

While athletes participated in sports mostly because it was good for their health and they perceived sports as pleasurable events, non-athletes reported that they did not participate in sports mainly because of personal reasons or past experiences (Table 5).

Table 5. Reasons why athletes participate in sports and why non-athletes do not participate in sports

<i>Reasons to participate in sports* (n=99, 1 missing)</i>	<i>n</i>	<i>%</i>	<i>Reasons not to participate in sports* (n=76, 7 missing[#])</i>	<i>n</i>	<i>(%)</i>
Good for health	83	(84)	Enough exercise during ADL	23	(33)
Good feeling (pleasure)	71	(72)	Hindering condition/ presence of injury/afraid to get injured	23	(33)
Want to participate in sports	42	(42)	Never participated in sports	21	(30)
Want to improve the physical functioning	40	(40)	“Don’t feel like it”	18	(26)
Always participated in sports	39	(39)	Insufficient time	18	(26)
Increase the number of social contacts	36	(36)	Desired sport can’t be practiced due to the current disability	10	(15)
Advised by doctor / physiotherapist	22	(22)	Insufficient information	9	(13)
Reduction of pain	9	(9)	Sport facilities are not adapted to the disability	6	(9)
Other	8	(8)	Too expensive	4	(6)
			Insufficient sport facilities in close	4	(6)

surrounding		
Lack of a sport partner	3	(4)
Other	6	(9)

* Respondents were allowed to provide more than one answer; # respondents who were less than 60 minutes active per week and those who were active in mind sports (n=7) considered themselves “active” and did not answer this question; ADL – activities of daily living.

DISCUSSION

More than half of individuals with a major ULD participate in sports mainly because of physical and psychological benefits. From the results of the regression analysis it became clear that the presence of additional medical problems hindering sports participation, and a more proximal ULD have a negative influence on the sports participation of individuals with ULD. For individuals with an acquired ULD, participation in sports before they sustained the upper limb amputation and a medium level of education has a positive influence on sports participation, regardless of the amputation level of the ULD. In the regression analyses we chose to use a $p \leq 0.2$, found in the univariate analysis, as a criterion to enter a variable in order to reduce the risk of making a Type II error.^[168]

In the Netherlands, more individuals with ULD (57%) participate in sports compared to individuals with LLD (32%).^[37] Individuals with ULD are, on average, younger than those with LLD.^[114] Major ULD is usually caused by trauma or congenital malformation and less often by vascular disease.^[41] By contrast, major LLD is caused mostly by vascular diseases and less often by trauma and cancer, while congenital malformations account for only a small fraction of the total number of LLDs.^[41;92] No significant association between age or the cause of ULD (congenital versus acquired) and the sports participation of individuals with ULD was identified. . Most likely, age and cause of amputation did not vary enough between individuals with ULD to identify a significant association with sports participation. Similar to the literature addressing individuals with LLD, we identified that a more proximal onset level of the limb deficiency and the presence of an additional medical problem have a negative influence on the sports participation of individuals with ULD.^[36;37;77;85]

The majority of athletes with ULD who were members of a sport club chose an able-bodied sport club (91%). For individuals with LLD, this percentage was 60.^[37]

In the Netherlands, there are a large number of clubs and sport associations for individuals with physical disabilities; therefore, the choice of an able-bodied sport club may not have been dictated by necessity. Additionally, the high rate of sports participation and the practiced sports of individuals with ULD appear more similar to the patterns of able-bodied individuals than individuals with LLD.^[107] Therefore, it is possible that programs aiming to increase sports participation by able-bodied individuals may also prove effective in increasing the sports participation rate in individuals with ULD.

Although various sport prostheses are available^[169], the majority of athletes did not use a prosthetic device during sports, mostly because they did not need it. This finding is in accordance with previous findings suggesting that individuals with LLD chose to participate in sports for which their prosthesis is neither needed nor required.^[80] Identifying in greater detail the reasons why individuals with ULD choose not to use their prosthesis during sports may be useful. Additionally, the fact that most of the athletes with ULD who used a prosthetic device during sports chose for a regular arm prosthesis instead of a specialized sport prosthesis is interesting. Future research should focus on identifying the reason behind this choice and the influence of prosthesis on sports participation.

Between 37%^[170] and 56%^[171] of the general Dutch population participate in sports weekly. Our results show that 57% of individuals with ULD participate in sports for at least 60 minutes /week; thus, individuals with ULD seem to be as active as the general Dutch population. This hypothesis cannot be verified due to the differences between research methodology of the referenced studies and our own research. Also, athletes may have been more enthusiastic in answering our questionnaire than non-athletes. Poor health or the presence of an additional medical problem was identified as the factor with the greatest influence on the sports participation of individuals with ULD. Although this finding is neither new nor unexpected for the general population, our result is the first one which concerns individuals with ULD. Therefore, the rehabilitation team should perhaps focus on reducing the burden of comorbidity or specifically advise patients of what physical activities or sports they might be able to perform, considering their current health status.

A theoretical model, like for example the Theory of Planned Behavior^[172] may help us to better understand the factors athletes and non-athletes associate with

sports participation. This model contains three categories of factors Attitudes (Att), Perceived behavioral control (PBC) and Subjective norm (SN), and may be helpful in predicting behavioral change like sports participation. For example the reasons for athletes to participate in sports, included improvement of physical health or psychological benefits, such as pleasure and excitement can be all attributed to the Att category of this model. Beside this, these factors are similar to those reported in literature.^[4;173;174] Non-athletes' reasons not to participate in sports are generally characterized by insufficient or inadequate information, poor physical health or lack of motivation, factors that can be attributed to the PBC category. Insufficient information was not related to participation in sports ($p = .648$), with only 13% of non-athletes reporting this as their main reason for not participating in sports. Nevertheless, 33% of non-athletes believed that they exercised enough during their daily activities. This finding, also related to PBC, may imply that they don't perceive the difference between sports or physical activity as a standalone activity and the physical activity someone performs on daily basis. Although they were not specifically asked how they came to that conclusion, it may be that they were never informed about the difference between the two actions, which may imply that SN plays also a role. When participating in sports or standalone physical activities the athletes experience both physical as well as psychological benefits.^[6] These psychological benefits are mostly due to the specific state of mind associated with participation in sports. If we consider that 40% of athletes came into contact with their practiced sports through family or friends, it may be wise to use these channels to also provide information to non-athletes. This finding only confirms the importance of the SN domain in sports participation. Additionally, by involving family and friends, the social element of sports may be added to the equation. The social element was also mentioned as a reason to participate in sports by 36% of athletes, showing that participating in sports is a social experience, thus part of the SN domain.

LIMITATIONS OF THE CURRENT STUDY

Although a considerable number of individuals with ULD were investigated, only those residing within the Netherlands participated in this study. Therefore, the results of this study should be generalized to individuals in other countries with caution. The percentage of athletes with ULD in our study exceeds the

percentage of able-bodied athletes. This result might be because more athletes completed the questionnaire compared to non-athletes (selection bias) or because of the previously reported difference between actual participation rate and the self-reported rate.^[175] The questionnaire used was not previously validated. Due to the nature of data acquisition, we were unable neither to calculate the response rate nor to compare the characteristics of respondents and non-respondents. Finally, due to the limitations of the questionnaire, the influence of prosthesis on sports participation couldn't be analysed.

Although various definitions for sport are available, there is no standard definition used by scientists who investigate the sports participation of able-bodied individuals and individuals with physical disabilities. In addition to using various definitions for sport, some studies did not use a definition for sport.^[107] Consequently comparisons of participation rates in sports between different studies are difficult. Future research addressing sports participation should use a definition for sport to improve the interpretation of results. This definition should be based on an international consensus and should be applicable for both able-bodied individuals and disabled individuals. An important element of this definition should be to operationalize the frequency and intensity of sports participation that will enable us to differentiate between physically active individuals, athletes and top-athletes.

CONCLUSIONS

More than half of the individuals with ULD participate in sports for at least 60 minutes per week. The presence of an additional medical problem, the level of the ULD, educational level and participation in sports before amputation are associated with participation in sports. Not participation in sports before amputation and lack of motivation are the most common factors associated with not participation in sports.

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What are the new findings?

- Presence of additional health problems as well as a more proximal ULD has a negative influence on the participation in sports of individuals with ULD.
- The characteristics of the sports participation of individuals with ULD are more similar to the ones of able bodied than with the ones of individuals with LLD.
- Friends or family represent an important source for information on sports for individuals with ULD.
- The majority of athletes with ULD do not use their prosthesis while participating in sports.

How might it impact on clinical practice in the near future?

- Medical professionals working with individuals with ULD should try and become the first source of information on sports for these individuals.
- More time and energy should be spent on identifying the motivation based on which individuals with ULD may start participating in sports.
- Family and friends play an important role in sports participation of individuals with ULD, therefore at least in the beginning they should be part of the process.

Appendix 1

Questionnaire used to gather data

Paper based version

First we would like to know some general information

- 1. Date of filling in the questionnaire/...../.....

- 2. Your birth date/...../.....

- 3. Your gender:
 - Man
 - Woman

- 4. What is your civil status
 - Living alone
 - Living together / Married
 - Divorced
 - Widow (-er)

- 5. Do you have children who still reside with you?
 - No
 - Yes. If Yes, how many and what is their age?
Number:; Age,.....,

- 6. What is your highest level of finished education?
 - Low level (no education or basic school)
 - Medium level (high school, professional or secondary school)
 - High level (bachelor or above including PhD)
 - Other, namely.....

- 7. What is your working status now?
 - I have paid work. I workhours/per week
 - I'm retired
 - I have no paid work
 - Other, namely.....

For question 8 to 10 you have to select an answer, in accordance with your amputation side. For example, if you have an upper limb deficiency located at the right arm you will fill in only the column under **Right arm**, if you have an upper limb deficiency located at the left arm you will fill in only the column under **Left arm**; if you have an upper limb deficiency located both on the left arm as well as at the right arm then you should fill in

	Left arm	Right arm
8. Starting from what level do you miss a portion of your upper limb?	<input type="checkbox"/> Shoulder blade <input type="checkbox"/> Shoulder <input type="checkbox"/> Arm <input type="checkbox"/> Elbow <input type="checkbox"/> Forearm <input type="checkbox"/> Wrist <input type="checkbox"/> Other, namely:	<input type="checkbox"/> Shoulder blade <input type="checkbox"/> Shoulder <input type="checkbox"/> Arm <input type="checkbox"/> Elbow <input type="checkbox"/> Forearm <input type="checkbox"/> Wrist <input type="checkbox"/> Other, namely:
9. What is the reason that you miss a portion of your upper limb?	<input type="checkbox"/> Congenital <input type="checkbox"/> Cancer <input type="checkbox"/> Trauma <input type="checkbox"/> Vascular <input type="checkbox"/> Diabetes <input type="checkbox"/> Other, namely:	<input type="checkbox"/> Congenital <input type="checkbox"/> Cancer <input type="checkbox"/> Trauma <input type="checkbox"/> Vascular <input type="checkbox"/> Diabetes <input type="checkbox"/> Other, namely:
10. When did the amputation occur? Please fill in month and year. If your upper limb deficiency is congenital, please advance to question/...../.....
11. Do you miss also a part of a leg?	<input type="checkbox"/> No <input type="checkbox"/> Yes.....	
12a. Do you have additional health problems (besides the reasons for the limb deficiency stated at question 9)?	<input type="checkbox"/> No, I don't have any additional health problems. Please go to question 13 <input type="checkbox"/> Yes	
12b. Which of the health problems, enumerated on the right side do you have at the moment? (You may provide multiple answers.)	<input type="checkbox"/> Rheumatism <input type="checkbox"/> Cardiovascular disease <input type="checkbox"/> Erosion of joints <input type="checkbox"/> Complications of the respiratory system <input type="checkbox"/> Kidney disease <input type="checkbox"/> Other, namely.....	

both columns.

12c. Do these conditions hinder your possible participation in sports? No Yes

13. Do you consider yourself well informed about the available possibilities of participation in sports for people with upper limb deficiency? No, because..... Yes, because

By sport we understand a moderate physical activity, with or without game or competition elements, where skills and physical condition is either required or to be improved, which takes place at least two times a week with a **minimal duration of 30 minutes per time**, thus **minimal 60 minutes a week**. For example: you **cycle or walk for 30 minutes at least two times a week** with a moderate intensity.
 Attention: mind sports like chess or checkers do not fall under this definition.

14. Did you sport before the onset of your limb deficiency? No Yes NA (in the case you have a congenital limb deficiency)

15. Do you take part in sports now? No. Please advance to question 29a Yes

16. Why do you participate in sports? (You may provide multiple answers.)
 Because It's good for my general health I want to improve my physical functioning I feel better when doing it My pain reduces through sport My family or friends suggested it My physician / physiotherapist suggested it I want to The social contacts I develop through it are important I always participated in sports Other, namely

17. Which sport (s) did you practiced in the last 6 months and you're still practicing now?

18. How did you come in contact with the sport you are practicing now? (You may provide multiple answers.)
- Through:
- Attending physician outside Rehabilitation Center
 - Other health professionals outside Rehabilitation Center namely.....
 - Previous experience (I practiced this sport before)
 - Friends/ Family
 - Internet
 - Members of attending sport club
 - Attending physician inside Rehabilitation Center
 - Other health professionals inside Rehabilitation Center namely.....
 - Prosthetist
 - Other, namely:
19. Do you participate in sports through a sport club or an association?
- No. Please go to question 21
 - Yes
20. Through what type of club or association do you participate in sports?
- Association for disabled individuals
 - Association for able bodied
21. On which level are you participating in sports?
- Recreational (only training)
 - Match/Competition (not on national or international level)
 - Top sport (competition at national or international level)
22. How often did you participate in sports in the last 6 months?
- Less than once a week
 - 1 time a week
 - 2 times a week
 - 3 times a week
 - More than 5 times a week
23. What is the average duration of your regular participation in sports?
-minutes/time
24. Do you use helping aids during your participation in sports?
- By "*helping aids*" we mean all means/materials, other than sport clothing, that you use during your exercise. For example prosthesis or any other helping aid.
- No
 - Yes. Please go to question 26

25. Why don't you use a helping aid? (You may provide multiple answers.)
- I don't need it
 - I find it too expensive
 - Other, namely.....

Please advance to the end of the questionnaire

26. Which of the helping aids mention on the right side do you use during your participation in sports?(You may provide multiple answers.)
- Daily prosthesis without sport modifications
 - Daily prosthesis with sport modifications
 - Special sport prosthesis
 - Others, namely..... If you chose "Others" please advance to question 28

27. What type of prosthesis do you use during your participation in sports? (You may provide multiple answers.)
- Myoelectric
 - Body powered (cable manoeuvring)
 - Cosmetic
 - Not applicable
 - Others, namely

28. Did your insurer cover the cost of the device you use during your participation in sports?
- No
 - Yes.

Please advance to the end of the questionnaire

29a. What is the reason (s) for not participating in sports? (You may provide multiple answers.)

- Because
- Now I have an injury
 - I'm not in the mood to
 - There are no sport facilities in my surrounding
 - The available sport facilities are not adapted for my handicap
 - I received insufficient information
 - I don't have a sport partner
 - I don't have sufficient time
 - I get enough physical activity during my daily routine
 - I have other hindering health problems
 - I'm afraid to get injured (again)
 - Due to my handicap I can't participate in the sport I like
 - My favourite sport is not available in my surrounding
 - I was never actively participating in sports
 - Other, namely.....

29b. Do you consider participating in sports (too) expensive?

- No. Please go to question 30
- Yes

29c. Please specify for which of the items mentioned on the right side you consider participation in sports as (too) expensive. (You may provide multiple answers.)

- Prosthesis
- Transport
- Monthly fee for fitness center
- Sporting equipment
- Other, namely.....

30. Will you please specify what needs to change in order for you to participate in sports?
.....
.....

Thank you very much for your cooperation

Chapter 5

Sports Participation of Dutch Lower Limb Amputees

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ABSTRACT

To analyse sports participation of Dutch lower limb amputees and factors influencing sports participation. A cross-sectional survey was performed. Dutch lower limb amputees (N=2039) were invited to participate in a postal survey addressing personal and amputation characteristics, physical limitations, sports participation, skin problems, and prosthesis use. Only data concerning personal and amputation characteristics together with the data concerning sports participation were used for this study. Of the 816 questionnaires received, 780 were suitable for statistical analysis. The mean age of the participants was 59.6 years (SD 14.8), 62% were men and 27% of the amputations was due to vascular diseases or diabetes. Only 15% of all respondents participate in sports at least 5 hours a month. Smoking (odds ratio: 0.55), an age older than 60 (odds ratio: 0.97 per year), and a vascular cause of amputation (odds ratio: 0.42) were negatively associated with sports participation. Less than 15% of the Dutch lower limb amputees participate in sports at least 5 hours per month. Older age, smoking and a vascular cause of amputation have a negative influence on the sports participation of these individuals.

INTRODUCTION

In the near future the number of lower limb amputees (LLA) is most likely to increase due to an increase in age and an increase incidence of diabetes mellitus and cardiovascular conditions.^[41] Regular participation in sports and physical activity (PA) improves physical functioning and overall quality of life in LLA.^[107] After a physical training program cardio-pulmonary function and physical fitness^[24;28], walking speed and walking distance^[33] as well as overall functioning with the prosthesis^[32;85] improve. Additionally, LLA who participate in sports (athletes) also experience an improvement in psychosocial functioning. Athletes mention that sports participation helps them to increase the number of social contacts, to cope better with their amputation and it also gives them a higher self-esteem.^[29;32] Sports participation rate of LLA has been scarcely investigated.^[107] Most of the studies addressing this topic are characterized by selection bias^[35;37;75;83] and or do not mention criteria to differentiate between athletes and non-athletes. Consequently, large differences exist in reported sports participation rates of LLA. For example in the Netherlands sports participation rates of LLA range from 32% to 39%^[37;83], while in the United States this rate is 60%^[38].

Literature concerning the factors that influence sports participation of LLA is scarce and contradictory.^[107] Some studies identify older age,^[35;36;38;76;80] a proximal level of amputation^[36;76;77;85] and a vascular cause of amputation^[38] as factors which have a negative influence on sports participation of LLA; while other studies either did not identify the those factors or identified other factors, such as sports participation prior to amputation^[37] or gender.^[80] Selection bias may have caused these contradictory results. Identifying the factors which influence participation in sports or PA of LLA may help rehabilitation professionals to predict more accurately the odds of such an individual to participate in sports.

Consequently, our aim was to analyse sports participation rate of LLA and factors influencing sports participation.

METHODS

Data used by the current study originated from a larger database used in previous studies.^[176;177] The aim of those studies was to identify skin problems, determinants of skin problems of the stump in LLA and to analyse the influence of skin problems on functioning in daily life. Detailed information regarding the sampling procedure can be found in those studies.^[176;177] In short, Dutch LLA ≥ 18 years old were invited, either via an orthopaedic workshop (Orthopedische Instrument Makerij - OIM) or via the National Society of Amputees (Landelijke Vereniging voor Geamputeerden - LVvG), to participate in the study. If they agreed, they had to return the signed informed consent together with their address details. Afterwards they received an envelope containing the questionnaire, which they were asked to answer and then return. If an incomplete set of data was received, the sender was contacted in order to remediate the issue. No formal permission on behalf of the local medical ethical committee was needed to conduct this study.^[178]

For the purpose of the current study the answers to two questions, not previously investigated, together with personal characteristics and amputation characteristics were analysed. These questions were related to sports participation and were formulated as following: *“Did you participate in sports in the last month? If so, how many hours did you participated in sports last month? Please chose one of the followings: less than 1 hour, between 1 and 5 hours, more than 5 hours”* and *“For what sports did you use a prosthesis and how many hours did you spent at those sports?”* Participants were divided in 2 different groups according to their sports participation level: LLA who participated in sports more than 5 hours per month (athletes) and those who participated less than 5 hours per month (non-athletes).

Data analysis

Statistical analyses were performed in the Statistical Package for the Social Sciences for Windows (Version 18.0.3, SPSS Inc., Chicago, IL). Possible associations between sports participation (athletes versus non-athletes) and, gender, civil status, education, work status, smoking, presence of additional health problems, presence of complaints of the sound leg and aetiology, side and the level of amputation were investigated using Pearson’s Chi square test. A t-test for

independent samples was used to analyse differences in age of athletes and non-athletes. The influence of the time elapsed since the amputation and sports participation was analysed using a Mann-Whitney test. The significance level for all tests was preset at 0.05. In order to facilitate the statistical analysis the following variables were categorized; level of amputation into trans-tibial, knee-disarticulation and trans-femoral and amputation aetiology into vascular and non-vascular. Age was centred at 60 years. Factors that were associated with sports participation ($p \leq 0.1$), were entered in logistic regression analysis (method backward LR).

RESULTS

A total of 2.309 LLA, representing 25% of the possible Dutch population of LLA, were invited to participate of which 872 agreed to complete and to return the questionnaire, while 816 actually returned the questionnaire.^[176;177] Eventually, the responses of 780 (34%) participants (mean age 59.6 (SD14.8)) were suitable for statistical analysis (Table 1). In total 665 (85%) were non-athletes and 115 (15%) were athletes. No significant differences were found between non-athletes and athletes regarding gender, presence of complaints at the sound leg, presence of bilateral amputation or the level of amputation. Age, work status and the reason of amputation significantly associated ($p < .001$) with participation in sports for athletes. Age centred at 60, civil status, cause of amputation, months since amputation, additional health problems, work status and smoking, were entered in the regression analysis. Individuals older than 60 years, with an amputation due to vascular aetiology and who are smoking were less likely to be athletes (Table 2).

Of the athletes 93 (81%) used their prosthesis during sports. LLA used their prosthesis for participating in 22 different sports. Most practiced sports with a prosthesis was cycling (37%) followed closely by fitness (30%) and walking (12%).

Table 1. Overview of the characteristics of the participants divided in non-athletes and athletes

		Total (N=780)		Non-athletes (N=665)		Athletes (N=115)		p
		n	%*	n	%*	n	%*	
Age in years: mean (SD)		59.6 (14.8)		60.9 (14.5)		52.5 (14.5)		<.001
Gender	Woman	294	38	254	38%	40	35%	.496
	Man	486	62	411	62%	75	65%	
Civil status	Alone	129	17	102	15%	27	23%	.021
	Married	532	68	452	85%	80	70%	
	Divorced	47	6	43	6%	4	3%	
	Widowed	69	9	65	10%	4	3%	
Paid Work	Yes	236	30	182	27%	54	47%	<.001
Smoking	Yes	197	25	175	26%	22	19%	.102
Additional health problems	Yes	365	47	322	48%	43	37%	.029
Complaints sound leg	Yes	349	44	305	46%	44	38%	.091
	NA / Bilateral	43	6	38	6%	5	4%	
Bilateral amputation	Yes	44	6	39	6%	5	4%	.515
Months since amputation		245.1(222.1)		241.9(224.5)		263.5(208.9)		.091
Cause of amputation	PVD	212	27	200	30%	12	10%	<.001
	NonPVD	568	73	465	70%	103	90%	
Level of amputation	BKA	432	55	361	54%	71	62%	.313
	AKA	261	34	227	34%	34	30%	
	KneeDis	87	11	77	12%	10	9%	
Prosthetic use during sports	Yes	na	na	na	na	93	81%	

SD – standard deviation; N – total number of participants; PVD – peripheral vascular disease; BKA – below knee amputation; na – not applicable; AKA – above knee amputation; KneeDis – knee-disarticulation. * – column percentages. Due to rounding percentages may exceed 100.

Table 2. Results of logistic regression analysis (Backward LR) to statistically predict sports participation (>5hrs per month) in lower limb amputees

	β	S.E.	Sig.	Exp(β)	95% CI EXP(β)
Age Centered 60	-.034	.007	<.001	.967	.953; .981
Smoking	-.601	.265	.023	.548	.326; .922
Amputation Cause Vascular	-.861	.333	.010	.423	.220; .812
Constant	-1.560	.130	<.001	.210	.163; .270

B – regression coefficient; S.E. – standard error; Sig. – significance; Exp(β) – odds ratio; 95% CI Exp(β) – the 95% confidence interval of odds ratio.

DISCUSSION

Of the 780 LLA that participated in the current study only 15% participate in sports more than 5 hours a month. An age above 60 years, smoking and a vascular cause of amputation were negatively associated with sports participation.

Previous research in a small national^[83] or a regional sample^[37] of Dutch LLA found a sports participation rate of 32% and 39%, operationalized as ≥ 1 hour per week. Our sports participation rate, based on the analysis of a national sample of Dutch LLA, was considerably less. But a difference in the definitions of sports participation is present between this study and the previous ones. Therefore the group of athletes, according to the current study (>5 hours per month), may exclude individuals that were considered athletes according to the definition used in the previous studies (≥ 4 hours per month).^[37;83] Our results are in even larger contrast to those of American LLA (60%).^[107]

According to recent studies between 37% and 56% of the general Dutch population participates in sports at ≥ 1 per week^[170;171;174;179] thus more people in the general population are active than LLA. This statement is also supported by previous findings stating that individuals with physical disabilities, including LLA, achieve up to 40% of the physical activity level of the general, able bodied, population.^[35] Additionally, this large difference between the participation rate of general population and the one of LLA may imply that the current strategies to advocate sports participation of LLA are ineffective and that the factors that promote or prevent sports participation of LLA are yet inadequately addressed. Future research on this topic is recommended as its results can be used to

develop programs which will ultimately lead to an increase in sports participation of the LLA.

According to our analysis, factors usually associated with poor health namely an age above 60 years, smoking and an amputation due to vascular aetiology have a negative association with sports participation of LLA. Age above 60 years was also identified by others as a predictor for not participating in sports of LLA^[35;36;38;76;80] as well as for the general population.^[4;173] The negative association between an amputation due to vascular aetiology and sports participation of LLA comes to support previous results.^[38] Similar to earlier studies^[4;173], our univariate analysis identified an association between civil and working status and sports participation of LLA. The working status, namely having a paid job, usually relates to a better economic status. The influence of the marital status, being married or having a partner may imply that family plays an important role in the participation in sports of LLA. However, in the logistic regression analysis civil and working status did not predict sports participation. Several studies identified that a more proximal level of amputation has a negative impact on the sports participation of LLA.^[36;76;77;85] Additionally, it was identified that the energy expenditure during walking is directly proportional with the level of amputation.^[9;10] Contrary to these statements and in agreement with others^[37;38;75], our analysis did not identify a significant association between the level of amputation and the participation in sports of LLA. The fact that 81% of the athletes used their prosthesis during sports comes to support earlier findings which mention that the use of prosthesis is an important element of the rehabilitation and social reintegration of lower limb amputees.^[165;180]

STRENGTHS AND LIMITATIONS

The response rate in our study was rather low (34%), which may have led to selection bias, but the rate is in agreement with that of a postal survey.^[181] The extent of selection bias cannot be analysed in detail, because we do not have access to the characteristics of the source population.^[176;177] One form of bias is clear; the small amount of the participants that had an amputation due to a vascular problem while the majority of amputations is performed for a vascular problem. Next to this, the participants in our survey were relatively younger compared to the general population of lower limb amputees.^[92] LLA who

participated in this study were not focused on sports participation we therefore believe that selection bias (of sports enthusiasts) which may occur in studies which specifically focus on sports participation is not present. Our estimate of sports participation rate of LLA is therefore probably lower than that of others. Using a clear cut-off point to differentiate between non-athletes and athletes makes our results easier to compare with the results of others.

Due to limitations of the instrument used to gather data, it was impossible to calculate the exact number of hours per week each LLA participated in sports. Because it was our intention to include only those persons who are active at least one hour per week, similar to previous research^[37], we decided upon the use of a cut-off point of ≥ 5 hours per month.

CONCLUSION

Sports participation rate of LLA is only 15%. Age above 60 years, smoking and a vascular cause of amputation are negatively associated with sports participation.

Chapter 6

Barriers and Facilitators of Participation in Sports: A Qualitative Study on Dutch Individuals with Lower Limb Amputation

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ABSTRACT

Although individuals with lower limb amputation may benefit from participation in sports, less than 40% do so. To identify the barriers and facilitators that influence participation in sports for individuals with lower limb amputation. Twenty six individuals with lower limb amputation, all originating from the Dutch provinces of Groningen and Drenthe, of which 13 athletes, were interviewed. Semi-structured interviews were used to gather information. Following thematic analysis, emerging themes were organized in three categories Technical, Social and Personal. Sport was perceived as enjoyable activity that would help participants to become and stay healthy, improve the number of social contacts, reduce phantom pain and decrease daily tension. Inadequate facilities, problematic transportation, trivialization from others, poor health and lack of motivation or the lack of a sports partner were barriers commonly mentioned by non-athletes. Remarkably, while all athletes were successful prosthetic users, the majority chose to participate in sports for which prosthesis was neither required nor needed. Each individual with lower limb amputation needs to be counselled according to the barriers and facilitators he/she personally experiences. Athletes appeared to be more proactive in searching for a solution and also appeared less discouraged by failing.

INTRODUCTION

According to the general perception, regular participation in sports or physical activities (PA) is considered a fundamental element of a healthy life style. Literature also supports this general opinion by presenting the numerous benefits regular participation in sports or PA has on reducing type 2 diabetes and improving cardio-vascular function^[182], physical functioning^[183], social environment and the psychological traits^[184]. Several reviews showed that regular participation in sports or PA has at least the same positive influence on the individuals with a physical disability as for the able bodied ones^[4;17;166]. Amputation of a limb is a physical disability that appears to have a significant negative impact on physical and psychosocial functioning^[25;26]. Regular participation in sports or PA improves the physical^[27;28;81] and psycho-social^[29;32] functioning of individuals with lower limb amputation (LLA), thereby decreasing to some degree the burden of amputation^[107].

The participation rate in sports or recreational PA for individuals with LLA ranges from 11% to 60%^[107]. For example in the Netherlands, between 32 and 39% of individuals with LLA participate in sports^[37;83]. Participation in sports of individuals with LLA was negatively associated with various factors, such as older age, vascular cause of amputation, a more proximal level of amputation and the fact that the individual did not participated in sports before the amputation^[107]. Although these factors may be used to predict the likelihood of participation in sports for an individual with LLA based on his or her personal characteristics, these factors do not explain why only a third of the Dutch individuals with LLA participate in sports^[37;83] while around 56% of the general Dutch individuals participate in sports^[171].

Participation in sports and/or PA of able-bodied individuals is influenced by various factors, such as socioeconomic status, presence of a sports partner, education, the amount of free time, age and health status^[164;173]. Some may suppose that the above mentioned factors may also influence the participation in sports or PA of individuals with LLA. Nevertheless, individuals with LLA differ from the general population in terms of physical and psycho-social functioning^[24;25;185]. Factors related to the amputation itself are expected to influence participation in sports for individuals with LLA. Therefore, it is important to address individuals

with LLA as a separate group with specific requirements, needs and experiences. For example, it was identified that through regular participation in sports individuals with LLA increase their number of social contacts^[32], have a better self-esteem^[31] and a better body-image of themselves^[30]. Unfortunately these factors were only associated with participation in sports or PA, while the causality of the relation was not thoroughly investigated.

In the last decade, regular participation in sports or PA has become widely advocated through various media channels as well as by various health professionals^[186]. Unfortunately, still a large percentage of the general population does not participate regularly in sports or PA^[6]. The situation is similar also for individuals with physical disabilities, including individuals with LLA. There is the general opinion that the percentage of individuals with physical disabilities that participate in sports has to increase in the coming years^[16;187;187]. Identifying the barriers for sports participation of individuals with LLA may offer an explanation of the low participation rate recorded by the literature^[16;17;107;187]. In addition, identifying the facilitators of regular participation in sports may lead to the development of better strategies aimed to increase participation in sports of those individuals. Consequently, the aim of this study was to identify the barriers and facilitators that influence participation in sports for individuals with LLA. With regards to the status of sports participation, an individual with LLA will either participate in sports (athlete) or not participate in sports (non-athlete). In order to get an overview of the barriers and facilitators that influence sports participation of individuals with LLA one should address both athletes and non-athletes alike. In this manner the barriers experienced by non-athletes as well as the possible facilitators for sports will become clear and a specific plan of action may be developed. When developing this action plan, the facilitators (motivators) experienced by athletes as well as their strategies to overcome various barriers to sports participation may be useful.

Participation in sports represents a human behaviour and as any human behaviour is a complex cognitive process which implies decision-making based on the assessment of various factors related to personality, beliefs, attitudes, personal goals, social norms and environment^[188]. Qualitative research methods focus *“more on the (whole) person in his/her life world, relying more on subjective reports and experiences, giving more room for meaning of life, allowing for more*

openness for unanticipated meanings and connections..."^[189]. Additionally, focusing on the individual allows him to express his own feelings and personal experiences, thus "giving him voice" ^[190]. Depending on the methods used for gathering and analysing data there can be three major types of qualitative research: Ethnography, Grounded Theory and Phenomenology^[191]. Ethnography is most commonly used in anthropology and is characterized by using ethnographic data sources like stories, legends or even the general perceptions of a group. Grounded Theory aims to develop a theory about the phenomena of interest by coding and analysing the data and later organizing the emerging factors into categories. Phenomenology aims to describe individual experiences and behaviour and is preferred when there is little known about the subject of research and the researcher aims to acquire a broad and a complete set of data. Considering that the aim of the current study is to identify personal barriers and facilitators that influence participation in sports of individuals with LLA a Phenomenological approach will be ideal.

METHODS

Ethics statement

The medical ethical committee of the University Medical Center Groningen was informed on the exact research methodology of this study and it judged that no specific approval was needed for this study (M10.085238). Participants who agreed to be interviewed were asked to sign the informed consent and return it to the sender along with their current status of participation in sports and contact details. All the interviewed participants signed the informed consent form.

Data collection

Personal semi-structured interviews were held to capture both the interviewee's opinion and to gather a sufficient and broad amount of information. The interviews were conducted in Dutch by two people: SR was the interviewer (Dutch native speaker), and MB was the observer (conversationally proficient in Dutch). The observer assessed non-verbal reactions and verified the topics discussed. The interview took place at the participant's home to provide a relaxed environment. Interviews were recorded on minidisks (MD[®]) and transcribed

verbatim by SR. Prior to this study, SR received interview training, and the interview guide was piloted three times. The first two pilots were performed with one of the members of the research project (RD) playing the role of an individual with LLA, while the third and final pilot was performed with an individual who had a LLA. The three tests were not used in the analysis. Following each test, the interview guide was adapted and improved in order to be able to record at its best interviewee's meanings. The last version of the interview guide was applied in all interviews.

The interview started with informal conversation aimed at relaxing the interviewee and creating a venue for discussion. This conversation was also used also to inform the interviewee about the aim of the project and to present an overview of the interview. Thereafter, the interviewee was asked if he/she had any questions, and if he/she agreed to proceed. First, personal characteristics, such as age, gender, education level, and comorbidities, and amputation characteristics, such as level and cause, were asked for. Next, the interviewee was invited to speak freely about why he or she did or did not participate in sports. When short answers were provided, interviewees were invited to explain their answer in greater detail. If the conversation deviated from the topic or the interviewee centred on one specific topic only, the interviewer used the interview guide to start a new topic of discussion. The questions contained by the interview-guide (Appendix 1) were all open-ended and related to 1) personal characteristics such as attitudes toward sport, self-efficacy or past behaviour; and 2) social and technical environment. Additionally, factors identified by means of a systematic review^[107], including age, gender, civil status, education level, employment status, amputation's level, aetiology and date, health status, prosthesis, access to sports facilities, information, time, pain, fear, shame, dependence on others, previous experience with sports, costs, and pleasure from sports, were organized into a list that was to be assessed at the end of the interview as a consistency check or to be utilized if the interview grew stagnant^[192]. At the end of the interview, SR asked the observer if any topics require further probing.

Participants

Inclusion criteria for participants were: a) 18 years of age or older; b) a minimum of 12 months since the amputation; c) LLA more proximal than the

ankle; d) able to speak and understand Dutch. Participants were organized in two groups: individuals who participated in sports (athletes) and individuals who did not participate in sports (non-athletes). In order to be able to distinguish athletes from non-athletes, sport was defined as “an activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour per time and a minimal duration of 60 minutes per week and where skills and physical endurance are either required or to be improved”^[39]. A total of 47 individuals with LLA agreed to participate in the study, of which 26 were interviewed.

Table 1. Participants characteristics

<i>Code</i>	<i>Gender</i>	<i>Age</i>	<i>Level of education</i>	<i>Level of amputation</i>	<i>Years since amputation</i>	<i>Cause of amputation</i>
NA1	man	76	High	TT	20	Vascular
NA2	man	59	Low	TF	8	Trauma
NA3	man	72	Low	KD	7	Vascular
NA4	man	59	High	KD	16	Trauma
NA5	man	64	Low	TT	6	Vascular
NA6	man	72	High	TT; TF	10	Vascular
NA7	man	73	Low	TF	2	Vascular
NA8	man	64	Low	TT	10	Vascular
NA9	woman	61	Low	TF	9	Oncologic
NA10	man	67	Average	AD	30	Vascular
NA11	woman	49	High	HD	4	Vascular
NA12	woman	55	Low	KD	8	Vascular
NA13	man	69	Low	KD	14	Vascular
A1	man	53	High	KD	10	Vascular
A2	man	63	High	TT	6	Trauma
A3	man	50	Average	TT	35	Trauma
A4	woman	77	Low	TT	2	Vascular
A5	woman	21	Average	TF	7	Oncologic

A6	man	30	Average	KD	6	Vascular
A7	woman	48	Average	TT	3	Vascular
A8	man	51	High	HD	7	Oncologic
A9	man	44	High	TF	19	Oncologic
A10	man	63	Low	TT;KD	12	Trauma
A11	woman	36	Average	TF	15	Trauma
A12	man	69	Low	TT	5	Vascular
A13	man	44	High	TT	14	Trauma

NA – non athletes; A- athletes; high– university or college equivalent; average- vocational training; low – primary school or high school; AD – Ankle disarticulation; TT – trans-tibial amputation; KD – knee disarticulation, TF – trans-femoral amputation; HD – hip disarticulation.

Sampling

According to purposeful sampling, participants were recruited from a group of individuals with physical disabilities who regularly participated in sports organized by a rehabilitation centre and a prosthetic manufacturer located in one of the Northern provinces of the Netherlands. During a group meeting, the individuals with physical disabilities were informed about the purpose of the study, the interview and the possible burden associated with it and data confidentiality. Individuals fulfilling inclusion criteria were invited to participate in the study by either SR or MB. The interview was scheduled after written informed consent was given. Additional participants were recruited through a prosthetic manufacturer who sent an invitation letter and a form for informed consent to every individual in their database who fulfilled the inclusion criteria. The letter contained information identical to the one presented to the participants of the sports group.

Participants recruited through the prosthetic manufacturer were contacted in two rounds. Initially, 87 individuals with LLA were invited to participate, 17 of whom (7 athletes) agreed to participate. One of the individuals with LLA who agreed to participate could not be contacted. The remaining 16 individuals with LLA and 2 others recruited from the group of individuals with physical disabilities were interviewed including 9 athletes. After these interviews data saturation was not reached. Consequently, a second round of interviews was scheduled, and invitations were sent to 147 participants recruited through the same prosthetic manufacturer, of which 28 (17 athletes) agreed to participate. Sampling continued

until data saturation was reached. Interviewees were randomly selected from the pool of remaining participants. Characteristics of the 26 interviewees are summarized in Table 1. Athletes were on average younger (49.9 ± 15.7 years) and had less vascular amputations (38.5%) as compared to non-athletes (64.6 ± 7.89 years) respectively (77%). All participants in the study received a flower bouquet of symbolic value (10 euro). The individuals who wanted to participate but were not interviewed were contacted and told that data saturation had been reached and therefore they would not be interviewed. These individuals all received a check by mail (10 euro).

Data Analysis

Immediately after the interview, the name of the participant was replaced with a code representing the level of sports participation and the interview number. For example, the first athlete interviewed received the code A1, whereas the first non-athlete received the code NA1. Data analysis was intertwined with the interview process from the beginning. This analysis helped the interview process, provided new topics and enabled detection of data saturation. Data saturation, meaning that no new codes emerged from the analysis, was reached after 24 interviews. Two additional interviews were performed in which data saturation was confirmed. Because we were undertaking the first qualitative study aimed at identifying both barriers and facilitators of participation in sports for individuals with LLA, thematic data analysis was conducted: 1) data familiarization; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; 6) producing the report^[193]. ATLAS.ti[®] computer software was used to facilitate organization of the data and emerging factors into themes and categories of themes and to visualize the relationship between these.

Prior to data analysis, SR and MB developed a codebook based on the available literature. During the preliminary assessment, several inductive and open codes were added to the codebook. Data were coded by SR using the codes already existent in the codebook. Along the way, emerging new codes were also added to the codebook. After coding the 26 interviews, the codebook contained all of the identified deductive, inductive and open codes. To check coding consistency, PvW independently coded 10 randomly selected interviews. The

differences in coding were discussed until an agreement was reached. The resulting codebook and coding strategy were considered definitive. For the final step, MB checked for consistency and validity of the coding using the final version of the codebook. In case of coding inconsistency a third person was asked to give a binding verdict. Similar codes were grouped together and formed a factor. Later, similar factors were grouped into themes and, finally, into 3 categories: technical, personal and social. The factors, themes and categories were developed by MB in consensus with SR. The final construct was presented during a group meeting to the entire research group. The quotes were translated into English by a native Dutch speaker who took into consideration regional characteristics and idioms. To ensure the accuracy of the translation, a second native Dutch speaker was asked to translate a sample of randomly selected quotes from English to Dutch. The two versions of the same quote were compared for consistency, and a final version was chosen.

RESULTS

The identified factors emerging from the interviews were organized into specific themes and consequently into bigger and broader 3 categories (figure 1).

Barriers

A number of factors, such as older age, poor weather or high cost, were negatively associated with participation in sports by several interviewees. We decided not to address these factors in the results because they are not specific to our population. Instead we focused on the factors which are either specific to our population or appeared most frequently in the interview.

Technical

Technical barriers include factors and themes related to transportation, infrastructure (sports facilities), information and prosthesis.

Transportation In general, individuals with LLA use either their own vehicles, or a bus or taxi (covered by their health insurance) to travel to and from sports facilities. A barrier mentioned by athletes and non-athletes alike was their dependency on a bus or taxi. The general opinion was that it either takes too long to reach the destination or that the transportation is unreliable. *“That is also*

unpleasant and tiring <going to the sport school> with the taxi...Once I've been waiting for 3 hrs. I don't want that again" (NA7)

Sports facilities Sports facilities were generally perceived as minimal and not well-adapted to the needs of individuals with LLA. Additionally, the availability of sports facilities was generally perceived as a barrier. Non-athletes mentioned that they *"...would prefer to go to a sports facility in their neighbourhood."* (NA11). Unfortunately, there were insufficient sports facilities in close proximity to their homes, and this condition was unsatisfying. Athletes also mentioned that *"if a regular sports school would have better access for wheelchair users then they would have chosen for a regular one"*. (A6)

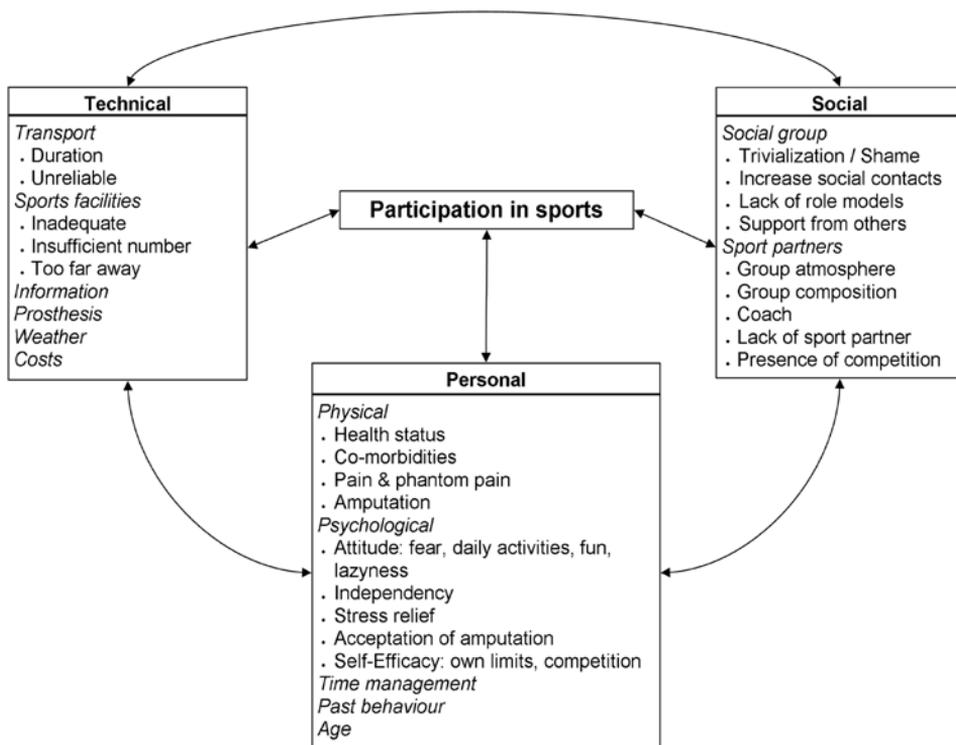


Figure 1. The 3 categories that summarize the factors and themes that influence participation in sports for individuals with LLA. Categories are presented in **bold**, themes are *italics* and factors are in plain text.

Prosthesis The majority of non-athletes mentioned that their prosthesis may be a potential barrier to their participation in sports. *“I can’t walk further than 200-300 m and afterwards that thing <prosthesis> begins to cause corns or blisters, thus I have to stop.”* (NA10). When the interviewee was asked if a better prosthesis would help him to exercise more, the answer was *“No, because I have the best there is.”* (NA10). Thus, it appears that the prosthesis had no influence whatsoever on his participation in sports. A number of athletes felt that their prosthesis was a hindrance when participating in sports or was unnecessary, and therefore, chose to take part in wheelchair sports or another type of sports in which the prosthesis was not required. *“As a matter of fact, I feel better if I participate in sports without my prosthesis...I actually find it more comfortable, <because> the prosthesis just feels like a block on your leg...is not actually yours. If I participate in sports without the prosthesis I’m more relaxed, I don’t have to think about it. <prosthesis>”* (A5). Overall, the prosthesis was not perceived to be a barrier for participation in sports. Athletes for whom the prosthesis represented a barrier for sports proactively searched for a solution to their problem *“with my previous prosthesis I didn’t dare to get into the water...so I actively requested that my following prosthesis would allow me to use it in water, even in salt water.”* (A2)

Social

Social barriers include factors and themes related not only to the interactions of individuals with LLA with their social groups or sports partners but also to the perceived lack of support they received from their social groups.

Social group The social group includes the individuals with whom the interviewee interacts on a regular or irregular basis, such as friends, family or other individuals, on the sports field or at the gym. Shame and support are the main factors in this theme. Sometimes, able-bodied individuals stare at the individual with LLA or even refuse to attend the same sports centre. This behaviour generates a state of discomfort and may have a negative impact on participation in sports, as one individual with LLA mentions: *“...some things you have to accept, however it may be...but yeah, the people who went to that gym, they did not accept me. Some people stopped attending <the same gym>, because of me. Yes, that was unpleasant for me but also for the people. And afterwards I had to make a choice. And my choice was, that I don’t want to sport in that group anymore....Afterwards I tried in another place, but it was exactly the same, people*

can't accept it <interviewee starts to cry>.” (NA12). These negative experiences were not limited only to the non-athletes group with some of the athletes sharing similar experiences “People do not seek contact by a normal sports school, they just stare in a weird way at you, but they will never come to you and ask what is wrong with you. Then you feel looked at in a weird way.” (A5).

Sports partners Negative interactions with the team members or the coach may influence sports participation in athletes and non-athletes alike. Lack of a sports partner was viewed by non-athletes as a major barrier. *“I think that this <alone> is the reason...I don't like this at all...” (NA5). Additionally, some non-athletes and athletes alike also mentioned that they would not like to be in the same group as other physically disabled individuals, “...and I don't have to sit between disabled...it is so annoying and unpleasant, I go sick from it.” (NA9) or “I do it <sport> preferably together with normal individuals than with handicapped ones. It does not appeal to me to be part of that group.”(A3).*

Personal

Personal barriers include factors and themes related to physical health or psychological attributes of individuals with LLA. In addition, past experience, time management and age were assigned to this category.

Physical Current health status, medication and pain were frequently addressed in this theme. Both athletes and non-athletes stated that if they have a stump wound, other problems with their stump or any other serious health problems they would end their participation in sports, temporarily or indefinitely. For some interviewees, pain, whether from a stump or phantom, acted as a barrier. *“Because I have a low pain threshold, I can't participate in sports adequately” (NA8)*

Psychological Feelings, thoughts and perceived barriers were included in this theme. Interviewees' thoughts about what others may think, acceptance, self-efficacy and their feelings and core beliefs are some examples of these factors.

Confrontation with their own limits or with other obstacles that they were unable to overcome was a barrier for some. This confrontation may be experienced when comparing their capabilities prior to the amputation or by comparing themselves to other individuals who have different performance levels. *“Now, if I swim, the speed is gone and you always have a disadvantage...”*

swimming is not what it used to be, all elderly swim faster than me.....I stopped with it...” (NA4). Even if they do not feel physically disabled, asking for help from others, or feeling dependent on others, is unacceptable for most of the individuals. *“You always need help <when participating in sports>...That’s a disability....Now, I don’t feel disabled, I can do everything...”* (NA13) or *“If others have to help me, then you still get sometimes an unpleasant feeling.”* (A9).

Sometimes even the thought of becoming injured acted as a barrier. *“If I ever fall again on a tile, stone floor or whatever, then I know that I will break my hip...”* (NA10). Several of the non-athletes had the impression that they obtained enough PA during their daily activities and that therefore they did not need to participate in sports. *“I do my own household ...the 30 minutes physical activity per day I get easily.”* (NA9). They also mentioned that their core beliefs can be a major barrier for participation in sports. Common factors depicting their core beliefs were, for example, a lack of interest in sports, not being in the right mood for sports or just laziness: *“I’m too easy and I think also that I’m too lazy by nature...”* (NA4).

Past behaviour Participation in sports prior to the amputation was never mentioned as a major barrier for participation in sports following the amputation. Past participation was usually mentioned in association with another “free quoted” factor, such as, *“I wasn’t an athlete before the amputation and afterwards, also due to my amputation, I did not become one...”* (NA2). Regardless of the association with other factors, most of the non-athletes mentioned that they were also inactive prior to the amputation.

Time management A busy schedule or a busy daily life can be a barrier. In general, taking care of children, daily household activities or work were responsible for decreasing the amount of time available for sports. *“Time has some influence, I have to take care of my household, thus you get less and less time to do something else <sport>...”* (NA10).

Facilitators

Technical

Factors and themes related to information and the assistive devices used during sports were included in this category.

Information Being advised by their attending physician or general practitioner is a motivation to start participating in sports. The vast majority of interviewees remembered receiving information about sports, either during their rehabilitation or in the period closely following it. *"In the rehabilitation center, immediately following the amputation, we had to participate in wheelchair sports. In this way you see what you can do."* (A5) Even so, some of the non-athletes were not motivated by this to start participating in sports *"Yes, that was good <receiving information>. The only thing is that I never used that information."* (NA1).

Prosthesis The prosthesis was not viewed as a direct motivator for sports but as an indirect one. For example, athletes stated that participating in sports would help them to make the best use of their prosthesis. *"If I keep my body in a good condition ...then I can walk for a full day on my prosthesis. Thus, if I'm more active, I can use my prosthesis better..."* (A2).

Social

Support from social or sport peers, the atmosphere on the team or the feeling of unity or being one with the team, increasing the number of social contacts and the presence of a sports partner were factors that were characteristic of this category.

Social group Having the support and encouragement of others allowed individuals with LLA to feel important. *"I noticed that a lot of people from my community appreciate the fact that I sport.....and the reactions that I receive really stimulate me..."* (A2). Their families or close friends are also important to constantly motivate and support their actions. *"My wife chases me out of the house. <laughs> ... Now, that's enough."* (A9) or *"my partner supports me in everything I do."* (NA11).

Sports partners Increasing the number of social contacts or even the desire to be part of a group motivates individuals with LLA to participate in sports. Some mentioned that *"the social contacts are really important"* (A1) and that during sports you have the opportunity *"...to be part of a group..."* (A13). Taking part in group sports is *"fun"* (A9) and also gives the athlete the feeling of becoming *"one with the team"* (A13). Some individuals with LLA prefer to be part of a team in which teammates have a similar or somewhat equivalent degree of disability and this motivates them to participate in sports more frequently. *"It doesn't matter how you do it because everybody has something, then you feel more at home and*

less stared at you feel less different.....and then you accept it <your disability>...” (A5). Non-athletes mentioned that if they would have a sports partner this would help them to start participating in sports: “If I would have somebody, who will do the same thing.....then you go more easily there <sport>, than alone.” (NA5).

Personal

Factors and themes related to physical health or psychological attributes of individuals with LLA were included in this category. Additionally, themes represented by personal characteristics such as age and previous experience are also part of this category. It is worth mentioning that athletes mentioned a change in the facilitators to participate in sports before and after amputation. If prior to the amputation *“sport was never a priority, due to a rich social life and a busy schedule...” (A1)*, it became more important following the amputation. This change in priority was often triggered by personal factors related to physical or psychological characteristics. In general it was observed that athletes were also active prior to their amputation *“Before my accident I used to ice-skate a lot and also to play football and to cycle.....and this always leaves an imprint” (A10).*

Physical Improving or maintaining physical health was the motivator to participate in sports mentioned by all 26 interviewees, including both athletes and non-athletes. The need to reduce the body weight or to increase physical fitness were two of the reasons most commonly identified during data analysis. *“I was really overweight; I had a bad physical condition. After 100 meters I began to feel tired, but that was no disadvantage, I found it more stimulating” (A1)* The second most commonly seen factor was pain. Even if pain was perceived as a barrier for sports by some athletes, for most pain represented a motivator to participate in sports because *“...pain disappeared in the moment I exercised enough.” (A2)* or possibly because they became aware of the fact that *“...if I do not exercise I will experience pain, more pain...” (A5)*. An interesting finding is that the majority of the athletes who experienced (phantom) pain mentioned that *“<it> decreased in intensity or even completely disappeared” (A10)* as a consequence of participating in sports.

Psychological Athletes and non-athletes alike considered participation in sports to be a *“really nice and fun activity to do...” (A2 & NA9)*. Athletes were more enthusiastic in their responses, saying that they “love sport” or that they

“really can’t live without it”. For the ones who stated that they cannot live without it, “*sport is more a necessity*” (A4) and, even if it was “*not perceived as a fun activity*” (A5), the individual still participated in sports because otherwise he or she had the feeling that it would have negative consequences for his or her health. “*...I feel that is compulsory...I have to go and do it <sport>...*” (A5). Participation in sports helped individuals to “*release part of the daily tension*” (A1) and to “*become more relaxed and strong <psychologically>*” (NA6). Competition, an element present in most of the sports, was valued by all athletes. This competition can be with others or with oneself, to show oneself that you are capable of participating, or just to establish one’s own limits and afterwards to try and “*push them <own limits>*” (A8). If you are “*...successful, then you feel good and really enjoy this <sport>*.” (A12).

DISCUSSION

This qualitative study showed that various Technical, Social and Personal factors can be both barriers and facilitators for participation in sports for individuals with LLA. While the most frequently mentioned barriers had either a technical or a psychological background, trivialization from others and a lack of predisposition for participation in sports appeared to be more difficult to overcome. Regardless, athletes were able to find a solution to their problems and therefore they overcame most of the barriers that they faced. Athletes focused either on the various advantages that regular participation in sports has for physical and psychosocial well-being, or they were more aware of the negative impact physical inactivity may have on health. Remarkable for this study is how phantom pain and prostheses appear to influence participation in sports. Athletes mentioned that participation in sports represented one of the most effective remedies for (phantom) pain whereas most of the non-athletes mentioned that even better prostheses would not motivate them to be more active. Therefore, programs aiming to encourage individuals with LLA to participate in sports should focus on providing personal counselling aimed at identifying and solving specific personal problems and to provide personally tailored sport advice.

Even if we assigned the identified themes into 3 distinct categories, an interaction between these categories was observed during data analysis. For example, a technical factor such as transportation may deter participation in

group sports and therefore may motivate an athlete to become more active in sports that do not involve a team (individual). Therefore, transportation may indirectly influence both the number of social contacts and the effect of group competitiveness. This relationship may be positive, with the individuals able to identify solutions to their problems and becoming more active in their close surrounding, or negative, as others will become inactive as they give up looking for additional possibilities in their close surroundings. As can be observed from the above example, a motivator for one individual can represent a barrier for another.

Technical

Being dependent on public transportation, inadequate sports facilities and insufficient information were viewed by the majority of interviewees as barriers, similar to findings in the available literature ^[4;164;194]. One remarkable finding of our study concerns the influence of the prosthesis on participation in sports. Our data suggests that the prosthesis may have a minor influence on participation in sports of individuals with LLA. Even if there were some individuals with LLA who mentioned that their prosthesis influences their participation in sports in a negative way, these individuals were all non-athletes and had either limited or no experience with their prosthesis during sports. Some of the non-athletes considered that they have “the best possible prosthesis”. This statement can be interpreted in two different ways; one, they consider that they will never get a better prosthesis (specialized sport prosthesis) than the one they have at the moment; and two, they are satisfied with their prosthesis and they don’t consider it as a barrier for participation in sports. These considering, the prosthesis and its influence on sports participation should be addressed during each individual assessment. In the existing literature, the prosthesis is described as one of the most important factors influencing physical functioning, locomotion, aesthetic appearance and social interaction of individuals with LLA ^[107;165;180]. Most of the athletes preferred to participate in wheelchair sports or other sports that generally placed less stress on their residual limbs, fact also similar to previous findings ^[38;80]. All athletes mentioned that the choice to use or not use a prosthesis was entirely personal and was not influenced in any way by the technical characteristics of the prosthesis.

In summary, it seems that technical factors may more likely represent a barrier for sports than a motivator. Additionally, considering the fact that most individuals with LLA participate in sports without their prosthesis, it may be wise to pay special attention to other technical factors, such as transportation and inadequate facilities.

Social

Similar to findings in the relevant literature, both athletes and non-athletes considered sports to be a social event, allowing them to come in contact and interact with individuals that they otherwise would not ^[32;195;196]. Considering that the number of social contacts decreased following amputation, sports may represent a means by which individuals with LLA connect with other individuals, either with or without LLA, to increase the number of social contacts and also to feel they are part of a group. Some individuals with LLA identified trivialization from others as one of the main reasons to stop participating in group sports, or even worse, to stop participating in sports completely. This aspect is not new, and almost all individuals with physical disabilities encounter this issue ^[197]. Overcoming this trivialization is therefore imperative for taking part in mixed-group sports ^[165]. All interviewees also mentioned the important role their family and friends plays in their choice to participate or not in sports. Therefore it may be so that the family may be able to help or at least may motivate them to regularly participate in sports.

In summary, interaction with others is important and may sometimes be the single- most important factor that influences participation in sports for individuals with LLA. Special attention should be directed towards providing adequate counselling during which individuals with LLA learn stigma management and strategies for how to deal with trivialization from others. Additionally, it may be useful to involve the individual's family and friends in this entire process.

Personal

Consistent with findings in the available literature, most of the non-athlete who did not have a medical contraindication for exercise mentioned that the main barrier they experience is their own attitude towards sports; either they do not want to exercise, are too lazy to get out of bed or they are not in the mood to exercise ^[4;173]. The presence of injuries or poor health represented the most common barrier for sports mentioned by both athletes and non-athletes. Athletes

believed that a poor health status would motivate them to be more active, and only a serious health condition would hinder their participation in sports. Non-athletes, however, observed no difference between various levels of physical health; they simply stated that poor health status would have a negative impact on their participation in sports. Remarkably, athletes mentioned that the presence of phantom pain is a strong motivator to participate in sports, mostly because they felt that phantom pain disappears with exercise. Non-athletes did not have this experience, and they relied almost entirely on pain medication or other therapies to reduce pain. Using sports as therapy for phantom pain is in agreement with recent findings, which state that a combination of mind-body therapies may be effective in reducing phantom pain temporarily or in the long term^[198].

An individual's own experiences and thoughts about participating in sports related to personal attributes such as fear of injury, feeling dependent, self-efficacy, and one's own limits or mental attributes, including laziness or lack of disposition, appears to influence the participation in sports in individuals with LLA. While participating in sports, some individuals with LLA may realize that they are no longer able to achieve the same level of athletic performance as prior the amputation. Some individuals may accept this fact and try to constantly improve themselves through constant practice. Others may find it difficult to accept the impact their disability has on their sport performance and, in the more fortunate case, try to find an alternate sport where their disability may be less hindering their performance or either stop completely with sports. For the last category of individuals, before trying to motivate them to participate in sports, perhaps it may be wiser to decrease the burden of amputation by adequate coaching focusing on disability acceptance. One of the major differences between athletes and non-athletes can be observed in the problem-solving strategies each category adopts. Athletes appeared to be more proactive in searching for a solution and also appeared less discouraged by failing. This trait helped the individuals in the group not only in relation to their participation in sports but also in everyday life. Except for the individuals who experience barriers impossible to remove or overcome, such as an extremely poor physical state that makes it impossible to be physically active for more than 5 minutes at time, the process of choosing to participate or not participate in sports appears to be based on the assessment of risks and benefits associated with participation^[199]. They stated that "choices involving

gains are often risk averse and choices involving losses are often risk taking". Translated to our research this may imply that individuals with LLA who are more aware of the risks (e.g., injuries, costs, problematic transport, etc.) than the gains (e.g., physical and psycho-social well-being) may be more likely to be non-athletes, while the individuals with LLA who are more aware of what they may lose (e.g., physical and psychosocial well-being) if they do not participate are more likely to be athletes. For example, individuals who experienced first-hand the negative impact of not participating in sports are the ones who perceived participation in sports as compulsory. Therefore, future campaigns for public awareness should focus more on the importance of sports and weigh the benefits of sports against the possible losses/risks.

In summary, if the major advantages of participation in sports are presented in an adequate manner it may allow non-athletes to overcome personal barriers and become athletes. Additionally, the influence of core beliefs should be taken into consideration during the first assessment or first contact with a rehabilitation specialist.

STRENGTHS AND LIMITATIONS

To the best of our knowledge, this is the first qualitative study that aims to identify perceived barriers and facilitators for participation in sports in athletes and non-athletes with LLA. A systematic review^[107] formed the framework of our research and it helped us to gather a vast but specific amount of data^[200]. In addition, most of criteria of good qualitative research^[201] were either met or addressed by the current research: 1) The topic of research is relevant and of interest for the professionals working with individuals with LLA and its results may help to increase the percentage of individuals with LLA that participate in sports; 2) Data gathered was analysed by individuals with both clinical and theoretical experience; 3) All research steps are present in a transparent manner through the manuscript; 4) The results are accompanied by multiple participants quotes; 5) Transferability of the results was addressed, while known literature is used for comparison; 6) Considering that less is known about sports participation of individuals with LLA, more specific on the factors that promote or hinder it, the insight provided by this study has both practical and theoretical importance; 7) Local medical ethics committee assessed the research methodology and

concluded specific approval was needed for this study and the regional specifics were considered when the semi-structured interview guide was constructed; 8) This study is coherent considering that the results and the methods of data gathering are in agreement with the aim of research.

Selection bias, given that we used only the database of a prosthetic manufacturer to recruit our interviewees, may represent a limitation to our research. Another possible limitation of our study is represented by the use of a rigid definition for sport. Some may argue that using our definition the individuals who are active 3 sessions per week maximum 29 minutes per session will be labelled as non-athletes while they may gather more weekly exercise time than athletes. Nevertheless, a theoretical cut-off point is needed in order to differentiate between athletes and non-athletes. Our definition intends to do merely this using a well-known and used parameter in the field of physical exercise. In general, athletes were younger, better-educated and had a more distal amputation (for reasons other than vascular disease) compared to non-athletes who were on average older, less educated and exhibited a more proximal amputation due to vascular reasons. Even so, neither groups considered these factors influential for participation in sports. Therefore, it may be that the differences in population characteristics between athletes and non-athletes did not represent a limitation for the current study.

CONCLUSIONS

Programs aiming to promote participation in sports by individuals with LLA should first address the barriers and facilitators for participation in sports and only afterwards provide tailored advice that considers individual characteristics, such as sport desires, area capabilities, physical traits, psychological traits and previous experiences. Athletes appeared to be more proactive in searching for a solution and also appeared less discouraged by failing.

Appendix 1

Semi structured interview used to gather data

Athletes' interview

1. Warming up / Informal conversation
2. Questionnaire with personal details
3. Semi-structured Interview

Why do you sport?

- What is your reason to sport?
- What could be a reason for you to stop participation in sport?
- Did you sport also before amputation?
- Is there a difference in the reasons to sport between pre and post amputation?
- What do you see as advantages and disadvantages of sport?
- Do you experience support during your regular participation in sports?
- From whom DO you receive and from whom DO you NOT receive?
- What motivates / demotivates you?
- What situations did you experience, during your participation in sports, that were at first problematic but later you manage to overcome?
- What situations did you experience, during your participation in sports, that were at first problematic and you did not manage to overcome them?

Last question

Do you want to add something / do you feel that we missed something, related to the topic of the interview?

Checklist factors

- Other disabilities
- Health (prefer to do other things / tired)
- Prosthesis
 - Yes / No prosthesis during sports?
 - Satisfaction related to prosthetist / prosthesis?
- Sport facilities?
- Information/advise
 - Received? Yes / No
 - Who do you consider to be the right person to provide information about sports and how?
- Time
 - Too much? / too less?
- Pain / phantom pain
- Awareness of own limits
 - + (increase?)
 - - (facing problems?)
- Fear
- Shame for others
- Dependence of others (e.g. transport/dressing)
 - Do you find it unpleasant to ask for help? Yes / No
- Age
- Previous negative experience
- Costs / income
- Sport companionship
 - + (e.g. yes, fun.)
 - - (e.g. nobody / no intention to group sport / unnecessary (alone/enough social contacts))

Chapter 7

General Discussion

The aim of this thesis was to study sports participation of individuals with limb amputations, factors influencing sports participation, and the barriers and facilitators for sports participation.

From the systematic review presented in Chapter 2 it became clear that sports participation is beneficial for individuals with lower limb amputations (LLA). In general sports participation was associated with 1) decrease of rehabilitation time and improved rehabilitation outcome^[33;69;202]; 2) increase in cardio-pulmonary function and overall physical functioning^[27;28;33;69;108;203]; 3) increased self-esteem, disability acceptance and perceived body image as well as increased number of social contacts^[23;29-31;73;74;120;165].

In the review presented in Chapter 3 it was found that for running and playing golf several biomechanical analyses of sport prostheses were available. For upper limb prosthesis these analyses were lacking. A large discrepancy was found between what is practically available concerning sport prostheses or prosthetic adaptations for sports from manufacturers and what is presented in peer-reviewed journals.

The study presented in Chapter 4 showed that 57% of individuals with upper limb deficiency (ULD) participated in sports at least one hour every week. Thirty three percent of them participated in sports at least 3 times per week (average training session 76 (\pm 44) minutes). A hindering medical condition and a shorter residual upper limb had a negative influence on sports participation. Factors that might motivate people, who do not participate in sports, to start participating, were “*better information/coaching*” and “*more free time*”. To our surprise more than 200 individuals with ULD participated in this survey. Some of them were so enthusiastic about the topic of this research that they even send a copy of their sports diplomas together with their answers or mentioned that “*it was finally the time someone investigated this topic*”.

The study presented in Chapter 5 showed that 27% of the individuals with LLA participated in sports between 1 and 5 hours a month, 15% participated in sports at least 5 hours a month. An age above 60, smoking and a vascular cause of amputation were negatively associated with sports participation.

The qualitative study presented in Chapter 6 showed that barriers for one person might be facilitators for another. Sports were perceived as enjoyable

activities which helped participants to become/ stay healthy, improve social functioning, reduce phantom pain and decrease daily tension. Inadequate facilities, problematic transportation, trivialization from others, poor health and lack of motivation or the lack of a sports partner were barriers for non-athletes. Remarkably, while all athletes were prosthetic users, the majority participated in sports for which prosthesis was not needed. In general individuals with LLA who want to participate in sports go to great lengths to achieve their goal and are more proactive in identifying solutions.

The last date for literature search for systematic review, thesis was February 21st 2011. Therefore an update of search was performed. An overview of the results of this update is presented in Chapter 2, Appendix 2. The newly identified papers supported our conclusions of Chapter 2. In the update 14 papers were identified published in 18 months. Thus the body of knowledge concerning sports participation of LLA is increasing. Nevertheless, randomized controlled trials and longitudinal studies were also scarce in the update. Additionally studies addressing injury characteristics or individuals with ULD are still scarce.

CLINICAL RELEVANCE

Based on Chapter 2 clinicians should advise participation in sports to individuals with a LLA. The study presented in Chapter 6 may help clinicians to get more insight in the factors that influence sports participation of individuals with LLA. Although there is no clear differentiation between barriers and facilitators, clinicians should base their advice on an individual assessment including for instance past experiences, personal desires and aims, stigma management, coping, self-efficacy, disability acceptance, general health, physical capacity, functional outcome and regional possibilities. According to some of the persons interviewed in Chapter 6, the rehabilitation time is the best moment to receive information about sports.

When asked *“why they do not participate in sports”*, most of the non-athletes answered that they get enough physical activity during their daily activities, they never participated in sports before or they have an unpleasant memory/experience related to sports participation. Clinicians should emphasize that sports does not have only physical benefits but also important psychological ones and that physical active work is not equivalent to sport. In addition in the

post rehabilitation period, a question addressing sports participation should become part of the standard evaluation.

Older lower limb amputees with a poor health are less likely to participate in sports; therefore rehabilitation professionals working with this patient group should try to involve them in other types of physical activity.

Contrary to what was found in the systematic review we found in Chapter 6 that availability of the lower limb prosthesis did not seem to influence sports participation of LLA. Based on clinical experience, the accounts of the individuals interviewed in Chapter 6 and the results of the systematic review (Chapter 2) we may say that having a prosthesis is important for transportation and social life and that sometimes its availability may restrict and hamper sports participation of LLA. For a well-informed advice regarding sport prostheses information from peer reviewed journals is not enough. Internet sites of manufacturers and patient associations (e.g. USA) provide complementary and recent information. When choosing the right type of prosthetic foot, the following factors should be carefully considered a) the physical profile and physical capacity of the amputee; b) the characteristics of the particular physical activity for which the foot is intended; c) future athletic expectations of the amputee; d) the regional availability of spare parts/service.

Elite athletes require special sport prostheses. Runners, sprinters and long jumpers use in general a specialized prosthetic foot, like for example Cheetah^[204], CSprint^[205] or the Nitro.^[206] These feet are intended for use during competition and are not suitable for daily use because running or sprinting prostheses have a spring like design in order to store and release energy more efficiently.^[54] Due to this design, asymmetry in length between the prosthetic limb and the intact limb occurs. For the individuals who are physical active and wish to use the same prosthesis on daily basis and still be able to participate in sports at a moderate rate, a wide range of energy return prosthetic feet available from various manufacturers. These feet are usually categorized under K4 level, according to the Medicare Classification Level (MFCL) classification^[207]. Nevertheless, the use of specialized sport prostheses may increase the performance and may facilitate sports participation.^[169]

Upper limb sport prostheses or prosthetic adaptations for sports are more diverse in number, design and functionality and they appear to be limited only by

the creativity of their designers/users.^[169] The exact number of these devices is difficult to quantify because they are usually developed by users themselves and rarely made commercially available. The skills individuals with ULD employ when developing these devices should be thoroughly investigated by clinicians in order to identify skills which can be later transferred to the individuals with LLA.

Contrary to data originating from individuals with LLA, age or the cause of amputation had no influence on the sports participation of individuals with ULD. This result emphasizes the differences between the two groups. The cause of ULD was also investigated for its influence on sports participation but no association was found.

STRENGTHS AND LIMITATIONS OF THIS THESIS

In this thesis qualitative as well as quantitative techniques (questionnaires and systematic review) were used to investigate sports participation of individuals with LLA or ULD. The systematic reviews identified knowledge gaps regarding sports and amputation. Some of these gaps were filled in by the studies presented in this thesis. The main limitations of this thesis are related to the study samples and the instruments (questionnaires and semi structured interview) used. Participants in this thesis were younger and had more often a “non-vascular” amputation than the general population who had an amputation. Participation rate was low (34%) in the study described in Chapter 4 and could not be calculated for the study described in Chapter 5. In addition the population was recruited either at a regional level (Chapter 6) or at a national level (Chapter 4 & 5). Therefore the results of this thesis and its conclusions should be addressed with caution when other populations are considered. In addition, the results of the study presented in Chapter 4 may be influenced by selection bias. Participants were invited for a study into sports participation. Participants who actively participated in sports were more likely to participate in this study than those who do not participate in sports. This limitation was not present in the study presented in Chapter 5 since participants were not aware that the questionnaire addressed (also) sports participation. Despite the limitations of the study presented in Chapter 4, this study was the first to investigate the characteristics of sports participations for individuals with ULD. None of the instruments used in this research were tested for reliability or validity. Another limitation of this thesis is

its cross-sectional design. Associations found may not be causal and our advices regarding sports participation have not been investigated in a longitudinal study. One strength of this thesis is that we used a clear threshold for sports participation, contrary to most previous studies. Unfortunately for the study presented in chapter 5, we used an already existent database, thus it was impossible to operationalize sports participation similar to the one presented in Chapters 2 & 4 of this thesis, namely a minimum of 1 hour per week, thus 4 hours per month. Based on the available options (< 30 min, 30 min to 1 hour, 1 hour to 5 hours and >5 hours per month) it was decided that individuals with LLA that participate in sports at least 5 hours a month best fit our previously used threshold of a minimum of 4 hours of sports per month.

Although it's widely known that participation in sports is beneficial to the overall health status and psychological wellbeing, still a significant percentage of the general population, and even more so of the disabled population, do not regularly participate in sports. Identifying the personal barriers and motivators for sports participation may perhaps provide an answer on how to increase sports participation. Qualitative research focuses more on perceptions and experiences rather than raw data. Taking into account that the aim of this study was to investigate feelings and emotions, a qualitative methodology rather than a quantitative one is more suited.

Theoretical models are rather commonly used in qualitative research as a way to structure the results and provide a structural basis for the research methodology. From the variety of available theoretical models, the Theory of Planned Behavior (TPB)^[208] was identified as the model most commonly used to help explain people's physical activity behavior.^[209] This model assumes that "individuals behave in a goal-oriented manner and that the implications of their actions are weighted up in a rational manner before the decision is taken whether to engage in the behavior or not".^[210] There are 3 major components in this model: Attitudes – the common sense representations that individuals hold in relation to objects, people and events^[211]; Subjective Norm – an individual's beliefs regarding whether important others would think that they should or should not carry out a particular action^[208] and Perceived Behavioral Control – an individual's belief that they have control over their own behavior in certain situations, even when facing particular barriers.^[188] In a meta-analytic review from

2002 it was identified that by adding two more components to this model, Self-Efficacy – an individual’s belief that they can perform a particular behavior in a given set of circumstances^[188], and Past Behavior – an individual’s past experience with the particular behavior^[208], the correlation between intention and behavior increases.^[209] Taking into account that the majority of lower limb amputees are older adults^[92] and that the above mentioned correlation between intention and behavior is significantly stronger in older adults^[209], the TPB, extended with Self-Efficacy and Past Behavior, appears to suits the best the purpose of the study presented in Chapter 6. Therefore the interview guide used during the 26 personal interviews was based on the 5 domains of the TPB (figure 1).

Using a theoretical model as the structural basis of our qualitative research enabled us to capture the emotions of the participants because they spoke freely and openly about their experiences, fears and motivators. For example when asked about the advantages of sports one athlete stated *“I think that the advantages of sports are on the wellbeing. Secondly, I think that it may help people with a disability to get over it. They will no longer feel useless and sit in their home, but they will find their way and regain their social life. It does not necessarily have to be for social contacts, more to get over it, this is important.”*

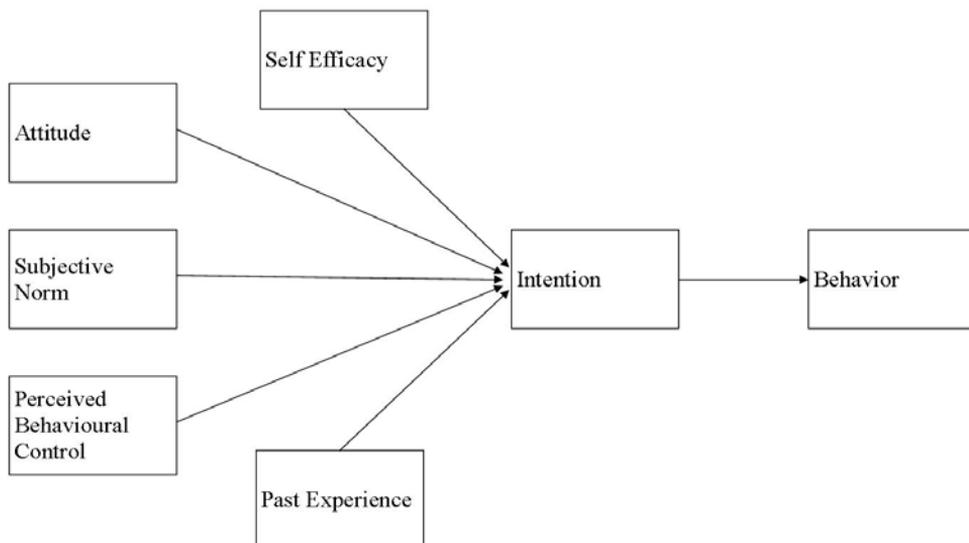


Figure 1. Modified model for TPB

FUTURE RESEARCH

As mentioned earlier, one of the main flaws of the research surrounding sports participation of individuals with limb amputations is the lack of a clear threshold for sports participation. It is not enough just to mention that individuals are active or “extremely active”. Researchers need to provide a unit of measure of this activity status, either in participation rate like hours per week, hours per month or even METs (metabolic equivalents). Although the use of MET may be more difficult to use, with the aid of additional measuring equipment, such as physical activity monitors, it should not be a problem.

The peer reviewed literature barely contains information on the participation rate in sports, the factors which influence this participation, patterns and incidence of sports injury of individuals with an ULD. Future research should focus on the sports participation of individuals with ULD. Similar to the research performed on individuals with LLA qualitative data on the barriers and facilitators associated with their sports participation are needed.

Future research should also focus on the development of a physical training program during rehabilitation to improve physical fitness. Such a program should be standardized but also adaptable to the physical characteristics and desires of the patient. It should contain set of exercises aiming at improvement of cardio-pulmonary function, muscle strength, core stability and balance. It should also include an introduction to several types of sports. Of course the type of sports and the intensity should also be adapted to personal characteristics.

Another direction of future research could be the characteristics of sports injuries related to amputation. As identified for the general population, sports injuries have wide emotional and physical implications.^[212] For the able bodied persons there is sufficient debate concerning sports injuries and benefits of sports. This discussion is missing for individuals with limb amputations. Also there is no information regarding the prevalence or incidence of sports injuries in the general population of individuals with limb amputations.

Future research should also focus on development and testing of sport prostheses or prosthetic adaptations for upper and lower limb amputees. For most of the individuals with limb amputations the prosthesis or wheelchair are essential for their mobility, social activity, performing daily tasks and even sports

participation.^[165;180;213] The demand of sport prosthesis or prosthetic components of K4 level is most likely to increase in the upcoming period due mostly to the increase of several factors such as a) number of amputees; b) awareness of the importance of sports and an active lifestyle for the physical and psychosocial function of individuals with limb amputations; c) media coverage of sports for the disabled; d) focus on physical active rehabilitation. In addition to this increase in demand, prosthetic manufacturers need to consider that the current trend in healthcare is to base a clinical decision on the available scientific evidence in place of the clinical expertise of the professionals. Prosthetic manufacturers should strive more to publish the characteristics of their products in the peer reviewed literature, at least in the form of a technical note. The information presented in peer-reviewed sources will help prosthetist draw an unbiased clinical decision based on available scientific evidence rather than clinical experience alone.

Longitudinal studies addressing sports participation pre and post amputation time or at various intervals following the rehabilitation are needed. These studies should also analyse the efficiency of the rehabilitation programs.

GENERAL CONCLUSION

This thesis offers an insight in the present level of knowledge in the domain of sports participation of individuals with limb amputations. Sports participation appears to be beneficial to the rehabilitation outcome, the physical and the psycho-social functioning of individuals with LLAs. Information available in the peer reviewed literature on sport prostheses is scarce. Individuals with ULD have a higher sports participation rate than individuals with LLA. Older age, a vascular cause of amputation, smoking and additional health problems have a negative influence on sports participation of individuals with limb amputations. Each individual has specific personal facilitators and barriers for sports participation.

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Summary

As identified in *Chapter 1*, the studies presented in this thesis investigated various aspects of sports participation of individuals with lower or upper limb amputation. Amputation of a limb influences psychological and physical wellbeing, mobility and social life of individuals with limb amputations. Sports participation and regular physical activities have a positive effect on the above mentioned areas in the able bodied. Although differences in physical or psychosocial functioning are present between able bodied individuals and the ones with limb amputations, it is possible that sports participation may be beneficial also for this group. In order to assess this relation, an overview of the information presented by peer-reviewed sources is needed. Having access to this information may enable researchers to draw a conclusion based on available scientific data rather than on clinical experience. Identifying the gaps present in scientific knowledge is a usual consequence of performing a literature search. This thesis aimed to 1) identify the present level of knowledge and 2) the gaps regarding sports participation of individuals with limb amputation. After having identified these, 4 studies were conducted in order to gather data that will fill in to some extent these gaps of knowledge.

As stated above, the first step of this research project was to perform a systematic review of literature. The aim of this study presented in *Chapter 2* was to gather data concerning sports participation of individuals with limb amputations together with its characteristics on a wide area of main outcomes like biomechanics, cardio-pulmonary function, psychology, rehabilitation, and sport injuries. A secondary aim was to identify the factors that influence sports participation. Medline (Pubmed), Embase, Cinahl and SportDiscus were searched, without time or language restrictions, using free text words and Mesh terms. The last search date was March 31st 2010. Books, internet sites and the references of included papers were checked for papers relevant to the topic of review. Papers were included if the research topic concerned sports and minimal 10 individuals with limb amputations were part of the study population. Papers were excluded if they concerned amputations of other body parts than upper or lower limb, or were more distal than the wrist or ankle, or if they consisted of case reports, narrative reviews, books, notes or letters to the editor. Title, abstract and full-text assessments were performed by two independent observers following a list of preset criteria. Of the 3689 papers originally identified, 47 were included in the review. Most of the included studies were older than 10 years and had cross-

sectional designs. Study participants were generally younger and often had more traumatic amputations than the general population of individuals with limb amputations. Heterogeneity in population characteristics, intervention types and main outcomes made data pooling impossible. In general, sports were associated with a beneficial effect on the cardiopulmonary system, psychological well-being, social reintegration and physical functioning. Younger individuals with unilateral transtibial amputations achieve better athletic performance and encounter fewer problems when participating in sports compared with older individuals with bilateral transfemoral amputations. Regardless of their level, individuals with limb amputations participate in a wide range of recreational activities. The majority of them were not aware of the sport facilities in their area and were not informed about available recreational activities. Sport prosthetic devices were used mostly by competitive athletes. For football, the injury rate and pattern of the players with limb amputations were similar to those of able-bodied players. The general conclusion of this systematic review was that individuals with limb amputations appear to benefit both physically and psychologically from participation in sports and/or regular physical activities. Therefore, sports should be included in rehabilitation programs, and individuals with limb amputations should be encouraged to pursue a physically active life following hospital discharge. Gaps in knowledge related to information about sport prostheses, sports participation of individuals with upper limb amputations and the barriers and facilitators for sports participation were also identified. Also large variation was observed concerning the rate of sports participation and on the factors influencing this participation.

Sport prostheses are used by individuals with both upper and lower limb amputations while participating in sports and other physical activities. Although the number of these devices has increased over the past decade, no overview of the peer-reviewed literature describing them has been published previously. Such an overview will allow specialists to choose appropriate prostheses based on available scientific evidence rather than on personal experience or preference. Therefore the aim of the study presented in *Chapter 3* was to provide an overview of the sport prostheses as they are described by the papers published in peer-reviewed literature. Four electronic databases were searched using free text and MESH terms. Papers were included if they concerned a prosthesis or a prosthetic adaptation used in sports. Papers were excluded if they did not originate from

peer-reviewed sources, if they concerned prostheses for body parts other than the upper or lower limbs, if they concerned amputations distal to the wrist or ankle, or if they were written in a language other than English. Twenty-four papers were included in this study. The vast majority of these papers contained descriptive data and consisted of expert opinions and technical notes. Data concerning the energy efficiency, technical characteristics and special mechanical properties of prostheses or prosthetic adaptations for sports, other than running, are scarce.

As observed in the peer reviewed literature surrounding sports participation of individuals with limb amputations, the number of studies involving participants with lower limb amputations outnumbers the one of studies involving individuals with upper limb amputations. Studies addressing sports participation make no difference from this rule. The systematic review performed at the beginning of the research project identified no studies addressing sports participation of individuals with upper limb amputations. Therefore a cross-sectional study aimed to analyze sports participation of individuals with upper limb deficiency (ULD) and the factors associated with this participation was performed; and to identify the reasons individuals with ULD associate with their sports participation. This study is presented in *Chapter 4*. Individuals with upper limb deficiency originating from the Netherlands were invited, via their attending physiatrist or prosthetist, to answer a digital or paper questionnaire. The questionnaire consisted of 34 items related to personal characteristics, type of deficiency and sports participation. Of the 175 individuals who answered the questionnaire, 57% participated in sports for at least 60 minutes per week (athletes). Results of logistic regression analysis indicated that presence of an additional health problem ($\beta = -1.31$, $p < .001$) and a more proximal onset of the limb deficiency ($\beta = 0.76$, $p = .022$) had a negative influence on sports participation. Individuals with an acquired upper limb deficiency who had participated in sports before their amputation were more likely to do so following their amputation ($\beta = 1.11$, $p = .007$). The desire to stay healthy and the pleasure derived from sports represented the main facilitators according to athletes. The presence of an additional medical problem and a lack of motivation represented the main barriers for individuals not to participate in sports. The majority of individuals with upper limb deficiency participate in sports regularly. The presence of an additional medical problem, the level of the upper

limb deficiency and sports participation before amputation were related to sports participation.

As mentioned in Chapter 2 of this thesis, large differences were observed concerning the sports participation rate and the factors influencing sports participation of individuals with lower limb amputation. The study presented in *Chapter 5* aimed to analyse sports participation of Dutch individuals with lower limb amputations and factors influencing sports participation. A cross-sectional survey was performed. Dutch individuals with lower limb amputations (N=2039) were invited to participate in a postal survey addressing personal and amputation characteristics, physical limitations, sports participation, skin problems, and prosthesis use. Only data concerning personal and amputation characteristics together with the data concerning sports participation were used for this study. Of the 816 questionnaires received, 780 were suitable for statistical analysis. The mean age of the participants was 59.6 years (SD 14.8), 62% were men and 27% of the amputations were due to vascular diseases or diabetes. Only 15% of all respondents participate in sports at least 5 hours a month. Smoking (odds ratio: 0.55), an age older than 60 years (β : 0.97 per year), and a vascular cause of amputation (β : 0.42) were associated with sports participation.

Despite the fact that sports participation is beneficial to individuals with lower limb amputations, their sports participation rate is lower than the one of able bodied individuals. Albeit an earlier study (Chapter 5) identified the physiological factors influencing this participation, this still does not explain the low participation rates, nor does it offer a direction on how to increase this participation rate. Therefore the study presented in *Chapter 6* aimed to identify the barriers and facilitators that influence sports participation for individuals with lower limb amputation. Using a qualitative approach 26 individuals with lower limb amputation, of which 13 athletes, originating from the Dutch provinces of Groningen and Drenthe were interviewed. Semi-structured personal interviews containing open-ended questions were used to gather information. Following thematic analysis, emerging factors were organized in 3 major categories Technical, Social and Personal. Overall, barriers could not be strictly differentiated from facilitators. Sports were perceived as enjoyable activities that would help participants to become and stay healthy, improve the number of social contacts, reduce phantom pain and decrease daily tension. Inadequate facilities, problematic transportation, trivialization from others, poor health and a lack of

motivation or the lack of a sports partner were barriers commonly mentioned by non-athletes. Remarkably, while all athletes were successful prosthetic users, the majority chose to participate in sports for which prosthesis was not needed. Each individual with lower limb amputations needs to be counselled according to the barriers and facilitators he/she personally experiences. Athletes appeared to be more proactive in searching for a solution and also appeared less discouraged by failing.

This thesis offers an insight in the present level of knowledge in the domain of sports participation of individuals with limb amputations. The general discussion presented in *Chapter 7* summarizes the main findings of this thesis while also presenting the implications of this thesis and its results may have for clinical practice. Direction for future research, strengths and limitations of the studies contained by this thesis as well as general conclusions are also presented in *Chapter 7*.

Concluding, it appears that sports participation may be beneficial to the rehabilitation outcome, physical and psycho-social functioning of individuals with lower limb amputation. Information available in the peer reviewed literature on sport prostheses as well on sports participation of individuals with upper limb deficiency is scarce. Individuals with upper limb deficiency have a higher participation rate in sports than individuals with lower limb amputation. Older age, a vascular cause of amputation, smoking and additional health problems have a negative influence on the sports participation of individuals with limb amputations. Each individual has specific personal facilitators and barriers for sports participation.

Samenvatting

-Dutch summary-

*Met dank aan Mark Bosloper en Eva Jaarsma
voor de vertaling van deze samenvatting*

Zoals beschreven in Hoofdstuk 1, zijn in het onderhavige proefschrift verschillende aspecten onderzocht omtrent sportparticipatie van individuen met een amputatie van de bovenste of onderste extremiteit.

Amputatie van een ledemaat beïnvloedt het psychologische en fysieke welzijn, mobiliteit en het sociale leven van individuen met een amputatie. Sportparticipatie en regelmatige fysieke activiteit hebben een positief effect op de betreffende lichaamsdelen van een valide persoon. Hoewel er verschillen in fysiek en psychosociaal functioneren bestaan tussen valide personen en personen met een amputatie, kan sportparticipatie ook een positief effect hebben op deze groep. Om dit verband inzichtelijk te maken, is een overzicht van de beschikbare informatie uit wetenschappelijke (peer reviewed) bronnen nodig. Toegang hebben tot deze informatie stelt onderzoekers wellicht in de staat om conclusies te trekken op basis van beschikbare wetenschappelijke data in plaats van klinische ervaring. Het blootleggen van lacunes in wetenschappelijke kennis is een logisch gevolg van het uitvoeren van een literatuuronderzoek. Het doel van dit proefschrift is 1) het inzichtelijk maken van het huidige kennisniveau, en 2) de lacunes ten aanzien van sportparticipatie van personen met een amputatie. Na het inzichtelijk maken van deze lacunes zijn vier studies verricht om gegevens te verzamelen die de ontbrekende kennis - tot op zeker hoogte – kunnen invullen.

Zoals bovenstaand beschreven bestond de eerste fase van dit onderzoeksproject uit het verrichten van een systematisch literatuuronderzoek. Doel van dit onderzoek (beschreven in Hoofdstuk 2) was het verzamelen van data omtrent sportparticipatie van individuen met amputaties in combinatie met de algemene uitkomsten zoals biomechanica, cardiopulmonair functie, psychologie, revalidatie en sportblessures. Een nevendoeel was het identificeren van de factoren die van invloed zijn op sportparticipatie. Medline (Pubmed), Embase, Cinahl en SportDiscus zijn doorzocht, zonder tijd- of taalrestricties, door middel van free text woorden en MeSH terms. De zoekstrategie is uitgevoerd tot 31 maart 2010. Boeken, internetsites en de referenties van geïnccludeerde artikelen zijn gecontroleerd op mogelijk relevante publicaties. Uitsluitend artikelen waarin het onderzoeksonderwerp 'sport' betrof en waarin de onderzoekspopulatie ten minste 10 individuen met een amputatie omvatte, werden in de de studie betrokken. Publicaties werden geëxcludeerd wanneer zij andere amputaties dan arm- of beenamputaties betroffen, of amputaties meer distaal waren dan pols- of

enkelgewricht, of zij een case report, narratieve review, boek, notitie of brief naar de editor waren. Beoordeling van titel, onderwerp en volledige tekst werden uitgevoerd door twee onafhankelijke lezers, aan de hand van vooraf vastgestelde criteria. Van de 3.689 oorspronkelijk geselecteerde artikelen zijn uiteindelijk 47 opgenomen in het onderzoek. Het merendeel van de onderzoeken was ouder dan 10 jaar en had een cross-sectioneel design. Onderzoekspopulaties waren in het algemeen jonger en hadden vaker een amputatie ten gevolge van een trauma dan de gemiddelde populatie van individuen met amputatie. Heterogeniteit in de populatie-eigenschappen, interventie typen en belangrijkste uitkomsten maakten het poolen van data onmogelijk. In het algemeen werd sport gerelateerd aan een positief effect op het cardiopulmonair systeem, psychologisch welzijn, sociale reïntegratie en fysiek functioneren. Jongere individuen met unilaterale transtibiale amputaties bereiken een beter atletisch presteren en ondervinden minder problemen bij sportparticipatie in vergelijking met oudere individuen met bilaterale transfemorale amputaties. Onafhankelijk van hun niveau nemen individuen met amputaties deel aan verschillende sportactiviteiten. De meerderheid van hen waren zich niet bewust van de sportfaciliteiten in de regio en waren niet geïnformeerd over het beschikbare sportaanbod. Sportprotheses werden het meest gebruikt door wedstrijdathleten. Voor voetbal is de frequentie en aard van blessures van atleten met een amputatie gelijk aan die van valide atleten. De algehele conclusie van dit literatuur-onderzoek was dat personen met amputaties zowel fysiek als psychisch baat lijken te hebben bij sportparticipatie en/of regelmatige fysieke activiteit. Hierom zou sport opgenomen moeten worden in revalidatieprogramma's, en personen met een geamputeerde ledemaat aangemoedigd moeten worden om een actieve leefstijl na te streven na ontslag uit het ziekenhuis. Lacunes met betrekking tot informatie omtrent sportprotheses, sportparticipatie van personen met een armamputatie en de belemmeringen en stimulansen voor sportparticipatie werden tevens onderscheiden. Een grote variatie was waargenomen ten aanzien van frequentie van sportparticipatie en de factoren die invloed hebben op deze participatie.

Sportprotheses worden zowel gebruikt door personen met een amputatie van de bovenste extremiteit als van de onderste extremiteit. Hoewel het aanbod van hulpmiddelen in het afgelopen decennium is toegenomen, is hierover niet eerder een overzicht van peer-reviewed literatuur gepubliceerd. Een dergelijk overzicht stelt specialisten in staat de juiste prothese te kiezen op basis van beschikbare

literatuur, in plaats van op basis van persoonlijke ervaring of voorkeur. Derhalve was het doel van het onderzoek beschreven in Hoofdstuk 3 het maken van een overzicht van sport protheses zoals die zijn gepubliceerd in peer-reviewed literatuur. Vier elektronische databases zijn doorzocht door middel van free-text worden en MESH terms. Artikelen werden geïnccludeerd als zij zich concentreerden op sportprotheses of sporthulpmiddelen. Artikelen werden uitgesloten indien ze niet van een peer-reviewed bron afkomstig waren, indien zij andere protheses beschreven dan voor arm- of beenamputaties, indien zij amputaties meer distaal dan pols- of enkelgewricht beschreven, of niet in het Engels waren geschreven. Vier-en-twintig artikelen zijn opgenomen in het onderzoek. De overgrote meerderheid van deze artikelen bevatte beschrijvende data en bestond uit deskundigen-verklaringen en technische notities. Gegevens betreffende de energie-efficiëntie, technische aspecten en speciale mechanische eigenschappen van protheses of prothetische aanpassingen voor sporten waren (met uitzondering van hardlopen) schaars.

Zoals te zien in de peer reviewed literatuur omtrent sportparticipatie van personen met een amputatie, is het aantal studies dat betrekking heeft op personen met amputaties van de onderste extremiteit groter dan het aantal studies over personen met amputatie van de bovenste extremiteit. Onderzoek naar sportdeelname vormt hierop geen uitzondering. Het literatuuronderzoek uitgevoerd aan het begin van het onderzoeksproject heeft hierover geen artikelen geïdentificeerd. Derhalve is een cross-sectionele studie uitgevoerd, met als doel de sportdeelname van individuen met arm deficiëntie (ULD) en de bijbehorende factoren vast te stellen. Dit onderzoek is in Hoofdstuk 4 beschreven.

Personen van Nederlandse afkomst met een armdeficiëntie werden - via hun behandelend fysiotherapeut of instrumentmaker - uitgenodigd om een digitale of papieren vragenlijst in te vullen. De vragenlijst bestond uit 34 vragen met betrekking tot persoonskenmerken, aard van de beperking en sportparticipatie. Van de 175 personen die de vragenlijst retourneerden nam 57% deel aan sport gedurende meer dan 60 minuten per week (sporters). De logistische regressie liet zien dat een bijkomend gezondheidsprobleem ($\beta = -1,31$, $p < 0,001$) en een meer proximale begin van de arm deficiëntie ($\beta = -0,76$, $p = 0,022$) een negatieve invloed had op sportparticipatie. Personen met een verworven armdeficiëntie die al aan sport deden voor hun amputatie deden dit vaak ook na hun amputatie ($\beta =$

1.11, $p = .007$). De wens om gezond te blijven en het plezier dat beleefd wordt aan sport vormde de grootste motivaties voor de sporters. De aanwezigheid van een bijkomend gezondheidsprobleem en gebrek aan motivatie vormden de grootste belemmeringen voor personen om aan sport deel te nemen. De meerderheid van personen met een armdeficiëntie neemt regelmatig deel aan sport. Het hebben van een bijkomend medisch probleem, het niveau van de armdeficiëntie en sportparticipatie voor de amputatie waren gerelateerd aan sportparticipatie.

Zoals genoemd in Hoofdstuk 2 van dit proefschrift werden grote verschillen waargenomen met betrekking tot de percentage van sportparticipatie en de factoren die deze participatie voor personen met een beenamputatie beïnvloeden. Het onderzoek beschreven in Hoofdstuk 5 had ten doel de sportparticipatie van Nederlandse personen met een beenamputatie en de invloedsfactoren voor sportparticipatie te analyseren. Een cross-sectionele vragenlijst werd verricht. Nederlanders met een beenamputatie ($N=2039$) waren uitgenodigd om deel te nemen aan een post enquête met betrekking tot persoonlijke en amputatie kenmerken, fysieke beperkingen, sportparticipatie, huidproblemen en prothese gebruik. Uitsluitend gegevens persoonlijke en amputatie kenmerken samen met data over sportparticipatie zijn gebruikt voor dit onderzoek. Van de 816 ontvangen vragenlijsten waren 780 vragenlijsten bruikbaar voor statistische analyse. De gemiddelde leeftijd van de deelnemer was 59,6 jaar ($SD\ 14,8$), 62% waren mannelijk en 27% van de amputaties waren gevolg van vasculaire aandoeningen of diabetes. Slechts 15% van alle respondenten sport minstens 5 uur per maand. Roken (odds ratio $p : 0,55$), een leeftijd boven 60 jaar ($\beta: 0,97$ per jaar) en een vasculaire oorzaak van de amputatie ($\beta: 0,42$) waren gerelateerd aan sportparticipatie.

Hoewel sportdeelname gunstig is voor personen met een beenamputatie, ligt de sportparticipatie lager dan die van valide personen. Hoewel het eerdere onderzoek (Hoofdstuk 5) de fysiologische factoren die van invloed zijn op participatie heeft geduïd, verklaart dit de lage participatie niet, noch biedt het een aanwijzing hoe deze participatie te verhogen. Derhalve tracht het onderzoek beschreven in Hoofdstuk 6 de belemmeringen en stimulansen te identificeren, die sportparticipatie van personen met een beenamputatie te beïnvloeden. Middels een kwalitatief onderzoek zijn 26 personen met een beenamputatie, waarvan 13 atleten, uit de Nederlandse provincies Groningen en Drenthe geïnterviewd. Semi-structureerde persoonlijke interviews met open vragen werden gebruikt om

informatie te verkrijgen. Middels thematische analyse zijn de gebleken factoren verdeeld in 3 overkoepelende categorieën Technisch, Sociaal en Persoonlijk. Over het geheel genomen konden belemmeringen en facilitatoren niet strikt gescheiden worden. Sport werd gezien als een leuke activiteit die bijdraagt aan fit worden en blijven van de deelnemers, dat sociale contacten verbetert, fantoompijn vermindert en de spanning doet afnemen. Onvoldoende faciliteiten, belemmeringen in het vervoer, trivialisering door anderen, een slechte gezondheid en gebrek aan motivatie of een sportmaatje waren frequent genoemde belemmerende factoren voor niet-sporters. Opvallend was dat ondanks dat alle sporters succesvolle prothese gebruikers waren, de meerderheid koos voor sportparticipatie waarbij een prothese niet nodig was. Ieder persoon met een beenamputatie dient te worden geadviseerd op basis van de door hem of haar ervaren belemmeringen en stimulansen. Sporters leken meer pro-actief te zijn in het zoeken naar oplossingen en minder gedemotiveerd te raken door falen.

Dit proefschrift biedt een inzicht in het huidige kennisniveau in het domein van sportparticipatie van personen met amputaties. De algemene discussie beschreven in Hoofdstuk 7 vat de belangrijkste bevindingen van dit proefschrift samen en geeft tevens de implicaties van deze bevindingen weer, voor de klinische praktijk. Een richting voor toekomstig onderzoek, sterke punten en beperkingen van de onderzoeken in dit proefschrift net als algehele conclusies zijn eveneens in Hoofdstuk 7 beschreven.

Concluderend lijkt sportparticipatie positief te kunnen bijdragen aan de uitkomst van de revalidatie, het fysieke en psychosociale functioneren van de personen met een beenamputatie. Informatie beschikbaar in de peer reviewed literatuur over sportprothesen en sportparticipatie van personen met een armdeficiëntie is schaars. Personen met een armdeficiëntie hebben een hogere participatie dan personen met een beenamputatie. Een hogere leeftijd, een vasculaire oorzaak van de amputatie, roken en bijkomende gezondheidsproblemen hebben een negatieve invloed sportparticipatie van personen met een amputatie. Ieder individu heeft specifieke, persoonlijke belemmeringen en stimulansen voor sportparticipatie.

Rezumat

-Romanian summary-

*Mulumiri pentru suportul de specialitate
domnului Bogdan Dimitriu*

Studiile prezentate in aceasta lucrare abordeaza diverse aspecte legate de participarea in sport a persoanelor cu handicap fizic, mai exact a celor care au amputata o portiune a membrului superior sau inferior (Amp). Amputarea unui membru are un impact major atat psihic cat si fizic, afectand in acelasi timp si mobilitatea si viata sociala a acestor persoane. In cazul persoanelor fara handicap s-a identificat ca participarea in sport sau in activitati fizice regulate se asociaza cu efecte pozitive asupra domeniilor mai sus mentionate. In ciuda diferentelor de natura fizica sau psihosociala existente intre persoanele fara handicap si Amp este posibil ca participarea in sport sau activitati fizice regulate sa fie in egala masura benefica si pentru cei din urma. Natura acestei relatii poate fi evaluata cu ajutorul datelor si informatiilor prezentate de literatura de specialitate, in cazul care acestea sunt organizate sub forma unei analize sistematice a literaturii. Avand acces la acest tip de informative, specialistii vor putea sa ia o decizie bazata mai mult pe date stiintifice spre deosebire de una bazata majoritar pe experienta clinica. Identificarea lacunelor existente in informative este o consecinta frecventa a unui studiu de literatura. Aceasta teza a intentionat in prima instanta sa identifice 1) nivelul actual si 2) lacunele prezente in informatiile stiintifice in domeniul participarii in sport a Amp. In continuare, patru studii au fost efectuate pentru a colecta date stiintifice cu scopul de a diminua lacunele in informative identificate de studiul de literatura intreprins la inceputul proiectului.

Dupa cum s-a mentionat anterior, primul pas al acestui proiect stiintific a fost intreprinderea unei analize sistematice a literaturii. Intentia primara a acestui studiu prezentat in *Capitolul 2* a fost sa colecteze date de natura biomecanica, cardio-pulmonara si psihologica legate de participarea in sport a Amp, dar si orice alte informatii, legate de recuperarea medicala sau leziuni sportive, asociate cu aceasta participare. Pe plan secund s-a intentionat identificarea factorilor care influenteaza participarea in sport a Amp. Patru baze de date electronice, Medline (Pubmed), Embase, Cinahl si SportDiscus au fost folosite pentru a identifica informatiile necesare. In strategia de cautare nu s-a tinut cont de bariere temporale sau lingvistice si s-au folosit atat cuvinte libere "*free text words*" cat si termini cheie "*Mesh terms*". In data de 31 martie 2010 a fost realizata ultima incercare de a identifica noi surse de informatie. O sursa aditionala de informatii au constituit-o cartile si site-urile de specialitate. Referintele studiilor incluse in analiza au fost analizate pentru a identifica eventualele studii care putea contine

informatii cu privire la participarea in sport a Amp. Au fost incluse in etapa finala de analiza doar studiile in care se facea referire la participarea in sport si care aveau cel putin 10 Amp in randul subiectilor. Au fost excluse studiile care faceau referire la alte amputari decat cele de membru superior sau inferior, amputari de membru superior sau inferior, mai distal decat incheietura mainii sau glezna, studiile de caz, cartile, notitele sau scrisorile catre editor. Titlul, abstractul si textul integral al studiilor selectate au fost evaluate de catre doua persoane diferite in conformitate cu o lista prestabilita de criterii. Din cele 3689 de articole identificate initial numai 47 au fost incluse in analiza finala. Marea majoritate studiilor incluse au fost mai vechi de 10 ani si au avut un design cross-sectional. Participantii in aceste studii au fost in general mai tineri si au avut mai frecvent o amputare de natura traumatica in comparatie cu populatia generala a persoanelor cu amputare a membrului inferior (Amp_i). Heterogenitatea populatiei, a tipurilor de interventie si a rezultatelor principale a facut imposibila o comparatie eficienta a datelor si efectuarea unei metaanalize. In general, participarea in sport a fost asociata cu un efect benefic asupra sistemului cardio-pulmonar, cu starea psihologica de bine, cu reintegrarea sociala si functionarea fizica. Persoanele mai tinere cu o amputare unilaterala transtibiala au obtinut o performanta atletica superioara si s-au confruntat cu mai putine probleme in momentul participarii in sport comparativ cu persoanele mai in varsta cu amputare bilaterala transfemorala. Indiferent de nivelul amputatiei, Amp_i participa intr-o gama variata de activitati recreationale. Marea majoritate a Amp_i nu au fost constienti de facilitatile sportive disponibile din imediata lor vecinatate si nu au fost informati cu privire la posibilitatile recreationale. Dispozitivele medicale (protezele) sportive au fost folosite in special de catre atletii competitionali. Rata si tipul leziunilor fotbalistilor cu amputatie a membrului inferior au fost similare cu cele ale personelor fara handicap. Concluzia generala a acestei analize a literaturii a fost ca Amp_i par sa beneficieze, atat psihic cat si fizic, de pe urma participarii regulate in sport sau/si a activitatilor fizice. De aceea sportul ar trebui introdus in programul de reabilitare medical al Amp_i, iar dupa externarea din centrul de reabilitare acestia ar trebui incurajati sa isi mentina un stil de viata activ. Lacune in informatia stiintifica au fost identificate in legatura cu protezele sportive, participarea in sport a persoanelor cu amputatie a membrului superior, si a barierelor si motivatiilor pentru sport. De asemenea, o mare diversitate a fost

observata referitor la rata participarii in sport si a factorilor care influenteaza aceasta participare.

Protezele sportive sunt folosite de Amp in timpul participarii in sport sau in alte activitati fizice. Chiar daca numarul acestor dispozitive a crescut constant in ultimul deceniu, niciun studiu nu prezinta o privire de ansamblu a protezelor sportive prezentate din surse stiintifice "peer-reviewed". Un astfel de studiu ar permite specialistilor sa ia o decizie bazata mai mult pe date stiintifice spre deosebire de una bazata majoritar pe experienta clinica sau preferinta profesionala. Considerand acestea, scopul studiului prezentat in *Capitolul 3* a fost sa ofere o privire de ansamblu asupra protezelor sportive prezentate in surse stiintifice. Aceleasi 4 baze de date electronice folosite si in cadrul primului studiu au fost investigate folosind cuvinte cheie si libere. Au fost incluse articolele care faceau referire la o proteza sportiva sau o adaptare a unui dispozitiv medical cu scopul de a-l folosi in timpul practicarii sportului. Au fost excluse articolele care nu proveneau din surse stiintifice si cele care erau scrise in alta limba decat engleza. In final 24 de articole au fost incluse in acest studiu. Marea majoritate a acestor articole a fost constituita de pareri ale expertilor sau note tehnice si au continut in general date descriptive. Date referitoare la eficienta energetica, caracteristici tehnice sau mecanice ale protezelor sportive, cu exceptia celor folosite in alergat, au fost rare.

In literatura stiintifica in domeniul Amp este evident faptul ca predomina studiile in care participanti sunt Amp_i iar cele in care participantii au o amputare de membru superior (Amp_s) sunt mult mai rare. Studiile care investigheaza participarea in sport a Amp nu fac exceptie de la aceasta regula. Analiza sistematica de literatura prezentata in *Capitolul 2* nu a identificat nici un studiu care sa adreseze participarea in sport a Amp_s. Drept urmare un studiu crossectional a fost intreprins cu scopul de a analiza participarea in sport Amp_s, de a identifica caracteristicile acestei participari si factorii care o influenteaza. Acest studiu este prezentata in *Capitolul 4*. Persoanele cu amputare sau deficient congenitala a membrului superior localizate pe teritoriul Olandei au fost invitati, prin intermediul doctorului lor curant sau tehnician ortoped, sa participe si sa raspunda la un chestionar electronic. Chestionarul a continut 34 de intrebari cu privire la caracteristici personale, tipul handicapului si participarea in sport. Dintre cei 175 de respondenti 57% participau in sport cel putin 60 minute pe saptamana

(atletici). Rezultatele regresiei logice au indicat faptul ca prezenta unei probleme aditionale de sanatate ($\beta = -1.31$, $p < .001$) si un handicap al membrului superior localizat mai proximal ($\beta = 0.76$, $p = .022$) au o influenta negativa asupra participarii in sport. Persoanele cu amputatie a membrului superior care au participat in sport inaintea dobandirii handicapului au continuat cel mai probabil sa participe in sport si dupa aceea ($\beta = 1.11$, $p = .007$). Dorinta de a ramane sanatos si placerea derivata din sport au reprezentat principalele motivatii, in opinia atletilor. Prezenta unei probleme medicale precum si lipsa motivatiei au reprezentat principalele bariere invocate pentru a nu participa in sport. In general, majoritatea persoanelor cu handicap al membrului superior participa in sport. Prezenta unei probleme medicale, nivelul handicapului si participarea in sport inaintea dobandirii handicapului au fost corelate cu participarea in sport.

Dupa cum se mentioneaza in *Capitolul 2* al acestei teze, o discrepanta majora a fost observata cu privire la rata participarii in sport a Amp_I si a factorilor care influenteaza aceasta participare. Studiul prezentat in *Capitolul 5* a folosit un design crosssectional si a intentionat sa analizeze participarea in sport a persoanelor cu amputare a membrului inferior precum si a factorilor care influenteaza aceasta activitate. Amp_i cu resedinta pe teritoriul Olandei (N=2039) au fost invitati sa raspunda la un chestionar postal. Chestionarul a continut intrebari cu privire la caracteristici personale, tipul deficientei, probleme dermatologice, folosirea protezei si participarea in sport. Numai datele referitoare la caracteristici personale, ale deficientei dar si participarii in sport au fost folosite pentru acest studiu. Din cele 816 chestionare returnate numai 780 au fost oportune pentru utilizare. Varsta medie a participantilor a fost de 59.6 ani (SD 14.8), 62% dintre respondenti au fost barbati si 27% dintre amputatii au fost de natura vasculara. Numai 15% dintre respondenti participau in sport mai mult de 5 ore pe luna. Fumatul (odds ratio: 0.55), o varsta mai mare de 60 de ani (β : 0.97) si o amputare de natura vasculara (β : 0.42) au fost asociate cu participarea in sport a Amp.

Chiar daca participarea in sport este benefica si pentru Amp_i, rata participarii lor in sport este mai mica decat cea a persoanelor fara handicap. Cu toate ca studiul prezentat in *Capitolul 5* a identificat factorii fiziologici care influenteaza participarea in sport a Amp_i, doar acesti factori considerati separat nu explica de ce atat de putini Amp_i participa in sport si nici nu ofera o solutie pentru a mari aceasta rata de participare. In consecinta, studiul prezentat in *Capitolul 6* a

intentionat sa identifice barierele si motivatiile care influenteaza participarea in sport a persoanelor cu amputatie a membrului inferior. Folosind o metoda calitativa 26 de Amp_i, dintre care 13 atleti, originari din provinciile Groningen si Drenthe ale Olandei au fost intervievati. Interviuurile au fost semistructurate si au continut in general intrebari deschise. Factorii influenti au fost identificati in urma unui proces de analiza tematica, si ulterior au fost organizati in 3 categorii majore Tehnic, Social si Personal. In general s-a observat ca barierele nu au putut fi clar diferite de motivatori. Sportul a fost perceput ca o activitate placuta care poate ajuta practicantii sa devina si sa se mentina sanatosi, sa imbunatateasca numarul de contacte sociale, sa reduca durerea fantoma cauzat de amputare si tensiunea acumulata peste zi. Facilitatile sportive inadecvate, transportul problematic, trivializarea de catre ceilalalti, sanatatea precara si lipsa motivatiei sau a unui partener de sport au fost principalele bariere identificate in raspunsurile persoanelor inactivate. Remarcabil a fost faptul ca in ciuda faptului ca toti atletii erau perfect familiarizati cu proteza si o foloseau zilnic, marea lor majoritate a ales sa practice sporturi in care proteza nu era necesara. Fiecare persoana cu amputatie a membrului inferior ar trebui sa fie sfatuita referitor la activitatile sportive tinandu-se cont de preferintele si de barierele/motivatii sale personale. In general atletii au parut mai proactivi in cautarea si identificarea unei solutii si au parut mai putin descurajati de un esec.

Aceasta teza ofera o perspectiva asupra nivelului actual de cunostite stiintifice in domeniul participarii in sport a Amp. Discutia generala prezentata in *Capitolul 7* face un rezumat al rezultatelor principale oferind in acelasi timp posibile implicatii clinice ale acestei teze. Sugestii cu privire la directii noi de cercetare, punctele forte si lacunele acestui proiect impreuna cu concluziile general sunt prezentate de asemenea in *Capitolul 7*.

Concluzionand, participarea in sport este aparent benefica pentru reabilitarea medicala, functionarea fizica si psiho-sociala a Amp_i. Informatia disponibila in surse stiintifice cu privire la proteze sportive si la participarea in sport a Amp_s sunt rare. Amp_s au o rata a participarii in sport mai mare decat Amp_i. O varsta inaintata, o amputare de natura vasculara, fumatul si probleme aditionale de sanatate pot avea o influenta negativa asupra participarii in sport a Amp. Fiecare persoana prezinta bariere si motivatii specifice cu privire la participarea in sport.

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Mihai,
Groningen, 12 iunie 2013

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Extemities, Pain and Disability
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Wetenschappelijk onderzoek afdeling Revalidatiegeneeskunde – Centrum voor Revalidatie UMCG

EXPAND

Extremities, Pain and Disability

Missie: EXPAND draagt bij aan participatie en kwaliteit van leven van mensen met aandoeningen en amputaties van de extremiteiten of met pijn aan het bewegingsapparaat.

EXPAND omvat twee speerpunten: onderzoek naar aandoeningen aan en amputaties van extremiteiten met nadruk op stoornissen, activiteiten en participatie en onderzoek naar chronische pijn en arbeidsparticipatie. EXPAND draagt bij aan het UMCG-brede thema Healthy Ageing.

Research Department of Rehabilitation Medicine – Center for Rehabilitation UMCG

EXPAND

Extremities, Pain and Disability

Mission: EXPAND contributes to participation and quality of life of people with conditions and amputations of the extremities and musculoskeletal pain.

EXPAND focuses on two spearheads: research on the conditions and amputations of the extremities with emphasis on body functions and structures, activities and participations, and chronic pain and work participation. EXPAND contributes to Healthy Aging, the focus of the UMCG.



About the author

Mihai (Mike) Brăgaru was born in 1980 in Strehaia, Romania. Since an early age he showed an interest for both the healthcare and technology and it was no surprise when he decided to follow the courses of the Medical Bioengineering Faculty, Iasi Romania. In 2005 he graduated with honours and received his BSc diploma (MSc equivalent) in "Biomaterials and Prosthetic technologies". During his studies he worked as a prosthetist and orthotist (CPO) gaining clinical expertise in rehabilitation, amputation and orthopaedics. In the last year of his studies he was for a short period of time an Erasmus exchange student at the Universite 12 Paris, Inserm Laboratoires. Since 2005 he entered the business environment working in sales and account management for various pharmaceutical companies. In 2008 he started his PhD research on the topic of Sports and Amputation at the University Medical Center Groningen, University of Groningen, the Netherlands. In the 4 years of his research he focused on the individuals with upper or lower limb amputation and used both quantitative and qualitative methods to investigate their participation rate in sports, the characteristics of this participation, and the barriers and facilitators associated with it.

During his career Mihai developed his business and scientific skills gaining expertise in orthopaedics, sports and physical activity, biomechanics, prosthetics, and account management. Upon graduation, Mihai would like to keep working in an international professional environment, where science and research meets business and communication. His main interests are in the areas of healthy living, sports participation of general population and those with physical disabilities, prosthetics and medical technologies.