University of Groningen

The most important activities of daily functioning

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Published in:
International Journal of Rehabilitation Research

DOI:
[10.1097/MRR.0000000000000392](https://doi.org/10.1097/MRR.0000000000000392)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2020

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

van Schaik, L., Hoeksema, S., Huvers, L. F., Geertzen, J. H. B., Dijkstra, P. U., & Dekker, R. (2020). The most important activities of daily functioning: the opinion of persons with lower limb amputation and healthcare professionals differ considerably. *International Journal of Rehabilitation Research*, 43(1), 82-89. <https://doi.org/10.1097/MRR.0000000000000392>

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LLA will be compared. The findings may provide further insight into the importance of certain ADL among persons with LLA and may guide clinicians on where to direct their focus in the rehabilitation process.

Methods

Medical ethical commission

The Medical Ethics Assessment Committee for Research of the University Medical Center of Groningen declared that this study did not fall within the Dutch law on Medical scientific Research involving humans. Consequently, formal approval from the committee was not required for this research (2016.393) and exemption was granted.

Study design

In this observational study, data are collected using questionnaires filled in by persons with LLA, and by healthcare professionals working with persons with LLA. Part of the methodology of this study was based on that of a previous study (Reneman *et al.*, 2018).

Participants in this study were included if they had LLA at Syme level or higher, ≥ 18 years of age, and understand Dutch language. All participants received written information about the study before taking the questionnaire and written informed consent was obtained. The questionnaires were distributed on paper at different prosthetic workshops in the Northern regions of the Netherlands and persons with LLA could sign up by email through the amputee association.

Healthcare professionals were included in the study if they were working with persons with LLA at the time of the study. The questionnaires were distributed on paper to professionals working in the Northern regions and were distributed in the 'Werkgroep Amputatie en Prothesiologie', which is a nationwide collaboration of rehabilitation specialists working within the field of LLA in the Netherlands.

From September 2016 to November 2016, the questionnaires were distributed among persons with LLA and healthcare professionals. The aim was to include at least 50 persons with LLA. Because the number of participants with LLA was too low, a second distribution round was performed from September 2018 to November 2018.

Composite of the questionnaire

The international classification of functioning (ICF)-model was used to create an overview for activities and participation (Üstün *et al.*, 2003; Radhakrishnan *et al.*, 2017). To create this overview, a scoping database search (PubMed, Embase, and Google Scholar) was performed to select studies using measurement instruments for activities and participation items, conform the ICF domains self-care, mobility, domestic life, major life

areas, and community/social life. Studies were excluded when they contained measurement instruments that conform the ICF domains learning and applying knowledge, general tasks and demands, communication, interpersonal interactions, and relationships. When in 50 studies (ordered chronologically and starting with most recent) no new measurement instruments were found, data saturation regarding items was assumed.

An overview was created containing all items for activities and/or participation identified in the instruments. Some instruments contained both items from the included ICF domains (e.g. self-care) and excluded ICF domains (e.g. communication). Only items that could be categorized under the previously mentioned domains, based on the ICF model, were included in the overview. Additionally, treatment-related items (e.g. use services provided by a medical clinic, hospital or rehabilitation center) were excluded. Duplicates or similar items were merged into one item. Lastly, the list was checked by the research group for possible missing items. In total, 40 items were included (Table 1).

Questionnaire

Two questionnaires were developed, one for persons with LLA and one for healthcare professionals.

In the questionnaire for participants with LLA, participant characteristics (gender, age, and comorbidities) and amputation characteristics (e.g. aetiology, side, level of amputation, time since LLA, and time since wearing prosthesis) were asked. Thereafter, participants were asked to select 10 out of the 40 items that they considered to be most important to perform independently (Table 1). Participants had to order these 10 items, from most to least important, scored 10 to 1, respectively. Additionally, participants were asked if they missed any important daily activity in the 40 item list. Finally, the questionnaire ended with four statements regarding the clearness and complexity of the questionnaire. The following statements were included: 'the instructions prior the questionnaire made clear what was expected of me', 'it was easy to distinguish the items in the overview', 'it was easy to choose the 10 items that I found most important', and 'the asked questions were easy to understand'. The answering options of the statements were as follows: strongly agree, agree, neutral, disagree, and strongly disagree (Reneman *et al.*, 2018).

The questionnaire for healthcare professionals working in the field of LLA asked for personal and professional characteristics and thereafter the questionnaire was the same as for participants with LLA.

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics 23 (Supplier: SPSS Inc. 233 S Wacker Dr. 11th Fl. Chicago, Illinois 60606). Descriptive statistics are

Table 1 The 40 items in the questionnaire

ICF domains	Items
Self-care	Bathing/showering
	Dress and undress
	Donning and doffing your prosthesis
	Going to the toilet
	Treat your stump
Mobility	Treat your foot and nails
	Get in and out of bed
	Sit and get up (e.g. chair)
	Walk around indoors on an even ground
	Walk outside around the house
	Walk outside on an even ground
	Walk outside on an uneven ground (e.g. snow, ice, gravel, grass)
	Walk up and down a steep hill
	Walk up and down a few steps
	Walk up and down stairs
	Hop over an obstacle on the floor (e.g. doorstep)
	Keep walking/standing when people bump in to you
	Get up from the floor if you fall
	Get in and out of a car
	Walk on the streets and sidewalks
	Keep up with others when walking
	Walk while carrying an object, food or drinks
	Lift heavy objects (e.g. groceries)
	Pick up an object from the floor
	Travel with public transport
	Drive yourself
	Bike yourself
	Sexual functioning
Domestic life	Prepare meals (plan, prepare and serve a main course)
	Perform 'light' household tasks (e.g. washing dishes and making beds)
	Perform 'heavy' household tasks (e.g. mopping, cleaning windows and vacuuming)
	Grocery shopping
Major life areas	Maintain your own house/garden/car
	Hold a job (paid or voluntary)
Community and social life	Undertake social activities (e.g. visit clubs, church and friends)
	Go on trips (e.g. visit the zoo or museum)
	Use public services (e.g. town hall, the bank and hospital)
	Participate in relaxing activities (e.g. painting)
	Participate in moderate physical activities (e.g. riding a bike)
	Participate in heavy physical activities (e.g. running and lifting heavy objects)

ICF, International Classification of Functioning.

presented using means and SD and nominal data as percentages and frequencies. The 15 items with the highest mean scores for participants with LLA were selected. The choice for 15 items was arbitrary. The mean rank scores of these 15 items were compared with the mean rank scores given by healthcare professionals for these items, using the Mann–Whitney U test with a Hochberg adjustment for α (Benjamini and Hochberg, 1995).

Participants with LLA were divided into six subgroups based on age (≤ 65 years vs. > 65), gender (male/female), time since LLA (≤ 12 months vs. > 12 months), level of amputation [above knee amputation (AKA) vs. below knee amputation (BKA)], reason of LLA (vascular vs. non-vascular aetiology), and unilateral vs. bilateral. For these subgroups, the same statistical analysis was performed.

Results

The overall response rate was 63% for participants with LLA (325 questionnaires distributed and 205 returned) and 67% for healthcare professionals (70 questionnaires

Table 2 Demographic characteristics of the included participants, mean $\pm$ SD

Characteristics participants with LLA (number of valid observations)		
Gender n (%) (n = 125)	Men	86 (68.8)
Age (years) (n = 125)		61.4 $\pm$ 13.7
Height (cm) (n = 123)		176 $\pm$ 10.7
Weight (kg) (n = 123)		78.5 $\pm$ 17.4
Smoking n (%) (n = 125)		17 (21)
Time since LLA (months) (n = 124)		204.0 $\pm$ 229.1
Wearing prosthesis (hours per day) (n = 123)		12.6 $\pm$ 4.9
LLA level n (%) (n = 125)		
Unilateral (n = 114)	Transfemoral	48 (38.7)
	Knee disarticulation	11 (8.8)
	Hip disarticulation	3 (2.4)
	Hemipelvectomy	1 (0.8)
	Syme	1 (0.8)
Bilateral (n = 11)	Transfemoral	6 (4.8)
	Transfemoral and	2 (1.6)
	Knee disarticulation and	1 (0.8)
	transfemoral	
	Transfemoral and forefoot	1 (0.8)
LLA aetiology n (%) (n = 122)	Trauma	50 (41.0)
	Vascular diseases (with or	30 (24.6)
	without DM)	
	Oncological	15 (12.1)
	Congenital malformation	4 (3.3)
Infection		13 (10.7)
	Others	10 (8.2)
Characteristics healthcare professionals (number of valid observations)		
Gender (%) (n = 44)	Men	23 (52.3)
Age (years) (n = 43)		45.2 $\pm$ 9.8
Occupation n (%) (n = 44)		
Rehabilitation specialist		21 (47.7)
	Physiotherapist	8 (18.2)
	Occupational therapist	5 (11.4)
	Certified prosthetist/orthotist	8 (18.2)
	Other	2 (4.6)
Experience in the LLA field (years) (n = 43)		13.4 $\pm$ 8.8

DM, diabetes mellitus; LLA, lower limb amputation.

distributed and 47 returned). In the group participants with LLA, 80 questionnaires were excluded due to various reasons. The majority of excluded questionnaires used the same ranking number multiple times, making ranking impossible. In the group healthcare professionals, three questionnaires were excluded because of missing data. In total, data of 125 participants with LLA and 44 healthcare professionals were included (Table 2). The majority of participants with LLA were male (69%, n = 86) and the mean age was 61.4 years. The majority of healthcare professionals worked as a rehabilitation specialist (n = 21) with an average of 13.4 years of experience in the field of LLA. The characteristics of the participants with LLA who filled in the questionnaire incorrectly are presented in Table 3. Characteristics of participants with LLA who filled in the questionnaire correctly and incorrectly did not differ significantly.

Participants with LLA rated 'driving a car', 'bicycling', 'ascending/descending stairs', 'heavy exercise' and 'preparing meals' significantly higher than professionals.

Professionals rated the items 'going to the toilet', 'getting in and out of bed', 'walking around indoors' and 'outdoor walking/walking around the house' significantly higher than participants with LLA (Fig. 1, Table 4). Additionally, 26 participants with LLA mentioned they missed a specific item. These items varied from 'ride through the forest with a wheelchair' to 'babysitting the grandchildren'

Table 3 Demographic characteristics of the participants of the excluded questionnaires, mean $\pm$ SD

Gender (%) (n = 79)	Men	45 (57.0)
Age (years) (n = 79)		64.1 $\pm$ 14.1
Height (cm) (n = 79)		176 $\pm$ 10.4
Weight (kg) (n = 78)		80.5 $\pm$ 17.5
Unilateral (n = 77)	Transfemoral	46 (60)
	Transfemoral	27 (35)
	Knee disarticulation	2 (3)
	Hip disarticulation	2 (3)
Bilateral (n = 3)	Transfemoral	2 (67)
	Knee disarticulation and transfemoral	1 (33)
LLA aetiology (%) (n = 80)	Trauma	28 (35)
	Vascular diseases (with or without DM)	29 (36)
	Oncological	6 (8)
	Congenital malformation	1 (1)
	Infection	8 (10)
	Others	8 (10)

DM, diabetes mellitus; LLA, lower limb amputation.

to 'canoeing'. There were no similar items mentioned by multiple participants.

The results of the six subgroups based on age, gender, time since LLA, level of amputation, reason of LLA and unilateral vs. bilateral LLA are presented in Fig. 2a–f. In the subgroup analysis for age (Fig. 2a), the items 'work' and 'heavy exercise' are rated significantly higher by participants ≤ 65 years compared to participants > 65 years. In the subgroup analysis for aetiology (Fig. 2e), participants with vascular aetiology rated 'going to the toilet', 'getting in and out of bed', 'walking around indoors', 'walk outside on even ground' and 'get in and out of a car' significantly higher than participants with other reasons for LLA. No significant differences were found in the other subgroups.

The results of the feasibility statements are presented in Table 5. The majority of the participants with LLA and healthcare professional agreed with the statements 'the instructions prior the questionnaire made clear what was expected of me' and 'the asked questions were easy to understand'. However, for the item 'It was easy to choose the items that I found most important' both

Fig. 1

The 15 most important activities to perform independently from perspective of participants with lower limb amputation (LLA) and healthcare professionals, ordered by highest rating by participants with LLA. The '*' indicates a significant difference between subgroups: *P* value smaller than the Hochberg adjusted alpha.

Table 4 The mean scores of the 15 most important activities to perform independently from perspective of participants with lower limb amputation compared to professionals

	Participants with LLA (n = 125)	Professionals (n = 44)	P value	Hochberg-adjusted alpha
Bathing/showering	4.8	3.9	0.15	0.04
Dressing and undressing	4.2	4.2	0.87	0.05
Going to the toilet	4.0	8.3	<0.001*	0.003
Put the prosthesis on and off	3.7	4.2	0.31	0.043
Driving a car	3.4	1.3	<0.001*	0.007
Getting in and out of bed	2.4	4.0	0.03*	0.03
Work (paid or voluntary)	2.1	0.8	0.10	0.037
Bicycling	2.0	0.7	0.01*	0.013
Walking around indoors	1.9	5.8	<0.001*	0.01
Outdoor walking/walking around the house	1.8	2.7	0.02*	0.020
Social activities outdoors	1.8	1.5	0.70	0.047
Ascending/descending stairs	1.7	0.7	0.01*	0.017
Grocery shopping	1.4	0.6	0.07	0.033
Preparing meals	1.4	0.5	0.02*	0.023
Heavy exercise	1.4	0.1	0.03*	0.027

The '*' indicates a significant difference between subgroups: *P* value smaller than the Hochberg adjusted alpha.
LLA, lower limb amputation.

groups (strongly) disagree with this statement, 65 and 57%, respectively.

Discussion

The aim of this study was to objectify the most important ADL according to persons with LLA and compare them with the scores from healthcare professionals. The five most important items determined by participants with LLA were 'bathing/showering', 'dressing/undressing', 'going to the toilet', 'donning and doffing your prosthesis', and 'driving a car' (Fig. 1). For 9 of the 15 most important items, a significant difference was found between the two groups. Participants with LLA scored five activities higher compared to healthcare professionals; 'driving a car', 'bicycling', 'ascending/descending stairs', 'heavy exercise', and 'preparing meals'. Healthcare professionals scored the activities 'going to the toilet', 'getting in and out of bed', 'walking around indoors', and 'walking around outdoors' higher compared to participants with LLA. These substantial differences are remarkable, since the group of participants with LLA was heterogeneous regarding age, aetiology, and level of amputation. From a clinical perspective, our findings indicate that healthcare professionals should question persons with a LLA before and during the rehabilitation process about the activities they find important to perform independently. If persons with a LLA have difficulties answering these questions, a list of activities as shown in Table 1 may be helpful.

The statistical analysis performed was based on the top 15 according to participants with LLA, because the aim of the study was to compare the perspective of the participants with LLA with the healthcare professionals and

not the other way around. The top 15 activities as scored by the healthcare professionals contained nine similar items and six different items compared to participants with LLA.

In this study, the participants with LLA were representative for the Dutch amputee population regarding age, gender and level of amputation. However, considering aetiology for amputation, the participants with LLA due to trauma is relatively overrepresented compared to participants with LLA due to vascular disease and/or DM (Fortington *et al.*, 2013; Fard *et al.*, 2018). This distribution might influence the results because persons with a traumatic LLA are usually younger at the time of amputation and have no/fewer comorbidities. It is possible that 'heavy exercise' ended up in the overall top 15 due to the relatively large group of traumatic LLA, but it did not end up in the top 15 of the subgroup participants with a vascular LLA (Fig. 2e).

When looking at the different subgroups of participants with LLA (Fig. 2), the ranking of items and mean scores differs. For example 'bicycling' is higher prioritized by participants with BKA, ≤65 years or LLA>12 months compared to participants with an AKA, >65 years or LLA≤12 months. Additionally, bicycling is a typical Dutch activity. In the Dutch population, riding a bicycle and/or driving a car are the main means of transportation, though in other countries, there can be other specific activities. Previous studies found, based on ICF model, that important concepts of walking and mobility are similar in different countries, with some specific activities based on culture or religion (e.g. praying positions and the use of motorised public transportation) (Radhakrishnan *et al.*, 2017, 2019).

In the subgroup analysis for age (Fig. 2a), the items 'work' and 'heavy exercise' are rated significantly higher by participants ≤65 years compared to participants >65 years. This difference can be explained by the fact that in the Netherlands persons retire from work around the age of 65. In the subgroup analysis for reason of amputation (Fig. 2e), participants with vascular aetiology rated 'going to the toilet', 'getting in and out of bed', 'walking around indoors', 'walk outside on even ground', and 'get in and out of a car' significantly higher than participants with other reasons for LLA. An explanation might be that persons with a vascular aetiology for LLA are usually elderly, have comorbidities, and have a lower physical capacity. Therefore, it is possible that basic ADL are intense (or difficult) enough.

No significant differences were found for the other subgroups, although in some figures the difference in mean scores seems substantial (e.g. the items 'ascending/descending stairs' and 'bicycling' in the subgroup unilateral vs. bilateral LLA (Fig. 2f)). This lack of significance can be explained by the small number of participants in

Fig. 2

Figures illustrating differences between the subgroups of persons with a lower limb amputation (LLA). (a) Participants ≤65 years vs. >65 years. (b) Male vs. female. (c) Time since amputation: ≤12 months vs. >12 months. (d) Below knee amputation (BKA) vs. above knee amputation (AKA). (e) Reason of amputation; vascular vs. nonvascular aetiology. (f) Unilateral LLA vs. bilateral LLA. The '*' indicates a significant difference between subgroups: *P* value smaller than the Hochberg adjusted alpha.

a subgroup (*n* = 11 participants with bilateral LLA) and the large SD's. This problem may also be the case in the figure time since LLA (Fig. 2c), with only 12 participants with LLA ≤ 12 months. In this subgroup, basic ADL is scored higher compared to participants with LLA > 12 months, but NS. This difference was expected, because the first goals after recent LLA are becoming independent for the basic ADL.

When analysing the results of the feasibility statements, both participants with LLA and healthcare professionals found it difficult to choose the 10 most important items and rank them. For participants with LLA with a high level of functioning, one of the explanations can be the fact that basic ADL such as dressing/undressing are taken for granted and they focus on more complex activities, where for less mobile participants the goals of basic ADL

Table 5 Feasibility of the questionnaires participants with lower limb amputation and professionals

Statement		Participants with LLA (n = 124)	Professionals (n = 44)
'The instructions prior the questionnaire made clear what was expected of me' (%)	Strongly agree	39 (31.5)	12 (27.3)
	Agree	72 (58.1)	25 (56.8)
	Neutral	10 (8.1)	2 (4.5)
	Disagree	3 (2.4)	3 (6.8)
	Strongly disagree	0	2 (4.5)
'It was easy to distinguish the items in the overview' (%)	Strongly agree	17 (13.9)	4 (9.1)
	Agree	57 (46.7)	21 (47.7)
	Neutral	32 (26.2)	8 (18.2)
	Disagree	11 (9.0)	9 (20.5)
	Strongly disagree	5 (4.1)	2 (4.5)
'It was easy to choose the items that I found most important' (%)	Strongly agree	3 (2.4)	1 (2.3)
	Agree	13 (10.6)	10 (22.7)
	Neutral	27 (22.0)	8 (18.2)
	Disagree	52 (42.3)	20 (45.5)
	Strongly disagree	28 (22.8)	5 (11.4)
'The asked questions were easy to understand' (%)	Strongly agree	42 (33.9)	17 (39.5)
	Agree	64 (51.6)	23 (53.5)
	Neutral	14 (11.3)	2 (4.7)
	Disagree	4 (3.2)	1 (2.3)
	Strongly disagree	0	0

LLA, lower limb amputation.

are already difficult enough. For healthcare professionals, a possible explanation for the experienced difficulty in selecting the 10 most important items can be that every person with LLA is unique in age, aetiology and level of amputation, living environment, and personal preferences. Since no specific instructions were given, they possibly filled in the questionnaire with a specific subgroup of persons with LLA in mind.

One of the limitations of the study is the sample size and the aetiology distribution, which is not representative of the population persons with LLA in the Netherlands. Also, there can be a selection bias. Probably the more healthy, higher participating persons with LLA (younger age and traumatic aetiology) participated in the study. Additionally, it was difficult for both groups to choose only 10 items where more items could be of importance. Although the response rate was relatively high, multiple questionnaires were not completed correctly. One of the main reasons for exclusion was when the participant scored multiple items with the same number, possibly indicating that these items are perceived equally important. Consequently, these data could not be used in the statistical analysis. It might also be possible items were missing in the overview. However, because participants mentioned no items multiple times, this chance is low. Lastly, it could be that other participant characteristics are of importance, which were not included in this study.

Conclusion

A significant difference in rating importance was found for 9 out of 15 activities between persons with LLA and healthcare professionals.

This result highlights the importance of shared decision making and communication with the person with

LLA in order to optimize their rehabilitation program. Healthcare professionals should carefully assess the personal importance of each activity when providing care, including prescribing a prosthesis, for persons with LLA.

Acknowledgements

We thank all the participants for their contribution.

Conflicts of interest

There are no conflicts of interest.

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