

PERSPECTIVES OF SUBJECTS WITH UPPER LIMB ABSENCE ON THE RISK FACTORS FOR MUSCULOSKELETAL COMPLAINTS.

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ABSTRACT

Background: Musculoskeletal complaints (MSCs) are a highly prevalent problem in subjects with upper limb absence (ULA). Studies have been conducted to better understand the risk factors for the development and persistence of MSCs, and show relations with psychological and work-related factors. The opinions of patients with ULA have not been taken into account so far. Their perspectives can contribute to address important factors and aid in the improvement of treatments. This study therefore executed a focus group with subjects with ULA, to get insight in the patient perspectives and to develop a framework of all factors involved in the development and persistence of MSCs.

Methods: A focus group was held with adult individuals with ULA. With open questions, the general topic of MSCs and the main topic of the risk factors for MSCs were addressed. The transcript of the focus group was used to build a framework, by formulation (sub)categories of risk factors in an inductive way. The final set of categories was entered in the Atlas.ti software to identify sections of the transcript corresponding to a (sub)category.

Results: Eleven subjects with ULA participated in the focus group, of which three experienced no MSCs and eight had MSCs in the previous year. The opinions of the participants resulted in five main categories containing 29 subcategories: prosthesis-related, psychological & cognition, environment, general, and activities. Especially the factors in the 'psychological & cognition' and 'activities' category were deemed important.

Conclusion: The outcomes of the focus group regarding the categories 'psychological & cognition' and 'activities' cannot be endorsed with current literature, as literature on these categories is limited. Future research should therefore address the gaps between the patient perspectives and the literature, to fill the gap and to extend the knowledge on risk factors for MSCs.

INTRODUCTION

Many subjects with upper limb absence (ULA) complain about musculoskeletal complaints (MSCs), as we noticed in our clinic. Frequently heard complaints are carpal tunnel syndrome, epicondylitis (tennis elbow), stenosing tenosynovitis (trigger fingers), shoulder impingement, and neck and back complaints. Several studies have investigated the prevalence of MSCs in persons with ULA and the related population characteristics [1-4]. The year prevalence of MSCs in Dutch individuals with ULA was shown to be twice as high compared to their two-handed peers (65% versus 35%) [1]. MSCs are often chronic and observed in the residual limb, unaffected limb, neck or back, and with higher pain intensity and resulting in higher disability [1, 2]. Presence of MSCs in single-handed individuals will result in dual disability; adding disability due to MSCs to the disability caused by single-handedness [5]. This has consequences for daily life and emphasizes the high personal and societal impact [2, 3].

Studies have been conducted to better understand the risk factors for the development and persistence of MSCs. In patients with ULA, the presence of MSCs was associated with higher perceived physical work demands and lower general and mental health [1, 3]. Additional risk factors for the presence of MSCs in individuals with ULA are: higher age, being divorced or widowed, and lower mental health [1]. Prosthesis wear (daily duration of prosthesis use, number of activities with prosthesis use, and type of prosthesis) did not appear to be related to the presence of MSCs [1, 2, 4]. A possible explanation provided for the differences in prevalence between the subjects

with ULA and the two-handed population, may be the use of compensatory movements, but this has not been examined so far [4].

The opinions of patients with ULA themselves on contributing and persisting factors for MSCs has remained underexposed at the moment. Their experiences with MSCs and their perspectives can highlight the importance of several factors, and can address the need for improvement of treatments. This study therefore executed a focus group with subjects with ULA, to get insight in their opinions and to develop a framework of all factors involved in the development and persistence of MSCs in this population.

METHODS

The Medical Ethics Review Board of the University Medical Center Groningen (METc UMCG) concluded that formal approval of the study was not necessary (METc 2019/228). All participants signed an informed consent before the start of the study.

Participants were recruited via a list of adult eligible patients composed by a clinician and via an advertisement in a magazine of the Dutch patient organization for persons with ULA. At the start of the focus group, which took place in April 2019 at the UMCG, the Netherlands, participants filled in a short questionnaire with socio-demographic data. During the 60 minutes-focus group, open questions about MSCs were asked. The first two questions introduced the topic of MSCs: 1) Who is familiar with MSCs, and if so what type of complaints have been experienced?; 2) Who is not familiar with MSCs, and how can that be explained? However, the main topic of this focus group were the risk factors of MSCs: 3) What are/could be the causes of these complaints?

The audio-recordings were transcribed verbatim. A framework was composed based on the transcript of the focus group. Two assessors (AAP, SGP) started with the familiarization process by reading the transcript of the focus group to get a sense of the whole text. Independently of each other, they developed a framework by formulating main categories and subcategories of risk factors in an inductive way. These (sub)categories were discussed and the data was reassessed. In a second discussion, differences were deliberated to reach consensus until a final set of categories was determined. In the next step, the transcript was entered in the Atlas.ti software. The framework was applied to the transcript and sections of the transcript that corresponded to a particular (sub)category were identified. The selected information was displayed in a list of quotes and corresponding categories. The results were analysed and discussed to draw conclusions until consensus was reached between the assessors.

RESULTS

Eleven participants (six males) participated in the focus group. Median age of the participants was 46.3 years (range 31.4 – 69.7 years). Three participants did not experience MSCs in the previous year, while eight did. Of these eight participants, seven experienced MSCs during the last four weeks. The median duration of MSCs was 3.5 years (range 0.5 – 20 years). Three participants perceived their pain as light, one had quite some pain, and one rated their pain as both these options (two subjects failed to fill in this question).

The opinions of the participants resulted in five main categories containing 29 subcategories (Fig. 1): prosthesis-related, psychological & cognition, environment, general, and activities. The two most mentioned categories were ‘psychological & cognition’ and ‘activities’. The main focus within the ‘psychological & cognition’ category was on the problem with setting boundaries. Participants felt that they had to give at least 150% in all of their activities, resulting in complaints: “..., with what I do have, wanted to overcompensate. More in a way to prove: I can do everything. What you can do, I can do too. And then some extra.” Difficulty to accept that they had a loss of function and, especially in those with acquired amputations, the wish to return to work in the same manner as before the amputation, contributed greatly to the development of MSCs. In the category ‘activities’, they addressed that compensation with the non-affected limb and performing physically demanding tasks were important contributors to the presence of complaints: “I am missing my left hand and I, in order to compensate, perform everything with the right side. And that makes me really chronically overload my right shoulder. But also my head, neck, just the whole area. Sometimes I have, what do you call that stupid stupid thing, ... a tennis elbow.”

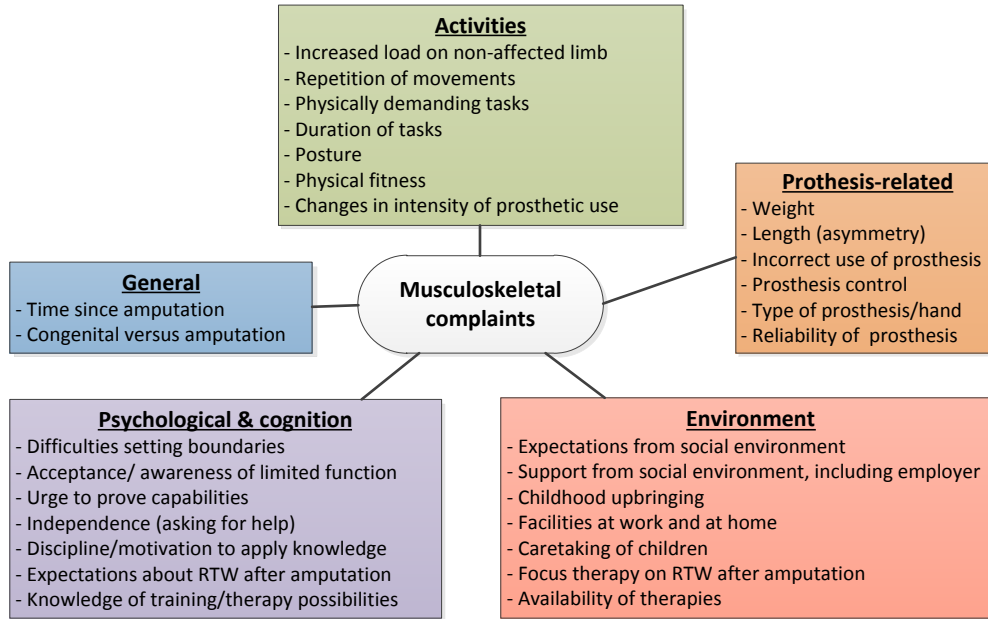


Figure 1: Framework of risk factors for the development and persistence of musculoskeletal complaints according to persons with upper limb absence. RTW: return to work.

DISCUSSION

A framework was made based on the opinions of patients with ULA on origin and maintenance of MSCs. This framework highlights themes that are risk factors for MSCs according to the patient population. Comparing this framework to several models [6-9], shows similarities with the International Classification of Functioning, Disability and Health (ICF) [9]. This framework will help to assess necessary treatment modalities of individuals with ULA, who experience MSCs. Using a distribution of risk factors comparable to the ICF-model is helpful to understand and measure consequences of MSCs, and can be used in clinical situations.

The opinions of the persons with ULA highlight the importance of psychological and physical factors. Psychological factors such as coping, support and work-related factors have been addressed in previous studies [1, 3]. On the contrary, studies about the physical factors have not been executed in subjects with ULA so far, even though studies mention compensation as a possible risk factor [4]. Investigating compensation strategies should be one of the research priorities for future studies.

Furthermore, to strengthen the framework, it should be supplemented with results of a literature review focusing on risk factors of MSCs in this population. Thus, creating an overview of all factors that may contribute to the development and persistence of MSCs. This overview may help synthesizing research priorities, which can then be taken into account in the development of new and better interventions to prevent and to treat MSCs in single-handed individuals.

In conclusion, patients suggest that psychological and physical factors play a major role in the development and persistence of MSCs. However, limited literature results are available to support these findings. Future research should examine the current scientific knowledge on MSCs in this population in order to complete the framework. Thereafter, discrepancies between patient perspectives and the literature should be addressed. Ultimately, more knowledge on population-specific risk factors of MSCs will allow to treat MSCs more effectively and reduce disability.

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