N Cuperus, TPM Vliet Vlieland, N Brodin, A Hammond, I Kjeken, H Lund, S Murphy, Y Neijland, CH Opava, S Roškar, R Sargautyte, T Stamm, XT Mata, T Uhlig, H Zangi & CH van den Ende (2015): Characterizing the concept of activity pacing as a non-pharmacological intervention in rheumatology care: results of an international Delphi survey, Scandinavian Journal of Rheumatology

To link to this article: http://dx.doi.org/10.3109/03009742.2015.1052552

Title

Characterizing the concept of activity pacing as a non-pharmacological intervention in rheumatology care: results of an international Delphi survey.

Category submitted: Article

Running head: Activity pacing in rheumatology care

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Abstract

Objective: To develop a consensual list of the most important aspects of activity pacing (AP) as an intervention within the context of non-pharmacological rheumatology care.

Methods: An international, multidisciplinary expert panel comprising 60 clinicians and/or healthcare providers experienced with AP across 12 different countries participated in a Delphi survey. Over four Delphi rounds, the panel identified and ranked the most important goals of AP, behaviours of AP (the actions people take to meet the goal of AP), strategies to change behaviour in AP and contextual factors that should be acknowledged when instructing AP. Additionally, topics for future research on AP were formulated and prioritized.

Results: The Delphi panel prioritized 9 goals, 11 behaviours, 9 strategies to change behaviour and 10 contextual factors of AP. These items were integrated into a consensual list containing the most important aspects of AP interventions in non-pharmacological rheumatology care. Nine topics for future research on AP with the highest ranking were included in a research agenda highlighting that future research should focus on the effectiveness of AP interventions and on appropriate outcome measures to assess its effectiveness, as selected by 64% and 82% of the panellists, respectively.

Conclusion: The diversity and number of items included in the consensual list developed in the current study reflect the heterogeneity of the concept of AP. This study is an important first step in achieving more transparency and homogeneity in the concept of AP in both rheumatology daily clinical practice and research.

Introduction

Activity pacing (AP) is a recommended non-pharmacological, non-surgical intervention for the management of rheumatic diseases in international clinical guidelines (1-3). In daily clinical practice, AP frequently emerges as a primary component of self-management programs within the context of multidisciplinary treatment (4-6). Furthermore, AP has been shown to be the advice most frequently given by British and Dutch rheumatology nurses to patients with rheumatoid arthritis (RA) (7). It is one of the self-management strategies most frequently applied by patients with a variety of rheumatic conditions (8-12). However, despite its wide endorsement in clinical practice, to date AP is still a poorly understood concept with a wide variety in definitions, interpretations and methods of delivery (13-15).

In research and clinical rheumatology practice, AP is mainly based on the principle of energy conservation, assuming that individuals with a chronic disease have limited energy resources and therefore need to undertake activity regulation to allow completion of valued activities (16). However, the widespread use of AP in rheumatology care is purely pragmatic as stated in a recently published review describing the current knowledge on AP (16). There is a large variation in goals and AP behaviours (the actions people take to meet the goal of AP) proposed in the literature (5,15,17,18). Also in chronic pain, in which AP is a central concept in theories and treatment, there is no consensus on the interpretation of AP due to a wide variety in how AP has been described (e.g. operant conditioning vs. energy conservation) (14,16,19). Recently, various attempts have been made to clarify the concept of AP in the chronic pain literature (16,20). In general, AP has now been conceptualized as an intervention whereby individuals balance activity and rest in order to maintain or increase physical function and to participate in necessary and valued activities (16,20,21).

The implications of a poor conceptualization of AP are significant in both research and rheumatology practice (14). Due to differences in conceptual constructs of AP, empirical evidence of the effectiveness of AP is limited and contradictory (14,22). In addition, diversity in perspectives among therapists on what AP is and how it should be applied as an intervention might impede an effective management of the disease (14,23). Considering this, we assume the initial issue in research on AP in rheumatology care is to clarify this poorly defined concept. Nielson et al. (16) concluded that identifying the goal(s) of AP, behaviours of AP, strategies to change behaviour in AP (e.g. overactivity or underactivity) and contextual factors influencing AP will be a first step towards assessing its effectiveness.

The aim of the current study was to develop a consensual list of the most important aspects of AP interventions related to all rheumatic conditions, including inflammatory and non-inflammatory (degenerative and soft tissue) conditions. An international expert panel prioritized the most important aspects for four dimensions of AP (i.e. the goals, behaviours, strategies to change behaviour and contextual factors that should be acknowledged when teaching AP). This list might be an important first step in achieving more transparency and homogeneity in the concept of AP in both rheumatology clinical practice and research. Additionally, a research agenda was developed highlighting topics for future research on AP.

Material and Methods

Design

As we aimed to develop a consensual list containing the most important aspects of AP interventions among international experts, we deemed the Delphi technique to be an appropriate method. The Delphi technique is a widely used and accepted iterative multistage process to transform expert opinion into group consensus within a certain topic (24). This method is especially applied when sufficient information or evidence regarding a certain topic is unavailable (25). Typically, round 1 is used to generate items and involves open-ended questions, allowing participants freedom in their responses. Subsequently, these items are grouped together and presented to all panellists in a questionnaire form to vote in 2-4 rounds (26). During this process the range of items is expected to decrease. The local ethics committee (CMO region Arnhem, Nijmegen) approved the study (protocol number: 2012/523).

International working group and panel selection

Prior to the start of the current study we appointed an international working group (all co-authors) consisting of 15 healthcare professionals or clinicians (i.e. 5 physical therapists, 4 occupational therapists, 3 psychologists, 2 specialized rheumatology nurses and a rheumatologist) experienced with teaching AP to patients with a rheumatic disease and/or with published studies on AP involving a rheumatic disease, across 12 different countries. The working group members participated as panellists and were involved in establishing the final study procedures and preparation of the manuscript. Additionally, we asked each working group member to nominate at least five individuals (preferably working in their own discipline) who were eligible to participate in the Delphi panel (snow-ball technique). To be eligible, individuals had to meet one of the following two criteria: 1.) having at least five years experience in treating patients with a rheumatic disease or 2.) having a publication record in the area of AP involving a rheumatic disease. Potential participants were contacted by e-mail to inform them about the study and to request their participation. There is no agreement on the optimal panel size for Delphi studies and no clear guidelines exists (25,27). Most studies use panels of between 15 to 35 experts (28). We considered 50 experts sufficient to ensure validity of the study results i.e. to cover the entire spectrum of perspectives from healthcare providers with different backgrounds and expertise, and to allow for drop-outs.

Data collection

Literature search

We conducted a pragmatic literature search in order to gather available evidence on the concept of AP. PubMed was searched for articles published up to July 2013 using the key words ((connective tissue diseases[MeSH] OR rheumatic diseases[MeSH] OR musculoskeletal diseases[MeSH] OR arthritis) AND (activity pacing OR "energy conservation")). With this search we included all rheumatic conditions. We only searched for energy conservation as different term for AP as in rheumatology care AP is mainly based on the principle of energy conservation (16). This search yielded 65 hits. Furthermore, included articles were hand searched for additional relevant studies. This literature search was not a systematic review and no judgment was made about the quality of the evidence. The results of the literature search assisted in defining the questions of the first Delphi round. Based on this search, we identified four important dimensions of AP that need to be clarified: i.e. the goal(s) of AP, the behaviours of AP, the strategies to change behaviour in AP and contextual factors influencing AP (such as environmental factors, personal factors or disease characteristics).

We therefore formulated the following questions of the first Delphi round, which were first reviewed by the members of the working group: 1.) describe all possible goals of AP; 2.) describe all possible behaviours of AP; 3.) describe all possible strategies to change behaviour in AP, and; 4.) describe all contextual factors that should be taken into account when teaching AP. This search did not highlight the need of a validated AP measure. Additionally, the literature search was used to identify individuals with a publication record in the area of AP involving a rheumatic disease who were invited to participate in the Delphi survey.

Delphi survey

The questionnaires of the Delphi rounds were delivered over four rounds by email. Only panellists who completed the first round questionnaire were invited to participate in the subsequent rounds. When panellists completed the first round questionnaire, non-completion of a preceding round questionnaire did not prohibit them from contributing to subsequent rounds. In order to increase response rates, reminders were sent after each Delphi round.

The first round was used to generate items. In order to reduce the number of items generated in the first round, the items of the first round were refined during 3 following rounds through merging items with a similar content and prioritizing the most important items (26,29). Anonymity among experts was maintained throughout all rounds.

Item generation – Delphi Round 1

Following the invitation, individuals who agreed to participate were asked to respond to the previous mentioned four open-ended questions. We used open-ended questions in order to generate items and to allow participants complete freedom in their responses (24). The results obtained in this round were collated and categorized according to their content independently by two researchers experienced with qualitative research (NC, CHvdE). During a consensus meeting the researchers discussed their categorization until agreement was reached. In order to guarantee transparency, we decided not to merge items with a more or less similar content in this stage.

Round 2

In the second round, we asked the panellists to rate the appropriateness of each item on a scale ranging from 1 (completely inappropriate) to 10 (completely appropriate). Considering the abundance of items generated in the first round, we decided to break up the work in the second round by asking each panellist to rate the items of only one of the four dimensions of AP. In this way we ensured the panellists' motivation to carefully rank the items and minimized the risk for drop-outs. Each dimension was ranked by 15 panellists. To ensure that all domains were equally distributed with regard to professional background and country, purposive sampling was used to allocate dimensions to the panellists. In order to cover all items, panellists were explicitly encouraged to include additional items that were considered missing in round 1. Furthermore, to collect the key scientific questions on AP, we asked the panellists to formulate topics for further research on AP.

Round 3

In order to significantly reduce the number of items and maintain those considered to be 'very appropriate' by the panellists, items with a median appropriateness score ≥ 8 in round 2 (arbitrarily defined) and the proposed additional items were subjected to Delphi round 3. In this round we asked all panellists to select the 10 items they felt were most appropriate for each dimension of AP and the topics for future research, respectively.

Round 4

Prior to the start of the final Delphi round, redundant items were eliminated by merging items with a similar content. Two researchers independently merged items (NC, CHvdE). Afterwards, the two researchers compared, discussed and finally established the remaining items through a consensus meeting. The researchers agreed on the items that could be merged. In total, 25 goals, 76 behaviours, 25 strategies, 38 contextual factors and 75 topics for further research were merged into 18 goals, 53 behaviours, 20 strategies, 29 contextual factors and 56 research topics. The scores of the merged items were combined. Then, items selected by <20% of the panellists in round 3 were removed. The remaining items were subjected to the final Delphi round. In this final round, we asked panellists to select the ten items they felt were most important for each dimension of AP and the research topics, respectively, and subsequently to rank those ten items from most important (1) to least important (10) within each dimension.

Ranking of items

After the panellists completed the final Delphi round, we ranked the remaining items in two ways: 1.) in order of the number of panellist that selected the item as being important and 2.) in order of the weighted sum ranking (0-100%) calculated by giving scores to the ranks given by the panellists in the final round i.e. the most important items (rank 1) scored 10 points and the least important items (rank 10) scored 1 point. For each item, the weighted rank scores were summed and divided by the theoretical maximum score (number of panellists x 10 points) and expressed as a percentage (100% maximum).

Results

Panellists

A total of 93 potential panellists were invited to participate in the Delphi survey, of whom 68 (73%) responded positively to the invitation. Of these panellists, 60 (88%) completed the first round questionnaire, whereas eight (12%) panellists only completed the demographic questions and were excluded from the current analysis. Demographic characteristics of the panellists are summarized in Table 1. The multidisciplinary Delphi panel consisted of 20 (33%) physical therapists, 17 (28%) occupational therapists, 12 (20%) specialized rheumatology nurses, 8 (13%) psychologists and 3 (5%) rheumatologists across 12 different countries. The majority was female (88%) and the mean (SD) age was 45 (10) years. Panellists were mainly active in clinical patient care (n = 27; 45%), research (n = 25 = 42%), education (n = 6; 10%) or another area (n = 2; 3%). The response rates in rounds 2, 3 and 4 were 49 (82%), 45 (75%) and 46 (77%) panellists, respectively (Table 2). In total, 38 (63%) panellists completed all four Delphi rounds.

Delphi survey

Item generation – Delphi Round 1

In the first Delphi round, the panellists formulated 132 goals of AP, 133 behaviours of AP, 165 strategies to change behaviour in AP and 157 contextual factors that should be acknowledged when teaching AP. All items generated in the first round could be categorized into one of the four dimensions of AP.

Item reduction – Delphi Rounds 2, 3 and 4

In the second round, the Delphi panel rated 22 goals, 61 behaviours, 25 strategies and 34 contextual factors with a median appropriateness score ≥ 8, which were together with the additional items (i.e. 3 behaviours, 15 behaviours and 4 contextual factors) subjected to the next Delphi round. Besides, 75 topics for further research on AP were identified by the panellists in round 2. In the third round, 17 goals, 21 behaviours, 18 strategies, 20 contextual factors and 18 topics for further research on AP were selected by ≥ 20% of the responding panellists as most appropriate items and thus subjected to the final round. Based on the ranks given by the panellists in the final round, we selected for each dimension of AP fifty percent of items with the highest weighted sum ranking. These items were included in our consensual list of most important aspects of AP interventions; resulting in 9 goals, 11 behaviours, 9 strategies and 10 contextual factors (Table 3). Also in this table, the number of panellists that selected an item in the final round as being important, are presented. Furthermore, nine topics for future research on AP with the highest weighted sum ranking were included in a research agenda (Table 4). According to our panellists, future research should focus on the effectiveness of AP interventions and on appropriate outcome measures to assess its effectiveness as selected by 64% and 82% of the panellists, respectively.

Discussion

In the current study, we developed a consensual list containing the most important aspects of AP interventions in non-pharmacological rheumatology care. An international, multidisciplinary expert panel prioritized 9 goals of AP, 11 behaviours of AP, 9 strategies to change behaviour in AP and 10 contextual factors that should be acknowledged when teaching AP. Given the poor conceptualization of AP in the literature, such a list is a first step in achieving more transparency and homogeneity in the concept of AP in both rheumatology research and daily clinical practice. Furthermore, the Delphi panel prioritized nine topics for future research on AP, showing that research should focus on the effectiveness of AP interventions and on appropriate outcome measures to assess its effectiveness.

Interestingly, our panellists agreed that the most important overall goal of AP is to facilitate participation in meaningful and valued activities. The two highest ranked goals of AP referring to participation in meaningful activities were selected by the vast majority of panellists. This finding is interesting as previous studies (survey and pilot studies) suggested reducing pain and fatigue, symptoms associated with rheumatic diseases as the most important overall goal of AP (7,22,30). Yet, a recent published concept analysis of AP as a chronic pain intervention supports our finding that the overall goal of AP is to participate in meaningful activities (20). Considering the findings of our Delphi study and the concept analysis of Jamieson-Lega et al. (20) increasing research points to the overall goal of AP i.e. to facilitate participation in meaningful and valued activities. Healthcare providers in clinical practice and researchers need to be aware of this overall goal of AP, that represents a consensus among an international group of health professions.

Based on a content analysis of AP in chronic pain, the two key categories of AP behaviours are ‘slowing down’ and ‘breaking up activities into smaller pieces’ (31). These behaviours appear to reflect what most researchers mean when using the term AP (31). ‘Breaking up tasks into manageable pieces’ was considered as one of the most important behaviours of AP by our panellists. In contrast, ‘slowing down’ was identified in the first Delphi round, but excluded in the final round. Interestingly, since ‘slowing down’ is reflected in many of the current pacing measures (31). It is possible that the panellists expected that ‘slowing down’ might enhance inactivity, which is in contrast to the overall goal of AP that was endorsed by the panellists (i.e. facilitating engagement in meaningful and valued activities). The more recently developed activity pacing questionnaire (APQ) supports our finding as the item ‘I did my activities at a slower speed’ was excluded as result of a Delphi technique (32). That study also shows ‘breaking up activities into manageable pieces’ to be an important aspect of AP. Planning and prioritizing activities was according to our panellists the most important AP behaviour, which is supported by Antcliff et al. (32). Furthermore, this Delphi study was the first to show that a patient’s self-efficacy, motivation to change behaviour and social support are likely to be the most important contextual factors that should be acknowledged when developing AP interventions.

This is the first consensus study on AP focusing on rheumatic diseases in isolation. Broadly, two approaches of AP can be distinguished i.e. the operant approach and energy conservation (16,19). Although similar in some respects, these two approaches emphasize different treatment goals: operant-based interventions aim to decrease disability and increase activity level whereas energy conservation interventions seek to preserve energy for valued activities while reducing pain and fatigue (16). In this Delphi study we did not specify the theoretical basis with which we evaluated AP, however it seems that our findings are mainly related to the approach of energy conservation.

Healthcare professionals in daily clinical practice can use the list of most important aspects when setting up AP interventions for patients with a rheumatic disease. Together with the patient, the healthcare professional can go through the list and select one or multiple aspects of each dimension of AP that can be combined into an intervention. The selected items can be individually tailored to the patient's specific needs and abilities. Tailored AP instruction is important; preliminary studies have shown tailored AP instruction to be more effective in reducing physical activity variability and joint stiffness than a more general approach in hip and knee OA (15,18). Furthermore, our list might improve a shared conceptual understanding of AP and reduce variability in applying AP approaches among healthcare professionals working within multidisciplinary treatment. This in turn, might improve alignment of care and a more effective management of rheumatic diseases.

To date, empirical evidence of the effectiveness of AP interventions in rheumatology care is limited and contradictory, which can be explained by a poor conceptualization of AP (14,33). For example, in some studies AP has been shown to be associated with lower levels of disability (34) or fatigue (22), where other studies found AP to be associated with higher levels of disability (5), pain and fatigue (19,30). A more uniform concept of AP might facilitate intervention studies that are needed to gain consistent empirical evidence on the effectiveness of AP and allows research studies to be more easily replicated and compared in systematic reviews. This need for research on the effectiveness of AP interventions was highlighted by our panellists. Yet, the panel considered the standardization of outcome measures to assess the effectiveness of AP as most important topic for future research. This need is supported by a recently published narrative review on the measurement properties of AP measures developed and used in research to date (like the Chronic Pain Coping Inventory or Coping with Rheumatic Stressors questionnaire) (31). The authors concluded that existing questionnaires measure a wide variety of outcome domains and that items within the same questionnaire often do not reflect a specific goal of AP. Since that study was the first to comprehensively evaluate existing AP measures (published after our literature search), our search did not highlight the need of a validated AP measure. Based on that review and the results of our study, the first step in future research is to develop outcome measures reflecting appropriate goals of AP.

It should be noted that although we achieved agreement on four important dimensions of AP, there was a great variety of experts' perspectives on the concept of AP given the abundance of goals, behaviours, strategies and contextual factors generated in the first round. Furthermore, as we considered it important to guarantee transparency of the panellists' responses, some overlap exists in items between the four dimensions of AP. For example, 'do activities which give energy' was considered an AP behaviour, whereas 'be aware of what gives and what takes energy' was selected as strategy. Future research based upon the consensual list presented here and experiences from clinical practice using our list is needed to further improve the conceptualization of AP.

A particular strength of the current study is the use of an international Delphi panel across 12 different countries, enabling generalization of the findings to other western countries. The results can however not be generalized to non-western societies and unfortunately we did not include panellists from Australia or New Zealand. In total, 60 panellists participated recognizing that no optimal number of experts for a Delphi study exist (25,27). In order to enhance external validity of the study results, effort was made to ensure panel diversity with respect to healthcare profession and work setting (24). A further strength is the relatively high response rate throughout all Delphi rounds. Although not all panellists were able to contribute to all rounds, results did not differ when analysing only the responses of panellists with complete input. The unique relation to all rheumatic diseases is another strength of the current study. However, a consequence of not specifying any condition within the questionnaires that were sent to the panellists is that the panellists might have referred to different conditions when completing the Delphi survey (e.g. some might have referred to inflammatory conditions, while others might have referred to soft tissue conditions). There are a number of limitations inherent to Delphi studies that should be considered when interpreting the results. First, we tried to reduce selection bias by using snow-ball sampling; nevertheless, some selection bias in the composition of the Delphi panel might have occurred as experts from the Netherlands, Norway and Sweden were over-represented. Besides, the majority of panellists were physical and occupational therapists what might have influenced the results. We qualitatively explored noticeable differences in responses across professions, but these differences were not apparent. Another limitation might be researcher bias, since cut-off scores were not defined prior to the data collection, but were based on pragmatic considerations (to keep the amount of data manageable to ensure the panellists' motivation to carefully rank the items and minimize the risk for drop outs). The cut-off scores were however discussed with all the working group members. Third, due to differences in background and expertise among panellists, items considered important by individual experts might have been eliminated during the four-round Delphi survey. Especially in the second Delphi round where we broke up the work between panellists, items considered important by individual experts might have been removed. Furthermore, the Delphi technique has been criticised as panellists only have a limited opportunity to discuss the issues raised or to elaborate on their views (24). In the current study we did not show panellists the group votes on subsequent rounds to reconsider their ideas what might be considered a limitation. Besides, it is important to note that the results of any Delphi study represent expert opinion rather than a correct answer or indisputable fact (24,25,27). Finally, the patient's viewpoint is lacking in the current study, constituting an important limitation. We recognize that patients might offer an alternative perspective on the concept of AP. The patient perspective needs to be included in the development of AP interventions or when developing appropriate outcome measures to evaluate its effectiveness.

In conclusion, we generated a consensual list including the most important aspects of AP interventions within rheumatology care. This is an important first step towards achieving more transparency and homogeneity in the concept of AP in rheumatology daily clinical practice and research. This in turn might improve an effective management of rheumatic diseases, facilitate intervention studies that are needed to gain consistent empirical evidence on the effectiveness of AP and allows research studies to be more easily replicated and compared. Future research on AP should focus on the effectiveness of AP interventions and on the development of standardized outcome measures to assess its effectiveness.

Acknowledgements

We would like to thank the following experts for taking part in the Delphi survey: Elin Andresen, Kristina Arekoug Josefsson, Eva Bailles, Dies Boonman, Carina Boström, Cary Brown, Saskia Decuman, Henny Doesburg, Mona Dür, Yvonne van Eijk-Hustings, Agnes Eijsbouts, Michaela Ernst, Camilla Fongen, Rinie Geenen, Sofia Hagel, Stefanie Haider, Toril Hennig, Maria-Jesus Herrero, Sarah Hewlett, Linda Humlesjö, Kathryn Jamieson-Lega, Petra Karsdorp, Meike Klinger, Åse Klokkeide, Mari Klokkerud, Marielle Kroese, Els Kuijpers, Ingrid Larsson, Åsa Lindkvist, Kaisa Mannerkorpi, Maria-Jose Martin, Jorrit Meesters, Quaintance Miller, Birgitta Nordgren, Randi Nossum, Tiziana Nava, Josep-Maria Peri, Simone Pobaschnig, Danute Povilenaite, Han Repping-Wuts, Aud Ronningen, Anne-Lene Sand-Svartrud, Stacey Schepens, Angel Soto, Saskia Spillekom-van Koulil, Sara Stråt, Jenny de la Torre-Aboki, Joyce Verheijen and Eric Vermeulen.

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Table 1. Demographic characteristics of the international multidisciplinary Delphi panel.

Demographic characteristics (n = 60)	
Female; n (%)	53 (88)
Age, years; mean ± SD	45 ± 10
Country: n (%)	
Austria	6 (10)
Belgium	1 (2)
Canada	2 (3)
Denmark	1 (2)
Italy	1 (2)
Lithuania	2 (3)
Norway	10 (17)
Spain	5 (8)
Sweden	11 (18)
The Netherlands	16 (27)
United Kingdom	2 (3)
United States	3 (5)
Primary health profession; n (%)	
Physical therapist	20 (33)
Occupational therapist	17 (28)
Specialized rheumatology nurse	12 (20)
Psychologist	8 (13)
Rheumatologist	3 (5)
Current work setting; n (%)	
Hospital	29 (48)
Ambulatory / Outpatient	32 (53)

Primary care	1 (2)
University / Professional Education	28 (47)
Public health	2 (3)
Private practice	6 (10)
Other	5 (8)
Mainly active in the last 5 years; n (%)	
Clinical patient care / Rehabilitation	27 (45)
Research	25 (42)
Education	6 (10)
Other	2 (3)

Table 2. Response to each round of the Delphi survey

	Round 1	**Round 2**	**Round 3**	**Round 4**	**Completed all rounds; n (%)**
Physical therapist	20	14	14	16	12 (60)
Occupational therapist	17	13	13	12	10 (59)
Rheumatology nurse	12	11	7	9	7 (58)
Psychologist	8	8	8	6	6 (75)
Rheumatologist	3	3	3	3	3 (100)

Table 3. Consensual list of most important aspects of activity pacing as an intervention in rheumatology care

	Goals of activity pacing *(n = 46)*	**Weighted sum ranking**	**Selected by panellists, n (%)**
1.	To balance between activity and rest according to individual goals, preferences and involvement in meaningful activities	55%	39 (85)
2.	To participate in daily activities that are essential or of great value for the individual	51%	37 (80)
3.	To enable the patient to make behavioural changes to reduce or avoid the cycle of being overactive or underactive	46%	34 (74)
4.	To maintain/improve health, quality of life and well-being	45%	33 (72)
5.	To increase the ability to participate in patient's prioritized areas	36%	30 (65)
6.	To increase awareness of what's important to one selves	33%	24 (52)
7.	To improve the level of functioning during the day	31%	29 (63)
8.	To move pain contingent activity to goal contingent activity	31%	27 (59)
9.	To be able to deal with fatigue in the activities of daily living	29%	30 (65)
	Behaviours of activity pacing *(n = 44)*	**Weighted sum ranking**	**Selected by panellists, n (%)**
1.	Plan and prioritize necessary and valued activities	53%	34 (77)
2.	Break up tasks into manageable pieces depending on individual patterns and context	45%	29 (66)
3.	Reflect upon activities and make a plan of how to manage, prioritize and distribute activities without getting exhausted	39%	29 (66)
4.	Listen to your body and how it responds to activity	38%	24 (55)

5.	Realistic planning	36%	27 (61)
6.	Perform physical exercise regularly	32%	24 (55)
7.	Be awareness of symptoms and how they are related to activities	30%	24 (55)
8.	Do activities which give energy	30%	22 (50)
9.	Perceive oneself as being able to self-manage	26%	22 (50)
10.	Cognitive reframing; how important is it really to do this?	26%	21 (48)
11.	Learn to find the right pace of doing activities	24%	23 (52)

	Strategies to change behaviour in activity pacing *(n = 44)*	**Weighted sum ranking**	**Selected by panellists, n (%)**
1.	Identify activities that are important, meaningful, necessary or enjoyable	58%	37 (84)
2.	Identify barriers and support to activity pacing	54%	36 (82)
3.	Start off with a small change (baseline) and building on this	41%	34 (77)
4.	Weigh the importance of different activities and prioritize between them	35%	27 (61)
5.	Discuss how to implement activity pacing in home and work environment with family and colleagues	35%	27 (61)
6.	Be aware of what gives and what takes energy	35%	26 (59)
7.	Use motivational interviewing	33%	25 (57)
8.	Set goals together with the health professional: starting with a goal that is meaningful	32%	26 (59)
9.	Be aware of thoughts connected to pain, activity and fatigue	31%	26 (59)

	Contextual factors *(n = 44)*	**Weighted sum ranking**	**Selected by panellist, n (%)**
1.	Patient’s readiness and motivation to change behaviour	65%	38 (86)
2.	Patient's self-efficacy	47%	33 (75)
3.	Patient's opinion on benefits and barriers of behavioral change	45%	31 (70)
4.	Social support form partner, relatives, friends or colleagues	38%	33 (75)
5.	Patient's own goals regarding activity	37%	27 (61)
6.	Patients need to be seen as experts in their illness and life situation	34%	24 (55)
7.	Ability to communicate, reflect on and discuss activity patterns and suggestions for change	31%	27 (61)
8.	Patient's resources and abilities to manage their lives	28%	20 (45)
9.	Patient’s comorbidities	25%	19 (43)
10.	Patient’s fear of exercise and injury	24%	23 (51)

Table 4. Research agenda representing consensus topics for future research on activity pacing in rheumatology care

	Research topics *(n = 44)*	**Weighted sum ranking**	**Selected by panellists, n (%)**
1.	Select appropriate outcome measures to assess the effectiveness of activity pacing	48%	36 (82)
2.	Assess whether or not activity pacing is effective	48%	28 (64)
3.	Develop and evaluate the effectiveness of various interventions aiming to improve activity pacing	40%	27 (61)
4.	Study whether activity pacing improves patients' activity level	38%	27 (61)
5.	Study whether improved activity pacing improves patients' well-being	35%	25 (57)
6.	Develop and test an evidence-based activity pacing group program	32%	24 (55)
7.	Study whether activity pacing improves fatigue	32%	22 (50)
8.	Explore how to help patients to self-manage activity pacing	31%	25 (57)
9.	Study if work, vocational or leisure activity increase after activity pacing	27%	25 (57)