In the workshops, 11 patients and 130 nurses participated. Eligible adult patients, diagnosed with a rheumatic disease, were recruited by newsletter from the Dutch Arthritis Foundation. Nurses were recruited by newsletter from the Dutch Nurses Organisation (VAVN).

According to participants, the framework alone is only useful when additional explanation and illustration of concepts will be provided and following missing topics are added; communication between specialisms, knowledge of the health-care system, responsibility allocation, faith, religion, culture, nutrition, lifestyle, prevention.

The self-management web appeared to be helpful. Not all cards with needs could be placed in this web. It was suggested to add following topics to the web: Peer support or experience experts’ contact, handling treatment recommendations, patient empowerment, defining limitations and supporting services like physiotherapy and municipality.

There is overlap between topics of the web: Lifestyle, leisure and self-care. It was suggested to place associated topics together or give the same colour.

Practical ideas for application of the web and about involving an experienced expert were discussed as well as the role of health professionals. Integration in e-health, linked to the medical file with visual support is preferred. Patients have to prepare themselves for consulting the nurse or doctor.

Communication plays a very important role for all elements. The tool should be usable for people with limited health literacy skills and nurses need skills like motivational interviewing for using the tool.

Conclusion: Existing frameworks seem useful as a scientific basis for the development of a communication tool for self-management support. Usability of a draft tool will be explored in a pilot study.

References:
[1] Ammerlaan J. Preferences and needs of patients with a rheumatic disease regarding the structure and content of online self-management support. Pat Educ Counsel. 2017;100(3):501-4

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Table 1. Fidelity scores of the components of the intervention for each session.

<table>
<thead>
<tr>
<th>Intervention components</th>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>78.1 (71.4, 93.7)</td>
<td>875 (50, 100)</td>
<td>875 (50, 100)</td>
<td>100 (93.7, 100)</td>
</tr>
<tr>
<td>Exercise</td>
<td>94.4 (88.9, 100)</td>
<td>889 (75, 94)</td>
<td>861 (72, 100)</td>
<td>75 (876, 82.8)</td>
</tr>
<tr>
<td>Adjunctive treatments</td>
<td>50 (45.83, 100)</td>
<td>0 (0, 50)</td>
<td>50 (0, 100)</td>
<td>-</td>
</tr>
</tbody>
</table>

*median (IQR)

17 participants were interviewed. Most found advice supplied straightforward. They were satisfied with the package, which changed their perception of good in 87.1%, decreased in 12.9%; stability is sufficient - in 64.5%, low - in 35.5%. In the operational side of thinking, a decrease in the level of generalization was revealed (48.4%); there were no disturbances in the motivational component, liability of thinking in the dynamic (12.9%). Various neurotic fears are characteristic for 54.8% of pts; the level of personal anxiety was increased in 41.9%, moderate - in 48.4%, low - in 9.7%. Signs of aggression were revealed in 19.4% of pts, a decrease in the level of social adaptation - in 9.1%. Communication difficulties experienced 83.9% of pts. According to the results of the clinical conversation, attention was focused on availability of conflict situations with peers in the disease onset in 38.7% of pts.

Conclusion: Cognitive disorders were detected in the majority of pts with JSLE regardless of the presence of neuropsychiatric disorders at the onset. The revealed features of the clinical and psychological status of pts with JSLE must be considered when working out an individual rehabilitation model and develop psycho-correctional programs.

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