

From research to practice: distal myopathy patients' HRQoL and their need for assistance and care

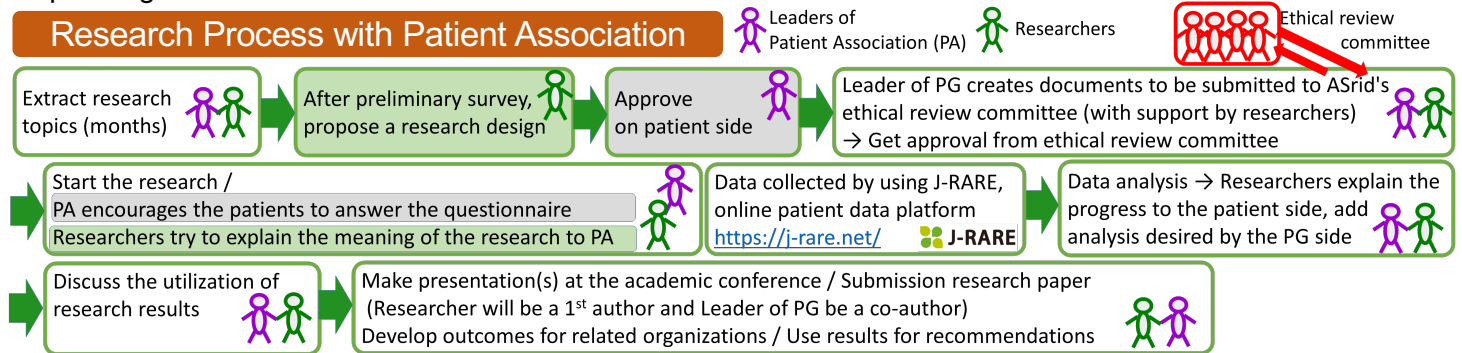
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*This is a further report of our ECRD 2018 poster

Objective

➤ We conducted research to find out the relationship between HRQoL (Health-related Quality of Life) and care needs among patients with distal myopathy in corporation with PADM (Patient Association for Distal Myopathy) from planning research to address the research results.

Research Process with Patient Association



Research outline

➤ We conducted this research in 2 steps along the above flow. The following table shows the outline of each step.

	First Step	Second Step
Objective	To find out the items about assistance and care needs in daily life among the patients	To make clear the relationship between HRQOL and assistance and care needs of what transpired in first step
Method	Acquired opinions about their assistance and care needs by free description questionnaire	Asked sufficiency and satisfaction level of the needs, severity of symptom (Barthel Index, BI; Vignos Scale, VS), and HRQoL (SF-12).
Analysis	Analyzed data by content analysis method	Summarized needs by principal component analysis (PCA). Then conducted correlation analysis among needs components, severity of symptom, and HRQoL
Ethical issues	Aside from an ethical committee member mailing list, committee admin mail list was made to prevent direct communication between applicants and committee member.	
Main Result	<p>[Participants] 42 patients (21 males), 6.1 ± 1.7 years have passed from onset to diagnosis, BI 40.9 ± 33.5</p> <p>[Assistance and care needs] As a result of content analysis, we identified 22 items about assistance and care needs.</p>	<p>[Participants] 28 patients (14 males), 6.3 ± 4.3 years have passed from onset, BI 40.9 ± 33.5, VS 6.4 ± 1.5</p> <p>[HRQoL] Physical/Mental/Social component summary (PCS/MCS/RCS) of HRQoL are 20.5 ± 9.7, 59.3 ± 9.7, 29.6 ± 14.4 respectively.</p> <p>[PCA of needs items] As a result of PCA, 4 components of needs (#1: Control and careful coordination of patient's position, #2: Understanding of the disease and patient's will and taste, #3: Safe care, and #4: Smooth communication with others) were identified.</p>

Social Dissemination

- After discussion with PADM about utilization of research result, we made an academic presentation at Japan Muscle Society and the pamphlet for the public.
- The pamphlet gave easy-to-understand explanations of research result and was distributed to care business institution all over Japan via PADM network
- You can see our pamphlet through QR code (only in Japanese)



[Correlation analysis] See the following table

	PCS	MCS	RCS
Age	0.09	0.11	-0.27
Duration from onset to diagnosis	0.2	0.24	-0.27
Duration from onset to present	-0.37	0.31	0.12
Vignos Scale	-0.5	0.23	-0.09
Barthel Index	0.73	-0.28	-0.18
Needs component #1	-0.04	0.17	-0.02
Needs component #2	-0.05	0.41	-0.2
Needs component #3	0.07	-0.23	0.41
Needs component #4	-0.11	-0.15	0.41
Spearman's ρ. Bold, p < .05			