Shared medical appointments improve QOL in neuromuscular patients

A randomized controlled trial

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ABSTRACT

Objective: To systematically study the effects of shared medical appointments (SMAs) compared with individual appointments for patients with a chronic neuromuscular disorder and their partners.

Methods: In this randomized controlled trial with a follow-up of 6 months, we included patients with a chronic neuromuscular disorder and their partners. Participants were randomly allocated to an SMA or an individual outpatient appointment. The primary outcome measure was patients' health-related quality of life (QOL) (36-Item Short Form Health Survey). Secondary outcome measures included self-efficacy, social support, patient and partner satisfaction with the appointment, and time available per patient.

Results: Two hundred seventy-two patients and 149 partners were included. Health-related QOL showed greater improvement in patients who had attended an SMA (mean difference 2.8 points, 95% confidence interval 0.0–5.7, $p = 0.05$). Secondary outcomes showed small improvements in the control group for satisfaction with the appointment ($p = 0.01$). Neurologists spent less time per patient during the SMAs: mean 16 minutes (range 11–30) vs 25 minutes (range 20–30) for individual appointments.

Conclusions: This study provides evidence that SMAs can improve aspects of QOL of patients with a chronic neuromuscular disorder. This could result in an alternative to individual appointments and improvements in both effectiveness and efficiency. Further research to optimize SMAs and to identify critical success factors seems warranted. These data extend evidence on SMAs for neurologic patients.

Classification of evidence: This study provides Class III evidence that for patients with chronic neuromuscular disorders, SMAs improve QOL as compared with individual medical appointments.

Neurology® 2014;83:240–246

GLOSSARY

CONSORT = Consolidated Standards of Reporting Trials; **EQ-5D** = EuroQOL 5 dimensions questionnaire; **HRQOL** = health-related quality of life; **INQoL** = Individualized Neuromuscular Quality of Life Questionnaire; **QOL** = quality of life; **QUOTE** = QQuality Of care Through the patient's Eyes; **RCT** = randomized controlled trial; **SF-36** = 36-Item Short Form Health Survey; **SMA** = shared medical appointment; **VAS** = visual analog scale.

Health care faces the challenge of finding an optimal balance between quality of care and time available per patient, prompting hospitals and physicians to search for alternative care options. Specifically for patients with a chronic neuromuscular disorder, it is difficult to fulfill their complex needs during a conventional individual appointment. Moreover, in absence of cure, the main treatment goals focus on optimizing quality of life (QOL) and improving self-management. Accumulating evidence suggests an association between shared medical appointments (SMAs) and improvements in patient-reported outcome measures for various common, mostly chronic, diseases.^{1–4} Feasibility of SMAs has recently been reported in Parkinson disease³; however, the evidence for effectiveness of SMAs compared with individual appointments for patients with Parkinson disease or other neurologic diseases has not been conclusive.

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Go to Neurology.org for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

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During an SMA, also known as group visit, a physician sees multiple patients simultaneously, combining individualized medical patient care with peer support and self-management education. This gives patients and partners the opportunity to not only share a health care professional's time but also share mutual experiences.⁵⁻⁷ In addition, the continuity and repetition offered during a series of multiple SMAs, as described in most previous randomized studies, may at least partly account for the observed outcomes.⁸ A series of SMAs is, however, not always feasible or desirable for most groups of neurologic patients.

With the present randomized controlled trial (RCT), we therefore wished to evaluate whether even a single SMA would yield beneficial effects on QOL relative to an individual appointment for patients with chronic neuromuscular disorders and their partners.

METHODS Study design. Methods are described in accordance with the CONSORT 2010 statement and have been reported in detail elsewhere.^{9,10} In brief, we conducted an RCT with a follow-up of 6 months and randomized participants to either an SMA or an individual appointment with one of the 2 participating neurologists (B.v.E., G.D.) at the outpatient clinic of the neurology department of the Radboud University Medical Centre.

The primary research question for this study was whether a single SMA improves health-related QOL (HRQOL) for patients with chronic neuromuscular disorders as compared with individual medical appointments.

The secondary research questions were whether a single SMA improves individualized neuromuscular QOL, self-efficacy, social support, and satisfaction with care for patients with chronic neuromuscular disorders, and QOL, self-efficacy, and satisfaction with care for the patients' partners.

This study provides Class III evidence that for patients with chronic neuromuscular disorders, an SMA improves QOL compared with an individual medical appointment.

Standard protocol approvals, registrations, and patient consents. This trial was approved by the regional medical ethics committee, and written informed consent was obtained from all participants, including partners. The trial was registered with the Dutch Trial Register, number NTR1412 (www.trialregister.nl).

Participants. Patients identified through CRAMP (Computer Registry of All Myopathies and Polyneuropathies), the Dutch neuromuscular database, were recruited between March 2009 and March 2011.¹¹ Eligible patients were invited to participate together with their partners. Patients were eligible if they were diagnosed with one of the selected chronic neuromuscular disorders (see table 1), were older than 18 years, currently in the care of our department, and had not seen their neurologist 6 months before study commencement. Exclusion criteria were severe hearing problems or insufficient command of the Dutch language.¹⁰

Randomization. Concealed randomization (1:1) balanced by diagnosis was performed using computer-generated randomization

software. In view of the nature of the intervention, physicians and participants could not be blinded to group assignment. The statistician who conducted the analyses was blinded to treatment allocation.

Intervention. Patients and partners randomized to the SMA group of the study were invited to attend an SMA of 1.5 to 2 hours in lieu of their annual appointment. During the SMA, one of 2 neurologists (either B.v.E. or G.D.) saw 5 to 8 patients with the same diagnosis and their partners simultaneously, addressing the same topics that are frequently covered during an individual appointment. The neurologist was supported by a group mentor who facilitated the group process by fostering interaction between patients and partners and by managing time. Both neurologists and the group mentor had received training in conducting SMAs before the study. For a more detailed description of the content of the SMAs, see appendix e-1 on the *Neurology*[®] Web site at Neurology.org. Patients (and their partners) randomized to the control group were seen individually by one of the neurologists during their regular annual 20- to 30-minute appointment in which the customary topics were addressed. In both conditions, patients were not necessarily seen by their regular consulting physician. For both intervention groups, care was tailored to the needs of the patients and their partners. Prescriptions, referrals, and medical record-keeping were as usual.

Outcomes. The primary outcome measure was HRQOL as measured using the 36-Item Short Form Health Survey (SF-36).¹² The secondary outcome measures included the following: (1) HRQOL as measured by the EuroQOL 5 dimensions questionnaire (EQ-5D) generating 2 indices—the descriptive profile was used to calculate a single summary EQ-5D index score and an overall self-rated health status as measured by the visual analog scale (VAS)^{13,14}; (2) the Individualized Neuromuscular Quality of Life Questionnaire (INQoL)^{15,16}; (3) the Generalized Self-Efficacy Scale by Schwarzer whereby the respondents rate the confidence they have in being able to perform specific behaviours¹⁷; (4) the emotional support subscale of the Dutch Social Support List-Discrepancies Questionnaire¹⁸; (5) Quality Of care Through the patient's Eyes (QUOTE) inventory consisting of questions on communication, treatment, symptoms, and medication¹⁹; (6) satisfaction with the appointment, rated on a 5-point scale; and (7) satisfaction with the marital relationship, rated on a 10-point scale and a VAS.²⁰

Potential differences in impact between the SMA and the individual appointments on the patients' partners were evaluated by the following: (1) the EQ-5D; (2) the Generalized Self-Efficacy Scale; (3) the QUOTE inventory; (4) satisfaction with the appointment (5-point scale); (5) satisfaction with the marital relationship (10-point scale and VAS); and (6) burden of care, specifically, how many hours per week the respondent spends on caring for and relieving the partner of household tasks.²¹

All outcome measures were obtained through standardized self-reported questionnaires. Patients and partners received these by mail at home 4 weeks before and 1, 12, and 24 weeks after the intervention. Severity of neuromuscular disorders was clinician-rated (B.v.E., G.D.) using the modified Rankin Scale.^{22,23}

Because of the type of intervention, we did not expect to see a change in incidence of adverse events, and thus information about adverse events was not collected systematically.

Statistical analysis. A sample-size calculation showed that 92 patients per group were needed to demonstrate an improvement of 5 points on the SF-36.¹² Assuming an SD of 12, a power of 80%, a 2-sided α of 0.05, and considering loss to follow-up, 135 patients had to be enrolled in both groups.

Table 1 Baseline participant characteristics for the 2 study groups

Variable	SMA		Individual appointment	
	Patients (n = 123)	Partners (n = 66)	Patients (n = 112)	Partners (n = 58)
Age, y, mean (SD)	50 (13.5)	54 (2.9)	52 (13.3)	56 (11.6)
Men	63 (51.2)	—	62 (55.4)	—
Relationship	86 (70.5)	—	79 (72.5)	—
Diagnosis				
Myotonic dystrophy type 1	45 (36.6)	25 (37.9)	30 (26.8)	12 (20.7)
Facioscapulohumeral muscular dystrophy	24 (19.5)	14 (21.2)	23 (20.5)	11 (19.0)
Nondystrophic myotonias: chloride and sodium channelopathies	9 (7.3)	4 (6.1)	12 (10.7)	6 (10.3)
Myositis: dermatomyositis and polymyositis	7 (5.7)	3 (4.5)	12 (10.7)	7 (12.1)
Polyneuropathy	14 (11.4)	6 (9.1)	15 (13.4)	6 (10.3)
Inclusion body myositis	4 (3.3)	3 (4.5)	5 (4.5)	4 (6.9)
Chronic progressive external ophthalmoplegia	4 (3.3)	1 (1.5)	1 (0.9)	1 (1.7)
McArdle disease	5 (4.1)	3 (4.5)	3 (2.7)	2 (3.4)
Oculopharyngeal muscular dystrophy	11 (8.9)	7 (10.6)	11 (9.8)	9 (15.5)
Modified Rankin Scale (higher scores indicate more severe symptoms)				
0	4 (3.4)	—	8 (8.2)	—
1	19 (16.0)	—	13 (13.4)	—
2	39 (32.8)	—	35 (36.1)	—
3	21 (17.6)	—	14 (14.4)	—
4	34 (28.6)	—	27 (27.8)	—
5	2 (1.7)	—	0 (0)	—
Level of education				
Low	28 (23.1)	15 (25.4)	25 (22.9)	13 (26.0)
Medium	58 (47.9)	25 (42.4)	55 (50.5)	23 (46.0)
High	35 (28.9)	19 (32.2)	29 (26.6)	14 (28.0)
Employment status				
Studying/in training	2 (1.7)	0 (0.0)	2 (1.9)	0 (0.0)
Paid work	42 (36.5)	35 (60.3)	33 (31.1)	22 (43.1)
Housework/volunteer work	8 (7.0)	4 (6.9)	7 (6.6)	7 (13.7)
Searching for a job	2 (1.7)	0 (0)	1 (0.9)	2 (3.9)
(Partially) medically retired	36 (31.3)	2 (3.4)	37 (34.9)	3 (5.9)
Retired	25 (21.7)	17 (29.3)	26 (24.5)	17 (33.3)
Attended SMA before	28 (23.0)	16 (27.1)	16 (14.5)	11 (21.6)
Membership of the Dutch patient association for muscle diseases	71 (58.2)	18 (31.0)	51 (46.4)	9 (18.0)
Appointment with own neurologist	20 (16.3)	11 (16.7)	34 (30.6)	23 (39.7)

Abbreviation: SMA = shared medical appointment.
Data are n (%) unless stated otherwise.

Statistical analyses were performed using SPSS software (version 18; SPSS, Inc., Chicago, IL). Descriptive statistics were used to present baseline characteristics. For the primary analyses, we used a Toeplitz covariance model to conduct separate repeated-measures analyses.²⁴ We included time, treatment, and the interaction between time and treatment as fixed factors in the linear mixed model. In addition, we added the baseline values of

the dependent variables as possible significant covariates to the model and corrected for variables that demonstrated an imbalance at baseline.⁷ When the interaction factor did not show significant results, it was discarded from the model. Residual plots from the mixed models were examined to assess model assumptions. All linear mixed-model analyses were performed on all participants, including those with incomplete datasets. Two-tailed analyses

were performed with a p value of 0.05. Similar analyses were conducted to determine differences in secondary outcome measures.

RESULTS A total of 880 patients were assessed for eligibility (see the figure [patient flowchart]), of whom 286 did not meet the inclusion criteria, leaving 594 eligible patients who were invited by telephone and subsequent information letter to participate in the study together with their partner, if relevant. Of these, 99 patients were not traceable, while 220 patients declined to participate, of whom 17.7% refused participation in an SMA, 29% reported practical barriers, 3.2% reported too low energy levels, and 50% declined for various other reasons. In total, 272 patients and 149 partners were included in the study, and 23 SMAs and 122 individual appointments were conducted.

Figure Patient flowchart: CRAMP

CRAMP = Computer Registry of All Myopathies and Polyneuropathies.

Patients and partners in the 2 groups were similar at baseline for most variables (see table 1). In the SMA group, slightly more patients were diagnosed with myotonic dystrophy type 1 and fewer patients were seen by their own neurologist. These differences were corrected for in the statistical analyses.

Modeled data (table 2) showed a beneficial effect of SMAs on the primary outcome HRQOL as measured by 2 SF-36 subscales: for general health, the mean difference between groups was 2.8 irrespective of follow-up time ($p = 0.05$); for social functioning, an interaction was found between treatment and time ($p = 0.03$), indicating that SMAs and individual appointments had a different impact on this aspect of the quality of the lives of the patients over time. The other SF-36 subscales showed no significant trends.

Secondary outcomes for patients showed higher values for QOL as measured by the INQoL fatigue scale in the SMA group relative to the control group, with different treatment effects across time points resulting from the interaction between time and treatment ($p = 0.03$). Patient satisfaction with the appointment was lower in the SMA group—QUOTE scores were lower by 0.2 points and ratings on the 5-point scale by 0.4 points ($p = 0.01$ and $p = 0.001$, respectively). Perceived social support scores were 1.1 points higher in the individual appointment group ($p = 0.004$). The remaining secondary outcome measures for patients showed no significant differences between intervention groups (see table e-1).

The data for the patients' partners showed no between-group differences, except for satisfaction with the appointment, in which the scores for the SMA group were 0.3 points lower on the QUOTE ($p = 0.01$) and 0.4 points lower on the 5-point scale ($p = 0.001$) (see table e-2).

The neurologists spent less time per patient during the SMAs, which lasted a mean of 16 minutes (range 11–30), compared with the individual appointments, which averaged 25 minutes (range 20–30). In less than 8% of the patients, individual attention was needed after the SMA. This did not significantly influence the total time spent per patient in the intervention group.

DISCUSSION The main finding of this RCT is that a single SMA resulted in a modest beneficial effect on self-reported HRQOL (SF-36) compared with individual appointments in patients with chronic neuromuscular disorders, even though on average considerably less time was spent per patient by the neurologist during the SMAs. Secondary outcome measures confirmed improvement of HRQOL on a disease-specific scale (INQoL), although patient and partner satisfaction with the appointment was slightly lower in the SMA group. Based on these

Table 2 Estimated means for the SF-36 (primary outcome measure) at baseline (–4 weeks), 1 week, 12 weeks, and 24 weeks postintervention for the 2 study groups

	Physical functioning				Role limitations due to physical health problems				Bodily pain				General health			
	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24
Time of measurement, wk	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24
Shared medical appointment, mean	47.8	47.4	46.8	46.6	46.1	45.6	48.6	49.0	72.5	70.9	70.6	71.5	46.1	45.9	47.1	47.1
Individual appointment, mean	47.8	48.7	48.2	47.9	46.1	41.3	44.2	44.6	72.5	73.4	73.0	74.0	46.1	43.1	44.3	44.3
Mean difference between groups (95% CI)	–	–1.3 (–3.7 to 1.1)	–	–	–	4.4 (–2.5 to 11.3)	–	–	–	–2.4 (–5.8 to 0.9)	–	–	–	2.8 (0.0 to 5.7)	–	–
p Value	–	0.27	–	–	–	0.21	–	–	–	0.16	–	–	–	0.05	–	–
	Vitality				Social functioning				Role limitations due to emotional problems				General mental health			
	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24
Time of measurement, wk	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24	–4 ^a	1	12	24
Shared medical appointment, mean	56.3	57.5	56.6	56.7	73.8	74.0	76.0	76.1	83.9	80.8	80.4	81.2	78.3	77.0	76.5	77.1
Individual appointment, mean	56.3	56.5	55.6	55.8	73.8	77.1	74.0	71.8	83.9	82.3	82.0	82.8	78.3	78.4	77.8	78.4
Mean difference between groups (95% CI)	–	0.9 (–1.9 to 3.8)	–	–	–3.1 (–7.8 to 1.6)	–	2.0 (–2.8 to 6.8)	4.3 (–0.4 to 9.1)	–	–1.6 (–7.8 to 4.7)	–	–	–	–1.4 (–3.6 to 0.8)	–	–
p Value	–	0.56	–	–	0.19	0.41	0.07	0.07	–	0.62	–	–	–	0.24	–	–

Abbreviations: CI = confidence interval; SF-36 = 36-Item Short Form Health Survey.

For the SF-36 (0–100), higher score indicates higher health-related quality of life. Estimates are based on a linear mixed model with time and treatment as fixed factors. The p values refer to the treatment factor except for the social functioning subscale in which the interaction factor was significant (p = 0.03), resulting in different treatment effects across time points.

^aBaseline values were measured 4 weeks before the intervention. Equal baseline values were assumed in the model.

results, we posit that even a single SMA has the potential to improve both effectiveness and efficiency of the care for patients with chronic neuromuscular disorders, offering a viable alternative to individual outpatient appointments. Further research to optimize SMAs and to identify critical success factors seems warranted before SMAs can be more widely implemented in this and other groups of neurologic patients. These data extend evidence on SMAs for neurologic patients.

The main difference with earlier randomized SMA studies is that we compared single SMAs with single individual appointments, whereas all previous studies except one evaluated a series of SMAs, in which it was consistently suggested that effectiveness was related to the number of SMAs patients attended.^{1,2,5,7,25,26} However, our study shows that even a single SMA is able to improve aspects of HRQOL. The one study that also evaluated a single SMA found no such benefits.²⁷ This difference in results may be attributable to the fact that communication was more unidirectional in the study by Abram et al., but for our SMAs, we adopted a patient-driven agenda and actively encouraged patients and their partners to share their experiences. It is likely that the sharing and learning from the experiences of fellow patients and peer support account for the effectiveness of the SMA model, regardless of the effects of the repetitiveness and continuity of a succession of SMAs. In contrast to previous reports,^{4,5,28} we found that patients (and partners) were slightly less satisfied with the SMA than those receiving individual care. This result, too, might be related to the fact that attending multiple successive SMAs gives participants the opportunity to build a relationship with peers and to acquaint themselves with the new care model over time.

Finally, previous studies found the burden of care for partners of chronically ill patients to be substantial and recommended tailoring health care to the needs of both patients and partners.^{20,21,29–33} To our knowledge, ours is the first RCT to evaluate the differential effects of an SMA and an individual appointment in patients' partners.⁸

Our study design was robust in that we were able to include a sizeable sample of patients and their partners in a randomized trial. Moreover, we prevented bias caused by interphysician variation by having 2 neurologists deliver both the experimental intervention and usual care. In addition, the wide range of neuromuscular disorders is reflective of clinical practice and improves the generalizability of our results. Also, refusal rates did not differ between intervention groups. With this design, we were able to align the intervention to usual care and to reliably compare the effects of single SMAs with the effects of individual appointments.

In addition to limitations such as limited generalizability because of a single-center design, possible influences of multiple outcome testing due to the subscales of the SF-36, and the inability to apply participant and physician blinding, 2 specific aspects of our study warrant further discussion. First, among patients who were invited to participate in the study, 25% refused to be allocated to an SMA, suggesting that the participants who did agree to the randomization were probably motivated to meet with peers and share coping strategies for a chronic condition. Second, although the effect sizes of the improvements on our 2 HRQOL primary outcome measures (SF-36) were similar to those obtained in previous SMA studies,^{1,34} they did not reach the minimally clinically important difference of 5 points.^{12,35} The modesty of the effects may be attributable to the progressive nature of chronic neuromuscular disorders.

Future research should focus on which determinants, under which circumstances, account for the effectiveness of SMAs. Among such determinants are the information exchange among fellow patients, peer support, and the sharing of experiences as well as the increased time to inform patients and attend to psychosocial aspects. Another research question meriting consideration is the effect SMAs have on physicians and nurses regarding job satisfaction. Finally, weighing the costs and effects of our SMA intervention completely will require further empirical data on the use of care resources.

An important implication of our study is that we showed a wider applicability of the SMA model patients whose intervals between successive appointments to the clinic may be lengthy. This supports applicability to other neurologic diseases provided that possibilities to improve patient satisfaction are further explored.

Although modestly, the single SMA in this study improved HRQOL, thus potentially offering patients with chronic neuromuscular disorders and their partners, as well as consulting neurologists, an alternative care option; albeit, further refinements are needed before SMAs can be more widely implemented in this and other groups of neurologic patients.

AUTHOR CONTRIBUTIONS

B.G.M.v.E. and G.J.v.d.W. wrote the grant application and supervised the study. B.G.M.v.E., G.J.v.d.W., F.M.S., and G.D. contributed to the research design. F.M.S. was responsible for recruitment of the participants and the data collection. F.M.S., G.D., and B.G.M.v.E. implemented the intervention. J.G. was responsible for the sample-size calculation. F.M.S. and J.G. were responsible for the data analysis, and F.M.S., G.D., J.G., G.J.v.d.W., and B.G.M.v.E. took responsibility for data interpretation. F.M.S., G.D., G.J.v.d.W., and B.G.M.v.E. wrote the first draft of the manuscript. All authors reviewed the final draft. F.M.S. is the guarantor.

ACKNOWLEDGMENT

The authors thank all patients and partners who participated in the study, the participating students for their contribution to the data collection, Anneke Pelgrom for assisting in data collection, and Corinne Horlings for contributing to the final draft of the manuscript.

STUDY FUNDING

Supported by ZonMw, The Netherlands Organisation for Health Research and Development (170882703).

DISCLOSURE

F. Seesing has received research grants from ZonMw, The Netherlands Organisation for Health Research and Development (ZonMw no. 170882703), for the submitted work. F.S. has received personal fees and consultancy fees from the Dutch Institute for Healthcare Improvement CBO and was consultant for FemkeSeesingAdvies outside the submitted work. G. Drost, J. Groenewoud, and G. van der Wilt report no disclosures relevant to the manuscript. B. van Engelen reports personal fees received as Research Director of the European Neuromuscular Centre (ENMC) and receipt of grants from Global FSH, Netherlands Organization for Scientific Research, Prinses Beatrix Fonds, and the Dutch FSHD Foundation, outside the submitted work. In addition, B.v.E. has a patent pending "Method of detecting autoantibodies from patients with sporadic inclusion body myositis," and license to commercialize knowledge in patent mentioned above. Go to Neurology.org for full disclosures.

Received July 4, 2013. Accepted in final form April 14, 2014.

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Femke Marie Seesing, Gea Drost, Johannes Groenewoud, et al.
Neurology 2014;83;240-246 Published Online before print June 18, 2014
DOI 10.1212/WNL.0000000000000588

This information is current as of June 18, 2014

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