

Telecoaching of Individuals With Multiple Sclerosis After Inpatient Multidisciplinary Rehabilitation: The Danish MS Hospitals Rehabilitation Study

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ABSTRACT

BACKGROUND: Inpatient rehabilitation improves health-related quality of life (HRQOL) for people with multiple sclerosis (MS). However, the obtained improvements decline once people return home. The challenge is to find ways to preserve the beneficial effects for the long term. We investigated whether monthly telecoaching after discharge would enhance the long-term carryover of improvements.

METHODS: We conducted a 1-year exploratory study with 2 delivery methods: telephone coaching and web-based coaching. After discharge, the telephone group received monthly calls; the web-based group responded to monthly online coaching questions. Based on their rehabilitation goals, we put patients into a neuropsychological group or a physical group. In addition, we matched each patient with similar wait-list control patients and treatment patients from the main study. The primary outcome was HRQOL measured by the Functional Assessment in Multiple Sclerosis (FAMS).

RESULTS: The neuropsychological group had long-term preservation of HRQOL with both delivery methods, with telephone coaching seeming to be superior. Mean differences in FAMS at the 12-month median follow-up for the neuropsychological group compared with the control wait-list control group were for the telephone group: +15.4 (95% CI, 3.5-27.4; $P=.011$); for the web-based group: +10.9 (95% CI, -3.3 to 25.2; $P=.130$); for the control treatment group: +6.9 (95% CI, 0.6-13.3; $P=.031$). The physical group saw no beneficial effects from telecoaching.

CONCLUSIONS: Following inpatient multidisciplinary rehabilitation, monthly telecoaching of individuals with MS with neuropsychological challenges enhanced the long-term carryover of HRQOL, with one-on-one telephone coaching showing more pronounced improvements than web-based automated coaching.

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Multidisciplinary rehabilitation¹ (MDR) seeks to optimize functional status and, ultimately, improve health-related quality of life (HRQOL) by building self-efficacy and self-management.^{2,3} It is gradually becoming well documented that MDR, especially inpatient MDR, is effective in giving people with multiple sclerosis (MS) the tools, strategies, and support they need to significantly improve their HRQOL.⁴⁻⁷ After discharge, however, they must reintegrate into the community and implement the skills and knowledge about managing daily life with MS at home. MDR rehabilitation plans often include recommendations for a range of additional community services after discharge. However, the community-based support system is often not strong enough to support patients sufficiently, and that limits the long-term benefits of inpatient rehabilitation.^{4,8} Without the necessary aftercare support from rehabilitation professionals, motivation and, subsequently, the acquired skills and tools are lost, causing a decline in HRQOL.^{4,8} The few longitudinal studies on MDR in MS show that the HRQOL improvements from an inpatient stay decline by approximately half 6 to 12 months after patients have returned home.^{4,7,9} The challenge is to *find ways to preserve the beneficial effects* by bridging the gap between inpatient MDR and community return.⁸

Previous research suggests that extended outpatient or home-based MDR may be a solution,¹⁰ but an emerging method is telerehabilitation, either synchronous (eg, telephone- or video-based) or asynchronous (eg, automated web-based or virtual reality). It has the potential to be a more cost-effective alternative to periodic outpatient or home visits or admissions to resource-intensive inpatient MDR. Unfortunately, there is limited evidence on the efficacy of telerehabilitation in improving HRQOL in people with MS.¹¹ At the onset of the present study, there was some evidence of stand-alone phone-based or web-based self-management interventions for physical activity,¹² fatigue,¹³ depression,¹⁴ and HRQOL in MS.¹⁵ Surveys had also revealed high interest among individuals with MS in telecommunication for health care

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TABLE 1. Baseline Statistics

Group	Telephone (n = 20)			Web (n = 20)		
	Neuropsychological ^a	Physical ^b	Control ^c	Neuropsychological ^a	Physical ^b	Control ^c
Number	18	2	96	12	8	89
Demographics						
Female, n (%)	12 (67)	1 (50)	74 (70)	8 (67)	5 (63)	65 (64)
Age (years), median (1Q, 3Q)	49 (47, 52)	51.5 (50, 53)	52 (46, 56)	55 (48, 57)	58 (47, 60)	51 (44, 58)
Disease characteristics						
MS type, n (%)						
Relapsing-remitting	10 (56)	1 (50)	47 (44)	7 (58)	4 (50)	43 (44)
Secondary progressive	6 (33)	1 (50)	41 (39)	3 (25)	4 (50)	43 (44)
Primary progressive	2 (11)	0 (0)	18 (17)	2 (17)	0 (0)	12 (12)
EDSS, median (1Q, 3Q)	4.0 (2.5, 4.5)	6.25 (6.0, 6.5)	4.0 (3.5, 6.0)	4.0 (3.5, 4.0)	4.5 (4.0, 6.5)	4.5 (3.5, 6.0)

EDSS, Expanded Disability Status Scale; MS, multiple sclerosis.

^aThe neuropsychological group is patients in the main focus areas of resilience, cognitive function and energy combined.

^bThe physical group is patients with physical function as their main focus area.

^cMatched treatment and wait-list control patients retrieved from the main study to be used as controls in the present analysis.

services.¹⁶ Investigators in a Dutch long-term study explored telecounseling after discharge from physical rehabilitation in a large group of patients, including some with MS, and found promising results on physical activity from 3 telephone counseling sessions that were 2 to 3 weeks apart.^{17,18} However, no previous inpatient MDR studies had monitored the benefits of regular, after-discharge telecoaching to support self-management and HRQOL in individuals with MS.

Based on this background data, we set out to investigate whether monthly telecoaching for individuals with MS after 4 weeks of inpatient MDR would enhance the long-term carryover of improvements in HRQOL.

METHODS

Study Design

We conducted an exploratory 2-group intervention study with 6- and 12-month follow-up (MFU) based on a protocol amendment (in Danish and unpublished) to the main protocol of The Danish MS Hospitals Rehabilitation Study.¹⁹ Initially, patients were admitted to 4 weeks of inpatient MDR in accordance with the main protocol. The protocol amendment added monthly coaching after discharge. The included patients were allocated to receive 1 of 2 different types of telecoaching after discharge: telephone coaching (20 patients) or web-based coaching (20 patients). The web-based content was exclusively text-only.

The study was approved by the Danish Research Ethics Committee (ref. no. 1-01-83-0002-07) and the Danish Data Agency (ref. no. 2011-41-6751). It was registered at isrctn.com (ISRCTN05245917). For further details of the study, please see the first report(s).^{6,7}

Study Cohort

Recruitment took place in August and September 2014. All referred participants were aged 18 to 65 years and had an

Expanded Disability Status Scale (EDSS) score equal to or less than 7.5. Exclusion criteria were as follows: people with MS who were within 3 months of relapse, who were within 6 months of diagnosis, who had participated in inpatient MDR in the previous 6 months, who had an EDSS cognition subscale score less than 2, or who had cognitive limitations or any other illness that could impede their participation in the study. All participants underwent full neurological examinations prior to enrollment in the study. The examining neurologists made the final decision on the patients' enrollment. Informed consent was obtained from all participants.

Prior to admission, participants had a one-on-one goal-setting conversation with their case manager to make a joint decision about functional rehabilitation goals.⁷ Based on the nature of their goals, they were assigned to the most appropriate of the 5 main focus areas (MFAs): resilience, cognitive function, energy, physical function, and personal needs. MDR included a patient-centered, collaborative, and goal-oriented team-based approach involving neurologists, nursing staff, physiotherapists, occupational therapists, social workers, dietitians, neuropsychologists, and psychologists. The MDR program offered during admission has been previously described.⁷

The first 20 consecutive eligible participants were enrolled in the telephone group, and the next 20 were enrolled in the web-based group. Blinding of participants' identifying information to the MS specialists was not possible. Different measures were taken to counteract this limitation. For example, only the case managers were directly informed about the participants' group assignments, and participants were urged not to discuss their groups with the MS specialists. No distinction was made among the study, wait-list, and control patients. Finally, the outcome measure was self-reported and completed at home online¹⁹ to avoid any influence from the MS specialists and researchers.

The total cohort was 40 participants. Of the 20 in the telephone group, 8 were assigned to the MFA of energy, 5 to cognitive function, 5 to resilience, and 2 to physical function. Of the 20 in the web-based group, 5 were assigned to energy, 2 to cognitive function, 5 to resilience, and 8 to physical function. Patients in the telephone group tended to be younger than patients in the web-based group (median of 49 years vs 56 years). Otherwise, the groups looked much the same at study start. The baseline demographics of patients with neuropsychological MFAs (resilience, cognitive function, and energy) and patients with physical function as their MFA are given in **TABLE 1**, along with disease characteristics. The median length of stay was 20 days (range, 14-20 days). No patients dropped out of the study, and all participants completed the 1-year follow-up. All were stable during the study period, with no overall progression in EDSS and no major changes in use of immunotherapy.

Outcome Measure

The primary outcome was MS-specific HRQOL assessed by the self-administered Functional Assessment in Multiple Sclerosis (FAMS).²⁰ FAMS consists of 44 questions (items) divided into 6 multi-item functional status scales: mobility (7 items), symptoms (7 items), emotional well-being (7 items), general content (7 items), thinking/fatigue (9 items), and family/social well-being (7 items). Each item is rated on a 5-point Likert scale (0-4), yielding a possible score range of 0 to 176. Higher scores reflect better functional status and higher HRQOL.

Telecoaching Intervention

The intervention consisted of structured coaching sessions focusing on goal attainment delivered via telephone or the internet. Sessions were scheduled once a month for 11 months beginning 1 month from discharge. The case managers (ie, MS nurse, physiotherapist, or occupational therapist) were all certified coaches, and they conducted the telephone coaching sessions and monitored the automated online coaching sessions, ready to act if necessary. During the study, case managers recorded completed sessions as well as the number and duration of telephone calls for both groups. For every patient, the case manager was the single point of contact. Support was available upon request from the case manager either by telephone or email in case of technical problems or personal concerns. Case managers made referrals to general practitioners or neurologists in situations of relapses, health evaluations, and medication reviews.

The typical telephone coaching session involved open-ended questions to facilitate conversation about progress toward goal achievement, adherence to the rehabilitation program, identification of new issues, strategies to overcome barriers, and long-term planning. If a participant did not attend the session, the case manager tried to connect by calling in the following 2 days or by sending an email.

Using a device of their choice, web-group participants responded to standardized closed-ended coaching questions to facilitate reflections on goal achievements. The ODD software system, developed and supported by the now-closed company OVAM ApS, was used for these sessions. The ODD system automatically notified the patients of upcoming sessions via email. Automatic reminders were sent to participants via email if they did not log on within 2 days and if they did not respond, the case manager telephoned. At each session, the patient's personal rehabilitation goal was highlighted at the top of the screen.

The 3 main questions were:

1. How active are you in relation to the goal you have set up? 0 (Not at all) to 10 (Very active every day)
2. How close are you to your goal right now?
0 (Far from the goal) to 10 (The goal has been achieved)
3. How important is your goal to you right now?
0 (Not important at all) to 10 (Very important)

Each of these was followed by a feedback question to promote reflection. The feedback questions were:

4. If the response to the corresponding main question was a reduction equal to or greater than 2 points: Your score is lower than your previous score. What do you have to do to turn the tide?
5. If the response to the corresponding main question was plus or minus 1 point: Your score is about the same as your previous score. What do you have to do to improve your result?
6. If the response to the corresponding main question was an increase equal to or greater than 2 points: Your score is better than your previous score. What did you do and what did you learn from your good results?

An email alert was sent to the case manager if the answer to 1 of the main questions was between 0 and 3, or if the response was a negative change of 3 or more to 1 of the main questions. The case manager then contacted the patient to assist. Case managers were instructed to keep the extent and duration of the telephone counseling to an absolute minimum in such cases.

Statistical Analyses

To establish a controlled analysis against the main study, each participant in the present study was matched with a similar wait-list control participant and treatment participant from the main study,⁷ thereby comparing both intervention groups with the 2 newly established matched control groups: control wait-list patients and control treatment patients. To control for confounder imbalances, we used 1-to-many caliper matching without replacement within the 2-dimensional Euclidean space defined by the first 2 components of a joint correspondence analysis carried out on baseline demographic, clinical, and HRQOL variables and MFA. We chose this multivariate matching strategy because the clinical and HRQOL variables were previously reported to be highly associated.⁶ Statistical analyses followed Trénel et al.⁷ Participants in the neuropsychological MFAs (ie, resilience, cognitive

TABLE 2. Changes and Differences in Health-Related Quality of Life

Functional Assessment in Multiple Sclerosis ^a									
	n	Adjusted LS-means	Baseline adjusted mean changes from baseline			Mean differences between groups at follow-up			
		Baseline	Discharge	6-MFU	12-MFU	6-MFU		12-MFU	
		Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	P	Mean (95% CI)	P
Neuropsychological group									
Telephone group	17	110 (106-114)	+13.2 (4.5-30.0)	+5.1 (-2.4 to 12.6)	+11.2 (0.1-22.3)	+9.4 (0.8-18.0)	.032	+15.4 (3.5-27.4)	.011
Web group	12	113 (108-117)	+9.9 (-0.8-20.6)	+5.1 (-4.2 to 14.4)	+6.7 (-7.0 to 20.3)	+9.4 (-0.8 to 19.6)	.071	+10.9 (-3.3 to 25.1)	.130
Control treatment ^b	64	111 (109-113)	+12.5 (8.0-17.0) ^d	+2.1 (-0.7 to 4.9)	+2.7 (-2.2 to 7.6)	+6.3 (1.5-11.1)	.010	+6.9 (0.6-13.2)	.031
Control wait-list control ^c	58	112 (109-114)		-4.3 (-8.3 to -0.2)		Ref		Ref ^f	
Physical function group									
Telephone group	2	116 (105-127)	+6.9 (-18.4 to 32.5)	-7.5 (-30.0 to 15.0)	-27.6 (-61.4 to 6.2)	-6.6 (-29.6 to 16.5)	.574	-26.6 (-60.7 to 7.4)	.124
Web group	8	114 (109-120)	+12.5 (-0.6 to 25.6)	+3.1 (-8.2 to 14.3)	+1.9 (-15.1 to 18.9)	+4.0 (-8.6 to 16.6)	.532	+2.8 (-15.0 to 20.7)	.755
Control treatment ^b	31	113 (110-115)	+14.1 (7.4-20.7) ^e	-1.7 (-5.7 to 2.3)	+2.2 (-4.8 to 9.1)	-0.8 (-7.5 to 6.0)	.819	+3.1 (-5.6 to 11.8)	.484
Control wait-list control ^c	32	113 (109-115)		-0.9 (-6.8 to 4.9)		Ref		Ref ^f	

FAMS, Functional Assessment in Multiple Sclerosis; LS, least squares; MFU, month follow-up.

^aFAMS total score ranges from 0 to 176: the higher the score, the better the health-related quality of life.

^bMatched treatment patients from the main study who were not offered telecoaching after discharge.

^cMatched wait-list control patients from the main study.

^dn = 63

^en = 29

^fData from 6-MFU.

function, and energy) were combined into 1 group in the outcome measure analysis to increase statistical power and, thus, all participants were divided into either neuropsychological or physical (physical function) groups. All analyses were performed using R (www.r-project.org).

RESULTS

The multivariate retrospective matching yielded a total of 33 match groups consisting of between 2 and 12 participants (median = 7). A total of 224 patients in the matched data were distributed into 4 groups: telephone group (n = 19; 1 patient was isolated in the joint control analysis and, hence, excluded from the main analysis), web-based group (n = 20), control treatment group from the main study (n = 95), and control wait-list control group from the main study (n = 90). All patients were assigned to a single match group (no replacement), with patients always assigned to the smallest possible match group to improve match group size balance. Because the match control treatment patients and the wait-list control patients originated from the main study, the present case

managers had no knowledge of and no interactions with these match patients.

Adherence

Overall adherence with the coaching intervention was 100%. The case managers successfully completed the planned 1-year follow-up sessions for all patients. In the 11 months after discharge, every patient was coached on 9 occasions. The telephone group had 180 coaching sessions in total with a mean duration of 25 minutes (range, 5-90 min). Mean duration of sessions was longest at the first scheduled session (32 min) and shortest at the sixth session (19 min). The web-based group had 33 unplanned telephone conversations with a mean duration of 13 minutes (range, 5-40 min). The number of telephone conversations peaked at the first scheduled session with 10 out of 20 patients in need of telephone counseling. It then dropped gradually during the first half of the study period to only 1 or 2 telephone calls at each scheduled web-based coaching session in the second half of the study. Mean duration of unplanned telephone calls in the web-based group was longest at the third scheduled



Inpatient rehabilitation of patients with multiple sclerosis should be followed by regular telecoaching to support the retention of the benefits in health-related quality of life obtained during the stay.

Telecoaching with a multiple sclerosis rehabilitation professional one-on-one is superior to text-only web-based coaching. ■

session (20 min; average of 5 telephone conversations), and shortest at the second session (11 min; average of 7 telephone conversations). According to the case managers, a majority of the unplanned telephone calls were about technical issues and not because of clinical needs. Internal semistructured focus group interviews after the end of the study revealed high satisfaction with both telecoaching interventions.

Changes and Differences in HRQOL

Baseline values as well as changes and differences in HRQOL during the study period are presented in **TABLE 2**. As shown, the adjusted baseline FAMS scores looked similar between the groups. This suggests that the matching method successfully controlled for any confounder imbalances. However, significant within-group increases in mean FAMS scores were found in all groups at discharge, indicating substantial improvements in HRQOL from inpatient MDR.

In the neuropsychological group patients, both telecoaching groups demonstrated sustained improvements in HRQOL throughout the study period when compared with the control patients, with telephone coaching being superior. In the telephone group, a major additional HRQOL improvement was seen from 6-MFU to 12-MFU. With the control wait-list control group as reference, mean differences in FAMS scores at 12-MFU compared with baseline were: telephone group +15.4 (95% CI, 3.5-27.4; $P = .011$), web-based group +10.9 (95% CI, -3.3 to 25.1; $P = .130$), and control treatment group +6.9 (95% CI, 0.6-13.3; $P = .031$). In contrast, the physical group patients had no beneficial effects from either telephone coaching or web-based coaching: the gains seen at discharge were lost during the study period.

DISCUSSION

The present explorative study finds that systematic coaching in the form of one-on-one calls for individuals with MS with neuropsychological rehabilitation goals seemed to

improve the long-term carryover of HRQOL improvements gained during inpatient MDR. However, due to the very low number of physical patients assigned to telephone coaching, we cannot draw any conclusions about this subgroup based on the present results.

We learned from the main study that the patients assigned to the resilience, cognitive function, and energy MFA groups shared similar neuropsychological challenges and also had comparable long-term improvements in HRQOL from inpatient MDR.⁷ Thus, we felt confident in combining the 3 groups in this analysis to increase statistical power. Despite a clear decline from discharge, continued improvements were seen for both telecoaching methods for the neuropsychological group at 6-MFU and 12-MFU when compared with the control groups. Telephone coaching seemed to be especially beneficial in the long term, with additional improvement in HRQOL from 6 to 12 months, almost reaching discharge values. This almost doubled the long-term benefits when compared to control treatment patients from the main study, who were not offered telecoaching after discharge.

Adding monthly telephone coaching after discharge changed the curve and largely prevented the expected decline in HRQOL for individuals with MS in the neuropsychological group compared with other longitudinal inpatient MDR studies.^{4,7-9} This suggests that the more comprehensive reevaluation and support for self-management in the personal one-on-one coaching in the telephone group made a significant difference and provided a basis for a solid long-term improvement in HRQOL. The delayed additional improvement in HRQOL in the neuropsychological telephone coaching group indicated that despite the advantage of the one-on-one coaching, community reintegration required time to transfer the acquired knowledge and tools for managing daily life with MS to the home environment. It is also possible the personal relationships between the patients and the case managers that were maintained through the regular telephone calls contributed to the favorable outcome. We know from surveys that interpersonal relationships are very important components of effective rehabilitation.^{3,21} We chose telephone coaching because we are familiar with this type of telesupport in our daily clinical practice; telephone administration has also proven to be effective for individuals with MS in other rehabilitation studies.^{17,22,23} Web-based coaching was included as a novel, less expensive, and less extensive alternative.²⁴

The present results are in line with the findings of Flachenecker et al, who have been the only ones to report the benefits of telephone-/web-based coaching for individuals with MS after inpatient rehabilitation.²⁵ They conducted their study at the same time as ours and, despite the fact that their primary objective was physical activity, they found that postdischarge coaching maintained improvements in HRQOL throughout the study period of 6 months, a time point where no support had been given for 3 months. That is impressive, but may also explain why they found no indication of additional improvements in HRQOL over time, as we did. In our study, the

closed-ended web-based coaching questions were insufficient to support the HRQOL improvements gained from the stay in the physical group patients. In our experience, more so than neuropsychological patients, physical rehabilitation patients face more challenges such as a sedentary lifestyle and the task of incorporating the physical activities of MDR into daily life. The physical group patients needed more comprehensive aftercare support and would probably have benefited from personal one-on-one coaching with a case manager, as was the case with the neuropsychological patients. Unfortunately, this study is unable to answer that question.

Previous research has found it difficult to prove the benefits of teleinterventions on HRQOL.^{11,23} Therefore, it is promising that our results support recent teleintervention studies, including the work of Flachenecker et al, showing that it is possible to support and improve the HRQOL of people with MS over time with home-based telecoaching/counseling, and also after inpatient rehabilitation.^{25,26}

Long-term preservation of HRQOL in chronic degenerative diseases such as MS should be considered a marker of therapeutic success.²⁷ Individuals with MS in general have decreasing HRQOL^{20,28} and a recent study found that additional worsening of HRQOL predicts progression of disability.²⁷ Given the progressive nature of MS and the unpredictable issues individuals with MS may face down the road, it is not sufficient to have an appointment with a rehabilitation professional occasionally.^{3,29,30} If our long-term aim is to continuously support self-management in order to optimize mental and physical capacity and maintain HRQOL in people with MS, regular reviews by MS rehabilitation specialists are necessary.^{4,29} Rehabilitation experts have proposed that individuals with MS would benefit from a personal coach who supports and gives advice when needed,³⁰ although the long-term effectiveness of coaching in rehabilitation has been unclear.³¹ Our results suggest that continuous one-on-one coaching of individuals with MS has substantial long-term potential in combination with inpatient MDR.

This study was limited by small sample sizes and the lack of a genuine control group. Also, the present study was never designed to stratify patients based on MFA, which regrettably resulted in a skewed distribution with a strong preponderance of neuropsychological participants in the telephone group and only 2 participants assigned to physical function. Thus, interpretation of these data should be made with some caution.

Integration of various telerehabilitation interventions to extend the carryover effects on HRQOL after MDR calls for further high-quality, long-term effectiveness studies of both current and rising technologies.

CONCLUSIONS

This study provides preliminary evidence that monthly telecoaching of individuals with MS with neuropsychological rehabilitation goals enhances the long-term carryover of improvements in HRQOL from inpatient MDR. Overall effects seemed more pronounced using a synchronous intervention

(telephone coaching) vs an asynchronous intervention (web-based coaching). ■

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